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Information Visualisation Practices for Improving Patient Readability of Blood Pressure, Health Data, and Health Literacy

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Resumo

Os dados de saúde pessoal obtidos através da auto-monitorização, são frequentemente apresentados através de representações padronizadas com pouco significado intrínseco para aqueles que mais precisam, uma vez que a baixa literacia em saúde está associada a uma saúde deficiente. Ao não conseguir informar os utilizadores sobre o seu estado de saúde, estas representações podem ser perigosas, levando os pacientes a sentirem-se perdidos, confusos, ansiosos e até deprimidos. A visualização da informação pode desempenhar um papel importante na ajuda aos pacientes que compreendem os seus dados de saúde e o seu estado de saúde, desde que esteja alinhada com as suas necessidades, motivações e objetivos. Seguindo as práticas do Design Centrado em Humanos (Human-Centred Design), foram aplicados métodos de pesquisa para compreender o contexto da auto-monitorização, bem como identificar quais as métricas que mais diferem dos modelos mentais dos participantes. Graças aos dados quantitativos obtidos a partir de um inquérito, a tensão arterial foi identificada como a variável de saúde mais problemática. Uma série de entrevistas permitiu aos doentes de doenças crónicas verbalizar os desafios que enfrentavam na gestão das suas doenças. Tendo em conta as informações obtidas a partir de etapas anteriores, foram exploradas várias formas de mapear dados da tensão arterial em elementos de design e foram desenhadas diferentes visualizações. Finalmente, estas visualizações foram testadas através de entrevistas guiadas com pacientes com problemas de tensão arterial. Os resultados mostraram que os participantes preferiram diferentes visualizações para diferentes objetivos, e gostariam de poder escolher livremente entre as mesmas; os participantes com menor literacia, mas que investiram profundamente na monitorização da sua saúde, consideram as tabelas como sendo as visualizações mais informativas; por último, os participantes identificaram as escalas de cor como o método mais intuitivo para representar o estado de saúde e o risco para a saúde.

Palavras-chave: Visualização da Informação; mHealth; Auto-monitorização; Tensão Arterial; Autorrastreio; Design.

Abstract

Personal health data obtained through self-monitoring is often presented through standardised representations with little intrinsic meaning for those who may need it the most, since low health literacy is associated with poor health. By failing to inform users about their health status, these representations can be dangerous, leaving patients feeling lost, confused, anxious and even depressed. Information Visualisation can play an important role in aiding patients making sense of their health data and health status, as long as it's aligned with their needs, motivations and goals. Following Human-Centred Design practices, user research methods were applied in order to understand the context of self-monitorisation, as well as identifying which metrics differed the most from participants' mental models. Thanks to quantitative data obtained from a survey, blood pressure was identified as the most problematic health variable. A series of interviews allowed patients of chronic conditions to vocalize the challenges they faced in the management of their conditions. Taking into account information obtained from previous steps, multiple ways to map blood pressure data onto design elements were explored and different visualisations were designed. Finally, these visualisations were tested through guided interviews with patients with blood pressure problems. Results showed that participants preferred different visualisations for different goals, and enjoyed being able to freely choose from them; participants with lower literacy but who were deeply invested in monitoring their health found tables to be the most informative visualizations; finally, participants identified colour scales as the most intuitive method to represent health status and health risk.

Keywords: Information Visualisation; mHealth; Self-monitoring; Blood Pressure; Self-Tracking; Human-Centred Design

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Seeing comes before words.
The child looks and recognizes before it can speak.
But there is also another sense in which seeing comes before words. It is seeing which establishes our place in the surrounding world; we explain that world with words, but words can never undo the fact that we are surrounded by it.
The relationship between what we see and what we know is never settled.

John Berger, Ways of Seeing

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Abbreviations

BMI	Body Mass Index
BP	Blood Pressure
BPM	Beats per minute
CD	Chronic Disease
COVID-19	Coronavirus disease - 2019
DBP	Diastolic Blood Pressure
DGS	Direção-Geral de Saúde
ERH	Electronic Health Records
FhP-AICOS	Fraunhofer-AICOS
HCD	Human-centred Design
HIT	Health Information Technologies
HR	Heart Rate
InfoVis	Information Visualisation
ISO	International Organization for Standardization
NHS	National Health Service
PD	Participatory Design
QS	Quantified Self Community
RtD	Research-through-design
SBP	Systolic Blood Pressure
SMD	Self-monitoring Devices
ST	Self-tracking
Sys	Systolic Blood Pressure

1. Introduction

1.1 Context

Personal health data has become widely available. From chronic disease patients monitoring their condition with self-monitoring devices (SMD) to self-trackers trying to improve their lives with mobile apps, personal health data has integrated users', patients', and even laypeople's lives. mHealth solutions, such as SMD, hope to play a democratising role, empowering users, improving their health literacy, and facilitating access to health (Lupton, 2013a).

Still, for this personal data to stand a chance at improving users' lives, users must be able to analyse and understand their data. Information Visualisation plays an important role in aiding users in their role of making sense of data (Card et al., 1999). Typical Information Visualisation methods are oriented towards data analysts and other professionals trained on quantitative data analysis (Dix, 2012). However, this is not necessarily the case for users of SMD, and not the norm amongst senior citizens, a group with a high prevalence of chronic diseases, therefore identified as target users of SMD (Verdezoto & Grönvall, 2015). Marginalised groups also display overall less health literacy, which has been associated with a lack of ability to interpret health messages and poor health status (Berkman et al., 2011).

Furthermore, standardised representations of personal health data are often detached from the lived experience of the patients, disregarding the specificities of their conditions. These representations often suffer from a *healhtist* bias, being presented from an ideal normative health perspective (Lupton, 2013a). Standardised values may have an adverse impact on the patient's health, being untrustworthy sources for comparison when patients lack understanding of the specificities of their particular case. (Kanstrup et al., 2018; Storni, 2010).

To improve patients' readability of personal health data, systems should be more inclusive. By bringing patients closer to the design process, through participatory design (PD) methods, resulting visualisations may come closer to participants' needs and mental models.

This research takes place as a collaboration with Fraunhofer AICOS (FhP-AICOS), a non-profit research centre for Assistive Information and Communication Solutions, a leading force in technological innovation, through applied scientific research benefiting both enterprises as well as society. FhP-AICOS contains three main research groups, Human-Centred Design (HCD)—where this work was developed—, Intelligent Systems, and Connected Things. The HCD research group aims to understand people in diverse settings, co-design meaningful technologies, and finally assess technology in real life. To help achieve these goals, FhP-AICOS established the Living Lab COLABORAR, a network of senior citizens and caregivers interested in technology and ready to take part in HCD research methods.

Amidst the work developed by FhP-AICOS, there is also a need to present information to the end-user, from gathered and generated data, as such considering how to best present information in a human-centred way, is of extreme value both to the research centre and the community.

1.2 Problem(s), Hypothesis and Research Questions

Currently, still there is a need to create systems that present information in a way that informs patients and contributes to their understating of personal health data, in light of their health status. This could be achieved by integrating target users in the process of designing personal health data visualisations, via participatory design tools and techniques.

The research questions leading to the solution proposal are:

Q1: Which visualization methods prove to be the most effective for representing and presenting health data generated through self-tracking devices? Which do not?

Q2: What are the implicit values of the representations?

Q3: How do patients perceive visual representations, and do they actually understand what is being visually presented?

Q4: What challenges do patients face regarding the visualization of their health data?

This research aims to design and propose visualisation methods for personal health data obtained from SMD, tested with chronic disease patients. Results suggesting which methods proved most informative to the user population ought to be summarized and presented as guidelines for effective patient-centred personal health information visualisation design.

1.3 Research Methodology

The first step in this research involves a thorough review of the literature intent on understanding patients' relationship with personal health data, considering how they obtain it, how they analyse it, how they incorporate insights gained from their data onto their lives, as well as their motivations and challenges during this process. The role of mHealth solutions in guiding users during self-monitoring and their desired impact on patients' lives is also considered. The domain of Information Visualisation (InfoVis) in its role of aiding users make sense of personal data was also reviewed, focusing on taxonomies, methods, practices, and limitations in personal health data solutions through the analysis of relevant work. The impact of InfoVis on improving the readability of data and health literacy was also contemplated.

This research follows a research-through-design (RtD) approach, using design methods as a legitimate method of inquiry (Zimmerman et al., 2010). From a co-design, participatory design, and human-centred design approach, participants representative of the user population were directly included in the design process to generate tacit and holistic knowledge about participants' experience with SMD. The standard ISO 9241-210:2019 of human-centred design for interactive systems as a structuring force of this research, which describes the iterative core activities of HCD, namely (1) Understand and Specify Context of Use (i.e. researching the user, the environment of use and their tasks), (2) Specify the User Requirements, (3) Produce Design Solutions to meet the user requirements, (4) Evaluate the design against requirements.

Another important aspect of the iterative nature of this research is the use of prototyping as a tool for giving direction to the research. By exercising co-design tools, such as workshops and design games that directly involve users in the design process, to generate contextual knowledge (Sanders & Stappers, 2014), fundamental for this study.

User research methods were used to gather quantitative information regarding the user population, i.e. surveys, and qualitative information obtained from interviews. Finally, usability evaluations were conducted for the designed solutions. All these methods tried to involve representative users as much as possible, although current social limitations resulted in obvious limitations.

1.4 Dissertation Structure

This dissertation is organized in 6 chapters, followed by appendices. This current chapter presents the context backing this research, followed by the identified problem, hypothesis, and associated research questions. Finally, research methods applied in the work are introduced and an overview of the structure of this document is given.

Chapter 2 lays down the theoretical foundation behind the work, beginning by establishing the relationship between users, personal health data, and self-monitoring, highlighting the role of technology in this setting. Then the role of InfoVis in aiding users make sense of personal health data, as well as its limitations, is considered. Consequently, the role and challenges of InfoVis in health solutions is briefly presented. Finally, state-of-the-art subsection documents current personal health data visualizations being used in self-monitoring mobile apps.

Chapter 3 describes the solution description and explains how participatory design can aid in answering the problem. Furthermore, this chapter discusses topics of HCD methodologies and further explains the applied research methods and tools for the design of personal health information visualisations.

Introduction

Chapter 4 documents the user research stage, intent on understanding participants' self-monitoring context and challenges with monitored metrics. Subsequently, this stage’s results are presented, identifying the need to improve visualisations of blood pressure information.

Chapter 5 documents the design stage, how blood pressure information was mapped onto visual graphical elements, and how visualisations were designed. The following section documents the evaluation stage which had users give their opinions on the considered methods of visually mapping BP data, and the designed visualisations.

Finally, chapter 6 reflects on the conclusions of our work and its contribution, identifying a range of open-ended issues that can be an object of future research.

2. Literature Review

This chapter lays down the theoretical foundation behind the work. It begins by exploring how patients are obtaining their health data, the concept of self-tracking, and the role of technology in said tracking; followed by motivations and challenges faced by users of mHealth solutions; next a definition of health literacy is presented as well as its relationship to health data. The following section considers the role of information visualisation in how systems help users understand their health. Finally, we analyse and categorize how systems are presenting health information to users.

2.1 Health Data and Self-monitoring

The process of obtaining, analysing and reflecting on personal data is known as Self-Tracking (Neff & Nafus, 2016), which is related to the Quantified Self Community[1] (QS) - the belief that each and every aspect of human life can be quantified and turned into data. Keeping track of data is a natural process that may happen unguided, in their memory, or using tools such as pen and paper, or through digital means, such as wearables, smartphones, computers, and self-monitoring devices.

Computational efforts inspired by the concept of Ubiquitous Computing[2] brought forth access to new quantifiable variables and new ways to self-track (Lupton, 2013b), as Neff & Nafus (2016) put it “The technologies extend the areas of life that can be measured, and they make it possible to keep track with greater frequency than ever before” (pp. 2-3).

Health and wellbeing data are the most prominent categories of tracked data and the ones that concern this dissertation. Thanks to user acceptance rates of self-monitoring devices, self-tracking apps, and other consumer health information technologies (Eysenbach, 2000), patients have access to multiple aspects of their health data from multiple sources.

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[1] https://quantifiedself.com

[2] Ubiquitous Computing is the concept of computation augmenting our lives, integrating into our habits and routines, becoming available at all time and at any place.

Literature Review

Mentioned mobile health-oriented technologies can be described (amongst other names) as *digital health* or *mHealth* technologies, while the resulting health data may play different roles. Lupton (2013a) identified multiple goals of mHealth solutions:

- **Facilitate communication between patients and health professionals**, although patients feel that health professionals disregard self-tracked data (Ancker et al., 2015).
- **Aid in monitoring health status**, Lupton (2013b, p. 264) identified in the literature that "when patients believe that better knowledge of their bodies is achieved via self-monitoring devices they feel as if they are more in control, and this leads to greater security and reassurance".
- **Improve adherence to treatments**, by reminding patients to take medication or other timely actions, e.g. taking a blood pressure measurement every day at the same time.
- **Encourage laypeople to engage in preventive health**, engaging in health monitoring, even if performed by a healthy individual, can help laypeople in maintaining a positive health status. Lupton (2013b, p. 266) further notices that health data may also be "represented as able to uncover hidden illness or disease that might otherwise not be detected using phenomenological experiences of embodiment".

Although health self-monitoring is usually prescribed by clinicians for managing chronic conditions such as diabetes and hypertension, health self-trackers have their own motivations. Gimpel et al. (2013)'s study on patients' self-tracking motivations, identified a *five-factor of self-tracking motivations*:

1. **Self-entertainment** - this approach to self-tracking is perceived as ludic for people who appreciate data and the embodied experience of self-tracking itself. Neff & Nafus (2016, pp. 80-83) identified a similar concept of *aesthetic curiosity*, where self-trackers recreationally explore visual representations of data.
2. **Self-association** - centred on the social phenomenon of self-tracking, from fitness-oriented social media apps to chronic disease support forums, these self-trackers look to their peers for comparison, support, and a sense of belonging. Dangers associated with this practice are explored in the following section. Neff & Nafus (2016, pp. 71-76) identified this social phenomenon as inherent to all self-tracking activities, although tracking practices focused on *monitor[-ing] and evaluat[-ing]* also invoke notions of reflection and comparison with others, "Social Networks are a way of representing social relationships; they are a tool for users to get support and compete with others".
3. **Self-design** - when self-trackers view their bodies as a system that can be optimized. Designing their system involves identifying the root of undesirable states and modifying those variables, adjusting their behaviour. Implications and the social context behind this motivation are explored later in this document.
4. **Self-discipline** - here self-tracking plays a role in motivating the user to accomplish a goal, from a weight loss goal to breaking bad habits. Likewise, Neff & Nafus (2016,

pp. 89-93) pointed out the motivation of *cultivating a habit* for self-trackers who use personal data to motivate themselves in cultivating habits.

5. **Self-healing** - with this form of self-tracking users hope to improve their health status by finding meaning for their symptoms in personal data. Gimpel (2013) also noted that self-trackers motivated by self-healing tend to present a “certain rebellion against the healthcare system” (p. 10). Neff & Nafus (2016, pp. 84-89) identified a similar construct of *debugging a problem*, following as a view of health as a system. When something is not right with their health, self-trackers look for symptoms, triggers, and potential relief-inducing changes. In both cases awareness of genetic expression, human variation, and health not being a one-size-fits-all solution. As Neff & Nafus (2016) point out “diagnostic categories and tests are designed for the peo-ple who fall in the centre of the bell curve, not outliers”, furthermore “medical professionals raise doubts about the veracity of patient stories” in this context. This form of self-knowledge regarding one’s health is further explored by Neff & Nafus (2016, pp. 78-80) in the form of *self-tracking to elicit sensations*, here users look at data as a “prosthetic of feeling” helping them make sense of physical signals and emotional states. Said tracking is regarded as being connected to mindfulness.

This notion of self-discovery is at the very heart of the QS, as said by Wolf (2010), a co-founder of the QS:

> Trackers focused on their health want to ensure that their medical practitioners don’t miss the particulars of their condition; trackers who record their mental states are often trying to find their own way to personal fulfilment amid the seductions of marketing and the errors of common opinion; fitness trackers are trying to tune their training regimes to their own body types and competitive goals, but they are also looking to understand their strengths and weaknesses, to uncover potential they didn’t know they had. Self-tracking, in this way, is not really a tool of optimization but of discovery. (para. 52)

On a contradictory note, although self-generated patient data may prove helpful if the patient can correctly interpret it, it may also have a nefarious impact when patients cannot fully understand their data and become obsessed with comparing their results in a distressing way (Storni, 2010). Lupton (2013a, p. 396) identified that “engaging in self-tracking led [some patients] to become overly focused on their health and to experience feelings of failure, anxiety or self-hatred”. Moreover, self-tracking itself is often described by patients as a complex and controlling chore (Kanstrup et al., 2018). Because of this, self-tracking technology fails to engage users, with 60% of users abandoning it after 6 months (Neff & Nafus, 2016).

Digital health data does not necessarily translate into meaningful information, both for healthcare practitioners and for patients. (Rind, et al. 2013) This lack of understanding may lead to an adverse impact on the patient’s health due to an over-awareness of their tracking, untrustworthy sources for comparison, or a lack of understanding of the specificities of their particular case (Kanstrup, 2018; Storni, 2010).

Literature Review

Part of the problem is rooted in healthism discourses that discriminate against outliers. *Healthism* is the name of a movement that places good health at the centre of our lives, “so that an individual’s everyday activities and thoughts are continually directed towards this goal” (Lupton, 2013a, p. 397), with a discourse of self-optimization and responsibility that ignores social-economic obstacles to achieving such goals. Failure to comply with healthism norms leads to discrimination. As Lupton (2013a) identified “*Healthist* discourses, therefore, value those who take such responsibility and represent them as ideal citizens, while people who are viewed as lacking self-responsibility or who are ill are positioned as inferior and morally deficient” (p. 397).

Healthism places the ideal as the acceptable norm, making the average into an outlier of sorts. Neff & Nafus (2016) illustrate this concept with the baseline 10.000 steps a day, set by default in a wide variety of activity trackers of the time. When one fails to achieve this goal one's perception of their health as well as their capabilities in relation to others start to be questioned. As a matter of fact, activity trackers fail to give context when comparing users' values with their peers – as the authors put it “What is average for one’s age? Fitness level? Medical Condition?”. Ethnographic factors such as the usage of cars and public transportation in a community and the amount of physical work in a person’s job also influence the average amount of steps in a group. To add insult to injury some activity trackers shame users for failing to achieve the unattainable (in their context) goal of 10000 steps, leaving said users feeling “not normal” and negative. Since then more and more activity trackers allow users to customize their goals. Healthism encourages comparison of health data expecting a normal distribution (i.e. bell-shaped) which is not necessarily the case in a medical environment, let alone for sufferers of chronic conditions. Furthermore, being at the extremes of the curve is regarded as negative, unhealthy, and problematic. (Neff & Nafus, 2016)

Pavel et al. (2010) believe health data can play a *democratising role*, “empowering individuals with more information about their health and the effects their lifestyle choices have on their wellbeing” (Introduction, para. 2). This notion of empowerment through health information lies on the basis of health literacy. While there are multiple dimensions to health literacy (Berkman et al. 2010), this work considers health literacy as one’s ability to procure, process, and understand health information properly (Ratzan & Parker, 2000). In the context of numerical data that represents health status, is also important to consider the notion of health numeracy, a specificity of health literacy that is described by Goldbeck et al. (2005) as one’s “ability to understand, communicate and act on numerical quantified concepts.”

In their study on the relationship between health literacy and health outcomes, Berkman et al. (2011) found that low health literacy is associated with poorer overall health, resulting in “more hospitalizations; greater use of emergency care; lower receipt of mammography screening and influenza vaccine; poorer ability to demonstrate taking medications appropriately; poorer ability to interpret labels and health messages; and, among elderly persons, poorer overall health status and higher mortality rates” (p. 97).

Health data should inform patients about their health status, but in order to do so, it must be presented in a way that makes sense for them, as noted by O'Grady & O'Grady (2008), "Information delivery is dependent on the clarity of communication to retain its relevance to a global audience. Designers provide that context by turning statistics into stories, providing meaning for the end-user."

SMD should inform patients, guiding them, aiding them in their quest for attaining knowledge about their own health. Information Visualisation helps patients transform health data into health information, by considering how to sort, process, and represent data to deliver valuable information in context.

2.2 Health Data and Information Visualisation

Spence (2014) defines *visualisation* as a human process of creating a mental model or mental image of information, while Dix defines Information Visualisation (InfoVis) as the domain focused on "making data easier to understand using direct sensory experience" (Dix, 2012, p. 2). Norman (1993) identified the role of external tools in amplifying human cognition; from this perspective, InfoVis has been defined as "the use of computer-supported, interactive, visual representations of abstract data to amplify cognition" (Card et al., 1999, p. 7). Card and colleagues also highlight that InfoVis is centred around the idea of *using vision to think* through the use of "special properties of visual perception to resolve logical problems"."

Dix (2012) identified two major end-users of data: *Data Analysts*, professionals that look at data with the goal of understanding and exploring (e.g. confirm a hypothesis, noticing expectations and seeking the unknown); the remaining group of users are *Data Consumers*, non-professionals in their relationship to data, as such visualisations need to be directed towards their needs; this last group looks at data in an effort to understand contextual information of specific rhetoric.

Visualisation methods focused on Data Analysts tend to be complex, often requiring prior training. InfoVis must allow users to interact with data, by changing focus, thus allowing the user to visualise new connections. Interaction is crucial in the face of complex data with multiple variables and a large sample (Spence, 2014). By contrast, visualisation for Data Consumers must be simple and easy to understand, usually providing a combination of imagery, graphical data, and text, i.e. infographics (Dix, 2012).

Recognising that traditional InfoVis lacks the ability to represent self-trackers' personal data, needs, and goals, Pousman et al. (2007) made the argument for *Casual Information Visualisation*, which they defined as "the use of computer-mediated tools to depict personally meaningful information in visual ways that support everyday users in both everyday work and non-work situations" (p. 1149). The authors defined the user population of Casual InfoVis as "a wide spectrum of users with different capacities and analytical skills", with a usage pattern that may integrate users' life, in momentary and periodical uses, i.e. a habit, or contemplative. Personal data invokes an emotional response in users. Finally, Pousman et al. (2007) concluded that the insight these users hope to gain from data differs from traditional InfoVis. These conditions are aligned with the previously identified needs of health data and self-trackers.

2.2.1 Health Information Visualization for Healthcare Professionals

Most visualisation methods in health are designed for healthcare professionals (Faisal et al. 2013), leaving patients in an unguided attempt to understand and reflect on their data (Choe et al. 2017). These visualisations often take the form of Electronic Health Records (EHR) (Rind et al. 2011; Roque et al. 2010; West et al. 2014). Patients' health information is routinely documented by healthcare practitioners into EHR, hoping to improve clinical quality by providing health information in a temporal visualisation, on-demand in real-time, Alas, due to poor visualisation methods of EHR, these systems often provide little to no benefits, and even decreased health care, when failing to support clinical tasks (Himmelstein et al., 2010; Rind et al. 2011). EHR often present extensive amounts of patient data requiring too much cognitive effort to be effectively manageable in clinicians' already busy schedules (Rind et al. 2011). Rind and colleagues (2011) further notice that improving visualisation methods can improve health care by facilitating medical analysis, highlighting the use of better interaction as a critical point to enable efficient data management.

Prominent results on improving patient readability of health information were obtained by De Croon and colleagues (2017). In their study using augmented reality to present medication and health information to senior citizens using interactive visualisations. Participants were presented four visualisations, each providing different contextual information such as presenting side effects information, where users could interact with the system to obtain the information they need.

General health InfoVis solutions focused on self-tracking often fail to communicate meaningfully with patients who suffer from specific conditions. To tackle biases posed by conventional visualisation methods, Snyder et al. (2019) performed an exploratory study integrating patients of bipolar disorder in the design process of visualisations that "encoded the lived experience" of the condition. Verdezoto & Grönvall (2015) applied HCD methods for designing visualisations that helped senior participants in understanding blood pressure readings, in a preventive health context.

In an effort to provide developers of mobile health apps best practices for integrating personal health data, Open mHealth (Open mHealth, n.d.) provides open-access documentation on handling data in a mobile health app. They provide a Visualisation Library3 that includes examples and best practices for designing health visualisations, albeit focused on clinicians'

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[3] Available at: https://www.openmhealth.org/documentation/#/visualize-data/visualization-library

needs. The metrics considered by Open m Health (n. d.) are *Blood Pressure, Heart Rate, Physical Activity,* and *Weight*; Overall, these metrics are identified as highly relevant for the management of multiple conditions, such as most forms of cardiovascular chronic conditions, such as hypertension.

Similar metrics were used in SmartBeat[4], a previous project by Fraunhofer-AICOS with the goal of helping users track their health data and of contributing to their health literacy, by connecting self-monitoring devices and a wearable tracker to a companion app. The app automatically recorded and presented visualisations of the four considered metrics - Weight, Blood Pressure, Heart Rate, and Number of Steps - while a previous iteration also considered Oxygen Saturation.

The rest of this section explores visualisation methods used in mHealth apps self-monitoring to represent said metrics.

2.3 State of the Art of Information Visualisation Methods used in mHealth Self-monitoring Apps

In order to understand how current smartphone apps are representing health data and informing users of their health, their weight, number of steps, their blood pressure and their heart rate, a critical analysis of a sample of self-monitoring apps available from the Apple App Store was performed. Multiple stand-alone apps, SMD companion apps, and Smartphone companion apps were considered.

2.3.1 Visualizations of Weight Data

Weight Data is an indication of mass values, usually obtained from domestic household scales, and is presented in the form of a numerical value, as such Weight Data is classified as quantitative/numerical data. Body Mass Index (BMI) is usually associated with this variable. BMI is a general indicator of health that compares a person’s weight in relation to their height. The numerical value is then translated into a qualitative/categorical ordered variable representing health status. This categorical order starts at Underweight, followed by Normal, then Overweight, and finally Obese. Some lists consider different stages of obesity. Other indicators of body composition such as Body Fat percentage are sometimes also considered as in the case of the PopWeight app (Figure 1).

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[4] This study was preceded by SmartBeat, a multidimensional mHealth System for heart failure patients developed by Fraunhofer-AICOS that included visualisations of self-monitored health data, although their legibility, readability and their relationship with users’ implicit values were not the study object.

Literature Review

Figure 1. Weight and Body Fat Visualisation**.**
PopWeight - Easily track and record your weight by Metaps Inc.

Virtually all visualisations of weight data are primarily concerned with the overall representation of the evolution of weight in time (in the shape of a graph), while also indicating the registered numerical value upon interaction (usually represented as circles). Open mHealth (n.d.) suggests that visualisations should also consider the following points: indicate the maximum and minimum registered values over a time interval; making weight value goals optional; and visually indicating the weight balance trend, such as represented below with the WW Weight Watchers Reimagined (Figure 2) and iHealth (Figure 3) apps.

Figure 2. Weight balance trend.

WW (Weight Watchers Reimagined) app by WW International, Inc.

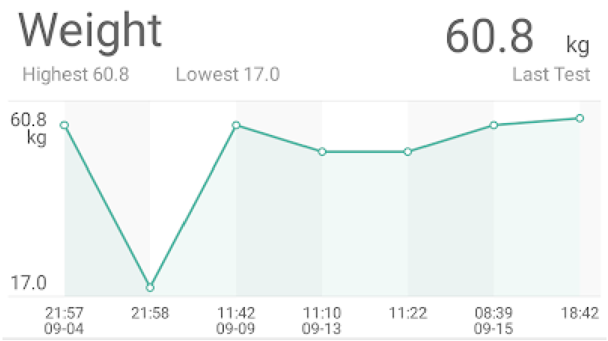
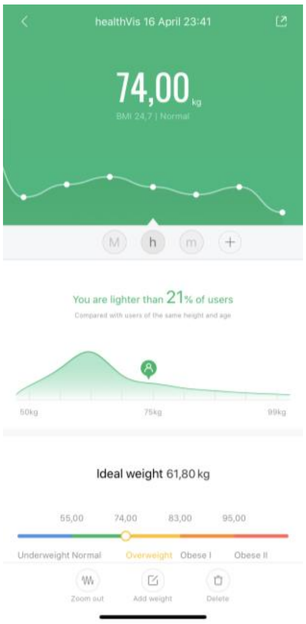


Figure 3. Weight evolution chart. iHealth MyVitals app by iHealth Labs, Inc.

Some apps such as Weight Loss Simple Tracker (Figure 4), Weight Diary Lite (Figure 5) and MiFit (Figure 6) compare user's values with either average health recommendations, specified health recommendations, or other users of the same gender and age group.

Figure 4. Weight Status. Weight Loss Simple Tracker App by Sttir, Inc.

Figure 5. Weight Diary Lite by Curlybrace Apps, Ltd.



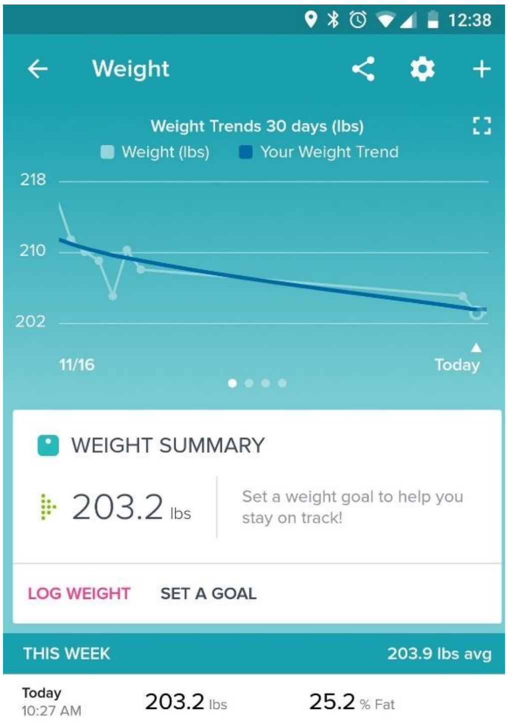
You are lighter than 21% of users

Compared with users of the same height and age

Ideal weight 61,80 kg

Figure 6. MiFit Weight Visualisations. Mi Fit app by Anhui Huami Information Technology Co., Ltd.

Fitbit (Figure 7) and Happy Scale (Figure 8) determine a weight trend in order to reduce fluctuations and make future weight value predictions.



WEIGHT SUMMARY

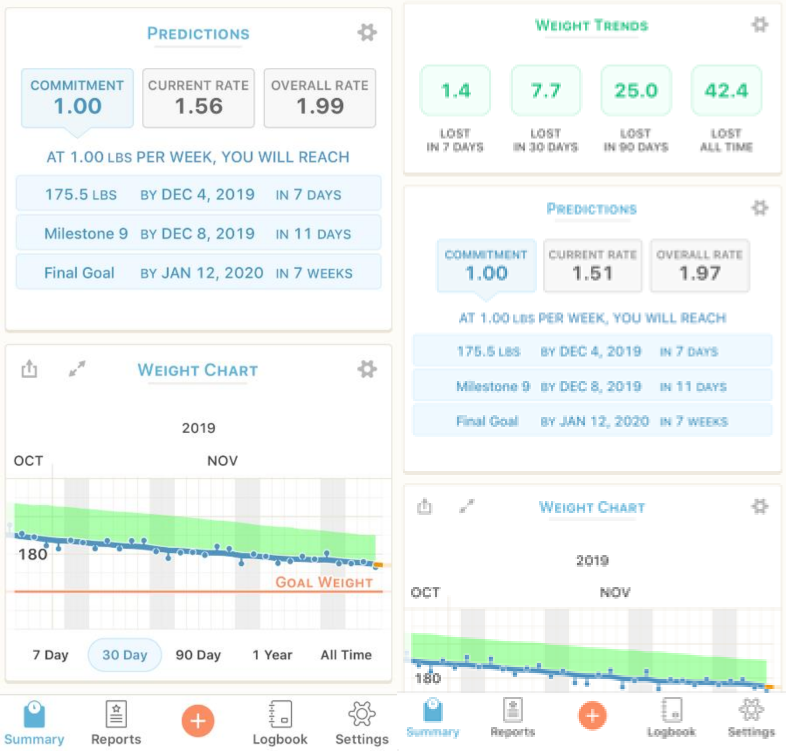
203.2 lbs

Set a weight goal to help you stay on track!

THIS WEEK 203.9 lbs avg

Today 10:27 AM 203.2 lbs 25.2 % Fat

Figure 7. Fitbit Weight Trend. Fitbit: Health & Fitness by Fitbit, Inc.



PREDICTIONS

COMMITMENT	CURRENT RATE	OVERALL RATE
1.00	1.56	1.99

AT 1.00 LBS PER WEEK, YOU WILL REACH

175.5 LBS	BY DEC 4, 2019	IN 7 DAYS
Milestone 9	BY DEC 8, 2019	IN 11 DAYS
Final Goal	BY JAN 12, 2020	IN 7 WEEKS

WEIGHT TRENDS

1.4	7.7	25.0	42.4
LOST IN 7 DAYS	LOST IN 30 DAYS	LOST IN 90 DAYS	LOST ALL TIME

PREDICTIONS

COMMITMENT	CURRENT RATE	OVERALL RATE
1.00	1.51	1.97

AT 1.00 LBS PER WEEK, YOU WILL REACH

175.5 LBS	BY DEC 4, 2019	IN 7 DAYS
Milestone 9	BY DEC 8, 2019	IN 11 DAYS
Final Goal	BY JAN 12, 2020	IN 7 WEEKS

Figure 8. Happy Scale Weight Trends and Predictions. Happy Scale app by Front Pocket.

Some weight-loss apps use goal-oriented visualisations that compare the tracked weight values with the desired value as seen in Figure 9. Some of these apps allow for the customisation of a given goal, while others consider intervals of values based on the BMI value and category (e.g. healthy or overweight). Weight visualisations in the Withings Health Mate app (Figure 10) consider both instances.

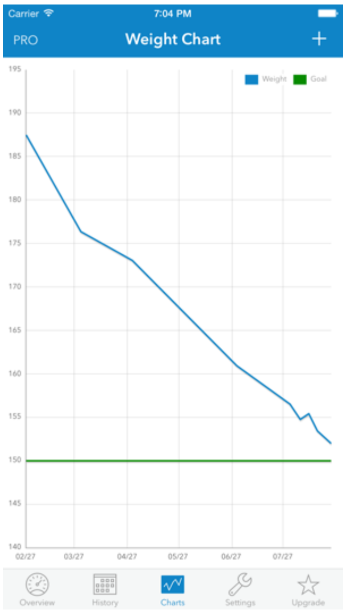


Figure 9. Weight Drop Desired Weight Goal. WeightDrop app by VisualHype GmbH.

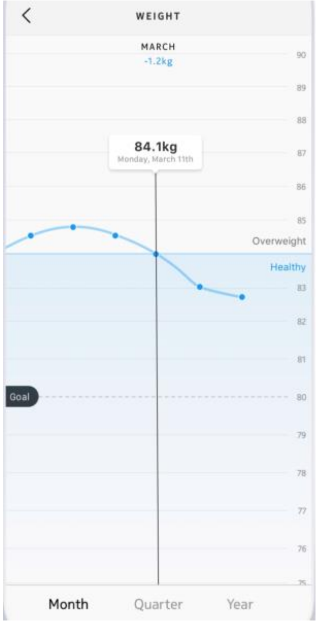
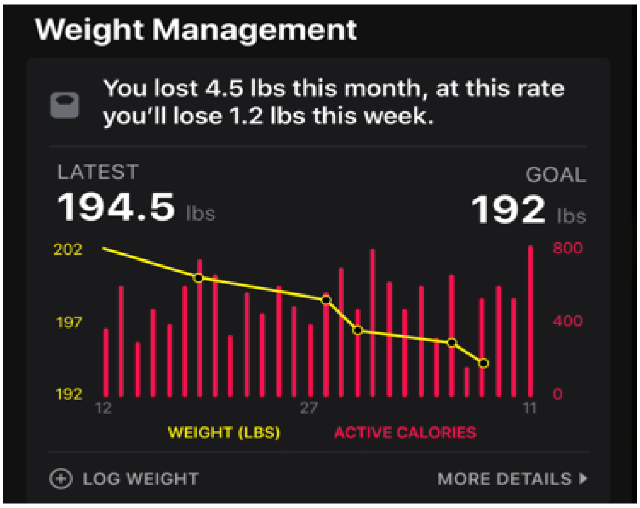


Figure 10. Withings Weight Value, Status and Goal. Withings Health Mate app by Withings.

Literature Review

Direct comparison of weight with calories was a unique comparison provided by FITIV Pulse Heart Rate Tracker (Figure 11), which may provide users with interesting insights.


Weight Management

You lost 4.5 lbs this month, at this rate you'll lose 1.2 lbs this week.

LATEST 194.5 lbs

GOAL 192 lbs

Figure 11. Comparison between Weight and Active Calories.
FITIV Pulse Heart Rate Tracker by MotiFIT Fitness Inc.

Although most goal-oriented apps focus solely on weight loss, some apps such as Fit Journey explore the concept of transforming body composition inciting users to record via photographic evidence how their body looks, as seen in Figure 12. This notion of the embodied experience of body composition transformation is further explored in Model My Diet (Figure 13) where virtual avatars change body composition accordingly to weight values.[MS1]

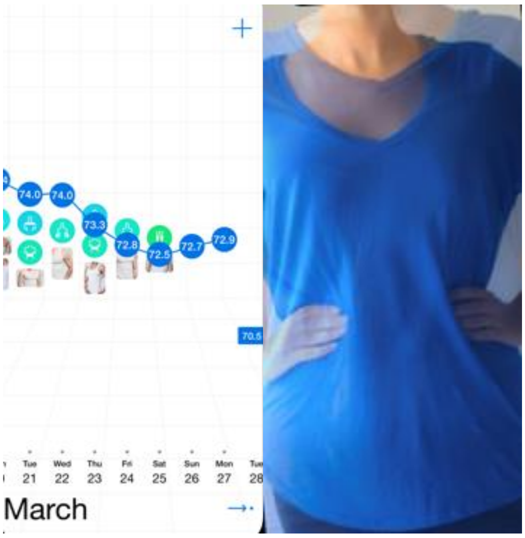


Figure 12. Fit Journey Photographic Evidence of Body Transformation.
Fit Journey - Not Just Weight app by Accessories.

Figure 13. Model My Diet Avatar Visualisation. Model My Diet – Men app and Model My Diet – Women app by Model My Diet Inc.

2.3.2 Visualisations of Blood Pressure Data

Blood pressure (BP) is an indicator of health that is measured in a numerical scale. This measurement is currently the only method to monitor hypertension (NHS, 2019), a chronic disease with high incidence amongst the Portuguese population, "being the cause of the 32% of deaths in Portugal". (DGS, 2013, p. 4) and around the world. (American Heart Association, n.d.; NHS, 2019) According to the UK's NHS (2019), "persistent high blood pressure can increase your risk of a number of serious and potentially life-threatening health conditions".

Blood Pressure, or "the pressure blood exerts against your artery walls" (American Heart Association, n.d.) is recorded in two instances:

1. When the heart beats, referred to as Systolic Blood Pressure, often abbreviated as Sys. or SBP.
2. When the heart rests, referred to as Diastolic Blood Pressure, often abbreviated as Dia. or DBP.

According to the American Heart Association, "Typically, more attention is given to systolic blood pressure (the first number) as a major risk factor for cardiovascular disease for people over 50." (American Heart Association, n.d.) Nonetheless, diastolic BP is still important and can also be used to diagnose hypertension. In a patient-oriented context the values are referred to as Maximum/Minimum (Translated from the Portuguese "Máxima/Mínima") (FPC, 2014), or as Top Number/Bottom Number, for systolic and diastolic blood pressure, respectively.

Although hypertension is the most commonly monitored condition, its polar opposite - hypotension or low blood pressure - must also be communicated by the self-monitoring device.

Due to BP readings consisting of two values they are usually either represented as two separate lines, as seen in Figure 14, or through two visual elements connected by a vertical line indicating the systolic and diastolic values of a reading, as seen in the Withings app, the Blood Pressure+Pulse Lite app, and HeartStar BP Monitor, Figures 17 through 19 respectively, although the style used in Withings visualisation is the most common. Some apps give users the ability to choose between multiple visualisations, as seen in Figures 15 and 16. Nevertheless, Open mHealth (n.d.)[5] suggests that "While interacting with the graph to get detailed readings, consider allowing the user to view blood pressure as one number (e.g. 145/72) instead of forcing them to look in two locations to mentally put together the reading".

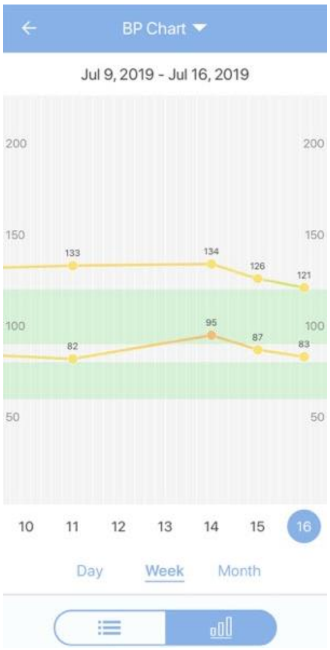


Figure 14. Systolic and diastolic values evolution. MedM Blood Pressure app by MedM Inc.

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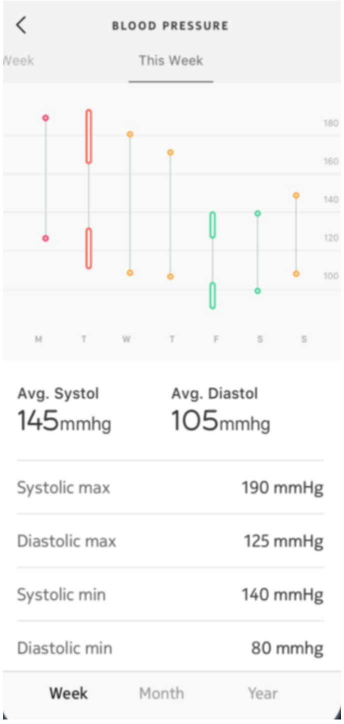
[5] Retrieved from https://www.openmhealth.org/documentation/#/visualize-data/visualization-library/blood-pressure

Figure 15. BP multiple visualisations. Blood Pressure Companion app by Zhao.

Figure 16. Multiple visualisations. Health+ Blood Pressure by Szymon Klimaszewski.

Visual representations of baseline values are provided in order to aid users in understanding their health status, the green areas in Figures 14 and 19, and the blue line in Figure 18.

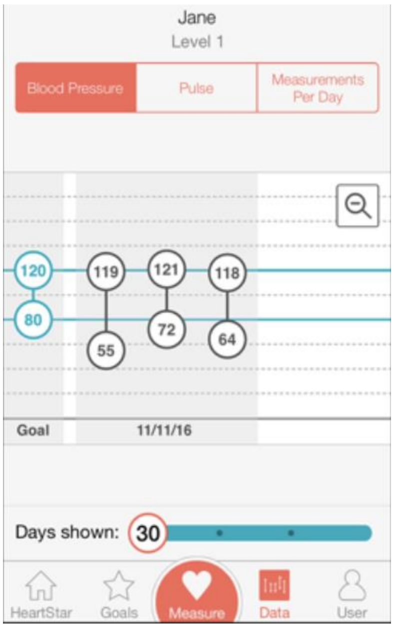


Avg. Systol 145mmhg

Avg. Diastol 105mmhg

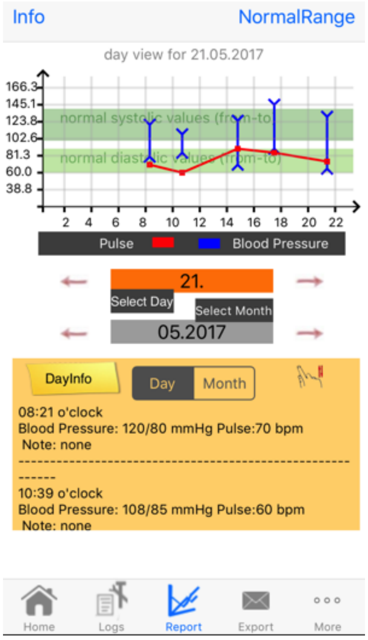
Systolic max	190 mmHg
Diastolic max	125 mmHg
Systolic min	140 mmHg
Diastolic min	80 mmhg

Figure 17. Colour coded BP values. Withings Health Mate app by Withings.



Days shown: 30

Figure 18. Visualisation highlighting baseline BP values (in blue).
HeartStar BP Monitor by Pattern Health.



08:21 o'clock
Blood Pressure: 120/80 mmHg Pulse:70 bpm
Note: none

10:39 o'clock
Blood Pressure: 108/85 mmHg Pulse:60 bpm
Note: none

Figure 19. Visualisation highlighting baseline BP values (in green).
Blood Pressure+Pulse Lite by Michael Heinz.

Contextual Information is integrated in various visualisations, usually only visible upon interaction, and represented through pictograms such as the icons seen in Figure 20, or the emojis present in Figure 21. Sometimes this information is provided in text form as seen in Figure 19.

July 16, 2019 at 4:54 PM

Data was typed in manually

Figure 20. Blood Pressure Visualisation - Icons for Contextual Information.
MedM Blood Pressure app by MedM Inc.

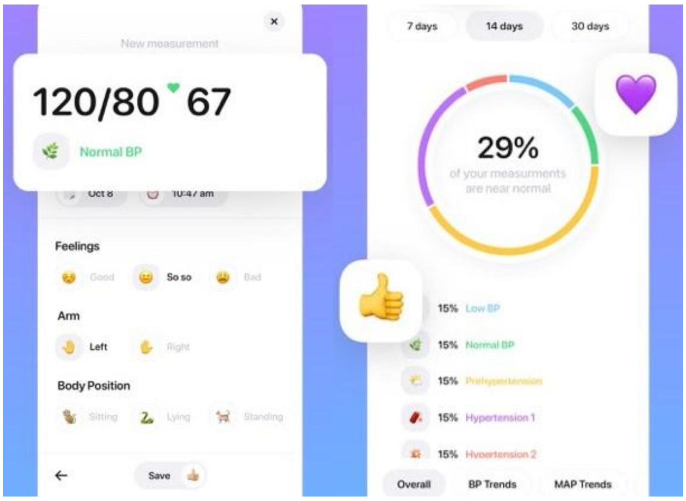
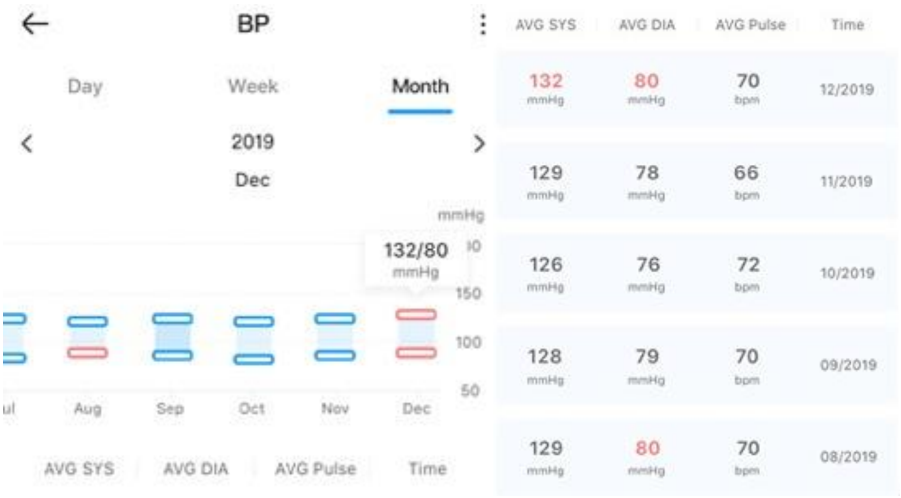


Figure 21. Emojis visualisation. Blood pressure app+ by Maxim Gudzik.

Blood Pressure is often associated with other hearth health data such as Heart Rate, as shown in Figure 19 and Figure 16.

Visualisations often indicate the status of blood pressure levels in readings using a colour-coded system (e.g. red for hypertension), although there is not a consensus on the exact colour code. Nonetheless, colours tend to follow a natural progression from blue to indicate low blood pressure, followed by green for either normal, ideal or healthy values, then yellow for pre-hypertension, orange for Hypertension Stage I, and red for Hypertension Stage II. Outliers include Blood Pressure app+ (Figure 21) which represents Hypertension Stage as purple; HeartStar BP Monitor (Figure 18) uses the colour blue for representing ideal values, while YHE BP Doctor (Figure 22) uses blue for indicating healthy values. Furthermore, as shown on Figure 22, YHE BP Doctor makes use of the colour red to help users identify high values. Health+ Blood Pressure (Figure 16) has a similar approach.

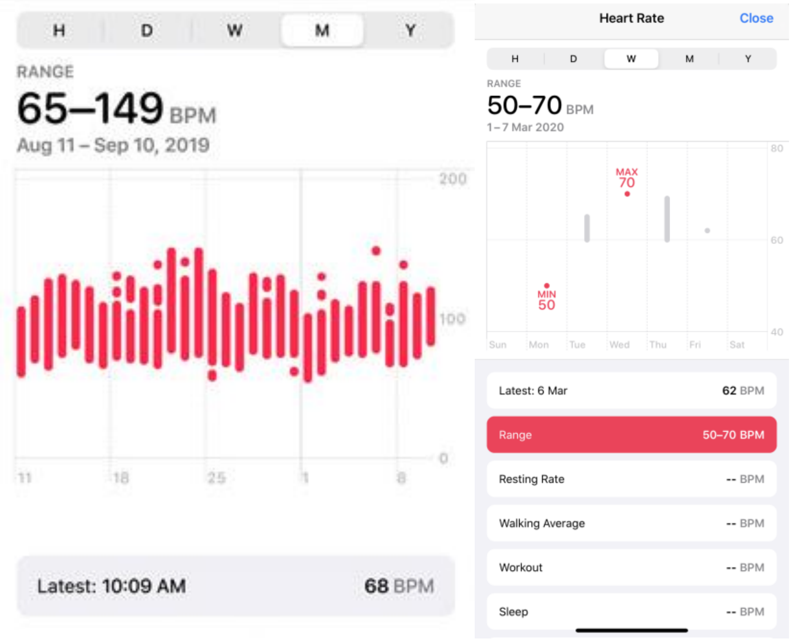


AVG SYS	AVG DIA	AVG Pulse	Time
132 mmHg	80 mmHg	70 bpm	12/2019
129 mmHg	78 mmHg	66 bpm	11/2019
126 mmHg	76 mmHg	72 bpm	10/2019
128 mmHg	79 mmHg	70 bpm	09/2019
129 mmHg	80 mmHg	70 bpm	08/2019

Figure 22. Use of colours to highlight ideal and high values. YHE BP Doctor app by YHE.

2.3.3 Visualizations of Heart Rate Data

The number of times the heart beats in a minute is known as Heart Rate and is measured in beats per minute (BPM). Heart Rate is often measured multiple times throughout the day with different motivations and goals. As such, presenting an average over a time period, as well as the highest and lowest values registered is common practice. Apple Health (Figure 23) uses a form of interaction that automatically indicates the maximum and minimum values registered. In most instances heart rate data is represented in the shape of a line graph (Figure 24, Figure 26, Figure 27, and Figure 28). Sometimes users are able to provide contextual information (Figure 29).



Latest: 10:09 AM 68 BPM

Latest: 6 Mar 62 BPM

Range 50–70 BPM

Resting Rate -- BPM

Walking Average -- BPM

Workout -- BPM

Sleep -- BPM

Figure 23. Apple Health Blood Pressure Graph and Range Interaction. Health app by Apple Inc.

Fitness-oriented visualisations usually categorise heart rate into zones for different activities, i.e. differentiating between resting, sleeping, and exercise, or for determining the intensity of an activity, as seen in Figure 24, Figure 25, Figure 26, and Figure 27.

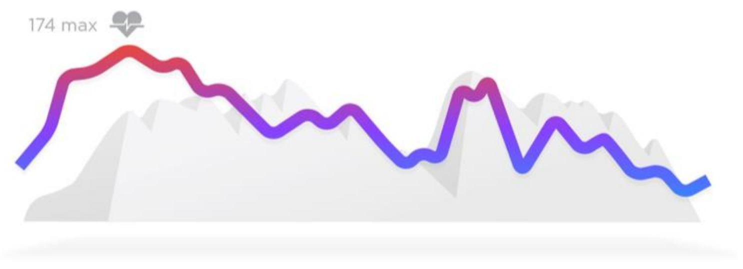


Figure 24. TomTom Sports Heart Rate Graph. Sports app by TomTom.

Figure 25. Garmin Health Heart Rate. Garmin Connect app by Garmin.

Figure 26. MiFit Heart Rate. Mi Fit app by Anhui Huami Information Technology Co., Ltd.

Instant Heart Rate: HR Monitor (Figure 28), along with its premium version, and Cardiio (Figure 29) allow users to measure their heart rate using the phone’s camera and flash, presenting a real time approximate visualisation of the users’ heartbeat.

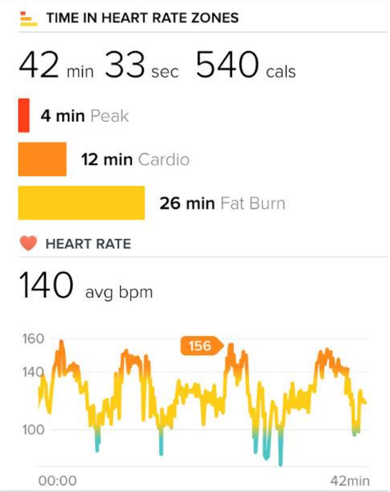


Figure 27. Fitbit Heart Rate Graphic. Fitbit: Health & Fitness app by Fitbit, Inc.

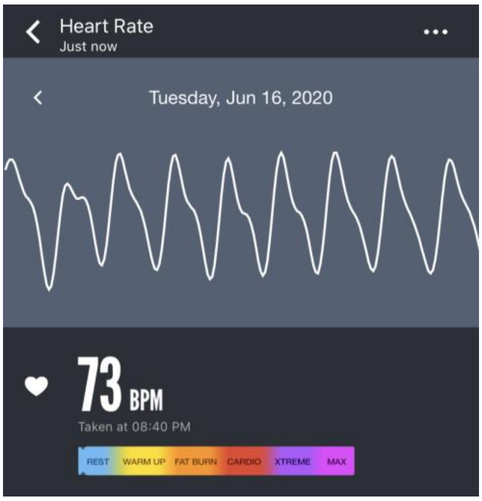
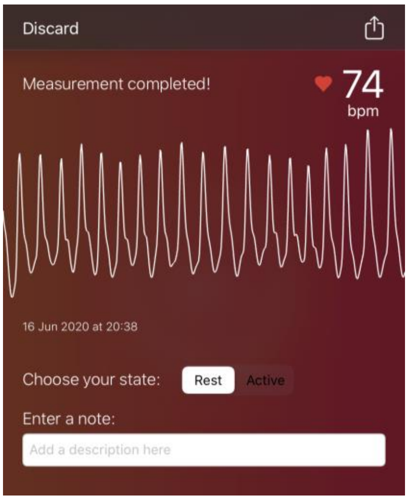


Figure 28. Heart rate visualization. Instant Heart Rate HRMonitor app by Azumio Inc. User screenshot.


Measurement completed!

Choose your state: Rest

Enter a note:

Figure 29. HR visualisation. Cardiio: Heart Rate Monitor app by Cardiio, Inc. User screenshot.

2.3.4 Visualisations of Number of Steps Data

The number of steps is an indicator of a users' activity level. As previously mentioned, the goal of 10000 steps a day is recommended, although most reviewed apps allow users to set their own goals. Fitbit (Figure 30) rewards users with a star icon on days they achieved their goal. As demonstrated by Kanstrup et al. (2018) such reminders may result in negative feelings for users who struggle to reach their goal, each day they can't do it is perceived as a failure. Apple Health (Figure 31) brings a different approach, by comparing users current step count with their average.

This Week 64,970 steps

Fri	11,259 steps	★
Thu	9,320 steps	★
Wed	7,309 steps	
Tue	11,172 steps	★
Mon	7,880 steps	

Figure 30. Steps Count. Fitbit: Health & Fitness app by Fitbit, Inc.

Number of steps data may be complemented with travelled distance data (Figure 32).

This data is usually represented either in a bar graph (Figure 30, Figure 31, and Figure 33) or a progress bar (Figure 34), usually presented as a radial progress bar as seen in Figure 35.

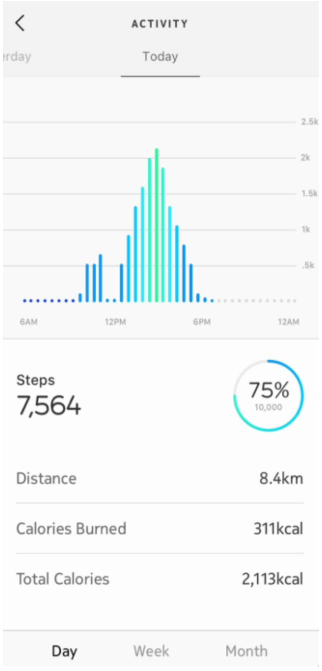

Steps

You're taking more steps than you usually do by now.

● Today 4,028 steps

● Average 2,640 steps

Figure 31. Apple Health steps count visualisation. Health app by Apple Inc.



Steps
7,564
75%
10,000

Distance 8.4km

Calories Burned 311kcal

Total Calories 2,113kcal

Figure 32. Number of steps data visualisation complemented with travelled distance. Withings Health Mate app by Withings.

Sometimes a colour scale is used to classify steps count, as seen in Figure 32 and Figure 33, although it isn't common practice.

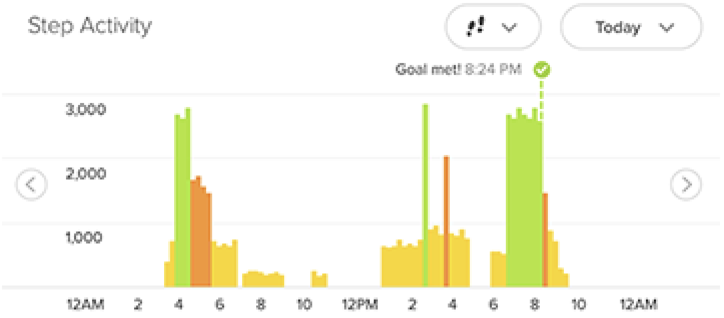


Figure 33. Fitbit dashboard steps count. Health & Fitness Dashboard by Fitbit, Inc.


Steps

12,750

GOAL
15,000

Figure 34. Garmin Connect Steps Count Garmin Connect app by Garmin.

Figure 35. Samsung Steps Count. Samsung Health app
by Samsung Electronics Co., Ltd. User screenshot.

2.4 Summary

Personal health data can play an informative role for users of HIT. As Lupton indicated, mHealth solutions can help patients communicate with health professionals; aid patients monitor their health status; improve adherence to treatments; and encourage laypeople to engage in preventive health measures. Users of these products, as identified by Gimpel et al.'s study, and Neff & Nafus review, look to health self-tracking solutions in order to understand their bodies, cultivate habits, improve their health status, optimize their bodies, interact and compare themselves with similar people, and even for entertainment. Information obtained from personal health data may contribute to improving users' health literacy, described by Ratzan & Parker as one's ability to procure, process, and understand health information properly. Improving health literacy is important because low health literacy is associated with poorer overall health.

When systems fail to inform patients, it may prove prejudicial, causing them anxiety and other negative feelings. As such, there is a need to design systems that present information while also contributing to the patient's understanding of personal health data and its role in their health status, considering their specific individual needs.

Information Visualisation plays an important role in aiding users in their journey of gaining insight from data, although traditional InfoVis methods are aimed at data professionals and do not fit self-trackers' needs. Furthermore, in the Health Domain, health information visualisations are often aimed at clinicians and not on patients.

Self-monitoring smartphone apps provide a class of health data visualisations meant for patients and laypeople. In order to understand how described systems, communicate with users a review of current available apps was performed. Overall, visualisations allow users to identify their average, the highest and lowest registered values, and evolution over a period of time. Specific conclusions are presented below:

- Weight Data is often represented through line graphs. Sometimes other related metrics are included such as BMI and Body Fat. Most weight data self-monitoring apps come from a weight loss perspective, thus are goal-oriented.
- Blood Pressure Data consist of Systolic and Diastolic BP values. Visualisations either separate these values into separate lines or group them together. Due to the prevalence of hypertension and associated risks, high values are given more importance. Risk assessment is often portrayed through a colour scale that usually goes from blue for low values, then green for normal, yellow for pre-hypertension, orange for hypertension type I and red for hypertension type II, although many apps use their own scheme. Users are often able to provide contextual information that may affect their readings, either in visual form or through written notes.
- Heart Rate Data is usually represented in a line graph. In fitness-oriented apps this data is categorised into heart rate levels, with an associated colour scheme.
- Number of steps data is an indicator of activity. Usually it is represented in a goal-oriented progress bar, for daily visualisations, and in a bar graph for longer timeframes. Sometimes line graphs are also used. Goal-achievement may be represented with pictograms, lines, or colours.

3. Human-Centred Design Methods for Health Information Visualization

3.1 Solution Description

Having identified the state of the art of health self-monitoring mobile apps and the subsequent need to design visualisations that meaningfully inform patients, this section presents the solution suggested by this research, and explains how it answers to the problem.

Current personal health visualisations are failing to aid marginalised users of SMD, such is the case of chronic disease patients who experience inequalities. The European Institute for Gender Equality (EIGE, n.d.) describes that people who belong to marginalised groups experience a higher "risk of inequalities in terms of access to rights and use of services and goods in a variety of domains, such as access to education, employment, health, social and housing assistance, protection against domestic or institutional violence, and justice".

Senior citizens have been identified with having a high prevalence of chronic disease, while experiencing challenges interpreting health messages, and overall poor health status, due to low health literacy (Berkman et al., 2011). Health information visualisations, designed for users and with users, have been demonstrated as being able to aid senior citizens understand the presented information. (De Croon et al., 2017, Verdezoto & Grönvall, 2015)

As such, by involving representative participants of the user population directly into the design process, through a participatory design approach, the resulting visualisations may come closer to participants' needs, mental models and implicit values, thus improving patient readability of heath data.

Ideally, the solution would directly involve senior citizens via PD practices such as workshops, cultural probes and focus groups. Unfortunately, the desired user population proved unavailable, due to the coronavirus disease (COVID-19) declared by the World Health Organization (WHO, 2020) as a pandemic, and consequent declaration of a national state of emergency by the Portuguese Republic (2020) decreeing a series of preventive measures to slow the outbreak spread of COVID-19, requiring social distancing, amongst other precautions. Furthermore, senior citizens and chronic disease patients, highlighting that “hypertensive, diabetic, cardiovascular, chronic respiratory disease, and oncological patients” (p. 2) ought to exercise further caution.

As such, the solution to approach the problem was divided into two stages - User Research, and Design & Evaluation.

The User Research, documented in chapter 4, consisted of a survey and exploratory interviews, while the Iterative Design Stage, chapter 5, consisted in designing visualisations and explore how visual graphical elements could map health data, both being tested with participants.

First, a survey was used to acquire a large amount of quantitative data on health self-monitoring context, habits, and challenges. The survey also served as a recruiting point for patients of chronic disease willing to participate in the next stage of the research. The survey had the additional goal of identifying which metrics, if any, were more challenging for participants to understand. From the analysis of the survey, blood pressure was identified as the metric to be less clear to users.

The next stage in User Research consisted of semi-structured interviews allowing participants to expand on their conditions and personal challenges. To conclude the interviews, participants were asked to evaluate current blood pressure visualisations.

Having retrieved insights from the user population, the Design & Evaluation (documented in chapter 5) stage began. Blood Pressure data variables were defined, classified, categorised, and then mapped onto visual design elements. These visual elements were then used to create three prototypes of visualisations (graphs, a table, and a calendar) with the intent to propose and evaluate improvements in the communication of blood pressure status. The designed data mapping scales and visualisations were evaluated via remote interviews. Participants were asked several exploratory questions about which scales they preferred for representing different blood pressure data and health risk. Participants then identified which visualisations they preferred for distinctive goals.

3.2 Methods

This research follows a research-through-design (RtD) approach, using design methods as part of the research process. RtD is established as a legitimate design research activity, being commonly used both in the field of Design and Human-Computer Interaction (HCI) (Zimmerman et al., 2010). These methods have been extensively discussed in the design community on how they should be practiced, and what they should produce, while the application of RtD methods aren’t established as a set of concrete tools, but “more of an attitude to doing work than a systematic method of inquiry” (Zimmerman et al., 2010, p. 311).

Furthermore, Zimmerman et al., (2010) identified that established researchers “view RtD as a designedly inquiry focused on the making of an artefact with the intended goal of societal change” (p. 311), and acknowledging their theoretical contributions, although also identifying some shortcomings, specifically, “a still-present romantic view of design, the implicit nature of design theory to come from the making of things, and administrative difficulties with doing this kind of work both in academic and industrial settings” (p. 316), on the other hand, they concluded that such a point-of-view can be “destructive when held by researchers, because it seems to say there is not a place for design inquiry to make a systematic, rigorous, and relevant research contribution.” (p. 316).

Another important aspect of this research is the use of prototyping as a tool for giving direction to the research, exercising participatory co-design tools that directly involve users in the design process. These methods hope to generate contextual knowledge fundamental for the purpose of this study. Sanders & Stappers (2014), described the roles iterative prototyping can play, in the following way:

- “Prototypes evoke a focused discussion in a team, because the phenomenon is ‘on the table’.
- Prototypes allow testing of a hypothesis.
- Prototypes confront theories, because instantiating one typically forces those involved to consider several overlapping perspectives/theories/frames.
- Prototypes confront the world, because the theory is not hidden in abstraction.
- A prototype can change the world, because in interventions it allows people to experience a situation that did not exist before.” (p. 6).

Furthermore, this research embraced a HCD approach, a set of iterative non-linear processes that place humans in the centre of the design process. HCD methods have been thoroughly described by the International Standards Association (ISO), through the standard ISO 9241-210:2019 of HCD for Interactive Systems (ISO, 2019), also illustrated in Figure 36 made by Beuscart-Zéphir et al., (2013).

- *Plan the HCD design process*: the first step to any activity should include the planning of the work that is about to be done.
- *Understand and Specify Context of Use*: this stage involves researching the user population, their environment, their tasks, and identifying the corresponding values, needs, motivations, and challenges.
- *Specify the User Requirements*: this stage follows a natural progression of the process, having user requirements be specified, considering the results of the previous step.
- *Produce Design Solutions to meet the user requirements*: during this stage is done the de facto design of prototype solutions.
- *Evaluate the design against requirements*: the designed solutions should be tested with end-users in order to assert if they answer users’ problems.

- Due to the iterative nature of the HCD process these stages may happen simultaneously with each other. Evaluations are often performed throughout the design process. Each time the produced elements should be critically analysed and iterated whenever necessary.

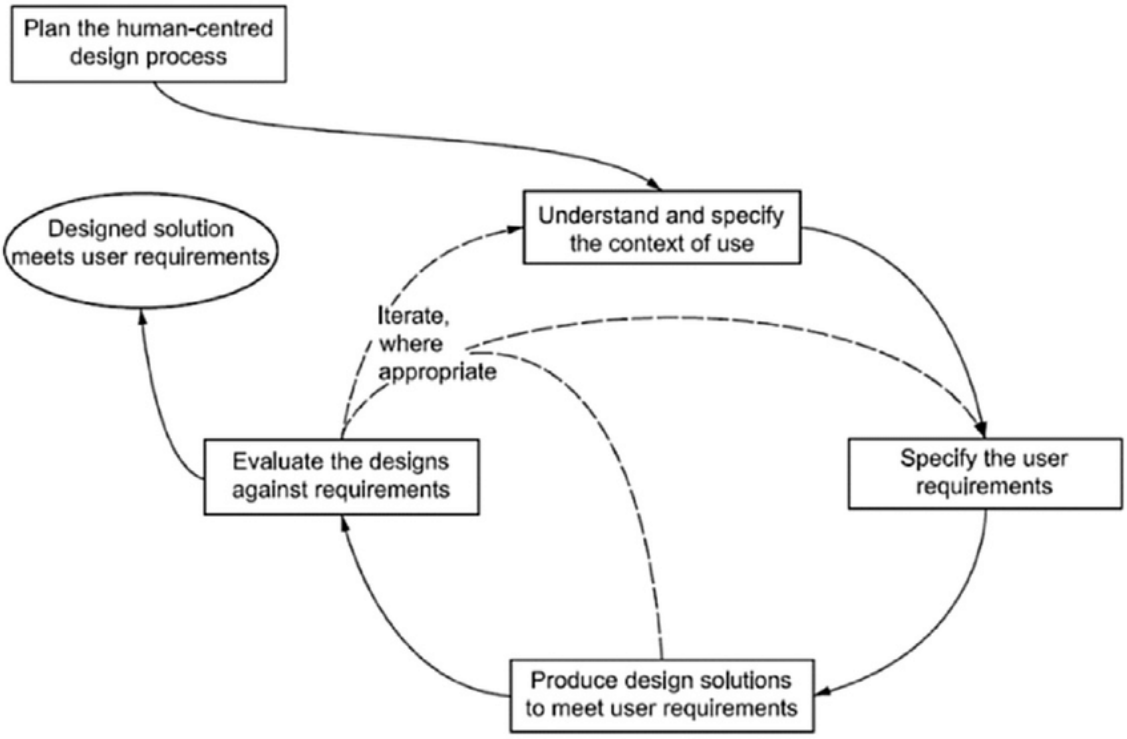


Figure 36. The Human-Centred Design (HCD) process adapted from the ISO 9241-210:2010[6]

ISO (2019) defines HCD as following:

In order to produce results focused on the user population, participants were incorporated into the design process, following principles of inclusivity, participatory design and co-design. The Scandinavian Tradition of PD involves the direct participation of users (and stakeholders) in the design process to generate tacit and holistic knowledge.

User research methods were used to gather contextual data about the user population. A survey was designed to obtain a large amount of quantitative data about health self-monitoring practices, in order to identify which metrics required a participatory redesign. Interviews were then conducted to obtain contextual knowledge about users' self-monitoring experience. The resulting qualitative data was analysed through thematic analysis (Braun & Clarke, 2012), which involves identifying recurring themes amongst the information provided by participants. These user research methods place the user as the subject of research (Sanders & Stappers, 2014).

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[6] Reprinted from "Evolution of Human Factors Research and Studies of Health Information Technologies: The Role of Patient Safety" (Beuscart-Zéphir, 2013)

During the design stage, a series of visual graphical elements were used to map blood pressure data values, and blood pressure information visualizations were designed. The designed solutions were approached from a explorative perspective, in an attempt to approximate the work to traditional codesign methods of workshop and design games. Gaver and colleagues (1999, 2004)'s cultural probes were a large influence for this work, in the sense that values were visually mapped in an ambiguous approach to obtain subjective information that represents users lived experiences.

Finally, usability evaluations were conducted for the designed solutions, and the results of the investigation structured into guidelines for human-centred health information visualisations.

4. User Research

This section describes the design, application and analysis of user research instruments. Following HCD practices, the solution had to begin with understanding the user population.

In order to define the context of health self-monitoring and which metrics users found the least clear, a survey was conducted. Following the survey, a group of semi-structured interviews was performed, in order to give participants a chance to elaborate their previous answers, provide insights on their personal health challenges, and to evaluate current visualisations.

4.1 Survey

The goal of the survey was to understand the demographics of self-trackers and the context of said tracking, considering corresponding challenges and opportunities for improving the tracking and visualisation experience. The survey contemplated questions for each of the previously established metrics: weight, number of steps, heart rate, and blood pressure. The last part of the survey acted as a recruitment point for the next stage of our research - interviews with chronic disease patients.

The survey, presented in Appendix A, starts with a selection of one from three possible routes: (A) participant self-monitors health, (B) participant monitored their health in the past, and (C) participant doesn't monitor their own health.

Route A inquires participants about the context of self-monitoring, this includes the frequency ("How often do monitor your [metric]?"), motivation ("Why do you monitor your [metric]?"), data source ("How do you obtain your [metric] data?"), self-monitoring physical environment ("Where do you monitor your [metric] data?"), tools used for data analysis ("How do you analyse your data?"), satisfaction with current methods ("How satisfied are you with [metric] data collection and analysis methods), and difficulty interpreting data ("How difficult do you find interpreting [metric] data?"). Questions about each metric were separated into different sections (weight, number of steps, heart rate, blood pressure). A final question asked users to identify other monitored metrics. The objectives, constructs, and questions are detailed in Table A1. Most multiple-choice questions included an open space for users to input non-considered instances, tagged as “Other”.

Route B posed questions designed for identifying which metrics participants used to monitor, and the reason for them to stop monitoring their health. The remaining questions focused on identifying the monitoring context, similar to the ones in route A.

Route C comprised one multiple-choice question, “Why don’t you monitor your health?”, contemplating an open option.

The final section of the survey, common to all routes, is meant for collecting sociodemographic data. It asks about participants’ age, gender, education, employment, and chronic disease status. Finally, participants identified with having a chronic disease were able to leave their contact information in order to participate in the following step of the user research: the interviews.

The survey was created on Google Forms and consequently distributed via University of Porto’s dynamic email to 9 different faculties, the Fraunhofer AICOS community, and shared on social media platforms.

Participants

Initially, the sample size consisted of 1100 responses, but 270 of them were considered invalid for having been left blank. Therefore, 830 responses were admitted, which translates into 75.5% of the initial sample.

Most participants (45,8%) belong to the age group between 20 and 29 years old, this is a consequence of the high number of participants from the university database. Nonetheless, the average age group was 30 to 39 years old, since the age range went from 17 or less to 70 or more. Gender wise, the vast majority of the participants identified as female, while only 4 as non-binary. Regarding education and employment, most participants had a bachelor’s degree and half of them were full-time students[7]. The remaining values can be observed in Appendix A, Table A2.

Results

More than half of participants reported practising self-monitoring, while about a third reported not monitoring their health. Only 63 participants used to monitor their health but no longer do so. The relationship between health self-monitoring and the sample’s sociodemographic distribution, i.e. age (Figure 37), gender (Figure 38), education (Figure 39), and employment (Figure 40), were visualised as radial treemap charts, allowing for insightful analysis regarding the distribution of self-monitoring acceptance.

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[7] A significant amount of the respondents had experience in the health domain (from students of the faculties of sports, medicine, biomedic sciences and pharmacy; researchers at Fraunhofer-AICOS who work with mHealth solutions; and healthcare providers working at a local hospital)

User Research

Figure 37 demonstrates the age distribution of participants. The only age group who is more likely not to monitor their health, albeit by a small amount, is the 18-19 range, while participants of the remaining groups were more likely to monitor their health.

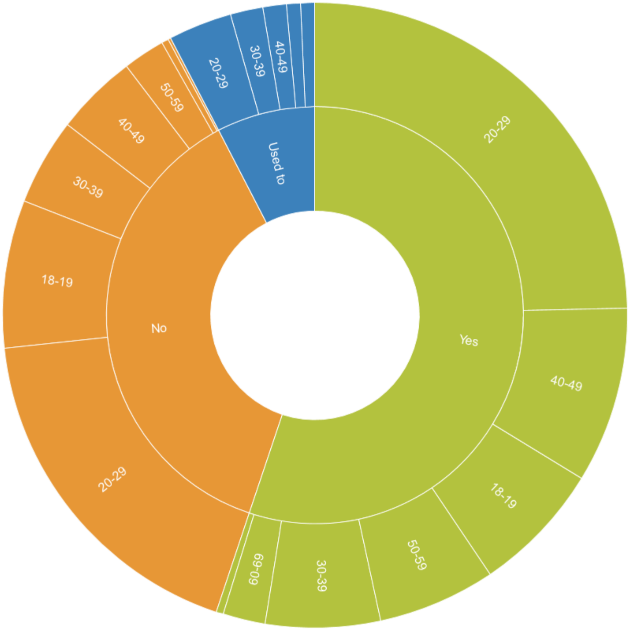

Figure 37. Radial Treemap Visualisation of Age Distribution of Self-monitoring Acceptance.

Since the sample was predominantly female, the same distribution was observed amongst all groups. The number of females that reported practising self-monitoring was substantially higher than the ones who don’t or used to. The number of males who reported self-monitoring was slightly higher than those who don’t. This suggests that participants who identified as female were more likely to self-monitor their health, as seen in Figure 38. From the 4 participants who identified as non-binary, half of them reported self-monitoring and the rest not doing it, although the sample of non-binary participants was too small to draw any conclusions.

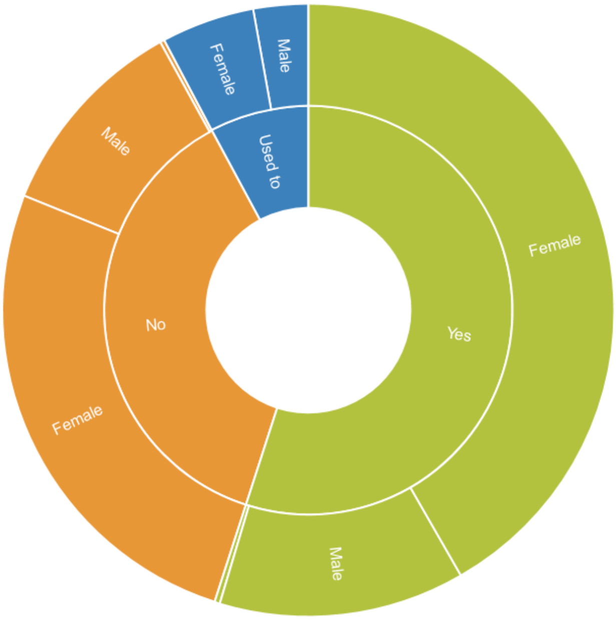

Figure 38. Radial Treemap Visualisation of Gender Distribution of Self-monitoring Acceptance.

Regarding the relationship between self-monitoring acceptance and education level (Figure 39), participants who completed higher education degrees (Bachelor, Masters, Doctorate) were more likely to self-monitor their health, while those who didn't (High School or equivalent, and Less than high school degree) presented almost the same proportion between monitoring and not monitoring.

Figure 39. Radial Treemap Visualisation of Education Distribution of Self-monitoring Acceptance.

User Research

The relationship between employment status and self-monitoring acceptance (Figure 40), shows that students are just as likely to self-monitor their health as they are not to. Their working counterparts and full-time workers were more likely to self-monitor than not to.

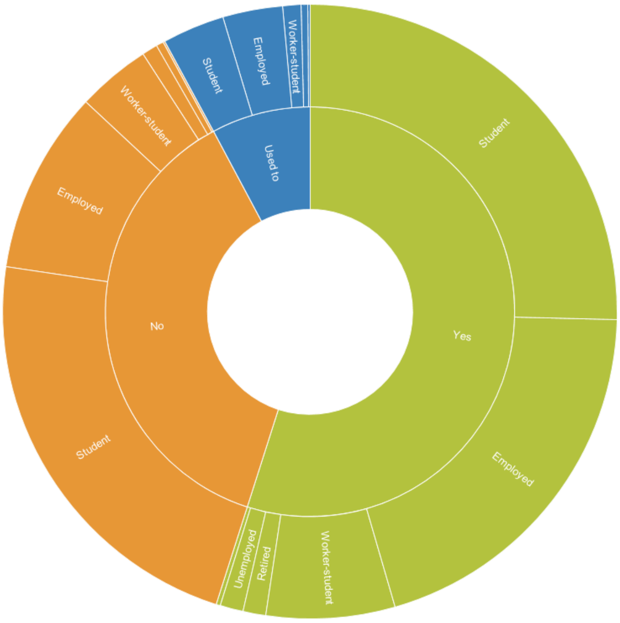

Figure 40. Radial Treemap Visualisation of Employment
Distribution of Self-monitoring Acceptance.

Finally, participants who reported having been diagnosed with a chronic disease were more likely to self-monitor their health (Figure 41), while participants with no chronic disease were just as likely to self-monitor or not.

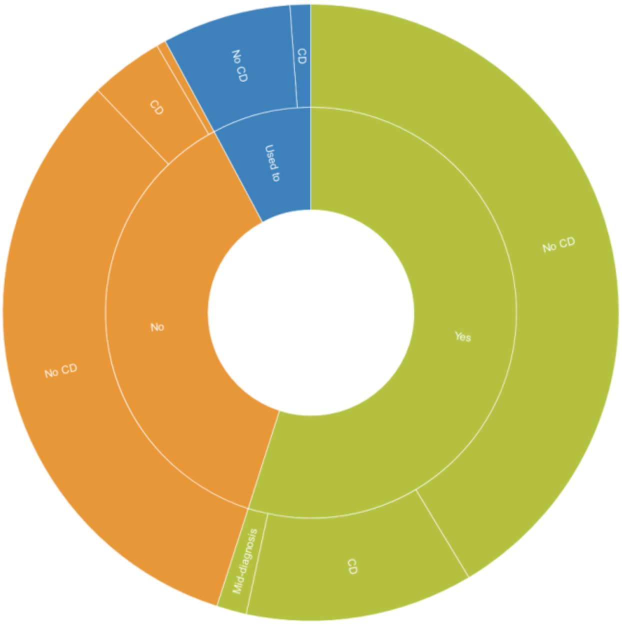

Figure 41. Radial Treemap Visualisation of Chronic Disease Status
Distribution of Self-monitoring Acceptance.

Route A – Comparing Monitored Metrics

From the participants who reported practising self-monitoring, the majority of them monitored their weight (398), less than half measured their steps (209) and their heart rate (188). The least measured metric was blood pressure (198), as illustrated in Figure 42.

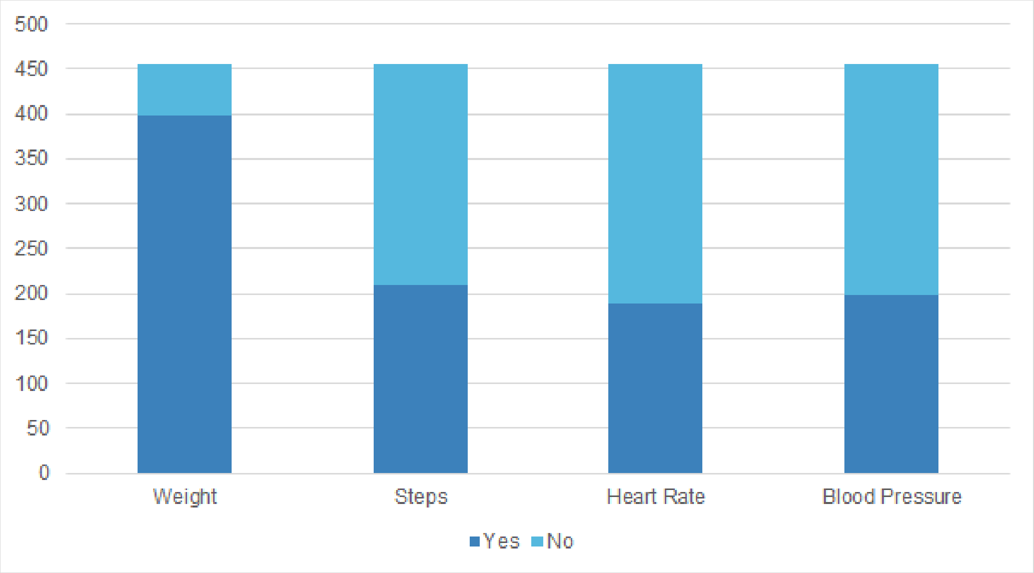

Figure 42. Distribution of monitored metrics.

In order to identify which metrics, the user population had trouble interpreting, participants were asked to rate their difficulty in interpreting each metrics data. Ratings were formalised as a Likert Scale, as recommended by Baxter et. Al (2015), a 7-point scale was used to measure the bipolar construct of difficulty. The scale labels went from 1-Extremely Difficult, 2-Moderately Difficult, 3-Slightly Difficult, 4-Neither Difficult nor Easy, 5-Slightly Easy, 6-Moderately Easy, and 7-Extremely Easy.

Table 1 shows that 74,1% of participants identified weight data as easy to interpret, easy being defined as values higher than 4. The mean value was 5.5, or between slightly easy and moderately easy. The most common option was 7, or extremely easy.

Table 1

Difficulty in Interpreting Weight Data

Likert Scale	Participants[a]	%
1	3	0.8
2	9	2.3
3	24	6.0
4	67	16.8
5	63	15.8
6	109	27.4
7	123	30.9

[a] *n*=398.

Table 2 shows that 75% of participants identified step count data as easy to interpret, easy being defined as values higher than 4. The mean value was 5.4, or between slightly easy and moderately easy. The most common option was 6, or Moderately Easy.

Table 2

Difficulty in Interpreting Step Count Data

Likert Scale	Participants[a]	%
1	2	1.0
2	8	3.8
3	12	5.7
4	30	14.4
5	39	18.7
6	63	30.1
7	55	26.2

[a] *n*=209.

Table 3 shows that 75,2% of participants identified heart rate data as easy to interpret, easy being defined as values higher than 4. The mean value was 5.2, or between slightly easy and moderately easy. The most common option was 6, or Moderately Easy.

Table 3

Difficulty in Interpreting Heart Rate Data

Likert Scale	Participants[a]	%
1	2	1.1
2	8	4.3
3	10	5.3
4	41	21.8
5	30	16.0
6	55	29.3
7	42	22.3

[a] *n*=188.

Table 4 shows that 72,2% of participants identified blood pressure data as easy to interpret, easy being defined as values higher than 4. The mean value was 5.3, or between slightly easy and moderately easy. The most common option was 6, or Moderately Easy.

Table 4

Difficulty in Interpreting Blood Pressure Data

Likert Scale	Participants[a]	%
1	2	1.0
2	5	2.5
3	21	10.6
4	27	13.6
5	35	17.7
6	62	31.3
7	46	23.2

[a] *n*=198.

Due to the complex nature of blood pressure data, participants were then asked to rate, in a 5-point Likert scale, how clear the following concepts were for them: blood pressure (Table 5), systolic blood pressure (Table 6), and diastolic blood pressure (Table 7). The scale labels were 1-Not at all Clear, 2-Slightly Clear, 3-Moderately Clear, 4-Very Clear, and 5-Extremely Clear.

Regarding the clarity of the general concept of BP (Table 5), 93.4% of participants identified the concept as Moderately Clear or higher. The average value was 3.9, almost very clear, and most participants (36.9%) identified the concept as 5-Extremely Clear.

Table 5

Clarity of the meaning of Blood Pressure

Likert Scale	Participants[a]	%
1	3	1.5
2	10	5.1
3	63	31.8
4	49	24.7
5	73	36.9

[a] n=198.

Regarding the clarity of the concept of Systolic BP (Table 6), 71.7% of participants identified the concept as Moderately Clear or higher. The average value was 3.4, between moderately clear and very clear, and most participants (26.8%) identified the concept as 5-Extremely Clear

Table 6

Clarity of the meaning of Systolic Blood Pressure

Likert Scale	Participants[a]	%
1	16	8.1
2	40	20.2
3	49	24.7
4	40	20.2
5	53	26.8

[a] n=198.

Regarding the clarity of the concept of Diastolic BP (Table 7), 71.2% of participants identified the concept as Moderately Clear or higher. The average value was 3.4, between moderately clear and very clear, and most participants (26.8%) identified the concept as 5-Extremely Clear.

Table 7

Clarity of the meaning of Diastolic Blood Pressure

Likert Scale	Participants[a]	%
1	17	8.6
2	40	20.2
3	48	24.2
4	40	20.2
5	53	26.8

[a] *n*=198.

Weight Data Monitoring Context

As shown in Appendix A, Table A3, the majority of participants reported monitoring their weight every week. Monthly measurements were the second most common frequency. The least common choices were "annually" and "several times a day".

The most-reported motivation for monitoring weight was managing personal health. Other significant reported motivations for self-monitoring are, in decreasing order, achieving a goal, curiosity, getting to know your own body, and cultivating healthy habits.

Most participants obtained their data through household scales. 12.6% of participants used professional monitoring devices such as gym's (or doctor's or dietician) scales, which may provide other information such as BF%, lean mass percentage, or BMI. Only 9 participants reported using biosensors to obtain their weight data.

The vast majority of participants reported weighing themselves independently at home, while only 1.3% reported needing assistance.

Most participants reported analysing and keeping track of their data through memory, or mobile apps, while 15.1% of participants reported not doing so. The least reported methods were charts or other visualisations, statistics, health records provided by health services, and web apps.

From the 398 participants who reported monitoring their health, 171 answers to the open question on how participants made decisions based on their data were left blank. The answers were coded into the following actions: Adjusting habits (61,9%), Monitoring evolution (11,3%), Doing nothing (10,5%), Achieving self-knowledge (8,8%), Reporting to healthcare providers (4,2%), and Comparing with other metrics (3,3%).

Step Count Data

The vast majority of participants reported monitoring their step count daily, while 11.4% reported monitoring several times a day. The least common options were “monthly”, “every six months” and “annually”, (Appendix A, Table A4).

The most-reported motivation for monitoring one’s step count was curiosity. Other significant reported motivations for self-monitoring are, in decreasing order: cultivating healthy habits, managing personal health, and achieving a goal.

More than half of participants obtained their data through mobile apps, or wearables, while only 6 participants reported using professional monitoring devices to obtain their step count data.

The vast majority of participants reported continuously monitoring their step count. No participants reported needing help to monitor their step count.

Most participants reported analysing and keeping track of their data through mobile apps, while 15.6% of participants reported not analysing it at all. The least reported methods were health records provided by health services, tables, analysis done by caretakers or health professionals, web apps, and pen and paper.

From the participants who reported monitoring their step count, 126 answers to the open question on how participants made decisions based on their data were left blank. The answers were coded into: Adjusting Habits (46,9%), Doing nothing (19.8%), Monitoring evolution (15,6%), Achieving self-knowledge (11,5%), Reporting to healthcare providers (3.1%), Comparing with other metrics (2.1%), and Sharing with peers (1%). All results are presented in Appendix A, Table A4.

Heart Rate Data

From the participants who reported monitoring their heart rate (HR), the majority reported monitoring it on a daily basis, while 13.3% reported monitoring several times a day. Other relevant frequencies were weekly, monthly, and when they felt the need to monitor. The least common frequency was annually, representing only 1.6% of participants (Appendix A, Table A5).

The most reported motivation for monitoring one’s heart rate were curiosity and managing personal health. Other significant reported motivations were getting to know one's own body function and understanding sensations or symptoms. Most participants obtained their data through self-monitoring devices, or wearables. Other relevant data sources were professional monitoring devices, mobile apps, and biosensors. Only 2.1% of participants reported manually monitoring their heart rate.

The vast majority of participants reported monitoring their HR at home, independently, with only 3.7% reported needing help. 30% of participants reported continuously monitoring their heart rate.

Most participants reported analysing and keeping track of their data through mobile apps while 15.4% of participants reported not doing any analysis. 22.8% of participants reported analysing by memory. The least reported methods were health records provided by health services and tables, both representing 3.9% of participants, followed by pen and paper, and web apps.

From the 188 participants who reported monitoring their HR, 102 answers to the open question on how participants made decisions based on their data were left blank, while 2 were regarded as invalid. The answers were coded into: Adjusting habits (31.5%), Doing nothing (19.6%), Monitoring evolution (21.7%), Achieving self-knowledge (13%), Reporting to healthcare providers (13%), and Comparing with other metrics (1.1%). All results are presented in Appendix A, Table A5.

Blood Pressure Data

From the participants who reported monitoring their blood pressure, the majority reported doing it monthly. 22,7% of participants reported only doing it when they felt the need of checking it, and 20.7% reported a frequency of once every six months. The least common frequencies were daily, annually, and multiple times a day.

The most-reported motivations for monitoring one's blood pressure were managing personal health, following health professionals' recommendations, understanding sensations or symptoms, curiosity, and self-knowledge.

Most participants obtained their data through self-monitoring devices or professional monitoring devices. While only a minority of participants using mobile apps, biosensors, or wearables.

More than half of participants reported monitoring their blood pressure at home, independently, while 5.1% reported needing help. 25.4% of participants reported measuring their blood pressure at a hospital or health centre, while the remaining options were not statically relevant (Appendix A, Table A6).

Most participants reported analysing and keeping track of their data by memory, not analysing it all, and 15.9% reported the analysis was performed by caretakers or health professionals. 7.5% reported using health records provided by health services, or pen and paper. Only 4.8% of participants reported using mobile apps.

From the 198 participants who reported monitoring their blood pressure, 104 answers to the open question on how participants made decisions based on their data were left blank, while 1 was regarded as invalid. The answers were coded into Adjusting habits (26.9%), Doing nothing (21.2%), Reporting to healthcare providers (22.1%), Monitoring evolution (18.3%), and Achieving self-knowledge (11.6%). All results are presented in Appendix A, Table A6.

Other metrics

The last section of route A, Appendix A, Table A7, documented other metrics monitored by participants. Said metrics may be important to consider when designing systems for allowing users to compare multiple health data variables. The most reported metrics were physical activity, sleep, temperature, water intake, and nutrition.

Route B - Health Monitoring in the Past

Route B was designed for participants who reported having monitored their health in the past, but not at the moment. Only 63 participants answered this route. The results are presented in Appendix A, Table A8.

As expected from the results of the previous route the most monitored metric was weight (18.3%). Other relevant metrics were, physical activity (11.1%), sleep (9.4%), steps (9.4%), heart rate (8.9%), blood pressure (8.1%), temperature (6.8%), nutrition (6.4%), body dimensions (5.5%). The most reported motivations were cultivating healthy habits, managing personal health, and following clinician’s recommendations. Most participants used mobile apps, or personal or professional monitoring devices to monitor their health. Participants reported monitoring happening independently at home or at a hospital or health centre. Participants used mobile apps, their memory, or charts or other visualisations to analyse their data. A relevant portion of participants (11.7%) reported the analysis was done by caretakers or health professionals. After the analysis most participants reported adjusting their habits (61.8%). Participants reported having stopped self-monitoring their health because it stopped being necessary (33.8%), due to loss of motivation (23.8%), loss of interest (13.8%), or forgetfulness (13.8%).

Route C - No history of health monitoring

Route C was designed for the 307 participants who reported not monitoring their health. The objective was to identify the reasons why participants did not monitor their health. Results (Appendix A, Table A9) indicate that most participants don't monitor their health due to not needing it, being presumably healthy. About a quarter of participants reported a lack of knowledge on the topic or a lack of interest, while about a quarter reported a lack of time. Finally, some participants reported not being able to monitor their health due to not being able to afford SMD.

Conclusions

Weight data proved to be the most accessible metric, with participants being able to collect, analyse, understand, and act on their data without needing constant professional guidance. Overall, participants who reported monitoring their weight did it to make sure their weight value stayed within a healthy range by adjusting their habits. Participants also reported keeping track of their data in their memory or mobile apps, while a significant number claimed not feeling the need to keep track of their data. Although weight was the most monitored metric, it was excluded from the next stage due to its accessibility and alignment between the needs identified in the literature and the tested users' needs.

Participants mostly look at step count data to satisfy curiosity, stay healthy, cultivate healthy habits, or achieve goals. Participants obtain their data continuously through mobile apps or wearables, as such participants either analyse their data on their smartphones or not at all. Most participants either used their data to adjust their habits or, aligned with the curiosity motivation, they do nothing with the data.

Heart rate data was monitored either in a preventive context (i.e., managing personal health) or to satisfy curiosity. Participants either obtained their data independently through SMD or continuously with wearables. Data was then analysed either by memory or using mobile apps. Following the preventive trend, participants used data to adjust their habits and monitor HR evolution. While following the curiosity trend, participants reported not using the data for anything else.

Results suggest that participants monitor their blood pressure as a preventive measure, while some of them used data to understand sensations or symptoms. This kind of data is obtained through SMD, usually independently at home, or professional monitoring devices, at a hospital or health centre. Participants reported analysing and keeping track of their data by memory or not analysing it since some of them reported the analysis was performed by caretakers or health professionals. Most participants used their health data to adjust their habits, monitor blood pressure evolution, or to report to healthcare providers.

Participants who reported not monitoring their health, chose not to monitor it mostly because they identified as healthy.

Although most participants identified the concepts of each metric as clear, with blood pressure having the least percentage of participants reporting it as easy to understand, a significant portion claimed not analysing this data, playing a more passive role, using data only to report to health professionals. About a quarter of participants reported the concept of systolic and diastolic blood pressure to be only slightly clear.

4.2 Interviews

The interviews provided an opportunity for participants to expand on the contextual information about the self-monitoring experience. 9 participants who had been identified as chronic disease patients took part in a remote semi-structured interview. Participants were informed of the interview's objectives, how their data was going to be handled, and their anonymity guaranteed. The interview's objectives were to understand the monitoring context (including exceptions), identify how SMD present health data and information, how chronic disease patients analyse their data, and how they handle extreme situations. The respective structure, constructs, and questions are presented in Table B1. To conclude the interview, participants were asked to evaluate current personal health data information visualisations.

Participants

Recruiting participants for the interview during the COVID-19 pandemic proved a challenge. With a declared national state of emergency and lack of access to senior citizens, the interviews were conducted with patients of chronic disease related to blood pressure. The sample resulted in a small poll of participants (Table B2), mostly female (8 out of 9). A third of participants belonged in the 20-29 age group, and another third in the 50-59. The oldest participant belonged in the 60-69 age group. Participants were highly educated, with only one participant not having finished secondary education. Participants reported diverse work or study domains. The sample's composition of chronic disease was predominantly related to blood pressure, in which three participants had hypertension or prehypertension, while two participants reported a history of low blood pressure that forced them to monitor their blood pressure. The second most common chronic disease category was diabetes, in its various forms. Other identified conditions were cardiac arrhythmia, asthma, and thyroid disease.

Results

Following Braun & Clarke's (2012) thematic analysis[8], the qualitative data was coded into four themes: (1) *Monitoring as a Ritual*, (2) *The Need for Contextual Information*, (3) *Obscure Blood Pressure*, and (4) *Identifying the Need for Professional Help.*

Theme 1. *Monitoring as a Ritual*

Participants who had been diagnosed with a form of diabetes had to rigorously measure their glycaemic index, at different times and following different activities, in order to identify the need to take appropriate actions to regulate their status. Participants with other conditions

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[8] Thematic Analysis (Braun & Clarke's 2012) involves identifying codes from the interviews and grouping them into recurring themes.

that required monitoring exhibited similar behaviours after identifying a value out of their usual range.

Theme 2. ***The Need for Contextual Information***

Participants both managing their health or identifying a health problem require the need to complement their values with contextual, qualitative data. Participants who monitored their health in order to identify triggers, causes and what brings relief, such as illustrated by a participant, "I measure my blood pressure whenever I feel dizzy, to see if it's related"; another participant said "I have chronic headaches (…) whenever I feel them I measure my blood pressure". Diabetic participants reported needing to monitor their food intake and exercise due to its relationship with glycaemic index. Figure 43 consists of photographic evidence on the appropriation of tables and health records to include reported contextual information and how it integrated their monitoring experience. These participants felt that current solutions were too restrictive, requiring multiple self-monitoring apps and other artefacts to communicate what they needed to.

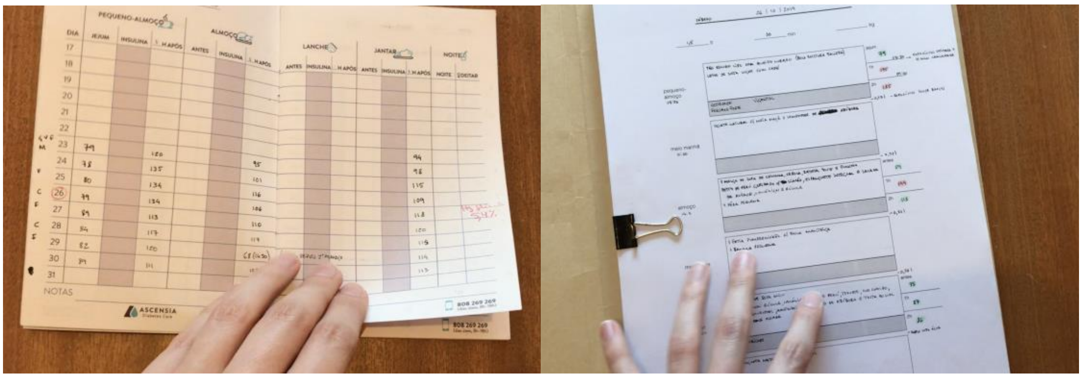

Figure 43. Participants self-monitoring experience.

Theme 3. ***Obscure Blood Pressure***

Participants who didn't have to monitor their condition regularly, but sometimes preventively measured their blood pressure were unclear on what blood pressure meant but were aware of some associated health risks. These participants rarely knew how to interpret their blood pressure values due to a lack of exposure to this data, since their blood pressure levels were healthy, as one participant noted, "My general practitioner does all the work. He just tells me that I'm healthy, I end up not even knowing the values". Another participant shared her detached experience with blood pressure monitoring: "When I want to know how my blood pressure is, I go to the pharmacy and have the pharmacist explain it to me". However, these participants also felt capable of obtaining this information if and when they needed it.

Participants with more monitoring experience were aware of their typical values and capable of identifying values outside of their healthy range, although participants without academic health knowledge were still not sure of the conceptual meaning of blood pressure. Nevertheless, participants were aware that blood pressure is related to the heart and circulatory system. These participants were able to associate the lived experience of blood pressure (e.g. symptoms) with their status, even if the conceptual meaning is not entirely clear. As one participant noted, “I can feel when my blood pressure is too high”.

Theme 4. ***Identifying the Need for Professional Help***

Participants reported being able to identify when their health was at risk and knowing how to act in these situations. When faced with extreme values (i.e. too high), when values stayed outside of their range for too long (one participant said “When I feel that something is wrong with my blood pressure, I play close attention to its evolution for a week”), or other situations that participants felt they couldn’t control, participants were able to recognize the need for professional help and felt capable of obtaining it. The same participant concluded, “If my condition doesn’t improve during this week, I’ll book an appointment with my general practitioner”. This theme is also present in the previously mentioned behaviour of having health professionals helping participants make sense of their data.

Evaluating Visualisations

Since participants had such a different clinical background, an exploratory evaluation was conducted. Participants were asked to pretend the data was theirs and interpret the visualisations previously identified in the state-of-the-art. Initially, participants were shown different visualisations for their specific conditions. However, due to a low participation rate and lack of consistency amongst monitored data, there was a shortage of grounded cohesive data. As such, after the third participant, we decided to present the same blood pressure visualisations[9] for the rest of the study. Following the thematic analysis from earlier, 2 themes related to the visualisations were identified:

Theme 1. ***Simple and Clean, but Informative Visualisations***

The nature of this theme can be compared to Tufte’s (2007) minimising data-ink ratio recommendation for the display of quantitative data, and to Nielsen & Molich (1990)’s usability heuristic of aesthetic and minimalist design. In the sense that participants appreciated simple and clean visualisations but felt lost when they were not too informative.

Participants with less literacy struggled with the visual interpretation of data. Too much visual information caused a state of information overload in some participants. Participants familiar with monitoring their (or others’) health responded better to numerical displays than other visualisations.

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[9] The visualizations in Figure 14, Figure 17, Figure 18, Figure 19, Figure 21, and Figure 22, were presented to the participants, who were then asked to interpret the data, with a focus on the meaning of visual elements.

Blood Pressure+Pulse Lite (Figure 19) was identified as too confusing, leaving some participants in a state of information overload. While Withings (Figure 17) minimalist and aesthetic design generated mixed results, with some participants finding it to be minimal and having difficulties in analysing data, while other participants praised its use of colour to display health risk, and its overall visual design. One participant even claimed he “would rather use this beautiful app even if there were a more informative one available”.

Theme 2. ***Different Visualisations for Different Contexts***

Different users responded better to different visualisations, as previously indicated. Participants with fewer statistical skills valued visualisations with numerical values, such as the table in YHE BP Doctor (Figure 22), and the blood pressure evolution visualisation in HeartStar BP Monitor (Figure 18). These participants also applauded Blood pressure App+ (Figure 21) use of emojis to represent contextual information, although most emojis failed to properly inform users. The same app use of colour to represent blood pressure classification was also perceived as confusing, with participants identified them as random. Furthermore, the pie chart in Figure 21 was also perceived as less informative than the previous visualisations. In conclusion, participants recognised that different visualisations might play different roles.

4.3 Summary

In compliance with HCD methods of designing solutions for humans, a survey was conducted in order to better understand the context of the self-monitoring experience, goals, needs, and challenges. More than half of the participants reported monitoring their health, highlighting body weight as the most commonly measured metric. Results suggest that participants who identify as female, who belong to an age group between 20-29 or higher than 40 years old, who display a high education level, and were not students were more likely to self-monitor their health. Chronic disease patients were also more likely to self-monitor their condition.

The survey then assessed the level of difficulty in interpreting weight, step count, blood pressure, and heart rate data, with results suggesting participants struggled with blood pressure data the most. Finally, the survey suggested that participants monitored their health at various time frequencies with different goals and motivations. Analysis methods were also dependent on goals and needs. After the analysis of personal health data, participants further reported adjusting their habits, obtaining self-knowledge, monitoring the evolution of their health status, and reporting it to healthcare providers.

Due to the COVID-19 pandemic, only 9 participants who had been identified as chronic disease patients took part in a remote semi-structured explorative interview. The participants were mostly women, coming from diverse ages and backgrounds. Participants were asked exploratory questions hoping to generate tacit and holistic knowledge about their lived monitoring experience. Following Braun & Clarke’s (2012) thematic analysis, the qualitative data were coded into four themes: Monitoring as a Ritual, The Need for Contextual Information, Obscure Blood Pressure, Identifying the Need for Professional Help.

On another segment of the interviews, the participants were asked to exploratory evaluate examples of current blood pressure information visualisations. Based on the participants’ comments, two main themes for the visualisation of blood pressure information were identified: designs should adopt Simple and Clean, but Informative Visualisations; and create displays that provide Different Visualisations for Different Contexts.

5. Design of Blood Pressure Information Visualisations

This chapter documents the design process of blood pressure information visualisations, starting with the classification of data, the resulting variables and relationships amongst them, followed by a contextual definition of the four identified variables, (1) Blood Pressure Readings; (2) Blood Pressure Health Status; (3) Annotations; (4) Time. The following section explains how this data could be mapped into visual elements. Different visualisations were designed. Finally, participants were asked to map blood pressure into the considered visual elements and the visualisations were evaluated via remote interviews with the testing user population.

5.1 Classifying Collected Data - Variables & Relationships

After identifying the self-monitoring needs and context of hypertension patients, the collected data was deconstructed, classified, and the variables defined, as well as the relationship between them. In the context of BP health data, the experiments are dealing with four different types of variables:

- Quantitative variables representing both systolic and diastolic BP readings (e.g. 120/ 80);
- Ordinal data in the form of a scale classifying the blood pressure status (e.g. Hypertension);
- Categorical data for occasional users' commentaries and annotations of other relevant data (e.g. Emotional State);
- Finally, the time variable inherent to any data logging activity (e.g. 20th March 2020).

As such the analysis can be defined as multivariate with a temporal relationship. (While the relationship between systolic and diastolic BP can be categorised as a network relationship).

5.2 Defining Data

As mentioned previously, this work considers four different variables - (1) Blood Pressure Readings; (2) Blood Pressure Health Status; (3) Annotations; (4) Time - which are defined below:

Blood Pressure Readings and Health Risk Status

Blood Pressure readings are the numerical representations of the displayed values measured, typically visually oriented either vertically or horizontally, with the value of Systolic Blood Pressure first, followed by the Diastolic value, separated by a slash (i.e. 120/80).

The system computes blood pressure by analysing the amount of mercury in millimetres. This unit of measurement is not entirely understood by participants, as does not concern users it is usually ignored, instead they focus their attention on the resulting values. The theme of Obscure Blood Pressure, identified in section 4.2, further explains the lack of understanding of certain aspects of blood pressure information on behalf of participants.

Such numerical representations are presented in a range that typically goes from 50 to 240 mm/Hg in extreme conditions for systolic blood pressure (SP) and 35 to 140 mm/Hg for diastolic blood pressure (DP).

While less extreme readings start at 70/50 for the low range and 180/110 for the higher values. These values are then classified according to the risk they pose to the patients' health. DGS (2013) classifies blood pressure values with corresponding colours as seen in the table 8.

Table 8

Blood Pressure Classification Values

Classification	Systolic Value	Diastolic Value
Hypotension	<90	<60
Ideal	<120	<80
Normal	120-129	80-84
High-Normal	130-139	85-89
Hypertension Level I	140-159	90-99
Hypertension Level II	160-179	100-109
Hypertension Level III	≥180	≥110
Isolated Systolic Hypertension	≥140	<90

Note. Adapted from DGS (2013) and complemented with hypotension information.

This classification scale is focused on monitoring hypertension, ignoring values corresponding to hypotension levels. However, in an interactive visualisation focused on self-monitoring and self-tracking activities, users may have singular motivations. As such, this must not be the only viewpoint. As we saw during our interviews, people measure their blood pressure to understand what their body is feeling (i.e. symptoms) - "Why does my head hurt? / Why do I feel dizzy?" - and evaluate their health status risk, "Should I seek medical help?". Blood Pressure Association (2008) defines low pressure as any value smaller than 90 for SP and 60 for DP.

User Annotations

Annotations by users that provide contextual information that may affect BP data values. This variable can be further differentiated into emotions (e.g. angry or excited), activities (e.g. physical exertion or drinking coffee), or measuring context (e.g. at home vs at the hospital or left arm vs right arm). Icons or emojis are intuitive visual marks that allow users to communicate effectively the qualitative variables, although the meaning portrayed by emojis must be aligned with users' mental models instead of following trends as seen in the Blood pressure app+ (Figure 21).

Time

The time variable is related to the time when BPD is logged into the system. The resulting visualisation allows users to preattentively detect patterns and outliers about their blood pressure over a specific period of time. Multiple dimensions are explored through interactions with the system, usually presenting users with four options:

1. Hourly View - showing data values logged over the course of a day and its consequent average if multiple values are available;
2. Daily View - average daily data registered over a week;
3. Weekly View - weekly average over a month;
4. Monthly View - with the average of all months over a year.

Averages of blood pressure readings and consequent classification are calculated for each chosen view, and each less specific timeframe (e.g. Yearly view) builds on the average of the previous view.

5.3 Mapping Data

Information Visualisation requires data to be mapped in a visual format. Data must be mapped onto graphical design elements by assigning one value to a corresponding visual element, creating a cohesive logical scale that connects them all. Wilke (2019) suggests data should be mapped onto "aesthetics", which he describes as "every aspect of a given graphical element" (p. 13), from which Wilke highlights position, shape, size, colour, line width, and line type. Hashimoto & Clayton (2009) identified line, shape, negative space, volume, value, colour, and texture as the elements of visual design. Taking both perspectives into account blood pressure data was mapped into scales of size, shape, colour, and line, while position scales were left for the design of visualisations. Due to the need to represent and distinguish between SBP and DBP, visual scales were also used for differentiating variables.

Data was mapped into different graphical elements to allow users to evaluate and give their opinion on them, in an effort to bring participants closer to the design process, since typical PD methods such as workshops were impossible to conduct with the user population, in compliance with social distancing norms.

Scales for Differentiating Variables

Visual graphical design elements were used for mapping SBP and DBP data, as illustrated in Figure 44. A grey circle was used as a basic representation, allowing users to easily identify specific variations.

- Size Scale: A linear size scale was represented with a large circle and a small circle.
- Shape Scale: Four different shapes were considered - circle, square, rhombus and triangle - all presented in grey and with similar sizes
- Colour Scale: To differentiate between variables, a variation of values[10] was considered, resulting in the starting tone of green, situated in the middle, the shade, created by adding a layer of black at 50% opacity, and the tint, created by using a layer of white in the same sense.
- Line Scale: Finally, to differentiate between variables, a continuous and dashed line were considered.

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[10] Value, defined by Hashimoto & Clayton (2009), as the “lightness and darkness of its [the colour’s] hue.” (p.235).

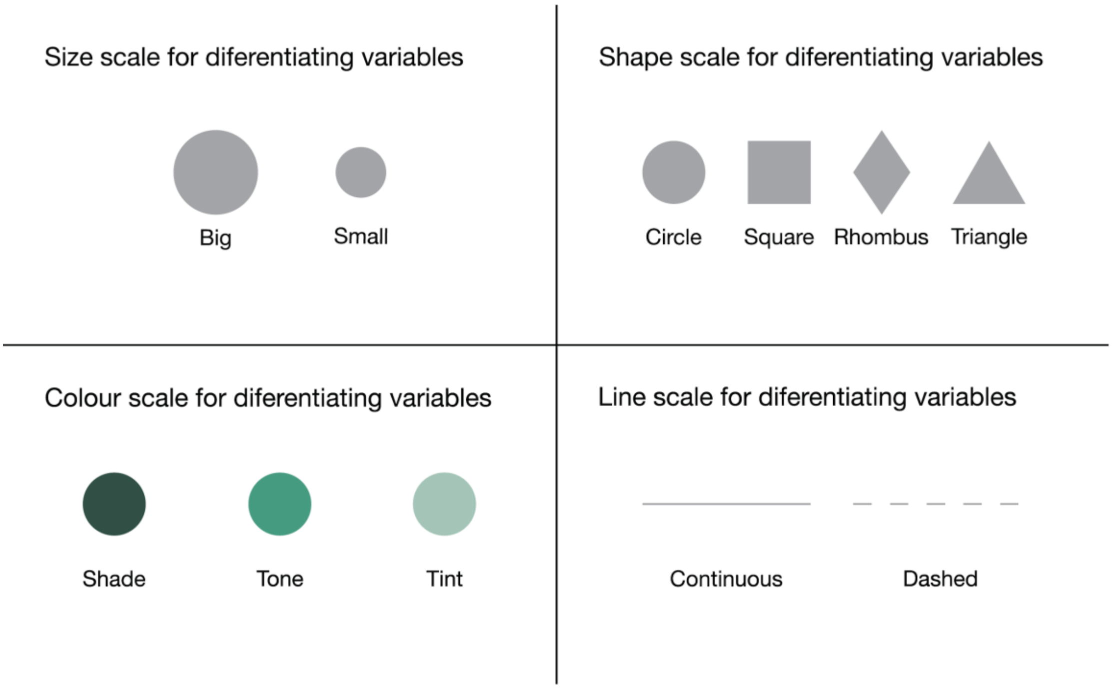

Figure 44. Scales for differentiating variables.

Scales for Mapping Values

In the design of variations for mapping blood pressure data, the same graphical elements were considered. This time, scales were designed in order to be able to represent both numerical values of BP as well as the associated qualitative categories of BP status, although trying to maintain a sense of exploratory nondirectional meaning. The approach for the design of data mapping scales, Figure 45, was the following:

- Size Scales: A natural approach to using size to map quantitative values involves scaling the shapes in 4 points increments.
- Shape Scale: The same shapes as considered before could also be used to represent quantitative and qualitative BP data.
- Colour Scale: Following the natural progression of the colour wheel (Figure 46), combined with the clinical categories described in Table 8 (grouping Ideal and Normal as the same category, and treating Isolated Systolic Hypertension simply as Hypertension), six hues were used to represent data - purple, blue, green, yellow-green, orange and red. The values of lightness were chosen to allow users who have difficulty differentiating between hues, such as colour-blind and senior users. The idea was to create a progressing grayscale of values from light to dark in relation to their health risk. In compliance with the grayscale values the yellow colour was changed to a yellow-green tone. Due to the iterative nature of this investigation, three different colour scales ended up being designed: a complete 8-step scale following the

previously mentioned clinical categories, the reduced 6-step scale, and finally a minimalist 4-step category. Figure 47 demonstrates all iterations of the colour scale.

- Line Scale: Finally, a line scale was created by variating the line width contouring the shape, going from light to bold.

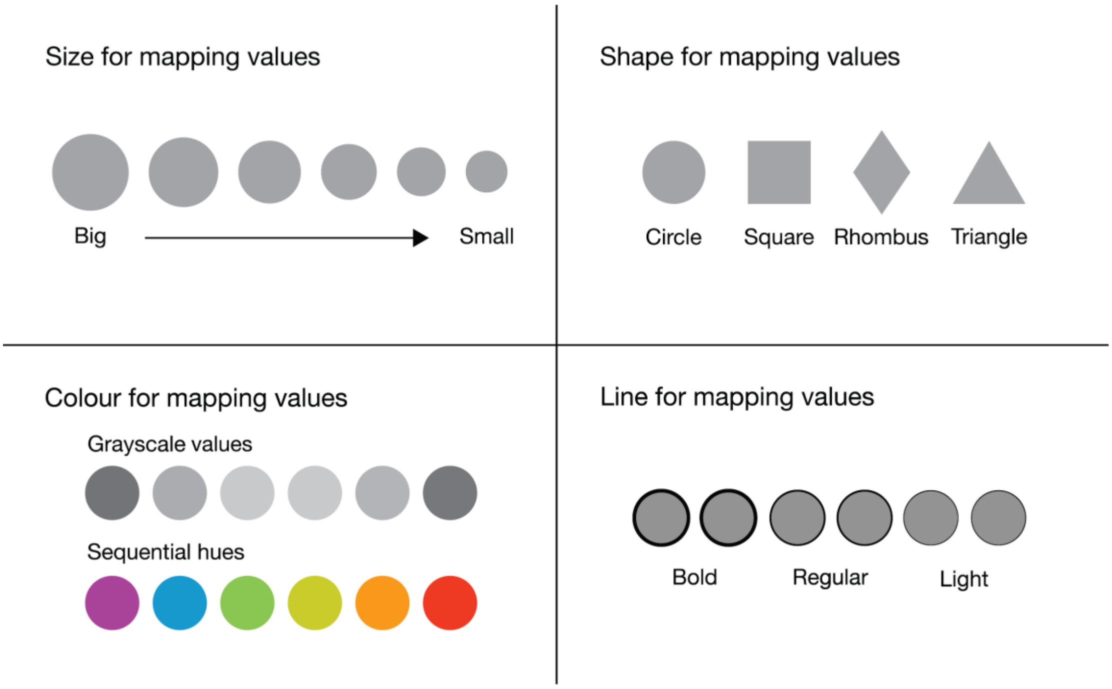

Figure 45. Scales for Mapping Blood Pressure Values.

Figure 46. 12-hue colour wheel retrieved from Hashimoto & Clayton (2009).

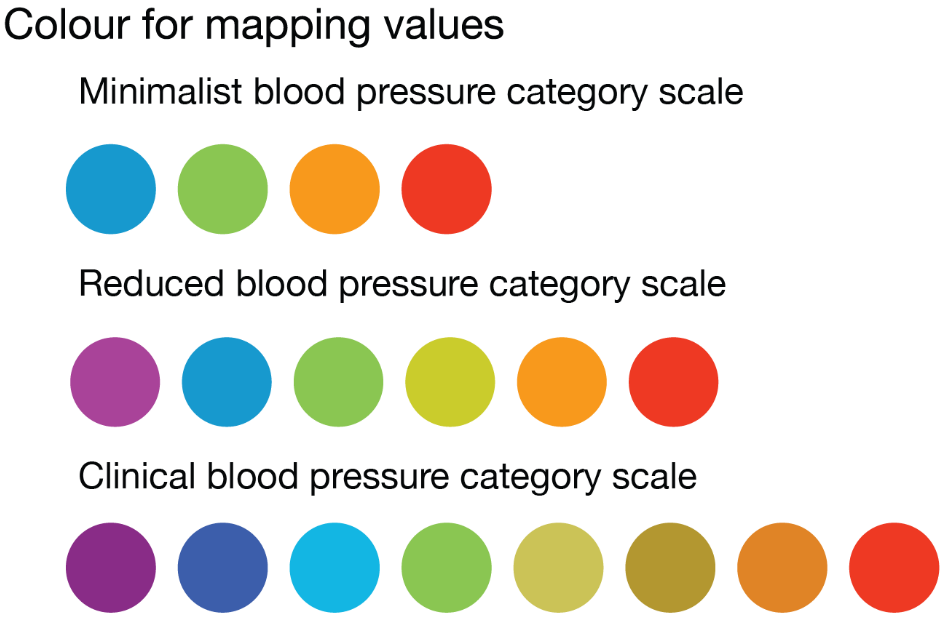

Figure 47. Designed colour scale iterations.

5.4 Designing Visualizations

Informed by the BP Information Visualisations identified in the literature review[11], the design process resulted in 4 variations of graphs and a table. A more exploratory calendar visualisation was also designed.

For the graphs, the x-axis represented the chosen time frame (monthly view), while the y-axis represented blood pressure values. Circles were used to represent data; their position mapped values following the axis. A size scale was used to distinguish between SBP and DBP, with a larger circle used for SBP and a smaller one for DBP. The minimalist colour scale presented earlier was used to represent health risk status, with red representing high blood pressure, orange for a mildly high value, green for healthy values, and blue for low values. These were the only elements considered for the first variation, Figure 48. The second variation included four lines in the background to provide a baseline for users to identify healthy values, as seen in apps such as MedM Blood Pressure Health+ (Figure 14).

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[11] Due to time constraints and overall difficulty in conducting the interviews in the pandemic context, the results of the visual data mapping research could not be used to inform the design of visualisations in this study.

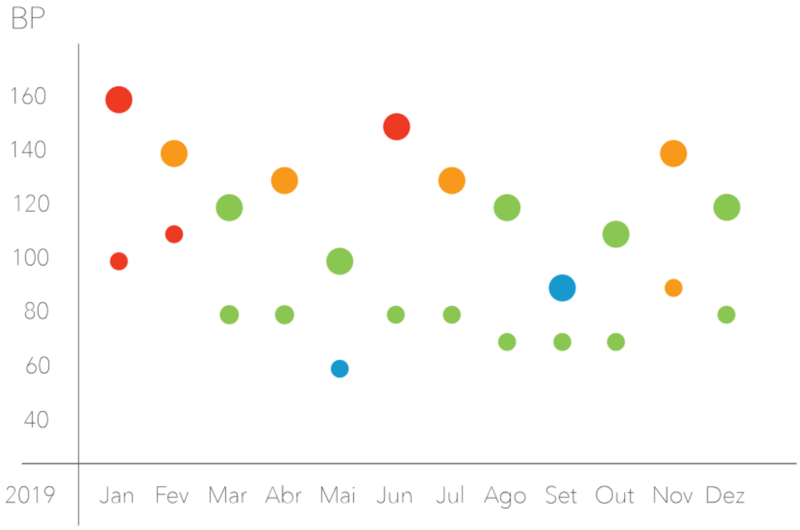


Figure 48. Basic Graph Visualisation.

A dashed line was used to represent DBP, and a full line for SBP, as seen in Figure 49. The upper end of the interval was represented with a larger line width.

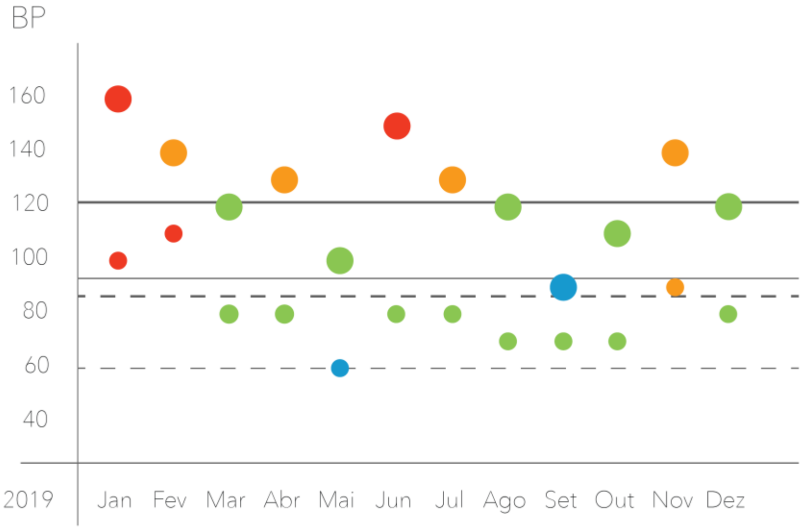


Figure 49. Baseline Graph Visualisation.

The next graph, Figure 50, included lines connecting the circles to focus on the evolution of the numerical values. SBP once again used a continuous line, while DBP used a dashed line.

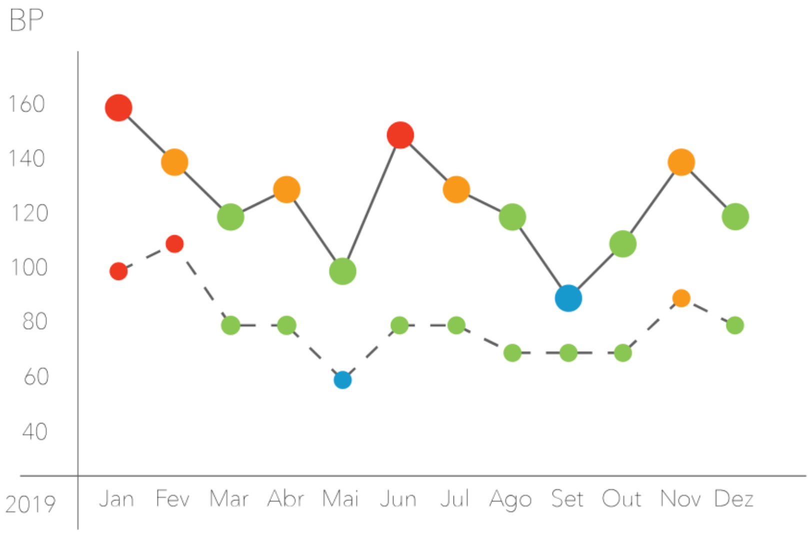


Figure 50. Evolution Graph Visualisation.

The final graph, Figure 51, used a vertical line connecting both SBP and DBP values for the same month, focusing on the interval of BP values, as seen in apps such as Withings (Figure 17).

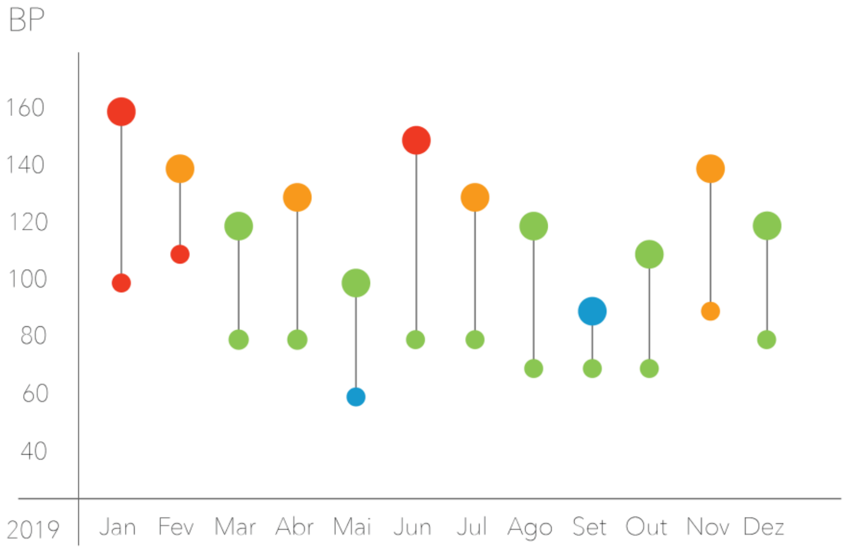
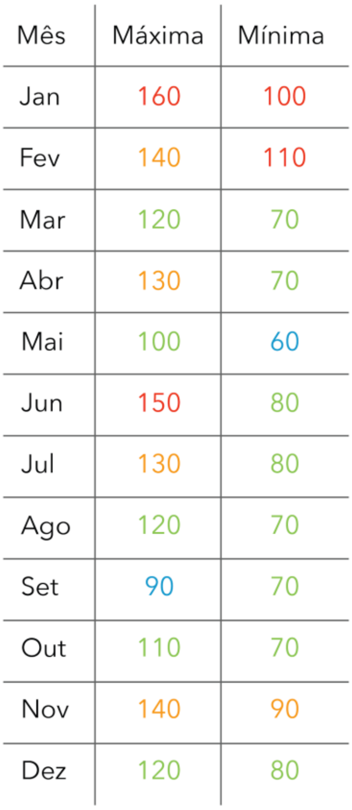


Figure 51. Intervals Graph Visualisation.

The designed table visualisation, Figure 52, presented the registered values over a year organized monthly. The Maximum and Minimum (following participants' own categorization) values are presented in the next columns. The same minimalist colour scale was directly applied over the numerical values.



Mês	Máxima	Mínima
Jan	160	100
Fev	140	110
Mar	120	70
Abr	130	70
Mai	100	60
Jun	150	80
Jul	130	80
Ago	120	70
Set	90	70
Out	110	70
Nov	140	90
Dez	120	80

Figure 52. Table Visualisation.

Finally, the calendar visualisation, Figure 53, was designed to answer the reported need for visualising blood pressure over time without using a graphic (as they were too challenging for some participants). Daily values for the month of May were presented in the shape of a calendar, with the respective colour filling in the squares of the day. This time the complete 8-step colour scale was used. Initially, a gradient was used to connect the colours for the DBP and SBP values, but early on it was identified as non-informative and confusing users. The gradient fill was swapped for a solid colour fill, corresponding to the SBP value.

Figure 53. Iterations of the Calendar Visualisations.

5.5 Evaluation

In order to identify the best data mapping methods for our user population, while at the same time testing the designed visualisations, a set of interviews was performed[12]. 7 Participants

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[12] Each participant was interviewed only once in this process.

were recruited for an online interview via Zoom. This time participants' ages ranged from 40 to 69 years old, 3 participants were female and 4 were male, as described in Table 9.

Table 9

Evaluation Interview Participants

Participants	Gender	Age
P1	Female	50-59
P2	Female	60-69
P3	Female	50-59
P4	Male	50-59
P5	Male	50-59
P6	Male	60-69
P7	Male	40-49

First, participants had to evaluate the scales for mapping values, being asked to try to interpret the data mapped onto the visual properties, considering both the blood pressure value and the health risk variable, for each scale.

Participants were shown the size scale (upper left part of Figure 44). All participants related the increasing dimension of the shape with an increase in value. Initially, participants identified a larger dimension with a greater health risk, but when asked if it applied to low BP, they concluded that the size scale was not enough to map health risk on its own.

For the shape scale, participants had to identify a hypertension value, a healthy value, and a hypotension value, as well as an indication of health risk. Most participants could not relate a shape with a hypotension value, although two of them chose a triangle. 4 participants identified circles as a healthy value, one of them chose a square and another a rhombus. Hypertension values were associated with health risk status, with the same shapes being chosen for both variables. 3 squares, 2 triangles, and 1 rhombus were identified as health risk indicators.

The same questions were done for the colour scale variable. Low blood pressure was associated with blue, by 2 participants, green by another 2 participants, 1 participant chose grey, another one chose red and another chose yellow. Healthy values were associated with green and blue, by three participants each and by brown for one participant. Red was chosen to represent hypertension by 6 of the 7 participants, while the remaining participant chose purple.

Finally, for the line scale, all participants identified a direct positive relationship between the line width and the blood pressure value. Only one participant identified the bold line as an indicator of health risk, while the remaining 6 concluded that the line scale was not enough to map health risk on its own.

To conclude the evaluation of visual scales to map BP data, participants were asked which scale they preferred and found most informative. 5 participants chose colour as the most informative visual element for representing both variables. Size scale and line width were identified as the best for representing BP values, by 1 participant each. From these participants, one chose colour as the best indicator of health risk, while the other chose specifically the triangle shape.

In the next stage, participants were shown the visual elements scales for differentiating between SBP and DBP and asked to try to interpret the data mapped onto the visual properties. To answer to an identified lack of cohesion on the terms patients use for referring to SBP and DBP, the first question explored this problem. 3 participants used the words Maximum/Minimum, while the remaining 4, used the pair High/Low.

Onto the evaluation of scales, all participants associated SBP with the larger circle while the smallest one represented DBP. The shape scale was identified by four participants as unable to represent the required data on its own. One participant used the triangle for SBP and a circle for DBP, while the remaining two both chose squares for SBP and triangles for DBP. As for the colour scale, all participants associated the shade with SBP, and the tint with DBP. Finally, 5 participants identified the continuous line with SBP, and the dashed line with DBP. The remaining 2 participants concluded that line constitution was not enough to map SBP or DBP on its own.

Finally, participants were asked to interpret the designed visualisations and to choose the one they thought was the overall best, the best for monitoring evolution, the best for identifying the highest and lowest registered valued, and the best for identifying health risk. For overall usage of the visualisations, 4 participants chose the interval chart visualisation, Figure 51, and 5 participants chose the table visualisations, either on its own or complementing other visualisations. For monitoring the evolution of BP data, participants preferred the evolution focused visualisation, Figure 49, with the table still being an important complementary visualisation. For identifying the highest and lowest registered values, the table was the most relevant visualisation. For identifying health risk, the evolution trend, complemented with the table were the most chosen visualisations.

During the interviews, the different colour scales were tested as part of the visualisations.

All participants associated SBP with a large size, and a dark colour, while DBP was associated with a small size and a light colour. Participants identified colour variations as the best scale for differentiating between SBP and DBP, although participants didn’t miss them in the designed visualisation, differentiating both variables just fine.

For the representation of blood pressure values and health risk, participants found colour scales as the most informative approaches to mapping data. The minimalist 5 step scale was preferred, although there was no agreement on the meaning of the colours, except for red for hypertension. A recurring theme on mapping BP values in a colour scale was the traffic lights metaphor, mentioned by some participants, allocating green to healthy, yellow to "somewhat dangerous" and red for hypertension.

5.6 Discussion: Guidelines for Effective Personal Blood Pressure Information Visualization Design

Due to the small sample of participants, drawing conclusions becomes difficult because of a lack of information to identify patterns.

Most participants failed to consider low pressure and hypotension, as they had been diagnosed with hypertension and were trained to identify high values. Only one participant reported regularly monitoring her BP looking for low values. Even though low BP values did not represent the lived experience of most participants, they still found it an important factor for systems to consider.

Results were summarised and presented as guidelines for the design of effective personal blood pressure information visualizations[13].

Presenting Multiple Visualisations

Participants identified being able to use complementing visualisations as essential in achieving their goals. Furthermore, participants identified that different visualisations proved best for different objectives, namely visualisations that facilitates the evolution of blood pressure through time, visualisations that facilitates recognition of the highest and lowest registered values, visualisations for providing overviews, and visualisations that highlight health risk status. Furthermore, tables were identified as a necessary complement to other visualisations.

Following traditional Information Visualisation practices, allowing users to interact with the system could be a relevant way to avoid information overload.

Minimal but Informative Design

As with general recommendations for designing interfaces and visualisations, a minimal approach should be considered, although taking into account challenges faced by users with poor literacy, as well as reduced cognition and perception in senior citizens.

Colours & Numbers

Using colour to map health risk, in a traffic light metaphor (as suggested by many participants), and visualisations centred around numerical values, as in Figure 52, were identified as the most informative and versatile visualisations. As tables are typical tools for

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[13] Results come close to Tufte's (2009) orientations for the design of visualisations, corroborating its importance in the domain of health information visualization.

self-monitoring blood pressure, participants who struggled with complex visualisations, felt more at ease with them.

Participants preferred a minimalist colour scale, perceiving more complex ones as harder to interpret, and feeling lost in the process of attributing values to the visual elements. As such, options should be kept to a minimum.

Allow for Contextual Information

The final guideline suggests allowing users to complement blood pressure data with contextual information about activities or feelings that might directly affect BP values. Although the need to visually provide this information was identified, it was not a study object.

6. Conclusions

The proposed problem and research questions were tackled from a participatory human-centred design approach that tried to integrate as much as possible representative participants in the design process to improve patient readability of personal health information visualisations.

Through user research methods, documented in chapter 4, we concluded that self-monitored metrics, such as weight and step count, were easier to understand for participants. On the contrary, heart rate and blood pressure were less clear for participants. Blood pressure data was identified as the most problematic metric, not only involving two values to consider, as well as requiring a certain level of knowledge and health literacy.

During the survey, various self-monitoring habits were identified, responding to unique motivations. The identified motivations were aligned with the ones described in the literature by Gimpel (2013) and Neff & Naffus (2015). After analysing their health data, participants reported adjusting their habits, further monitoring the evolution of their health, achieving self-knowledge, reporting to healthcare providers, or comparing with other metrics. Interestingly, some participants also reported doing nothing with their information.

Furthermore, participants were asked to evaluate current blood pressure visualisations from mobile apps. An overall lack of cohesion was identified. Certain visualisations, such as line graphs, tables, and strip charts, were identified as more informative than others.

Participants reported preferring minimalist visualisations, although some participants failed to interpret certain visualisations because they considered these were lacking in information, perhaps due to their lower education or statistical literacy than the previously mentioned participants. For this very reason, we recognised the need of enabling users to access different visualisations for different contexts.

With these results, we began a design stage of blood pressure information visualisations, which consisted of mapping blood pressure data onto different visual elements and having chronic disease patients who monitor their blood pressure interpret them by assigning values to the mentioned elements. Blood pressure visualisations were also designed considering results obtained from the user research. Results corroborated the theme of users needing different visualisations for different goals.

Conclusions

Results were summarized as guidelines for effective blood pressure information visualisation design.

The questions guiding this research were answered as following:

(1) *Which visualisation methods have proven to be the most effective for representing and presenting [blood pressure] health data generated through self-tracking devices? Which did not?*

Through the literature review, we identified the most commonly used visualisations for representing blood pressure data. Results from the final interviews show that tables, dual-line charts, and strip charts were the most effective visualisations to present blood pressure information, while, according to the results of the first interviews, pie charts and visualisations in busy screens were perceived as the least informative.

(2) *What are the implicit values of the [blood pressure information] representation*?

The representation of blood pressure information involves 4 variables, blood pressure values (both SBP and DBP), blood pressure health status (e.g. hypertension), contextual information (optional), and time. From the perspective of hypertension patients, it is implicit that any value higher than 120/80 is “bad” and a health risk, while lower values are “good” and “healthy”. Participants also reported identifying the relations between BP values and other tacit information such as lived sensations and symptoms, although highly subjective.

Furthermore, through the exploration of visual elements to map blood pressure data, we concluded that a bigger size was associated with a higher BP value, circles were associated with healthy values, while squares and triangles were associated with hypertension. The colour red was exclusively associated with health risk and high BP values. Other colours such as green and blue were both associated with healthy and low BP values.

(3) *How do patients perceive visual representations, and do they actually understand what is being visually presented?*

Less-educated participants had difficulties understanding visualisations, being intimidated by them, while appreciating being able to quickly identify the exact numerical value, using methods such as tables. This may also be an indication of low visual literacy, although we cannot reach such a conclusion due to a lack of information. In fact, the level of visual literacy is not directly correlated or even dependent on education.

Participants identified colour as the most informative indicator of health risk, preferring a colour scheme of 4 to 5 colours. Participants also perceived that different visualisations were best for obtaining certain goals.

(4) *What challenges do patients face regarding the visualisation of their health data?*

We were unable to identify additional challenges that patients face in visualisations, other than the previously mentioned ones, due to a poor representation of the desired user population. Although participants also found most of the current self-monitoring visualisations were too restrictive, failing to provide contextual information.

Having identified improvements on the readability of the designed visualisations, the objectives were carried out although with some limitations.

6.1 Limitations

The COVID-19 pandemic posed a tremendous challenge. The ideal user population of senior citizens became unavailable since access to nursing homes was hindered as a preventive measure to protect the senior citizens from the virus.

The most fundamental and innovative characteristic of this work was a human-centred approach that included co-design sessions where participants would be co-authors of visualisation solutions. The impossibility to achieve this, due to restricted access to the desired population, forced a change to the methodology. Naturally, this had an impact on possible results.

The novel approach had to be conducted with online methods, in compliance with social distancing norms and general fear of contracting the disease incapacitated presential methods.

In an attempt to overcome this challenge, an exploratory approach to the design and evaluation of visualisations was conducted, still directed towards obtaining insights from patients’ tacit knowledge.

Furthermore, the pandemic also resulted in a low participation rate, which diminished the quality of the results.

6.2 Contributions

The present research and the resulting guidelines hopefully contribute to future design decisions of patient-centred health information visualisations.

Moreover, we found that the results of this research are aligned with conclusions from similar researches from other nationalities (Verdezoto & Grönvall, 2015) suggesting that the Portuguese reality is comparable to that of other countries.

This research also corroborated the hypothesis that following a HCD approach yields satisfactory results for the design of meaningful visualisations for the user population. It also suggests that PD would bring satisfactory results, although such a conclusion can’t be reached due to the limitations previously mentioned.

6.3 Future Work

For future work, we found interesting to explore through a participatory design approach, how contextual information can be incorporated in personal health visualisations.

After the pandemic situation, and the return to a possible normal activity in a post-COVID-19 world, it would be important to effectively apply PD methods, with the collaboration of senior citizens.

Attending to the importance of HCD and this research findings, we suggest exploring how interaction can be used to provide a better blood pressure visualisation experience, with a focus on integrating multiple visualisations for multiple goals.

Furthermore, it would be relevant to test the guidelines by designing visualisations and evaluating them with users. Likewise, to compare the guidelines with similar work related to other personal health data metrics, looking for patterns.

A path to explore, due to the significance of the accessibility theme, is to evaluate the state-of-the-art, considering how these visualisations are accessible for senior, colour-blind, dyslexic, or blind users.

Finally, we propose to study how visual literacy can affect the interpretation of visualisations.

Conclusion

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9. Appendix A – Survey

Table A1

Route A objectives, constructs, and questions

Objective	Construct	Question	Question Type
Identify monitored metrics	Object of Monitoring	Do you monitor your [Weight, Steps, HR, BP]?	Binary Multiple-Choice Options: ● Yes/No
Understand how often participants monitor personal health	Frequency of Monitoring	How often do you monitor your [Weight, Steps, HR, BP] data?	Single response Multiple-choice Options: ● Several times a day ● Daily ● Weekly ● Monthly ● Every six months ● Annually ● When I need to

(continued)

Appendix A - Survey

Objective	Construct	Question	Question Type
Identify participants' motivation for monitoring their health	Motivation	Why do you monitor your health [Weight, Steps, HR, BP]?	Multiple response Multiple-choice Options: ● Achieving a goal ● Curiosity ● Cultivating healthy habits ● Getting to know own body ● Health Professionals ● Manage personal health ● Understand sensations or symptoms ● Other
Understand how participants obtain personal health data	Data Source	How do you obtain your health [Weight, Steps, HR, BP] data?	Multiple response Multiple-choice Options: ● Biosensor ● Professional monitoring device ● Self-monitoring device ● Continuous Monitoring[a] ● Mobile Apps[a] ● Wearable[a]
Understand where participants monitor their health	Physical Environment	Where do you measure your health [Weight, Steps, HR, BP] data?	Multiple response Multiple-choice Options: ● At home, independently ● At home, with help ● At a hospital or health centre ● At therapy, gym or similar ● Other

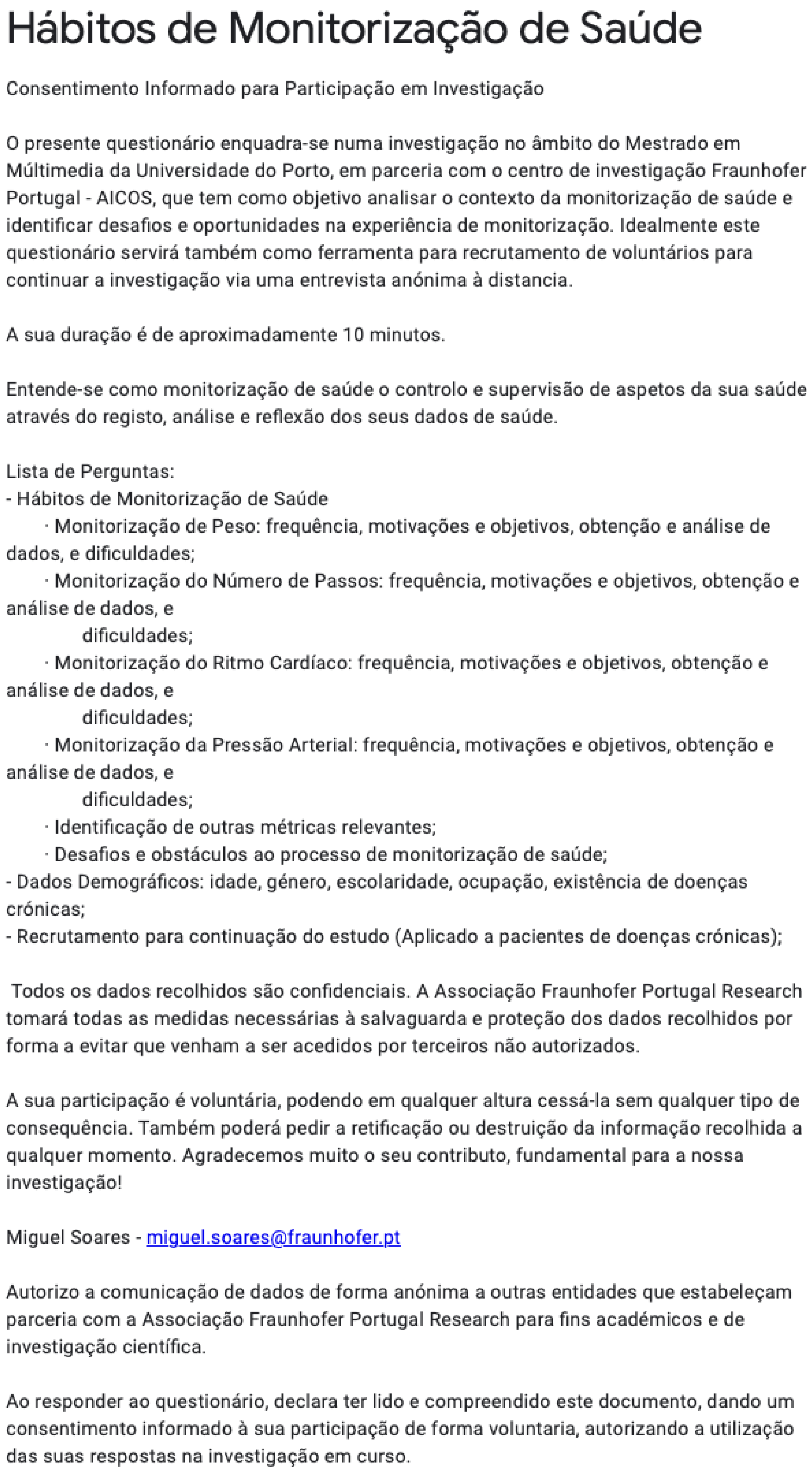
(continued)

Appendix A - Survey

Objective	Construct	Question	Question Type
Understand which methods participants use for monitoring their health	Data Analysis	How do you analyse your health [Weight, Steps, HR, BP] data?	Multiple response Multiple-choice Options: ● Analysis by caretakers or health professionals ● Charts or other visualizations ● Health records provided by health services ● Memory ● Mobile apps ● Pen and paper ● Statistics ● Tables ● Web apps ● No Analysis
Understand how participants incorporate the data into their lives	Acting on data	What do you do with the knowledge obtained from analysing your health [Weight, Steps, HR, BP] data?	Open question (Open Text)
	Difficulty		Likert Rating Scale 7-Point Scale (Extremely Difficult to Extremely Easy)
Identify other monitored metrics	Object of Monitoring	Which other metrics do you monitor?	Multiple response Multiple-choice Options:

[a]Only when applicable

Appendix A - Survey



Hábitos de Monitorização de Saúde

Consentimento Informado para Participação em Investigação

O presente questionário enquadra-se numa investigação no âmbito do Mestrado em Múltimedia da Universidade do Porto, em parceria com o centro de investigação Fraunhofer Portugal - AICOS, que tem como objetivo analisar o contexto da monitorização de saúde e identificar desafios e oportunidades na experiência de monitorização. Idealmente este questionário servirá também como ferramenta para recrutamento de voluntários para continuar a investigação via uma entrevista anónima à distancia.

A sua duração é de aproximadamente 10 minutos.

Entende-se como monitorização de saúde o controlo e supervisão de aspetos da sua saúde através do registo, análise e reflexão dos seus dados de saúde.

Lista de Perguntas:
- Hábitos de Monitorização de Saúde
    - · Monitorização de Peso: frequência, motivações e objetivos, obtenção e análise de dados, e dificuldades;
    - · Monitorização do Número de Passos: frequência, motivações e objetivos, obtenção e análise de dados, e dificuldades;
    - · Monitorização do Ritmo Cardíaco: frequência, motivações e objetivos, obtenção e análise de dados, e dificuldades;
    - · Monitorização da Pressão Arterial: frequência, motivações e objetivos, obtenção e análise de dados, e dificuldades;
    - · Identificação de outras métricas relevantes;
    - · Desafios e obstáculos ao processo de monitorização de saúde;
- Dados Demográficos: idade, género, escolaridade, ocupação, existência de doenças crónicas;
- Recrutamento para continuação do estudo (Aplicado a pacientes de doenças crónicas);

Todos os dados recolhidos são confidenciais. A Associação Fraunhofer Portugal Research tomará todas as medidas necessárias à salvaguarda e proteção dos dados recolhidos por forma a evitar que venham a ser acedidos por terceiros não autorizados.

A sua participação é voluntária, podendo em qualquer altura cessá-la sem qualquer tipo de consequência. Também poderá pedir a retificação ou destruição da informação recolhida a qualquer momento. Agradecemos muito o seu contributo, fundamental para a nossa investigação!

Miguel Soares - miguel.soares@fraunhofer.pt

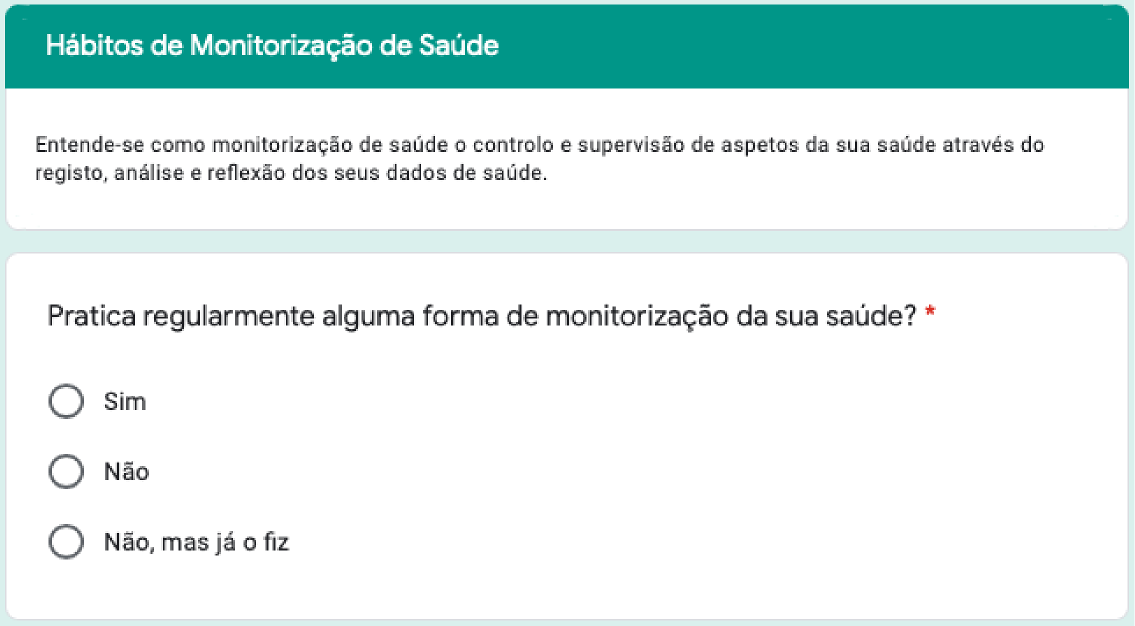
Autorizo a comunicação de dados de forma anónima a outras entidades que estabeleçam parceria com a Associação Fraunhofer Portugal Research para fins académicos e de investigação científica.

Ao responder ao questionário, declara ter lido e compreendido este documento, dando um consentimento informado à sua participação de forma voluntaria, autorizando a utilização das suas respostas na investigação em curso.

Figure A1. Introduction and Informed Consent.

Appendix A - Survey

Part 1 – Assessing Self-monitoring Habits



Hábitos de Monitorização de Saúde

Entende-se como monitorização de saúde o controlo e supervisão de aspetos da sua saúde através do registo, análise e reflexão dos seus dados de saúde.

Pratica regularmente alguma forma de monitorização da sua saúde? *

○ Sim

○ Não

○ Não, mas já o fiz

Figure A2. Assessing Self-monitoring Habits which Gives Access to Route A, B or C.

Route A – Health Self-monitoring

Section A1 – Weight

Peso - Parte 1

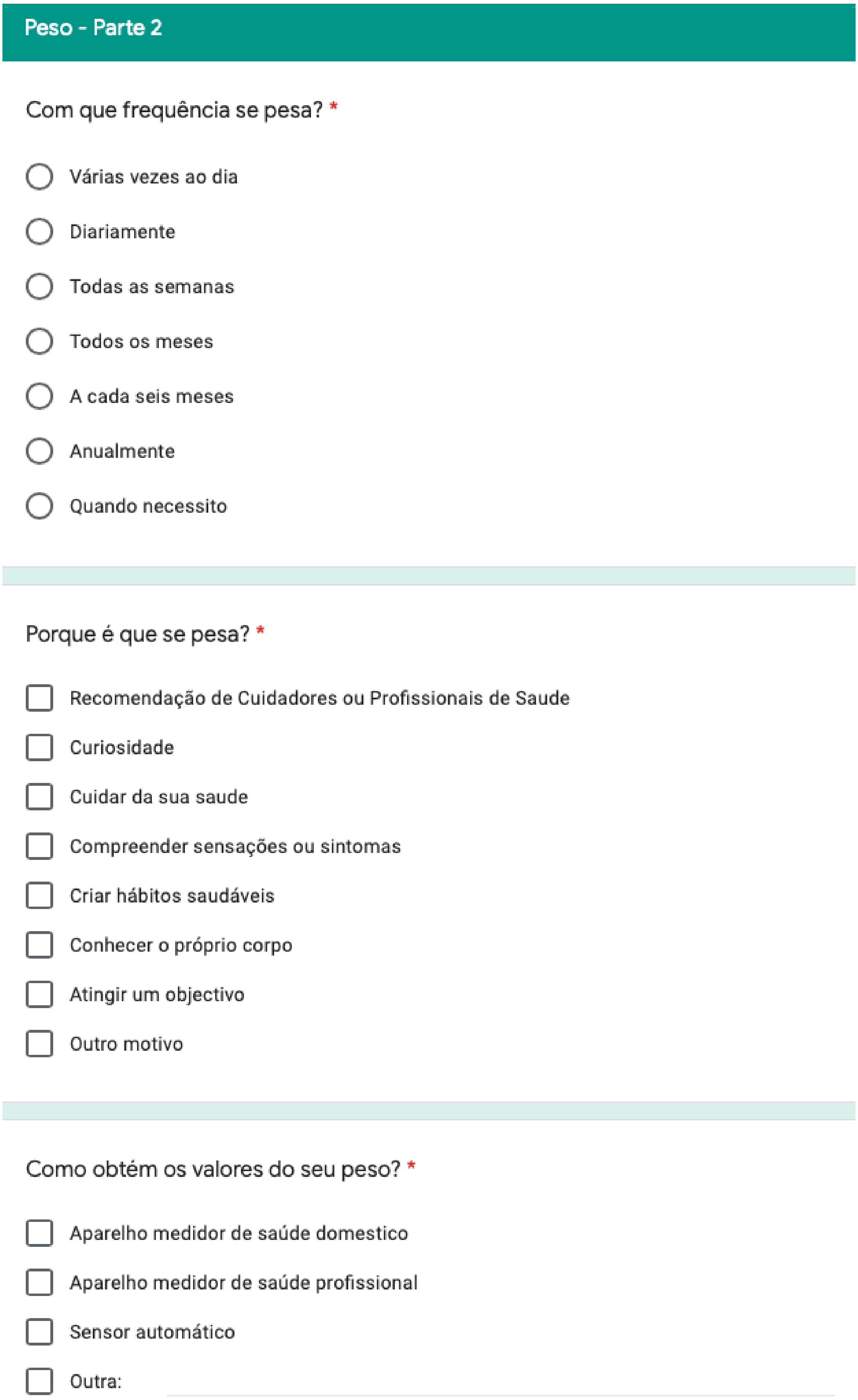
Monitoriza o seu peso? *

○ Sim

○ Não

Figure A3. Assessing Weight Monitoring. A positive answer further questions weight self-monitoring habits, while a negative answer leads to the next section.

Appendix A - Survey



Peso - Parte 2

Com que frequência se pesa? *

○ Várias vezes ao dia
○ Diariamente
○ Todas as semanas
○ Todos os meses
○ A cada seis meses
○ Anualmente
○ Quando necessito

Porque é que se pesa? *

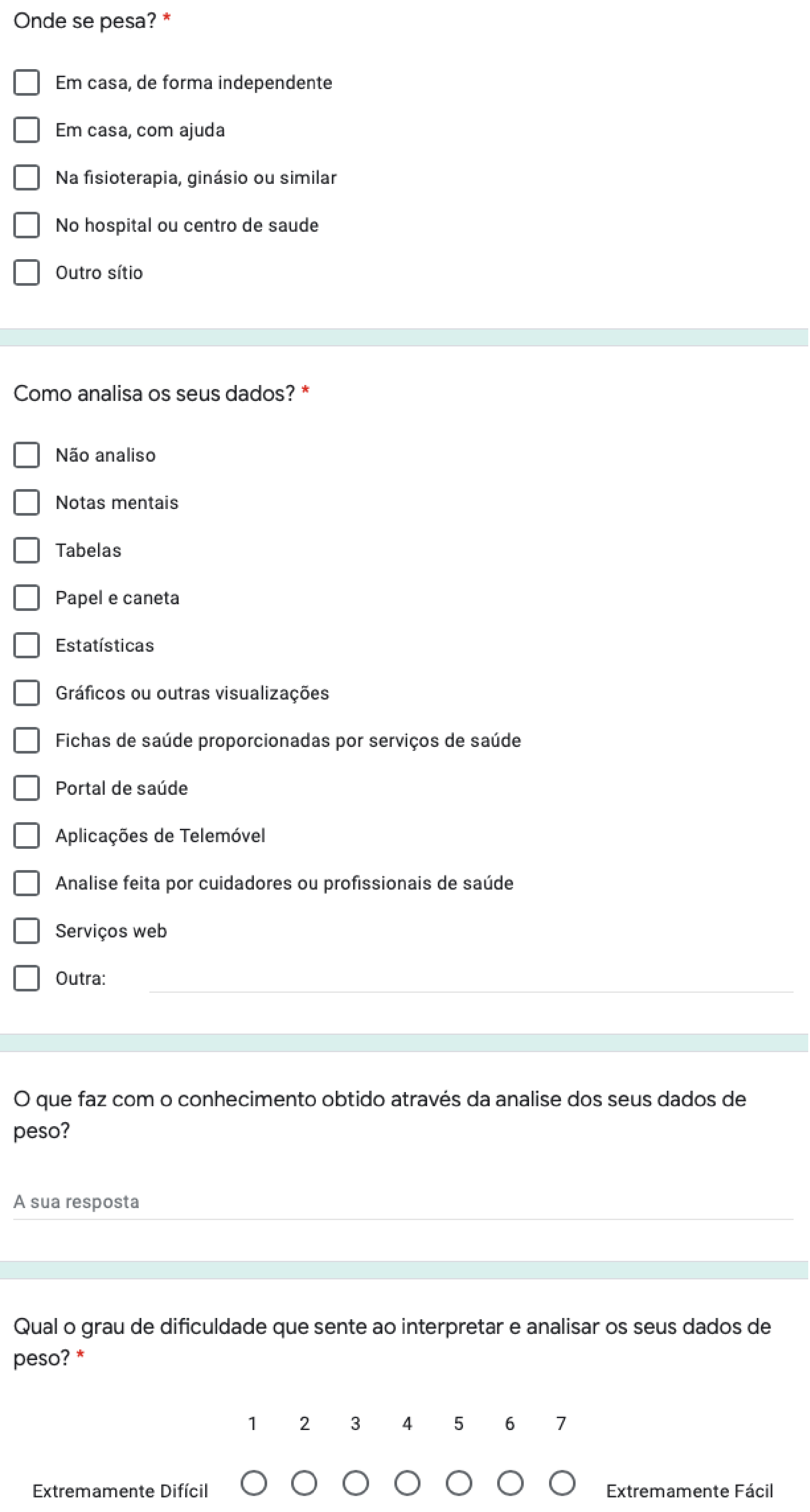
☐ Recomendação de Cuidadores ou Profissionais de Saude
☐ Curiosidade
☐ Cuidar da sua saude
☐ Compreender sensações ou sintomas
☐ Criar hábitos saudáveis
☐ Conhecer o próprio corpo
☐ Atingir um objectivo
☐ Outro motivo

Como obtém os valores do seu peso? *

☐ Aparelho medidor de saúde domestico
☐ Aparelho medidor de saúde profissional
☐ Sensor automático
☐ Outra: ______

Figure A4. Understanding Participants' Weight Self-monitoring Context (continued).

Appendix A - Survey



Onde se pesa? *

☐ Em casa, de forma independente
☐ Em casa, com ajuda
☐ Na fisioterapia, ginásio ou similar
☐ No hospital ou centro de saude
☐ Outro sítio

Como analisa os seus dados? *

☐ Não analiso
☐ Notas mentais
☐ Tabelas
☐ Papel e caneta
☐ Estatísticas
☐ Gráficos ou outras visualizações
☐ Fichas de saúde proporcionadas por serviços de saúde
☐ Portal de saúde
☐ Aplicações de Telemóvel
☐ Analise feita por cuidadores ou profissionais de saúde
☐ Serviços web
☐ Outra: ____________________

O que faz com o conhecimento obtido através da analise dos seus dados de peso?

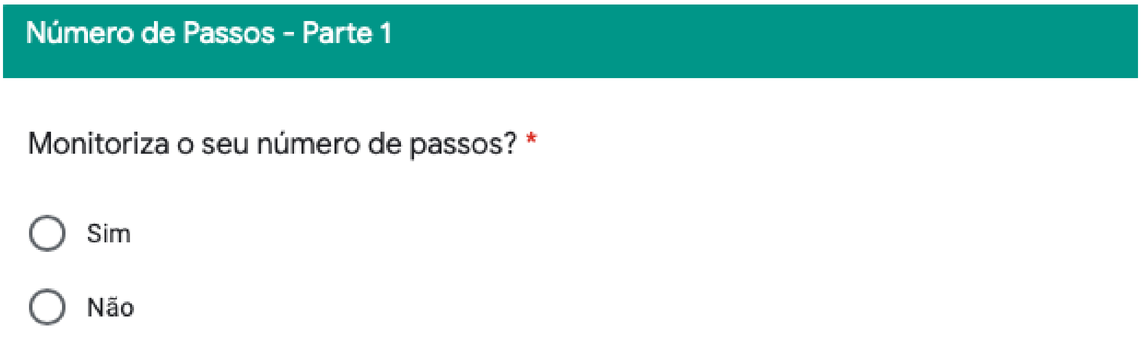
A sua resposta

Qual o grau de dificuldade que sente ao interpretar e analisar os seus dados de peso? *

	1	2	3	4	5	6	7	
Extremamente Difícil	○	○	○	○	○	○	○	Extremamente Fácil

Figure A5. Understanding Participants’ Weight Self-monitoring Context.

Section A2 – Number of Steps


Número de Passos - Parte 1

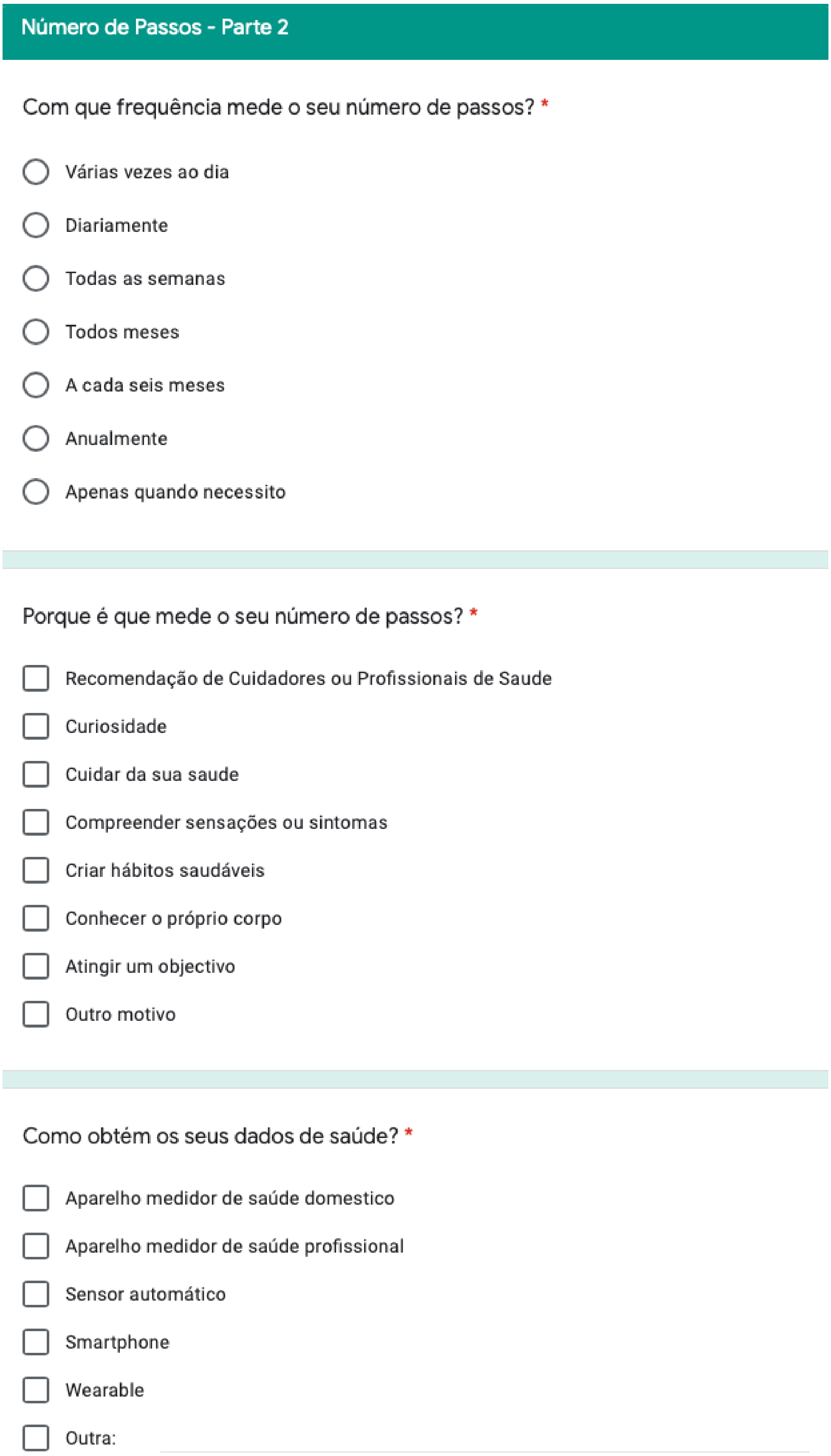
Monitoriza o seu número de passos? *

○ Sim

○ Não

Figure A5. Assessing Step Count Monitoring. A positive answer further questions step count self-monitoring habits, while a negative answer leads to the next section.

Appendix A - Survey



Número de Passos - Parte 2

Com que frequência mede o seu número de passos? *

○ Várias vezes ao dia
○ Diariamente
○ Todas as semanas
○ Todos meses
○ A cada seis meses
○ Anualmente
○ Apenas quando necessito

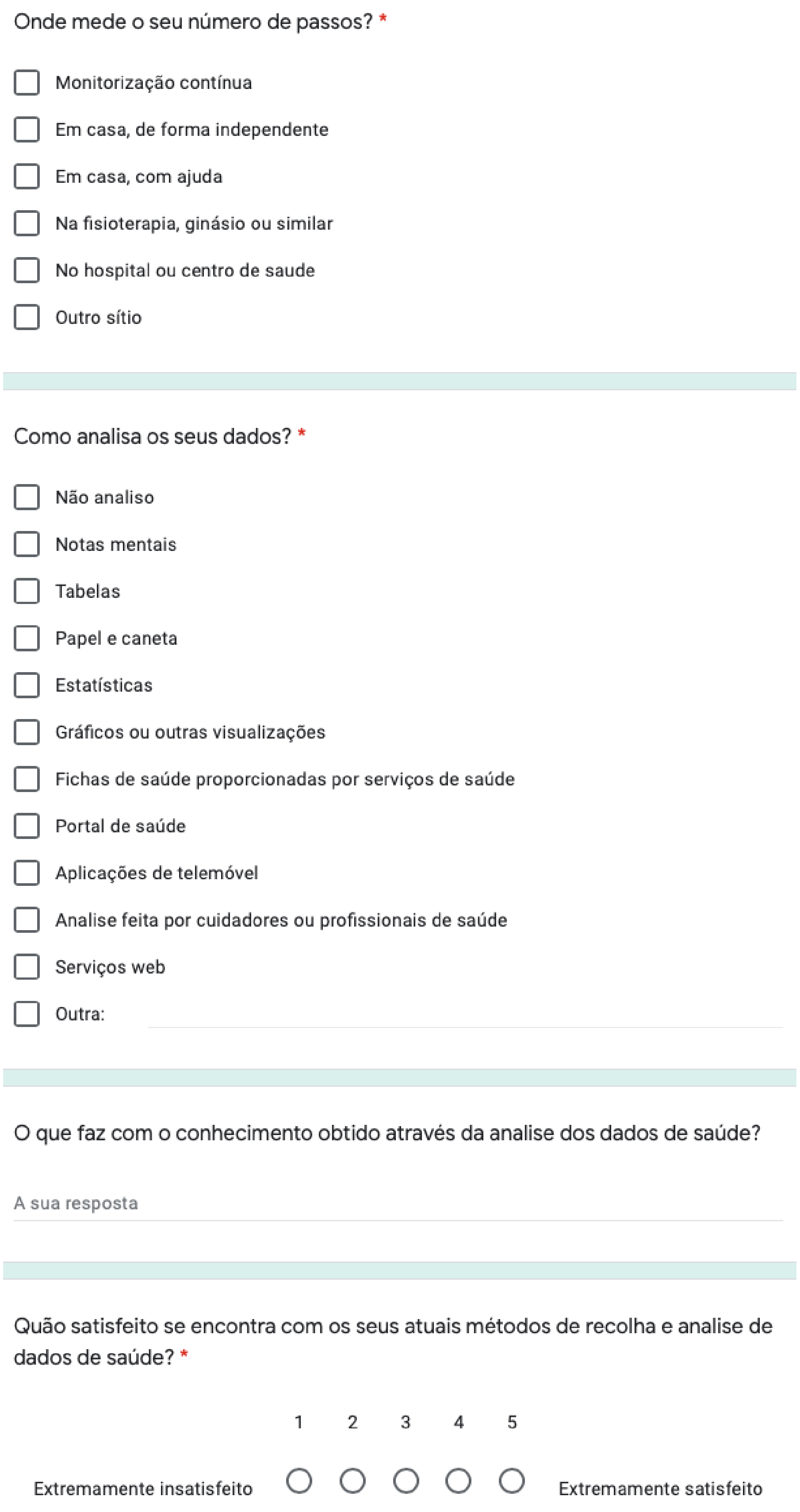
Porque é que mede o seu número de passos? *

☐ Recomendação de Cuidadores ou Profissionais de Saude
☐ Curiosidade
☐ Cuidar da sua saude
☐ Compreender sensações ou sintomas
☐ Criar hábitos saudáveis
☐ Conhecer o próprio corpo
☐ Atingir um objectivo
☐ Outro motivo

Como obtém os seus dados de saúde? *

☐ Aparelho medidor de saúde domestico
☐ Aparelho medidor de saúde profissional
☐ Sensor automático
☐ Smartphone
☐ Wearable
☐ Outra:

Figure A6. Understanding Participants' Step Count Self-monitoring Context (continued).



Onde mede o seu número de passos? *

☐ Monitorização contínua

☐ Em casa, de forma independente

☐ Em casa, com ajuda

☐ Na fisioterapia, ginásio ou similar

☐ No hospital ou centro de saude

☐ Outro sítio

Como analisa os seus dados? *

☐ Não analiso

☐ Notas mentais

☐ Tabelas

☐ Papel e caneta

☐ Estatísticas

☐ Gráficos ou outras visualizações

☐ Fichas de saúde proporcionadas por serviços de saúde

☐ Portal de saúde

☐ Aplicações de telemóvel

☐ Analise feita por cuidadores ou profissionais de saúde

☐ Serviços web

☐ Outra:

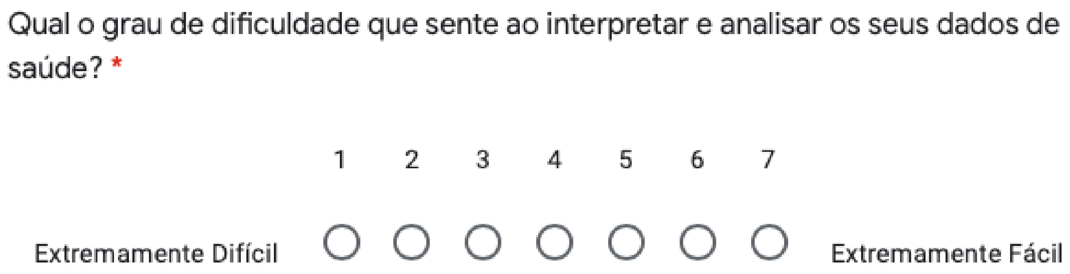
O que faz com o conhecimento obtido através da analise dos dados de saúde?

A sua resposta

Quão satisfeito se encontra com os seus atuais métodos de recolha e analise de dados de saúde? *

	1	2	3	4	5	
Extremamente insatisfeito	○	○	○	○	○	Extremamente satisfeito

Figure A6. Understanding Participants’ Step Count Self-monitoring Context (continued).

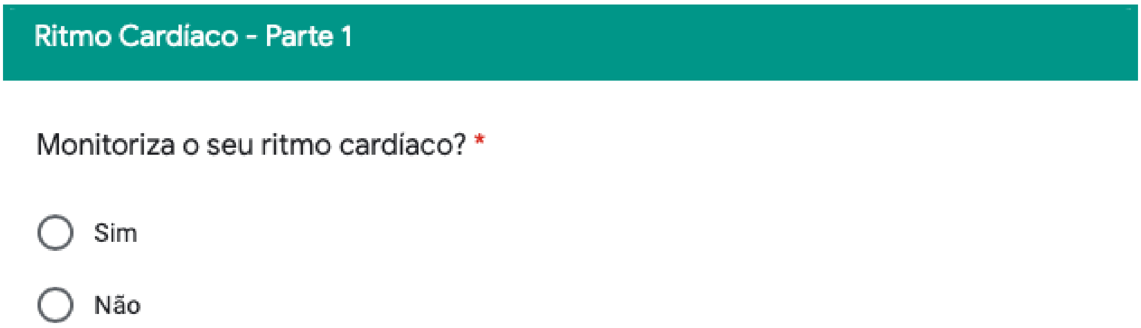


Qual o grau de dificuldade que sente ao interpretar e analisar os seus dados de saúde? *

	1	2	3	4	5	6	7	
Extremamente Difícil	○	○	○	○	○	○	○	Extremamente Fácil

Figure A6. Understanding Participants' Step Count Self-monitoring Context.

Section A3 – Heart Rate



Ritmo Cardíaco - Parte 1

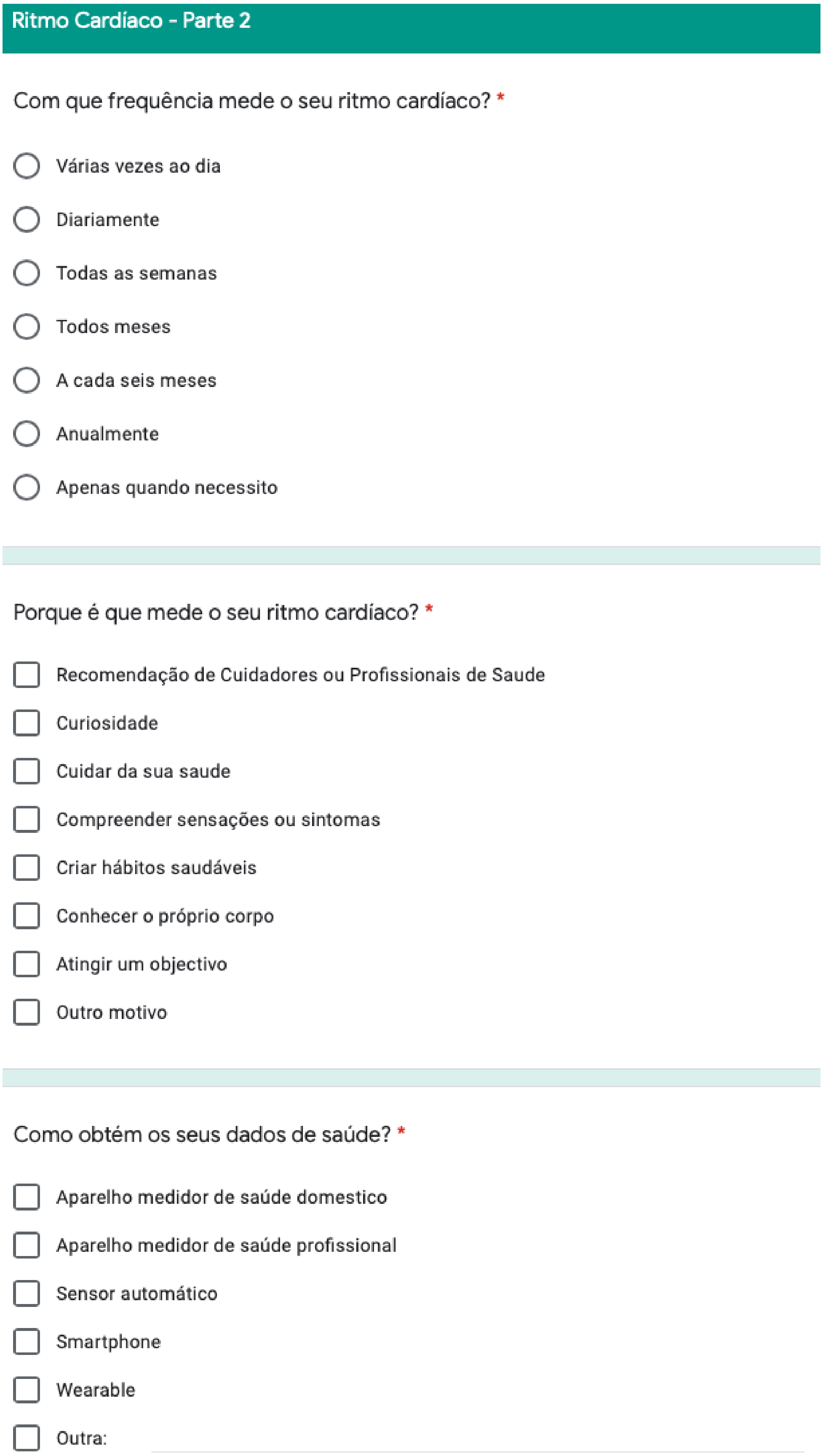
Monitoriza o seu ritmo cardíaco? *

○ Sim

○ Não

Figure A7. Assessing Heart Rate Monitoring. A positive answer further questions heart rate self-monitoring habits, while a negative answer leads to the next section.

Appendix A - Survey



Ritmo Cardíaco - Parte 2

Com que frequência mede o seu ritmo cardíaco? *

○ Várias vezes ao dia
○ Diariamente
○ Todas as semanas
○ Todos meses
○ A cada seis meses
○ Anualmente
○ Apenas quando necessito

Porque é que mede o seu ritmo cardíaco? *

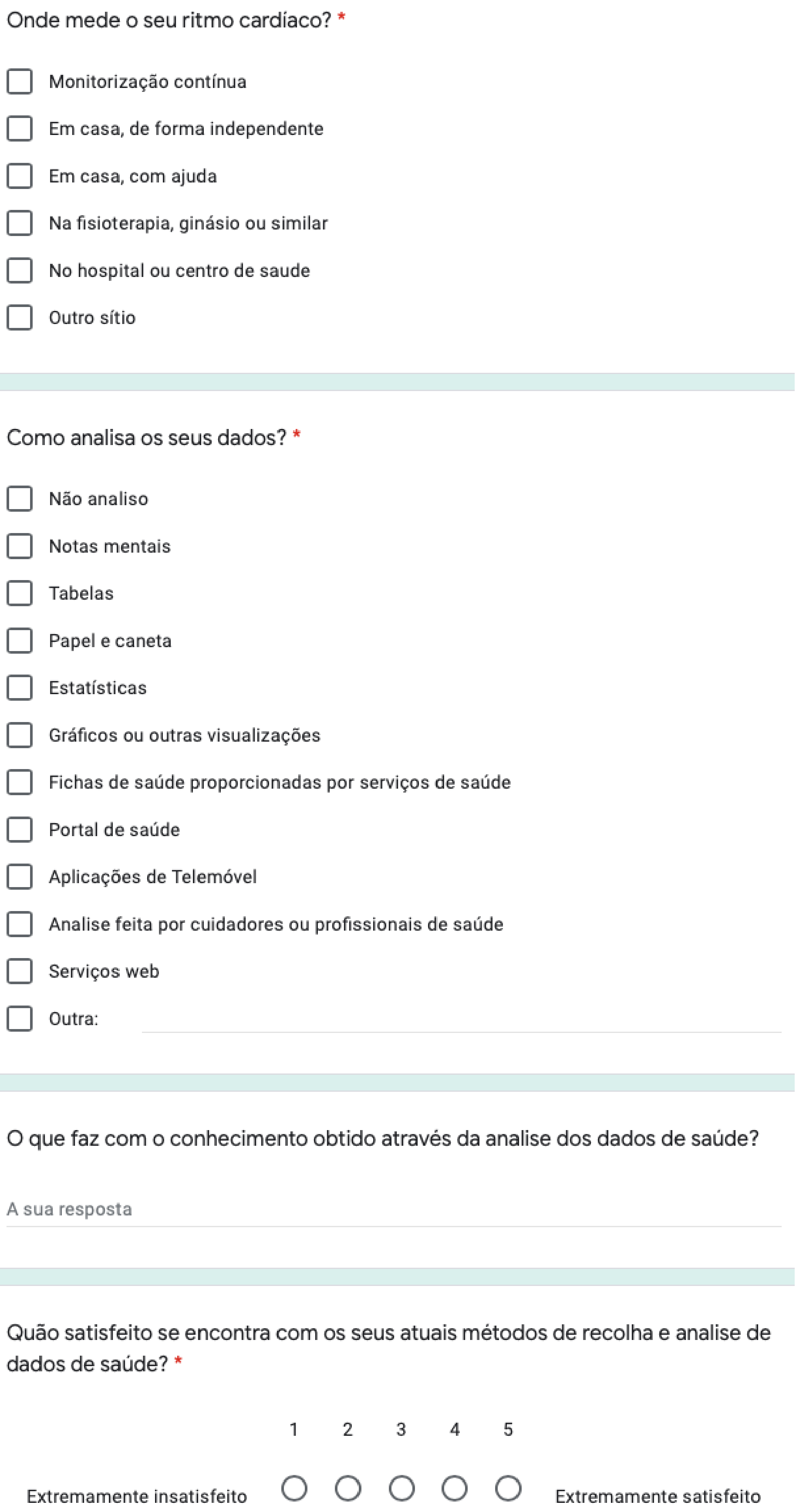
☐ Recomendação de Cuidadores ou Profissionais de Saude
☐ Curiosidade
☐ Cuidar da sua saude
☐ Compreender sensações ou sintomas
☐ Criar hábitos saudáveis
☐ Conhecer o próprio corpo
☐ Atingir um objectivo
☐ Outro motivo

Como obtém os seus dados de saúde? *

☐ Aparelho medidor de saúde domestico
☐ Aparelho medidor de saúde profissional
☐ Sensor automático
☐ Smartphone
☐ Wearable
☐ Outra: ____________________

Figure A8. Understanding Participants' Heart Rate Self-monitoring Context (continued).

Appendix A - Survey



Onde mede o seu ritmo cardíaco? *

- ☐ Monitorização contínua
- ☐ Em casa, de forma independente
- ☐ Em casa, com ajuda
- ☐ Na fisioterapia, ginásio ou similar
- ☐ No hospital ou centro de saude
- ☐ Outro sítio

Como analisa os seus dados? *

- ☐ Não analiso
- ☐ Notas mentais
- ☐ Tabelas
- ☐ Papel e caneta
- ☐ Estatísticas
- ☐ Gráficos ou outras visualizações
- ☐ Fichas de saúde proporcionadas por serviços de saúde
- ☐ Portal de saúde
- ☐ Aplicações de Telemóvel
- ☐ Analise feita por cuidadores ou profissionais de saúde
- ☐ Serviços web
- ☐ Outra: ____________

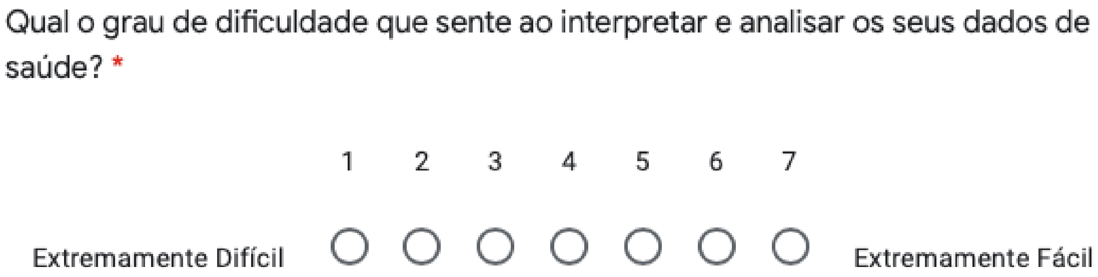
O que faz com o conhecimento obtido através da analise dos dados de saúde?

A sua resposta

Quão satisfeito se encontra com os seus atuais métodos de recolha e analise de dados de saúde? *

	1	2	3	4	5	
Extremamente insatisfeito	○	○	○	○	○	Extremamente satisfeito

Figure A8. Understanding Participants' Heart Rate Self-monitoring Context (continued).

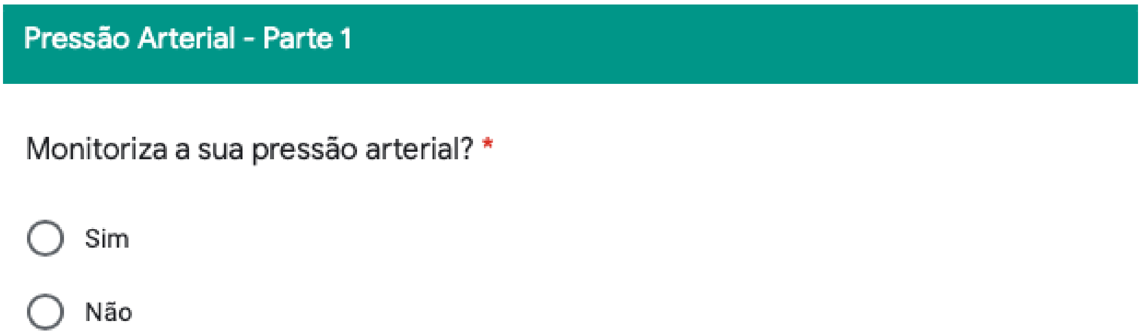


Qual o grau de dificuldade que sente ao interpretar e analisar os seus dados de saúde? *

	1	2	3	4	5	6	7	
Extremamente Difícil	○	○	○	○	○	○	○	Extremamente Fácil

Figure A8. Understanding Participants Heart Rate Self-monitoring Context.

Section A4 – Blood Pressure



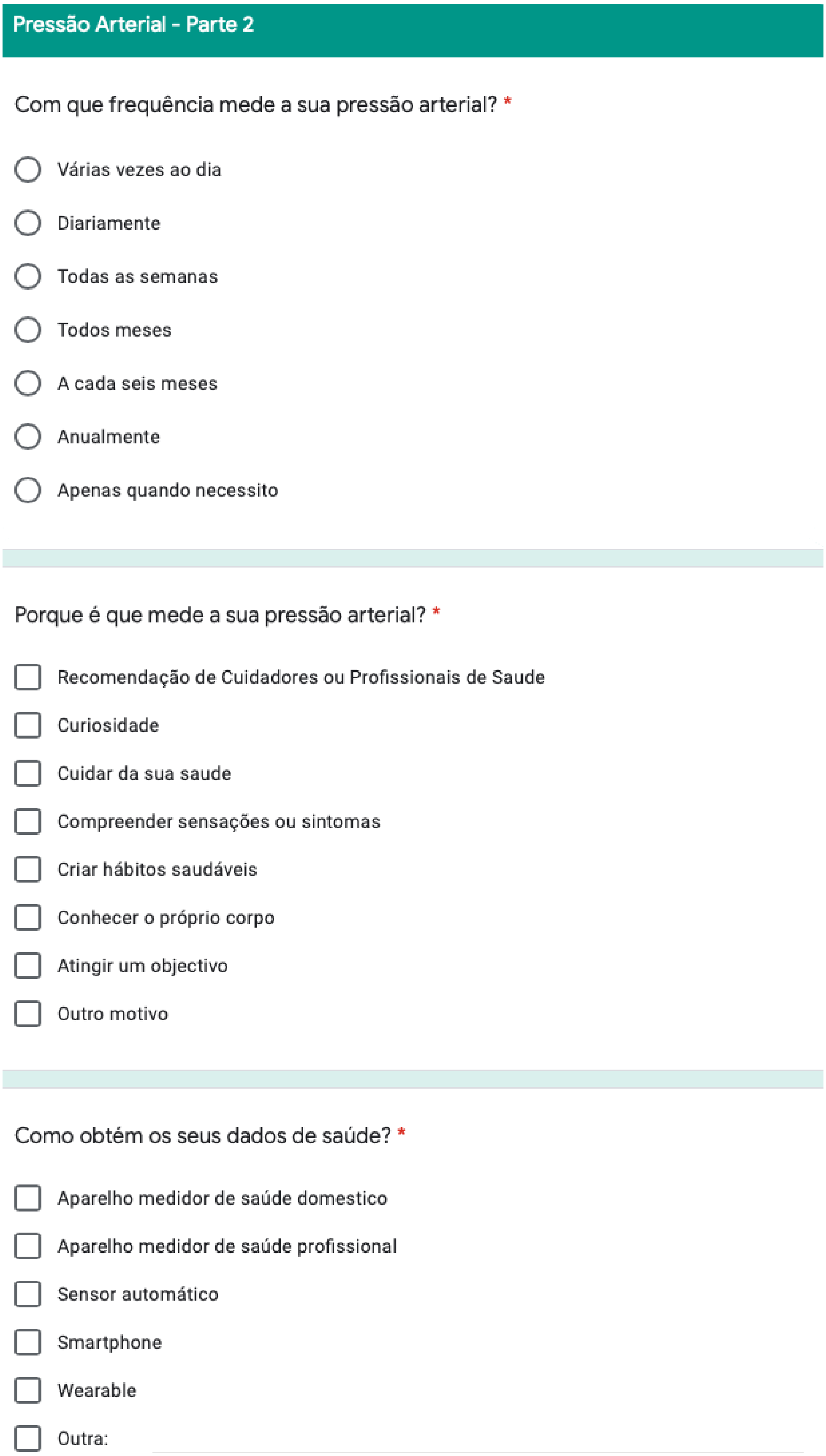
Pressão Arterial - Parte 1

Monitoriza a sua pressão arterial? *

○ Sim

○ Não

Figure A9. Assessing Blood Pressure Monitoring. A positive answer further questions BP self-monitoring habits, while a negative answer leads to the next section.



Pressão Arterial - Parte 2

Com que frequência mede a sua pressão arterial? *

○ Várias vezes ao dia
○ Diariamente
○ Todas as semanas
○ Todos meses
○ A cada seis meses
○ Anualmente
○ Apenas quando necessito

Porque é que mede a sua pressão arterial? *

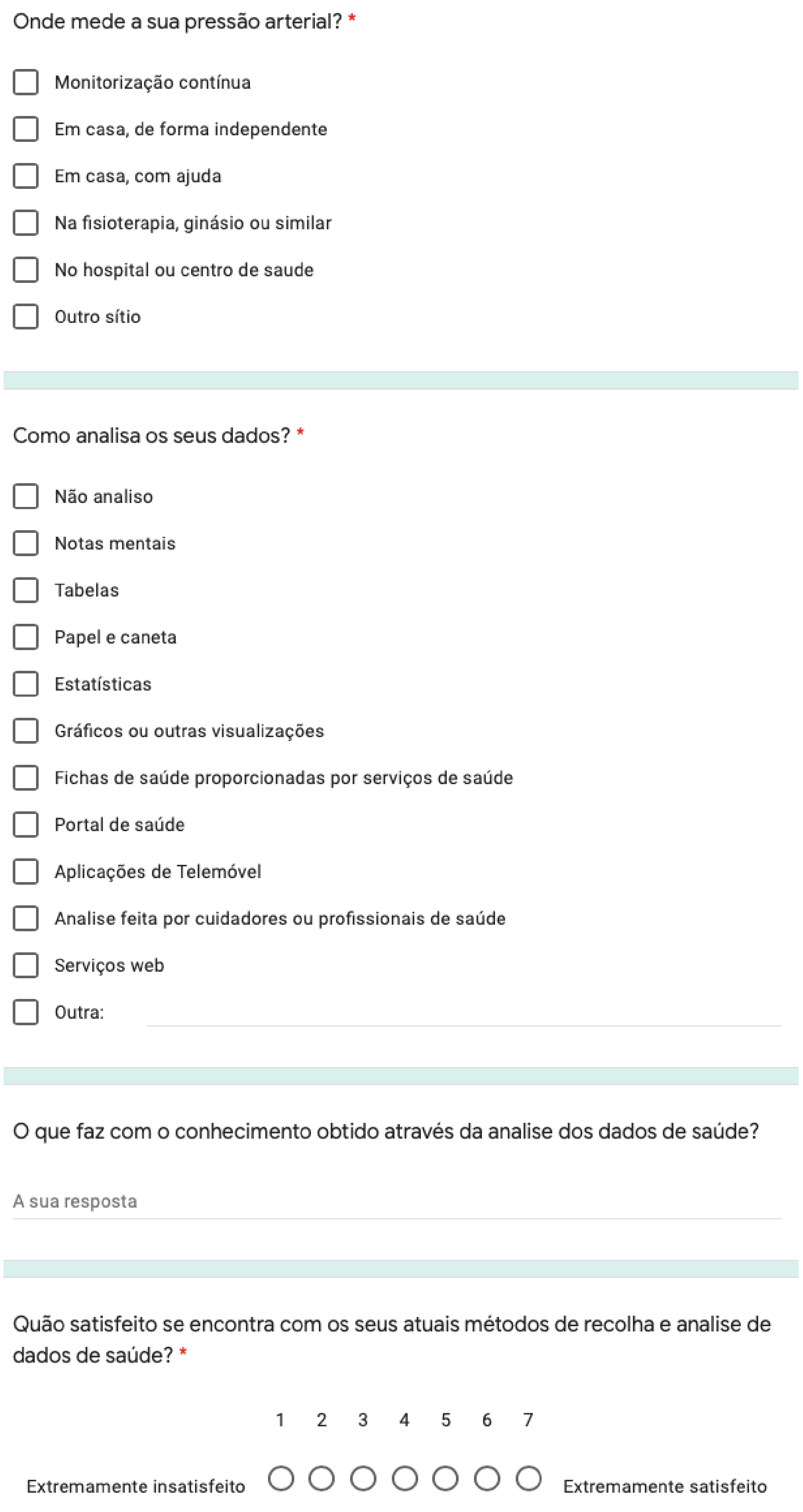
☐ Recomendação de Cuidadores ou Profissionais de Saude
☐ Curiosidade
☐ Cuidar da sua saude
☐ Compreender sensações ou sintomas
☐ Criar hábitos saudáveis
☐ Conhecer o próprio corpo
☐ Atingir um objectivo
☐ Outro motivo

Como obtém os seus dados de saúde? *

☐ Aparelho medidor de saúde domestico
☐ Aparelho medidor de saúde profissional
☐ Sensor automático
☐ Smartphone
☐ Wearable
☐ Outra: ____________________

Figure A10. Understanding Participants' Blood Pressure Self-monitoring Context (continued).

Appendix A - Survey



Onde mede a sua pressão arterial? *

☐ Monitorização contínua
☐ Em casa, de forma independente
☐ Em casa, com ajuda
☐ Na fisioterapia, ginásio ou similar
☐ No hospital ou centro de saude
☐ Outro sítio

Como analisa os seus dados? *

☐ Não analiso
☐ Notas mentais
☐ Tabelas
☐ Papel e caneta
☐ Estatísticas
☐ Gráficos ou outras visualizações
☐ Fichas de saúde proporcionadas por serviços de saúde
☐ Portal de saúde
☐ Aplicações de Telemóvel
☐ Analise feita por cuidadores ou profissionais de saúde
☐ Serviços web
☐ Outra: ______

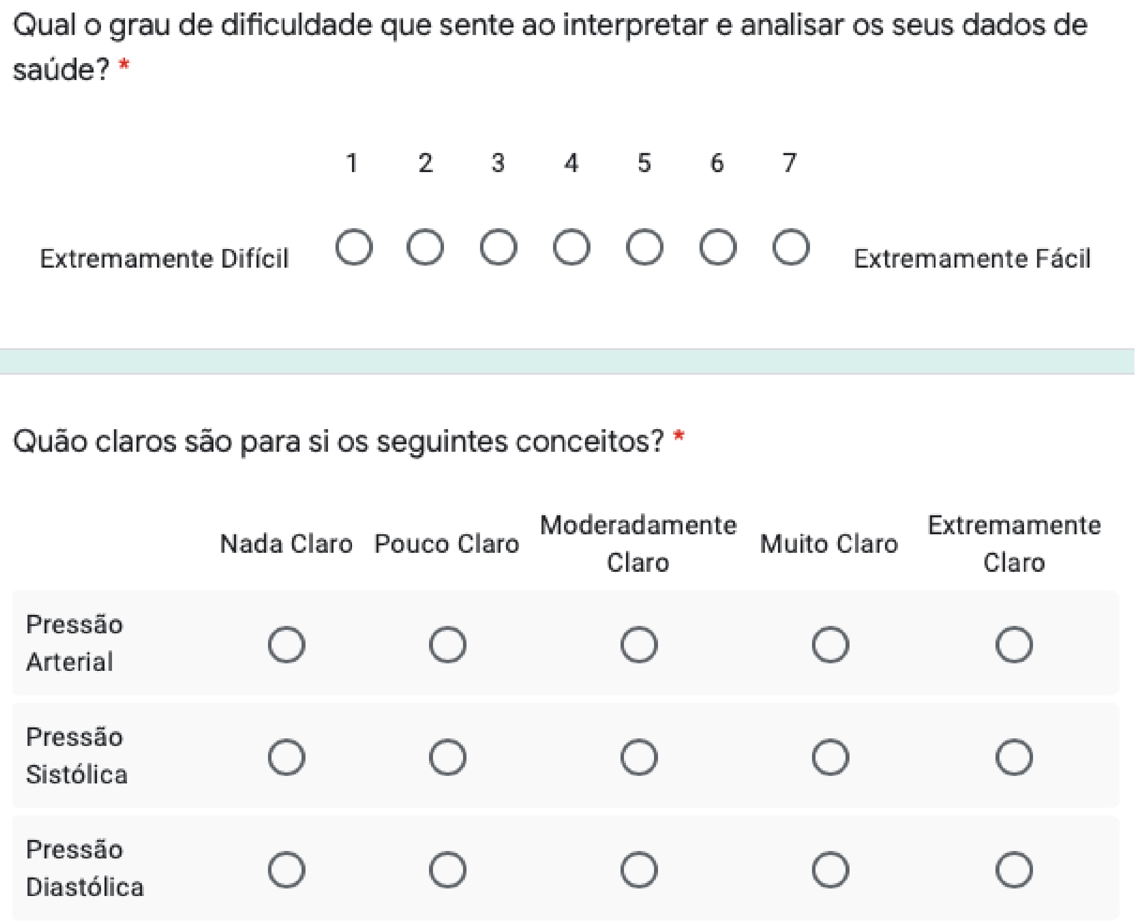
O que faz com o conhecimento obtido através da analise dos dados de saúde?

A sua resposta

Quão satisfeito se encontra com os seus atuais métodos de recolha e analise de dados de saúde? *

	1	2	3	4	5	6	7	
Extremamente insatisfeito	○	○	○	○	○	○	○	Extremamente satisfeito

Figure A10. Understanding Participants' Blood Pressure Self-monitoring Context (continued).



Qual o grau de dificuldade que sente ao interpretar e analisar os seus dados de saúde? *

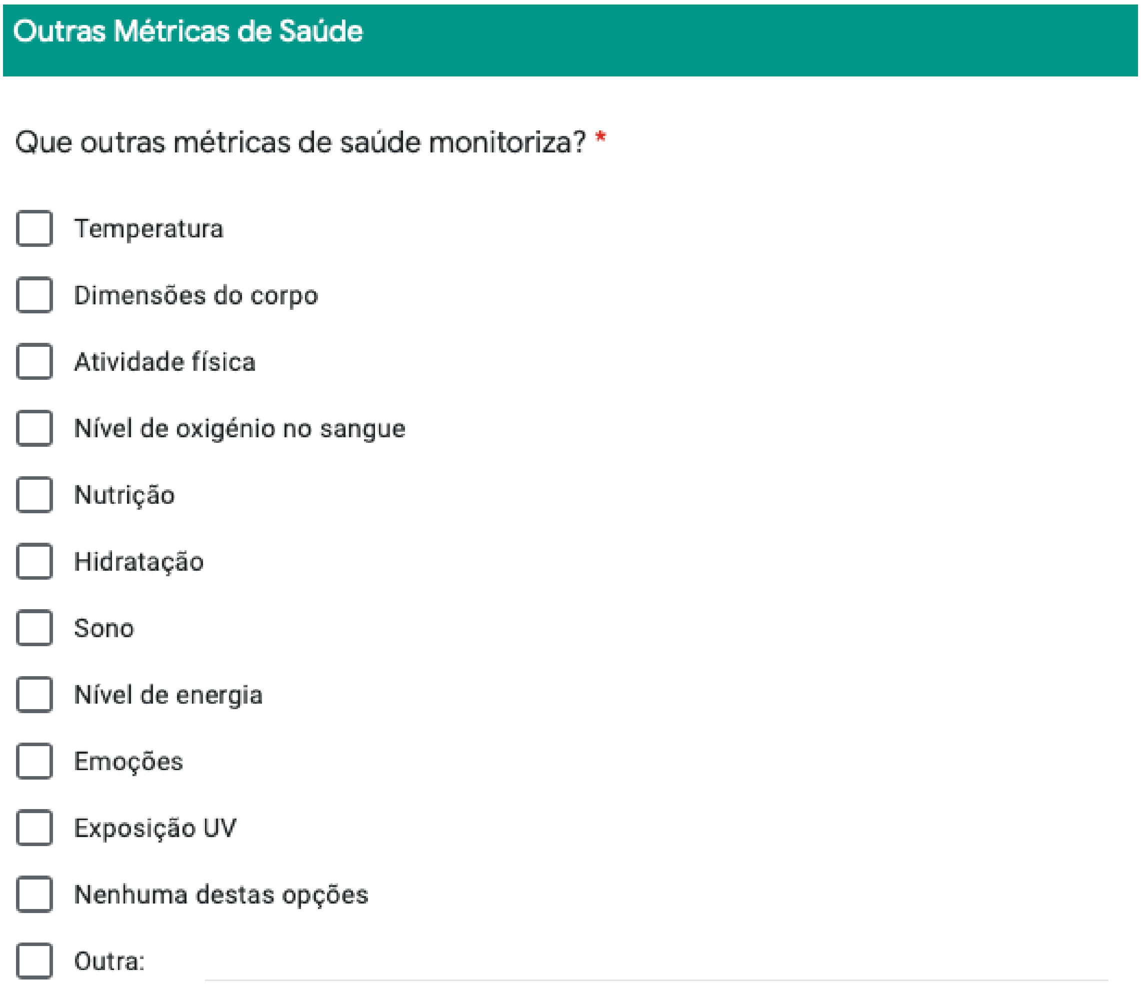
	1	2	3	4	5	6	7	
Extremamente Difícil	○	○	○	○	○	○	○	Extremamente Fácil

Quão claros são para si os seguintes conceitos? *

	Nada Claro	Pouco Claro	Moderadamente Claro	Muito Claro	Extremamente Claro
Pressão Arterial	○	○	○	○	○
Pressão Sistólica	○	○	○	○	○
Pressão Diastólica	○	○	○	○	○

Figure A10. Understanding Participants’ Blood Pressure Self-monitoring Context.

Section A5 – Other Metrics



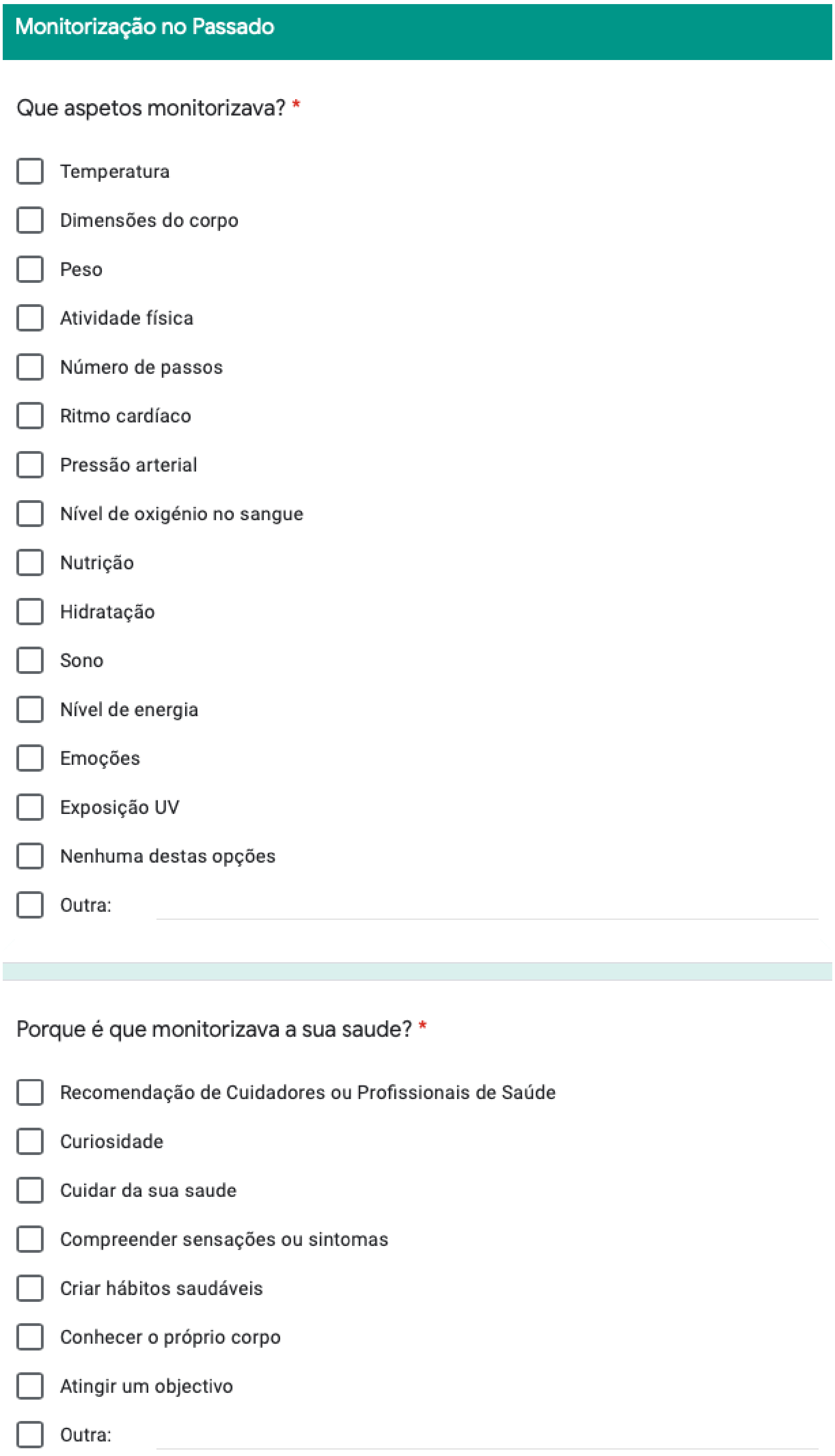
Outras Métricas de Saúde

Que outras métricas de saúde monitoriza? *

☐ Temperatura
☐ Dimensões do corpo
☐ Atividade física
☐ Nível de oxigénio no sangue
☐ Nutrição
☐ Hidratação
☐ Sono
☐ Nível de energia
☐ Emoções
☐ Exposição UV
☐ Nenhuma destas opções
☐ Outra: ____________________

Figure A11. Assessing Other Self-monitored Metrics.

Route B – Past Monitoring



Monitorização no Passado

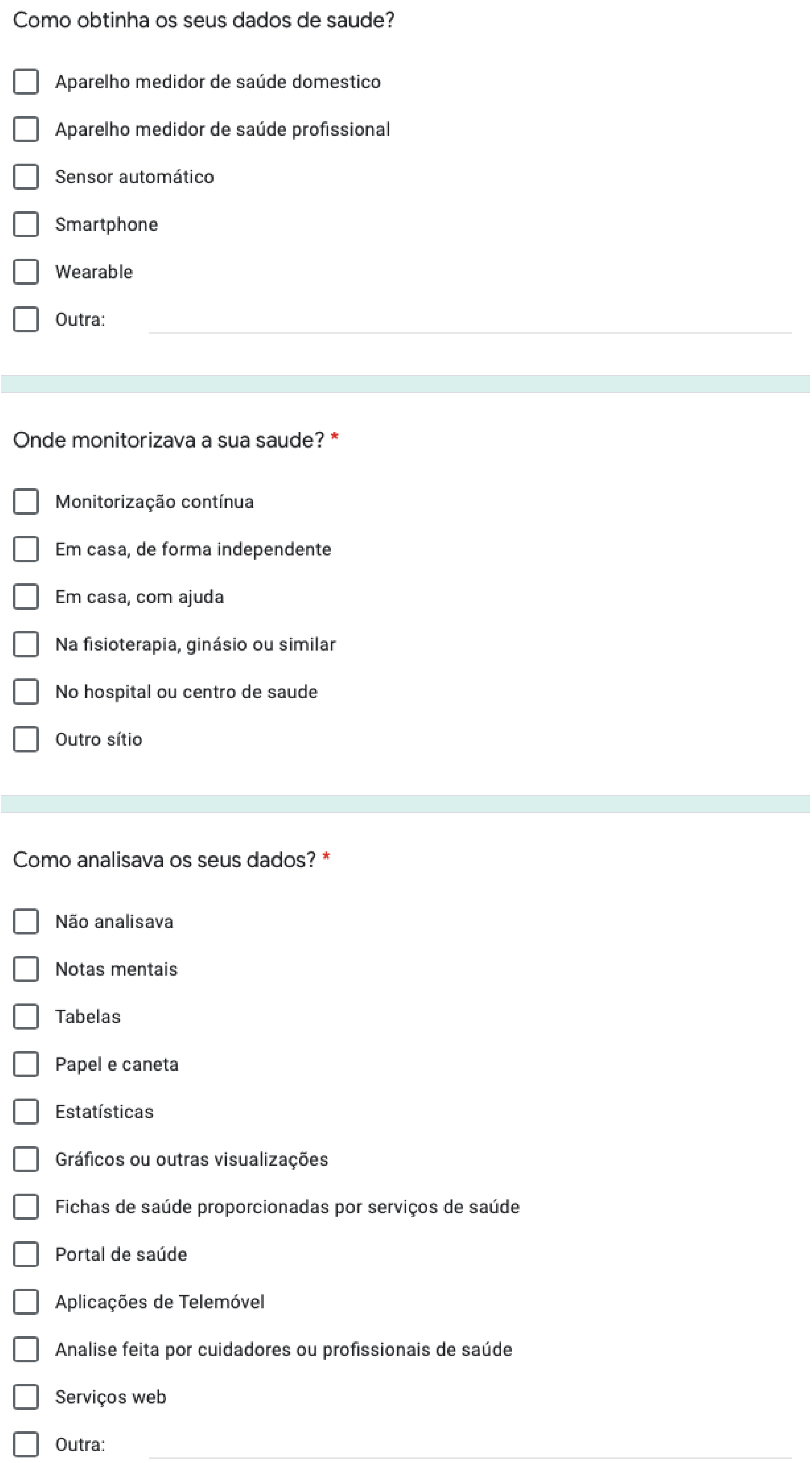
Que aspetos monitorizava? *

☐ Temperatura
☐ Dimensões do corpo
☐ Peso
☐ Atividade física
☐ Número de passos
☐ Ritmo cardíaco
☐ Pressão arterial
☐ Nível de oxigénio no sangue
☐ Nutrição
☐ Hidratação
☐ Sono
☐ Nível de energia
☐ Emoções
☐ Exposição UV
☐ Nenhuma destas opções
☐ Outra: ____

Porque é que monitorizava a sua saude? *

☐ Recomendação de Cuidadores ou Profissionais de Saúde
☐ Curiosidade
☐ Cuidar da sua saude
☐ Compreender sensações ou sintomas
☐ Criar hábitos saudáveis
☐ Conhecer o próprio corpo
☐ Atingir um objectivo
☐ Outra: ____

Figure A12. Understanding Participants’ Past Self-monitoring Experience (continued).



Como obtinha os seus dados de saude?

☐ Aparelho medidor de saúde domestico
☐ Aparelho medidor de saúde profissional
☐ Sensor automático
☐ Smartphone
☐ Wearable
☐ Outra: ____________

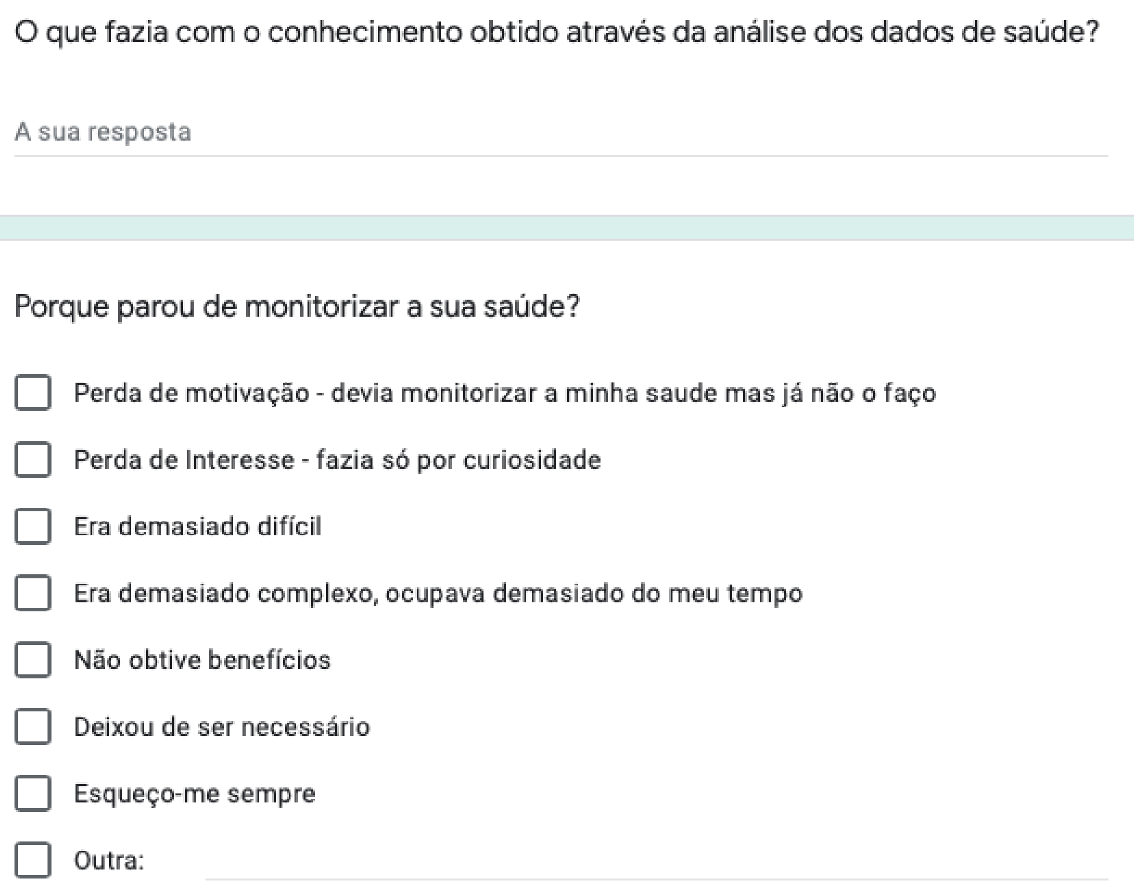
Onde monitorizava a sua saude? *

☐ Monitorização contínua
☐ Em casa, de forma independente
☐ Em casa, com ajuda
☐ Na fisioterapia, ginásio ou similar
☐ No hospital ou centro de saude
☐ Outro sítio

Como analisava os seus dados? *

☐ Não analisava
☐ Notas mentais
☐ Tabelas
☐ Papel e caneta
☐ Estatísticas
☐ Gráficos ou outras visualizações
☐ Fichas de saúde proporcionadas por serviços de saúde
☐ Portal de saúde
☐ Aplicações de Telemóvel
☐ Analise feita por cuidadores ou profissionais de saúde
☐ Serviços web
☐ Outra: ____________

Figure A12. Understanding Participants’ Past Self-monitoring Experience (continued).



O que fazia com o conhecimento obtido através da análise dos dados de saúde?

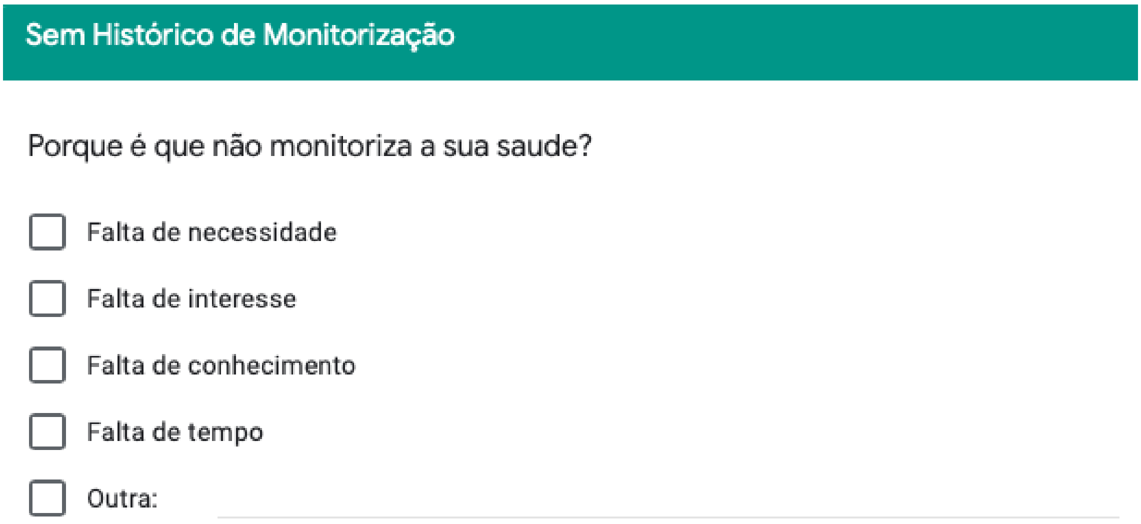
A sua resposta

Porque parou de monitorizar a sua saúde?

☐ Perda de motivação - devia monitorizar a minha saude mas já não o faço
☐ Perda de Interesse - fazia só por curiosidade
☐ Era demasiado difícil
☐ Era demasiado complexo, ocupava demasiado do meu tempo
☐ Não obtive benefícios
☐ Deixou de ser necessário
☐ Esqueço-me sempre
☐ Outra: __________

Figure A12. Understanding Participants' Past Self-monitoring Experience.

Route C – No Self-monitoring Experience



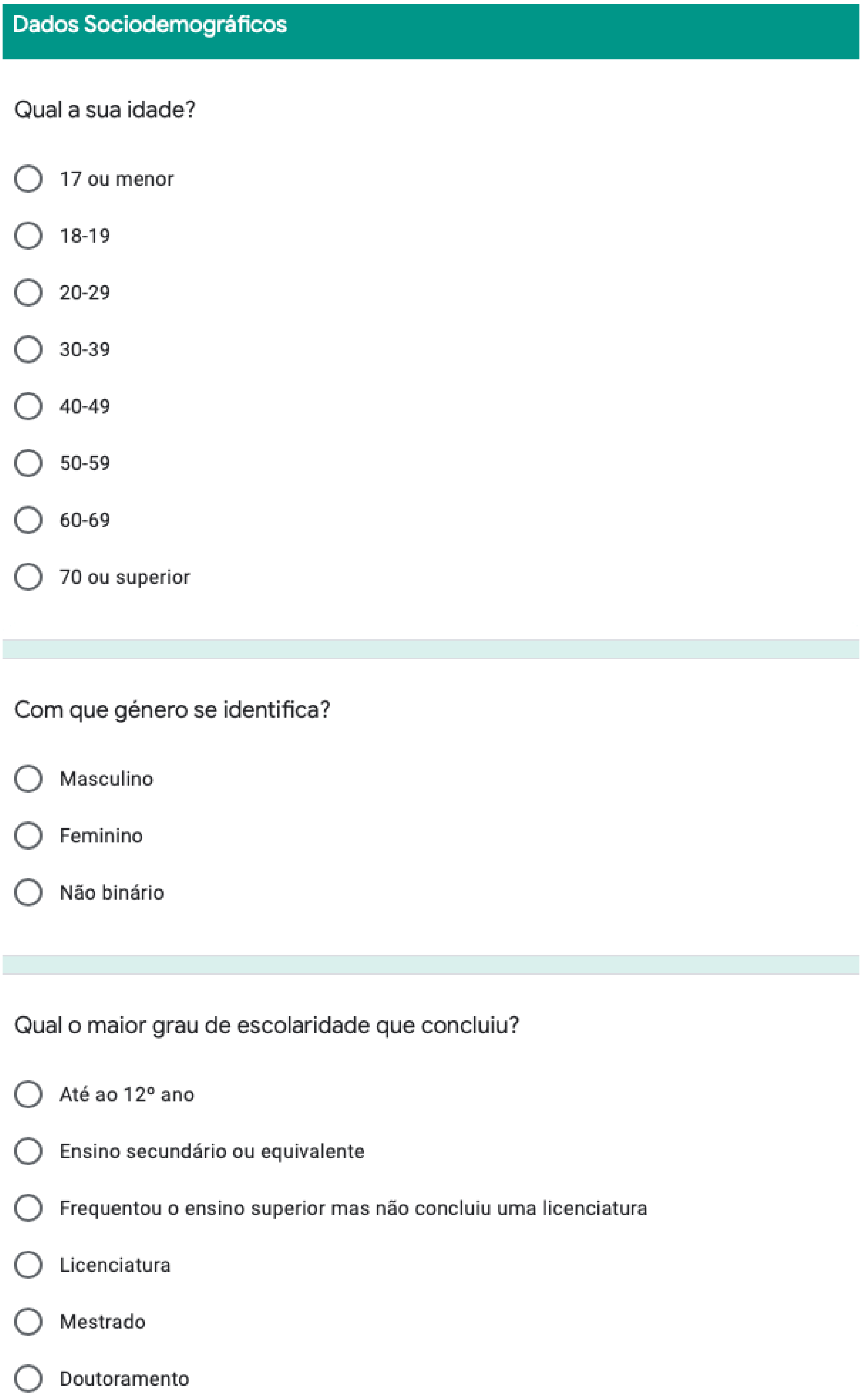
Sem Histórico de Monitorização

Porque é que não monitoriza a sua saude?

☐ Falta de necessidade
☐ Falta de interesse
☐ Falta de conhecimento
☐ Falta de tempo
☐ Outra: __________

Figure A13. Understanding why Participants did not Self-monitor their Health.

Part 2 – Sociodemographic Data



Dados Sociodemográficos

Qual a sua idade?

- ○ 17 ou menor
- ○ 18-19
- ○ 20-29
- ○ 30-39
- ○ 40-49
- ○ 50-59
- ○ 60-69
- ○ 70 ou superior

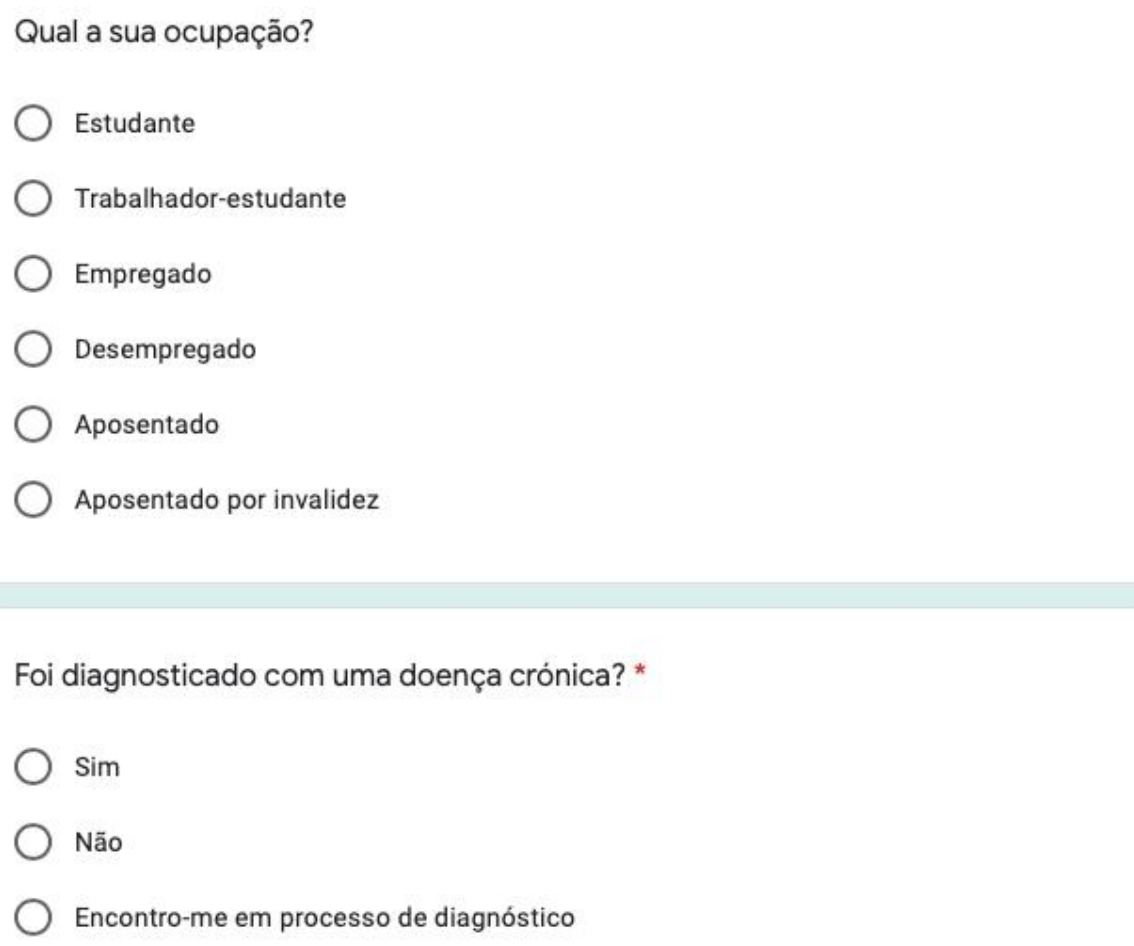
Com que género se identifica?

- ○ Masculino
- ○ Feminino
- ○ Não binário

Qual o maior grau de escolaridade que concluiu?

- ○ Até ao 12º ano
- ○ Ensino secundário ou equivalente
- ○ Frequentou o ensino superior mas não concluiu uma licenciatura
- ○ Licenciatura
- ○ Mestrado
- ○ Doutoramento

Figure A14. Sociodemographic Data (continued).



Qual a sua ocupação?

○ Estudante

○ Trabalhador-estudante

○ Empregado

○ Desempregado

○ Aposentado

○ Aposentado por invalidez

Foi diagnosticado com uma doença crónica? *

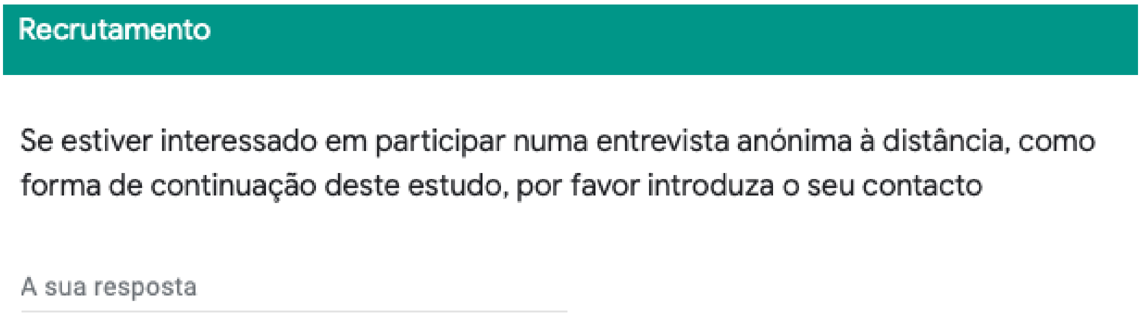
○ Sim

○ Não

○ Encontro-me em processo de diagnóstico

Figure A14. Sociodemographic Data.

Part 3 – Recruiting Chronic Disease Patients for the Interviews (Optional)



Recrutamento

Se estiver interessado em participar numa entrevista anónima à distância, como forma de continuação deste estudo, por favor introduza o seu contacto

A sua resposta

Figure A15. Recruiting Chronic Disease Patients for the Interviews.

Appendix A - Survey

Table A2

Survey Sample Sociodemographic Results

Variable	Category	Participants[a]	%
Age	18-19	125	15,2
	20-29	380	46,1
	30-39	100	12,1
	40-49	120	14,6
	50-59	74	9,0
	60-69	21	2,5
	≥ 70	4	0,5
Gender	Female	600	72,8
	Male	220	26,7
	Non-binary	4	0,5
Education	Less than high school degree	168	20.0
	Attended higher education but no degree	50	6.0
	High school degree or equivalent	138	17.0
	Bachelor Degree	292	35.0
	Masters Degree	158	19.0
	Doctorate Degree	18	2.0
Employment	Student	418	50,7
	Worker-student	96	11,7
	Unemployed	20	2,4
	Employed	273	33,1
	Retired due to disability	3	0,4
	Retired	14	1,7
Chronic Disease	Mid-diagnosis	17	2,1
	No	668	81,1
	Yes	139	16,9

[a] n=824

Appendix A - Survey

Table A3

Weight monitoring results

Variable	Category	n	%
Frequency	Weekly	170	42,6%
	Monthly	124	31,1%
	When I need to	28	7,0%
	Daily	42	10,5%
	Every six months	29	7,3%
	Several times a day	3	0,8%
	Annually	3	0,8%
Motivation	Achieving a goal	99	18,7%
	Curiosity	98	18,5%
	Cultivating healthy habits	73	13,8%
	Getting to know your own body	94	17,7%
	Health Professionals' recommendation	11	2,1%
	Managing personal health	151	28,5%
	Other	1	0,2%
	Understanding sensations or symptoms	3	0,6%
Data Source	Biosensor	9	2,1%
	Professional monitoring device	53	12,6%
	Self-monitoring device	357	85,2%
Physical Environment	Another place	29	6,2%
	At home, independently	358	76,7%
	At home, with help	6	1,3%
	In a hospital or health center	32	6,9%
	In physiotherapy, gym or similar	42	9,0%

(continued)

Appendix A - Survey

Variable	Category	n	%
Analysis	Analysis done by caretakers or health professionals	40	7,7%
	Charts or other visualizations	23	4,4%
	Don't analyse	79	15,1%
	Health records provided by health services	7	1,3%
	Memory	181	34,7%
	Mobile apps	109	20,9%
	Pen and paper	39	7,5%
	Statistics	11	2,1%
	Tables	30	5,7%
	Web apps	3	0,6%
Reaction to analysis results	Adjusting Habits	148	61,9%
	Comparing with other metrics	8	3,3%
	Monitoring Evolution	27	11,3%
	Doing Nothing	25	10,5%
	Reporting to healthcare providers	10	4,2%
	Achieving Self-knowledge	21	8,8%

Appendix A - Survey

Table A4

Steps monitoring results

Variable	Category	n	%
Frequency	Daily	154	73,3%
	Every week	15	7,1%
	Several times a day	24	11,4%
	Every six months	1	0,5%
	Monthly	5	2,4%
	When I need it	10	4,8%
	Annually	1	0,5%
Motivation	Achieving a goal	66	15,6%
	Curiosity	126	29,7%
	Cultivating healthy habits	98	23,1%
	Getting to know your own body	16	3,8%
	Health Professionals' recommendation	13	3,1%
	Manage personal health	85	20,0%
	Other	11	2,6%
	Understand sensations or symptoms	9	2,1%
Data Source	Biosensor	16	6,8%
	Mobile apps	139	58,6%
	Professional monitoring device	6	2,5%
	Self-monitoring device	14	5,9%
	Wearable	62	26,2%
Physical Environment	Another place	9	4,2%
	At home, independently	30	14,0%
	Continuous monitoring	175	81,4%
	In physiotherapy, gym or similar	1	0,5%

(continued)

Appendix A - Survey

Variable	Category	n	%
Analysis	Analysis done by caretakers or health professionals	3	1,1%
	Charts or other visualizations	37	13,5%
	Don't analyse	43	15,6%
	Health records provided by health services	4	1,5%
	Memory	26	9,5%
	Mobile apps	135	49,1%
	Pen and paper	1	0,4%
	Statistics	19	6,9%
	Tables	4	1,5%
	Web apps	3	1,1%
Reaction to analysis results	Adjusting Habits	45	46,9%
	Comparing with other metrics	2	2,1%
	Monitoring Evolution	15	15,6%
	Doing Nothing	19	19,8%
	Reporting to healthcare providers	3	3,1%
	Achieving Self-knowledge	11	11,5%
	Sharing with peers	1	1,0%

Appendix A - Survey

Table A5

Heart rate monitoring results

Variable	Category	n	%
Frequency of monitoring	Several times a day	25	13,3%
	Daily	40	21,3%
	Every week	39	20,7%
	Every six months	13	6,9%
	Monthly	39	20,7%
	When I need it	29	15,4%
	Annually	3	1,6%
Motivation	Getting to know your own body	64	17,3%
	Other	8	2,2%
	Achieving a goal	15	4,1%
	Curiosity	81	21,9%
	Cultivating healthy habits	32	8,6%
	Health Professionals' recommendation	34	9,2%
	Manage personal health	81	21,9%
	Understand sensations or symptoms	55	14,9%
Data Source	Biosensor	23	10,2%
	Manually	5	2.1%
	Mobile apps	33	14,7%
	Professional monitoring device	37	16,4%
	Self-monitoring device	65	28,9%
	Wearable	62	27,6%
	In physiotherapy, gym or similar	1	0,5%

(continued)

Appendix A - Survey

Variable	Category	n	%
Physical Environment	Another place	14	6,5%
	At a hospital or health center	18	8,3%
	At home, independently	97	44,7%
	At home, with help	8	3,7%
	At physiotherapy, gym or similar	15	6,9%
	Continuous monitoring	65	30,0%
Analysis	Analysis done by caretakers or health professionals	18	7,9%
	Charts or other visualizations	18	7,9%
	Don't analyse	35	15,4%
	Health records provided by health services	9	3,9%
	Memory	52	22,8%
	Mobile apps	62	27,2%
	Pen and paper	7	3,1%
	Statistics	14	6,1%
	Tables	9	3,9%
	Web apps	4	1,8%
Reaction to analysis results	Adjusting Habits	29	31,5%
	Comparing with other metrics	1	1,1%
	Monitoring Evolution	20	21,7%
	Doing Nothing	18	19,6%
	Reporting to healthcare providers	12	13,0%
	Achieving Self-knowledge	12	13,0%

Appendix A - Survey

Table A6

Blood Pressure monitoring results

Variable	Category	n	%
Frequency of monitoring	Daily	12	6,1%
	Every six months	41	20,7%
	Every week	25	12,6%
	Several times a day	1	0,5%
	When I need it	45	22,7%
	Monthly	63	31,8%
	Annually	11	5,6%
Motivation	Achieving Self-knowledge	36	10,5%
	Other	8	2,3%
	Achieving a goal	6	1,7%
	Curiosity	42	12,2%
	Cultivating healthy habits	22	6,4%
	Getting to know own body	4	1,2%
	Health Professionals' recommendation	73	21,3%
	Manage personal health	96	28,0%
	Understand sensations or symptoms	56	16,3%
Data Source	Biosensor	2	0,9%
	Mobile apps	3	1,3%
	Professional monitoring device	83	36,7%
	Self-monitoring device	137	60,6%
	Wearable	1	0,4%

(continued)

Appendix A - Survey

Variable	Category	n	%
Physical Environment	At a hospital or health centre	60	25.4
	At home, independently	136	57,6
	At home, with help	12	5,1
	Continuous monitoring	2	0,8
	In physiotherapy, gym or similar	8	3,3
	Other	18	7,6
Analysis	Analysis done by caretakers or health professionals	36	15,9%
	Charts or other visualizations	4	1,8%
	Don't analyse	40	17,6%
	Health records provided by health services	17	7,5%
	Memory	90	39,6%
	Mobile apps	11	4,8%
	Pen and paper	17	7,5%
	Statistics	2	0,9%
	Tables	9	4,0%
	Web apps	1	0,4%
Reaction to analysis results	Adjusting Habits	28	26,9%
	Monitoring Evolution	19	18,3%
	Doing Nothing	22	21,2%
	Reporting to healthcare providers	23	22,1%
	Achieving Self-knowledge	12	11,6%

Table A7

Other monitored metrics results

Metric	n	%
Physical Activity	236	18,2%
Sleep	220	17,0%
Temperature	157	12,1%
Water intake	157	12,1%
Nutrition	132	10,2%
Body dimensions	108	8,3%
Emotions	87	6,7%
None	65	5,0%
Energy level	48	3,7%
UV exposure	40	3,1%
Oxygen blood saturation	30	2,3%
Menstrual cycle	5	0,4%
Blood tests	3	0,2%
Glycaemic index	5	0,4%
Body composition	2	0,2%
Other	1	0,1%

Table A8

Past monitoring results

Variable	Category	n	%
Monitored metrics	Weight	43	18,3%
	Physical Activity	26	11,1%
	Sleep	22	9,4%
	Steps	22	9,4%
	Heart rate	21	8,9%
	Blood pressure	19	8,1%
	Temperature	16	6,8%
	Nutrition	15	6,4%
	Body dimensions	13	5,5%
	Emotions	10	4,3%
	Water intake	9	3,8%
	Oxygen blood saturation	5	2,1%
	Energy level	4	1,7%
	Blood tests	2	0,9%
	Glycemic index	2	0,9%
	None	2	0,9%
	UV exposure	2	0,9%
	Menstrual cycle	1	0,4%
	Other	1	0,4%

(continued)

Appendix A - Survey

Variable	Category	n	%
Motivation	Cultivating healthy habits	27	19,0%
	Manage personal health	26	18,3%
	Health Professionals' Recommendation	24	16,9%
	Curiosity	19	13,4%
	Achieving a goal	16	11,3%
	Getting to know your own body	15	10,6%
	Understand sensations or symptoms	14	9,9%
	Manage personal health	1	0,7%
Data Source	Mobile apps	29	30,9%
	Professional monitoring device	27	28,7%
	Self-monitoring device	28	29.8%
	Wearable	6	6,4%
	Biosensor	4	4,3%
Physical Environment	At home, independently	44	51,2%
	At a hospital or health center	15	17,4%
	In physiotherapy, gym or similar	11	12,8%
	Continuous monitoring	10	11,6%
	Another place	3	3,5%
	At home, with help	3	3,5%

(continued)

Appendix A - Survey

Variable	Category	n	%
Analysis	Mobile apps	31	25,8%
	Memory	19	15,8%
	Analysis done by caretakers or health professionals	14	11,7%
	Charts or other visualizations	14	11,7%
	Pen and paper	10	8,3%
	Health records provided by health services	9	7,5%
	Don't analyse	7	5,8%
	Statistics	7	5,8%
	Tables	5	4,2%
	Web apps	4	3,3%
Reaction to analysis results	Adjusting Habits	21	61,8%
	Doing Nothing	5	14,7%
	Monitoring Evolution	3	8,8%
	Reporting to healthcare providers	3	8,8%
	Comparing with other metrics	1	2,9%
	Achieving Self-knowledge	1	2,9%
Reason for stopping	Stopped being necessary	27	33,8%
	Loss of motivation	19	23,8%
	Forgetfulness	11	13,8%
	Loss of Interest	11	13,8%
	Too complex and time consuming	7	8,8%
	Other	3	3,8%
	Gained no benefits	2	2,5%

Table A9

Route C results

Reason	n	%
Lack of necessity	157	38,0%
Lack of knowledge	96	23,2%
Lack of interest	84	20,3%
Lack of time	70	16,9%
Lack of motivation	3	0,7%
Lack of resources	2	0,5%
Other	1	0,2%

10. Appendix B – Interviews

Table B1

Interview constructs, and questions

Construct	Questions
Introduction and informed consent	-
Monitoring context	“Describe a typical day”
Communicating health information	“How do devices inform you about your health?”
Data analysis	“How do you analyse your data?”
Exceptions	“Can you tell me about when that didn't happen?”
Handling extreme situations	“What do you do when a value is outside of your typical range?”
Blood pressure	“In order to evaluate how systems present health information, please explain what you understand as blood pressure?”
Open space for participants to include relevant information	“Would you like to include any extra information?”

Appendix B - Interviews

Table B2

Interview Participants

Participants	Gender	Age	Education	Domain	Disease	Metrics
P1	Female	20-29	High school degree or equivalent	Nutrition sciences	Diabetes	Weight; Glycaemic Index
P2	Female	20-29	Master's degree	Computer science	Pulmonary Disease	None
P3	Female	40-49	Bachelor's degree	Sociology	Thyroid Disease	Weight
P4	Female	30-39	Doctorate Degree	Industrial design	Gestational diabetes; Asthma	(Physical Activity, Nutrition, Water Intake, Sleep, Emotions, Glycaemic Index, Menstrual Cycle) [a]
P5	Male	50-59	Bachelor's degree	Hospital administration	Hypertension	Weight; Blood Pressure; Sleep
P6	Female	20-29	Master's degree	Marketing	Cardiac arrhythmia	Weight; Heart rate; Blood Pressure; Temperature; Physical Activity
P7	Female	50-59	Bachelor's degree	Law	Hypertension	Weight; Blood pressure
P8	Female	50-59	Bachelor's degree	Pharmacy	Hypotension	Weight; Blood pressure; Strep count; Heart rate
P9	Female	60-69	Less than high school degree	Clinical assistant	Prediabetes; Prehypertension	Weight; Blood pressure; Glycaemic Index.

[a] P4 stopped self-monitoring her health but had monitored these metrics in the past.

Appendix B - Interviews