Exploring the potential facilitators and barriers of using personal data collected by sensor-based technologies to promote health and well-being.

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Abstract

The growth of the ageing population worldwide raises concerns about human health and well-being. In this context, sensor-based technologies have the potential to support health monitoring activities. This thesis, developed in two studies, presents a detailed understanding of the facilitators of and barriers to acceptability and potential further adoption of sensor-based technologies by older adults. The first study, with twenty-six participants (middle-aged and elderly) from Brazil and England, investigates the acceptability of three sensor-based devices in different contexts. A survey and semi-structured interview were conducted using the vignette technique to explore different devices in three specific scenarios, to monitor mental and physical health and well-being. Using thematic analysis, twenty-eight sub-themes of barriers, facilitators or moderators emerged from the first study. These factors were categorised as data-related factors, user-related factors and technology-related factors. The second study explored the factors influencing participants' willingness to share personal data collected through sensor-based devices. In this second study, thirty-five participants of sixty-five years and upwards were divided into six focus groups. A mobile App of a sensor-based wearable device, in the format of wireframes, was used to explore aspects specifically related to data sharing and use. As a result of the thematic analysis of focus group data, facilitators and barriers were categorised as data-related factors, user-related factors, technology-related factors and the new theme: third-party-related factors. A total of thirty-five sub-themes of barriers, facilitators or moderators emerged. From these findings, a list of seven main facilitators and three barriers were identified that affect the acceptability of sensor-based technologies, and a further six main facilitators and eight barriers that affect willingness to share personal data. A set of thirteen guidelines based on the findings is presented that address the requirements of older adults to inform designers seeking to design better sensor-based health-related technologies. Overall, the conclusions of this research indicate that older adults see the potential in using wearable devices in their daily life. Many factors investigated in this research can contribute to an understanding of future technology adoption, considering that by exploring acceptability, useful insights for potential adoption can be gained; the adoption of some technologies can critically maximise independence for older adults and consequently improve quality of life. The material collected during these studies can be drawn upon to support the enhanced design of sensor-based technologies that addresses people's needs and overcomes concerns regarding data privacy and security. A key academic field that this thesis contributed to is the Human-Centered Design (HCD) field by exploring the factors influencing the acceptability and potential adoption of sensor-based technologies among older adults by providing a valuable understanding

of older adults' views on technology. The study helped identify areas for improvement in the design and usability of sensor-based systems to accommodate older adults' needs better. While this research represents a step towards understanding the relationship between ageing populations and technology adoption, it offers a foundation for further investigation and refinement of sensor-based solutions in the context of HCD. This thesis also contributes to Health and Personal Informatics by promoting the development of more effective and user-friendly health technologies that address users' unique needs and preferences while focusing on individuals' tracking and ethical and privacy concerns.

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List of Publications

Portillo, V.; Creswick, H.; Dowthwaite, L.; Zhao, J.; Patel, M.; **Venancio Santos, E.**; Perez Vallejos, E.; Frech, B. Jirotka, M., How do the over 65s experience online trust? A qualitative analysis of the antecedents of online trust amongst older adults. JHTR Journal of Human Tech Relations https://ojs.utwente.nl/index.php/jhtr/

Chapter 1

Introduction

1.1 Background

The unprecedented growth of the ageing population worldwide is having a significant impact on health concerns. In the United Kingdom, for example, there are more people aged 60 and over (22% of the population) than those under 18 (21% of the population) (United Kingdom (UK) Government 2011).

Efforts have been made to provide health services to this growing population, such as Universal Health Coverage (UHC). UHC is a movement supported by the World Bank (WB) and the World Health Organization (WHO), which aims to achieve better health and development outcomes and to help prevent people from falling into poverty due to illness (The World Bank 2007).

In this context, technology that provides information about the population's health, such as that generated by body-worn sensors, can help achieve these aims and support the efforts of organisations such as the UHC within the constraints described by The World Bank (2007). Furthermore, health information may interest many societal players, such as the public and private sectors, communities, families and individuals. However, there is a need to improve understanding and acceptability of health-related technologies to inform technological design which better caters for the needs of individuals who, as members of society, have different cultural backgrounds comprising a range of preferences and behaviours.

Acceptability and adoption of technology can improve older adults' quality of life and facilitate longer independent living; thus, teaching older people to use technology devices may reduce the technological generation gap. Older adults adopt new technologies slower than younger ones; however, they may do so if those technologies appear to have value (Vaportzis, Giatsi Clausen, and Gow 2017).

Technology adoption has been widely studied among the general population; however, research has shown it to be less popular among older adult users. Previous studies have focused mainly on safety issues and physical disabilities. Another factor highlighted by Lee and Coughlin (2015) is that due to differences in previous experiences and age, there is a gap between the needs of older adults and designers' and developers' understanding of such needs. A study by Lau (2006) found that while older adults value independence, social interaction and privacy, current products focus primarily on physical assistance and safety. An example of this gap can be observed in the use of personal emergency alarms, technology which is relatively well-known, but adopted by less than 5% of the potential market. Therefore, in this context, it is suggested that a more detailed understanding of the factors affecting acceptability is needed, to effectively promote further adoption of health-related technologies.

1.2 Motivations and Research Questions

Previous research in Human-Computer-Interaction (HCI) focuses on feature design and testing; however, little work to-date has focused on the motivation to use and acceptability of sensor-based technology by older adults with no associated specific health condition. Villalobos Zuñiga and Cherubini (2017) believe that developing particular design guidelines for older adults is relevant. Nevertheless, this should be parallel to any study of the desire of the elderly to embrace specific technology in their everyday lives. Therefore, this research focuses on understanding the factors that facilitate and prevent the acceptance and use of sensor-based technologies. According to the recommendations of Villalobos Zuñiga and Cherubini (2017), designers should not limit themselves to technological design. Still, they should also consider how to fully convey technology's value to users' lives and motivate its adoption.

These recommendations underpin the motivation for this research, which aims to identify the factors that affect the acceptability of sensor-based technology to address older adults' individual needs and their views about using their data to monitor physical and mental health. And to offer guidelines to promote device design tailored to older adults' needs based on a discussion of the factors that facilitate or disrupt technological acceptance and later adoption of sensor-based devices with a focus on data-sharing aspects.

The following objectives have been defined to help achieve the aim described above.

Objective A: Identify factors that affect acceptability in using sensor-based technologies to monitor health and well-being in different contexts. Many factors may affect the acceptability and potential further adoption of technologies' use. Therefore, exploring participants' views regarding different sensor-based technologies in multiple contexts is necessary. The scope of this objective is to obtain background information to understand people's perceptions regarding the use of sensor-based technology. The first study accomplished this objective, presented in Chapters 4 and 5, and further explored in the second study.

Objective B: Investigate factors that affect the willingness to share personal data collected by sensor-based technologies with other individuals, groups or organisations. There are many third parties with whom the data collected by sensor devices could be shared. This objective aims to understand the factors that impact user willingness to share (or not) the collected data. This objective emerged as a critical theme in the first study and became the focus of the second study reported in Chapter 6. Moreover, considering the complexity of the first study's findings, the second study deepened understanding by narrowing down to a specific context and a more detailed design proposal building on these findings. Overall, the outcomes of the studies support the achievement of the project aim, which is consolidated in the discussion presented in Chapter 7.

1.3 Potential value and contribution

This research develops a detailed understanding of the factors that affect acceptability in older adults, including key concerns about trust and data privacy. The findings from this research advance knowledge about the design of sensor-based, wearable technologies by exploring older adults' perceptions and attitudes towards their use. The methods used in this research of interviews and focus groups are applied to a population of elderly and near elderly people in England and Brazil. Moreover, the contribution of this study is to provide an understanding of the facilitators of and barriers to the acceptability of sensor-based technologies and, by extension, their potential adoption and impact on health and well-being.

A recent study by Pang et al. (2021) proposes that understanding how elderly people adopt technologies remains grounded in previous research based on the needs of earlier cohorts and the characteristics of older, now mainstream technologies (mobile technologies, including smartphones, tablets and e-readers) and new technologies (such as activity trackers and mobile health apps) that allow the user to monitor their wellness and health. The adoption of these new technologies among older adults is still nascent. This scenario presents additional questions regarding older adults' adoption; this research, therefore, offers the opportunity to explore the acceptability of new technologies to support understanding of adoption further, considering that in understanding acceptability and how people perceive the technology before use, potential adoption might be predicted.

Acceptability and adoption of technology can critically maximise independence for older adults, given the aforementioned existing scenario of an ageing population; increasing independence can promote a better perception of quality of life (Lee and Coughlin 2015). Improved sensor-based technologies that assess physical and mental health, including quality of life (QoL) and well-being, can improve services delivered to those in most need and increase independent living. Such technologies can promptly highlight specific situations where people suffer reduced mental and physical health, thus facilitating beneficial and preventative intervention. Government agencies could use the results of this thesis to develop public policies and take actions to increase and promote physical and mental health. Furthermore, analysis of the data collected during these studies presents a set of contributions that can be drawn upon to support the improved design of sensor-based technologies with a focus on health and well-being. Finally, the guidelines presented as a result of all findings from the studies conducted in this research offer recommendations regarding user requirements that could inform designers and developers about sensor-based technologies.

The research aim and objectives outlined above align well with the literature review on data sharing, privacy, and human-centred design, as they collectively contribute to understanding the factors that affect the acceptability of sensor-based technology for older adults in monitoring their physical and mental health. The literature review provides a foundation for investigating older adults' perspectives on using sensor-based technologies and sharing the collected data.

The first objective, which focuses on identifying factors that affect acceptability in using sensor-based technologies to monitor health and well-being in different contexts, benefits from the principles of human-centred design discussed in the literature review. By considering empathy, co-creation, iterative design, and inclusivity, this research identified potential barriers and facilitators to adopting sensor-based technologies among older adults. Additionally, the review's exploration of users' concerns, such as privacy and security, provides insights into the challenges that must be addressed to enhance the acceptance of these technologies.

The second objective, which aims to investigate factors that affect the willingness to share personal data collected by sensor-based technologies with other individuals, groups, or organisations, directly connects with the literature review's discussion of users' motivations and concerns related to data sharing and privacy. By examining the factors influencing data-sharing decisions, this research can better understand older adults' perspectives on sharing their sensor-based health data. Combining these insights with human-centred design principles can help develop more acceptable and user-centred solutions, fostering a more collaborative approach to managing physical and mental health in older populations.

1.4 Thesis structure

This thesis comprises eight chapters, including a literature review, description and analysis of two empirical studies, synthesis and discussion, conclusions, and future research. This chapter has introduced the background context, research, scope, aims, motivation, value and contributions.

Chapter 2 presents a critical evaluation of relevant literature underpinning this thesis, beginning with a presentation of concepts related to data, such as personal data and personal health data, data sharing and data privacy. After that, key topics related to well-being and QoL are reviewed, and finally, technology acceptability and related works are discussed.

Chapter 3 describes the various methods and approaches used to investigate the factors influencing older adults' technology acceptability that might further influence technology adoption. This mixed-methods approach helps elicit a large quantity of rich information, which can then be studied more profoundly or validated. Finally, the chapter details data collection, and data analysis approaches.

Chapter 4 presents and describes the findings from the first study based on quantitative data collected through WHOQoL-BREF questionnaires to understand QoL aspects that impact health and well-being and demographic data to understand the use of technology by the research participants.

Chapter 5 presents and describes the qualitative findings from the first study using thematic analysis to understand factors relating to participants' acceptability, prompted by three hypothetical scenarios presented using storyboards. These were designed to address Objective A of this research in identifying factors that affect acceptability. In addressing this specific objective and three further associated objectives, this chapter presents the three main emergent themes from thematic analysis. The findings from this study provide the basis for identifying topics for further investigation in the second study, outlined in Chapter 6.

Chapter 6 presents the findings from the second study, including quantitative questionnaire data and, in the main, a qualitative thematic analysis to explore participants' willingness to share data, prompted by two scenarios presented using wireframes to represent a wearable device application. This chapter addresses Objective B of this research to investigate factors that affect willingness to share personal data; to achieve this objective, this chapter presents four further study objectives and the four main emergent themes from thematic analysis. The findings from this study form the basis of defining the key facilitators, barriers and guidelines presented in Chapter 7.

Chapter 7 discusses the set of main factors based on all findings of this thesis that facilitate or disrupt technology acceptability and data sharing. Furthermore, to achieve the main project aim, a set of twelve guidelines based on these findings are presented, addressing the requirements of older adults, to inform designers regarding users' needs.

Chapter 8 summarises the work presented in this thesis, draws conclusions, discusses the overall limitations of the research, and proposes future research direction. Finally, this overview chapter provides a concluding summary of the research results and accomplished aims and objectives.

Chapter 2

Literature Review

This chapter critically evaluates the main literature and theoretical foundation underpinning this project. It begins with studies relating to personal data (2.1), personal health data (2.2), data sharing (2.3) and privacy (2.4), well-being and quality of life (QoL) and QoL technologies (2.5), then discusses technology acceptability (2.6), and human-centred design (2.7). This chapter represents the theoretical core of the research used to identify the research gap that this study aims to fill and to support and strengthen the research findings.

2.1 Personal data

Data from people about people volunteered or not, is known as personal data. The volume of personal data that is available increases daily. Personal data has different meanings when used in distinct contexts. In this study, the definition of The World Economic Forum (2011) is adopted as "digital data (and metadata) created by and about people". This personal data encompasses three types of data: volunteered data, which individuals actively and explicitly share; observed data, which is captured by recording the actions of individuals (highly connected to the Internet of Things); and inferred data, that is, data about individuals based on analysis of volunteered or observed information. Personal data and the infrastructure of the Internet of Things grow together. People can interact with these systems fluently and naturally, barely noticing the powerful informatics with which they engage.

According to The World Economic Forum (2011), personal data reflects a new wave of opportunity for the economy with an increasing volume and variety of data available about people. However, further advances are at risk due to end users' lack of confidence in privacy and concerns about their data being used for commercial interests. This lack of confidence can be explained, in part, by the conflict of interest between players (consumers or producers) involved in personal data. These players can be classified into three distinct groups: the private sector, the public sector and end-users. The interests of these groups can be diverse and even conflicting. Together, these groups can be considered the personal data ecosystem (The World Economic Forum 2011).

According to M. Brown et al. (2014), a complex data ecosystem generated by ubiquitous and pervasive computing has begun to raise issues about how people interact with these data. The use of this data ecosystem by companies and individuals is typically collaborative but can sometimes be combative. Considering this context, Brown proposes placing the human at the centre of data flow, proposing the term Human Data Interaction (HDI). HDI aims to provide a mechanism for people to interact with this complex data ecosystem. It is further suggested that HDI refers to three core themes of **Legibility** (regarding making data transparent and comprehensible to the people), **Agency** (regarding giving people the capacity to interact with the data ecosystem that includes the possibility of being in control, to be able to opt-in or to opt-out) and **Negotiability** (regarding the dynamic relationship around data, how people's attitude changes over time, and the processing of data). The author further considers that HDI should be treated as a distinct topic to ensure that people are the first consideration in a data-driven society and that technology designers should address this challenge by building ethical systems that offer both agency in intentional use and provide support for the outcomes of predicting users' involuntary behaviour.

Another area of concern regarding personal data is **Personal Informatics**, a classification of software and hardware systems that helps people collect personal information to improve their understanding (I. Li et al. 2012). The increasing availability of personal data presents new possibilities for technologies that support individuals' reflections, within which personal informatics can investigate people's engagement (Mamykina et al. 2022).

Epstein et al. (2020) present a mapping review of personal informatics literature that suggests that future research could identify barriers to tracking stages beyond collection and reflection and consider the issues of privacy and ethics concerning tracked data. It is suggested, based on analysis of the publications, that personal informatics research has focused primarily on studying and designing for the health and wellness domains and is predominantly focused on individuals' tracking needs, with some recent work beginning to examine collaborative and shared tracking such as among peers and families or between patients and providers, and that any addressing of ethical or privacy concerns about the use of self-tracked data has often been neglected.

2.2 Personal Health data

The personal data ecosystem, especially in relation to personal health data, has been the focus of a number of initiatives, with private companies such as Google and Microsoft having launched products such as Microsoft Health Vault and Google Health. Digital Health Ecosystems are a key sub-domain of Digital Ecosystems and provide crucial services to maintain the health of the main participants therein. Some studies have investigated the widespread ubiquitous computing environment comprising pervasive geographically dispersed and heterogeneous species, technologies and services (Dong, Hussain, and Chang 2011; Serbanati et al. 2011). Research focus has been defined in the context of the European Commission, with the concept of Digital Ecosystems initially coined in 2002 in Europe as “Digital Business Ecosystems” (Nachira, Dini, and Nicolai 2007) which can be further defined as, “the enabling technologies and paradigms for fostering endogenous local development, local capacity building and knowledge sharing processes providing tailored and personalised Information & Communication Technologies (ICT) services to citizens and business networks” (Nachira, Dini, and Nicolai 2007).

Currently, everyday technologies increasingly emphasise engagement with personal health data. The latest mobile phones come to the user with pre-installed health applications and watches commonly function as fitness trackers for example (Kirchner et al. 2021). Mobile Health (mHealth) apps are available for download and use on mobile devices. Even with the increase in availability and use of mHealth apps for Palos-Sanchez et al. (2021), there is still a paucity of research exploring user’s intention with these kinds of apps. The section 2.6 provides a discussion of factors related to technology acceptance.

In general, a healthcare system that holds personal health data can contribute to an individual’s overall quality of life; health is an important domain in quality of life, and the perceived quality thereof is affected by health care (Rahtz and Sirgy 2000). The section 2.5 describes the two concepts, considering that quality of life represents general well-being and both are frequently used interchangeably.

One topic that emerges in the discussion of personal health data is personal health informatics which is a growing subject in both research and practice and presents many challenges in designing applications that address people’s health needs in life, and facilitates collaboration with health care professionals. In this context, the ubiquity of personal health technologies provides a variety of tracking contexts in which health tracking is not only conducted by individuals, with the potential to promote their self-care (Claisse et al. 2022). Still, it can also be used in a family context (Kaziunas et al. 2017; Pina et al. 2017) and with health care professionals (Chung et al. 2016; Simpson et al. 2021).

2.3 Data sharing

The advent of ubiquitous computing devices offers the opportunity for services to use this rich data in diverse ways; however, at the same time, this requires understanding and the development of technologies enabling end-users to specify what data can be shared with whom and in what situations. A study by Olson, Grudin, and Horvitz (2005) shows that people's willingness to share data depends on with whom they are sharing the information. It was identified that participants' willingness to share information varied, with the highest variance observed around participants' various personal items being shared with co-workers.

Some researchers have proposed frameworks that provide a policy management infrastructure in the network with the aim of enforcing user preferences, for example Hull et al. (2004) presented the Houdini framework providing policy management and Kroner, Schneider, and Mori (2009) outlined a content-sharing framework. Recently, Powell, Deroche, and Alexander (2021) published work on data sharing with nursery home managers, finding perceived challenges in health data sharing (sharing of data between providers and from provider to patient) with residents, family members and external clinical partners that included variance in systems and software, security and privacy concerns. In contrast, the study showed perceived benefits of health data sharing, including improved care planning, improved communication, and anticipating future demand.

A study by Simpson et al. (2021) regarding sharing patient-generated health data, highlighted that barriers to sharing mostly relate to trust, identity, security and privacy and that little literature focuses attention on sharing health data with third parties, with the majority of literature on clinical settings.

2.4 Data privacy

The use of technologies and implications for privacy are linked in complex ways. Focusing on personal data, Graeff and Harmon (2002) explored the relationship between awareness of data collected, personal data privacy and internet shopping behaviour. It was found that despite universal concerns regarding personal data privacy, understanding how personal data is currently collected is low. Evidence suggests that Facebook users tend to report high levels of concern about personal data privacy; however, this does not strongly correlate with actual behaviour, with many ‘concerned’ individuals continuing to share significant amounts of personal information (Acquisti and Gross 2006).

A field of study into the intersection of privacy, security and usability is sometimes called usable privacy and security, user-centred security or the study of trust user experience (TUX) (Borsci et al. 2018; Bate and Robert 2007). This area focuses on a longstanding collaboration between computer science, information systems, and psychology related to usable privacy that explores how users understand what data is collected about them and for what it will be used (Iachello and Hong 2007; Acar, Fahl, and Mazurek 2016). In the case of privacy and security failures, there is growing recognition that this results from human errors and cognitive and behavioural biases (Cranor 2018). Many of these failures can be attributed to systems that have not made privacy and security usable. Therefore, they are poorly designed user interfaces or security systems that have not been built around the needs and skills of their human operators (Feng, Yao, and Sadeh 2021; Wong and Mulligan 2019). Karat, Brodien, and Karat (2006) noted that making systems secure and with appropriate attention to privacy, which depends on security systems but requires more than just technology, involves complex social issues that concern people’s right to know what information is being collected, who might see it, and how it might be used.

This complex subject directly impacts the range of privacy concerns about the emergence of pervasive computing technologies embedded in the fabric of everyday life Soppera and Burbridge (2006). It is suggested that these devices will "disappear so effectively that end-users will lose awareness of the devices' presence or purpose". It is further suggested that if "you cannot interact with the computer, how can you tell what data is collected, where the data is flowing to, and more importantly, what the consequences of your actions are?". To further explore these issues, the study refers to principles that form the Organisation for Economic Co-operation and Development privacy guidelines (OECD 2013) - a basis for standards in countries worldwide. It is argued that pervasive technologies disrupt the notion of 'personal' data, as devices may collect volumes of data not directly related to anyone. Nevertheless, a third-party can ascertain personal information through collation. Secondly, data collection guidelines suggest that this should be limited to appropriate situations where consent has been given, for a specified purpose; however, in pervasive systems, notifying and asking for permission could be difficult or impossible. Finally, the guidelines state that individuals should be able to obtain data about them. However, pervasive technologies may mean that many more hosts store data about individuals, and less awareness of or capability to identify who these might be.

The concepts of the Internet of Things (IoT) and Ubiquitous and Pervasive Computing have an oncoming interpretation. They aim to integrate the physical world, where human beings live, with the virtual world of the internet, where much of the current communication between human and computers takes place (Atzori, Iera, and Morabito 2010; Gigli and Koo 2011; Haller 2010). The IoT is a concept with origins in Ashton's work at the Auto-ID Center in the 1990s. Despite many definitions available for IoT, it is challenging to select one representing or describing all aspects of this concept, given the extensive range of technologies and scientific topics involved (Haller 2010). According to Haller (2010), invisible things represent objects in the physical world that can be monitored or controlled, such as goods in the production and shipping processes or patients and drugs in the healthcare system. Observing these objects is the role of a device that can connect with other devices or central systems over the Internet's infrastructure. These devices can be sensors within computers, mobile phones and radio-frequency identification (RFID) tags. Resources and services provide access to the data collected by the devices. These can use existing standards in the Internet's environment, such as web services using Service Oriented Architecture (SOA) and Representational State Transfer (REST).

Gigli and Koo (2011) categorised applications developed using the IoT according to the function of each application. The categories are 1) identity-related services; 2) information aggregation services; 3) collaborative-aware services, and 4) ubiquitous services. Identity-related services involve identifying the object in the physical world, such as goods or identifying a patient and are the primary functions used by other services. **Information aggregation services** involve the acquisition of data from or about the object, and are useful in monitoring situations, monitoring anything anywhere, such as the temperature of milk in a transport container, a patient's blood pressure, physiological data of patients, that automatically generates electronic medical records. **Collaborative-aware services** have evolved from aggregation services. They fall into the active category as they monitor objects by collecting data. Still, they can also send commands to control the object (e.g. the temperature in a transport container). Finally, **ubiquitous services** are the essence of the concept of IoT, evolving from one collaborative-aware service to another with everyone and everything at any moment; independent of protocols and distinctions amongst technologies, ubiquitous services can create feasible solutions to real problems such as urban congestion and preventive healthcare (Pinhanez 2007) through the use of automated machines. Ubiquitous services are already observable in our daily lives in technologies such as ATMs, ticketing, and vending machines (Aizpurua et al. 2019).

IoT services have several applications in various sectors such as transportation and logistics, intelligent environments, personal and social, and healthcare. In the healthcare sector, many activities can benefit from the use of IoT, such as tracking, identification and authorisation, data collection and sensing (Atzori, Iera, and Morabito 2010). Despite the many positive aspects of IoT in many human activities, many psychological and social aspects remain unexplored. In the health care sector, some examples relating to data collected are confidentiality, access control, use of data by private organisations, different levels of comfort with the utilisation of devices according to the patient's age, and so on. Some of these concerns are investigated in the field of Personal Informatics which investigates people's engagement with personal data (Mamykina et al. 2022) within the field of Human-Data Interaction (HDI) that proposes placing people at the centre of the data flow and providing a mechanism for the user to interact with these systems and data (Mortier et al. 2014). Personal data studies are a scientific topic closely related to IoT. The data generated by the IoT ecosystem on people's health provides a significant volume of data for personal data researchers to investigate (Karat, Brodien, and Karat 2006).

2.5 Well-being and quality of life

2.5.1 Well-being

While there is growing agreement that measures of well-being should be included, the issue of how well-being should be defined and measured remains unresolved; there is a lack of consensus on a single definition, resulting in a diverse range of definitions for the term. However, a considerable number of authors represent well-being as a multifaceted construct (Forgeard et al. 2011) and further, Hird (2003) proposes a representation of well-being broken down into three elements: subjective well-being, psychological well-being and objective well-being, each one having different measurement indicators. Subjective well-being is how happy the person is and to

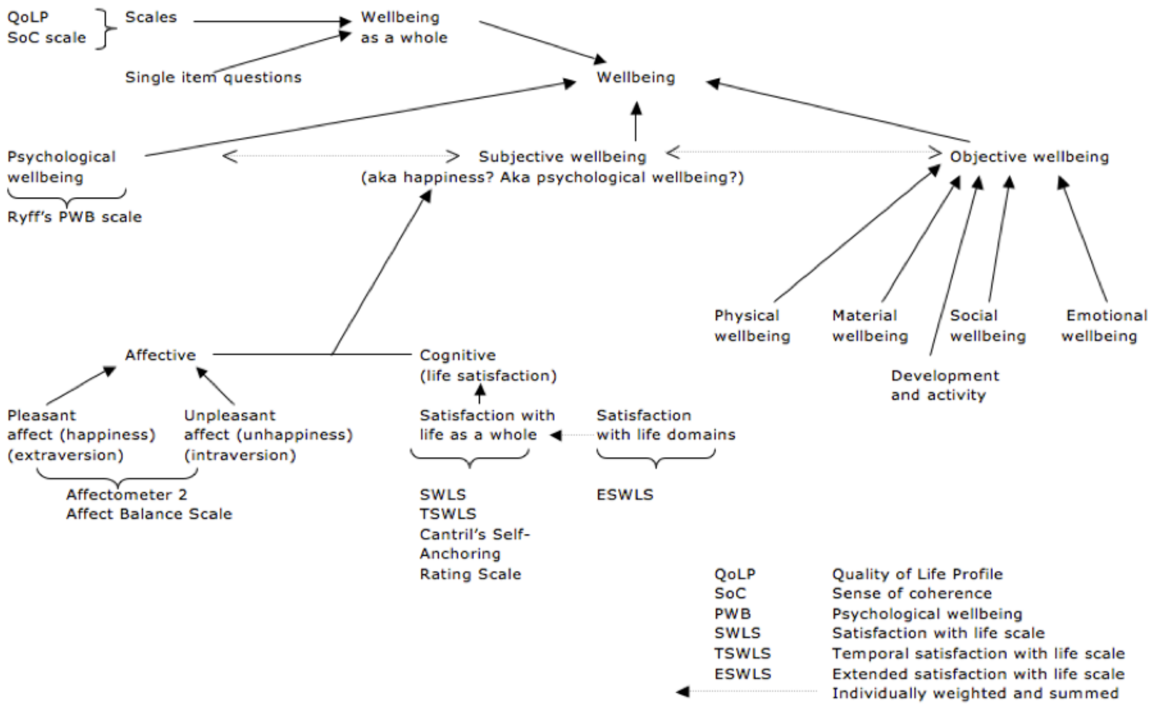

Figure 2.1: Model for well-being proposed by Hird. Source: Hird (2003).

what extent they are satisfied with life; psychological well-being relates to positive or good mental health, as an example, pursuing meaningful goals; objective well-being comprises five categories: physical, material, social, emotional well-being and development, and activity (Hird 2003). Figure 2.1 shows this segmentation in a well-being representation and sub-domains. Figure 2.2 presents the specific domains that comprise objective well-being.

2.5.2 Well-being and quality of life

Figure 2.1 represents the multifaceted construct divided into three aspects of psychological, subjective and objective well-being.

Considering objective well-being as shown in Figure 2.1, Felce and Perry (1995), this illustrates the relevant domains of quality of life based on a range of authors. Therefore, the domains that comprise objective well-being are presented in Figure 2.2. For Felce and Perry (1995), quality of life can be defined as general well-

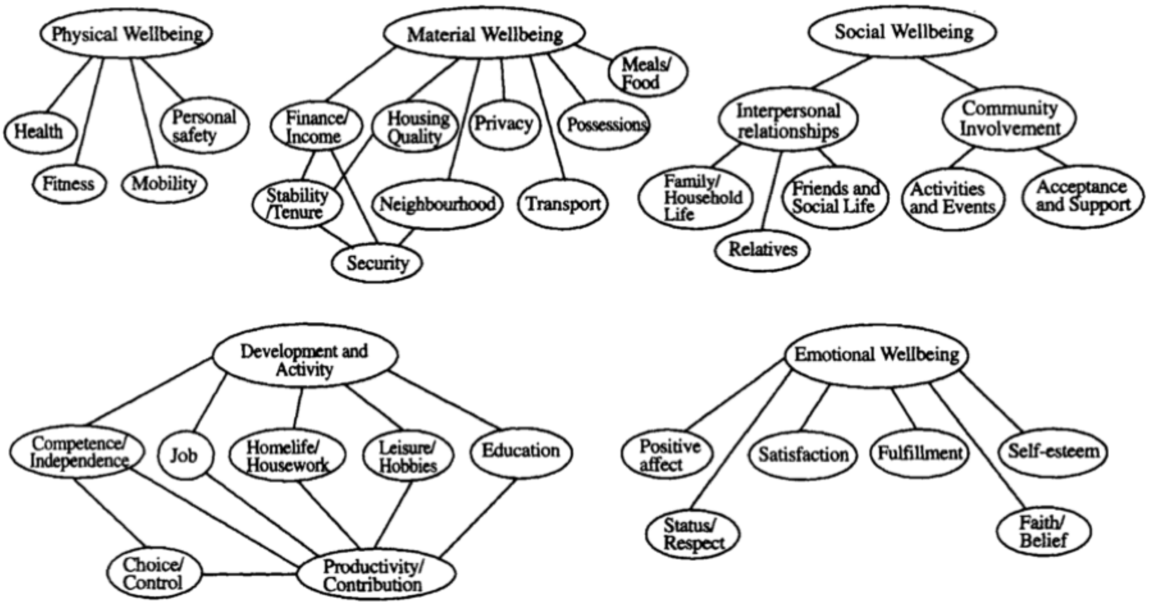

Figure 2.2: Domains relevant to quality of life defined as general well-being by Felce and Perry. Source: Felce and Perry (1995).

being that comprises objective descriptors and subjective evaluation of the domains: physical, material, social, development and activity and emotional well-being.

2.5.3 Measurement of well-being

Eid and Larsen (2008) suggest that self report measures of subjective well-being are indispensable as they refer to effective experiments and cognitive judgements. Forgeard et al. (2011) recommend the use of a dashboard approach to measurement with a combination of objective and subjective indicators. The UK-based New Economics Foundation proposed the National Accounts of Well-Being initiative to reform the way in which governments measure progress. A poll conducted in the United Kingdom by the BBC revealed that 81% of respondents believed the government's primary goal should be the 'greatest happiness' rather than the 'greatest wealth' (Easton 2006).

For OECD (2013), one of the major uses of subjective well-being measures is to contribute to a better understanding of the drivers of well-being at an individual level. If it is accepted that measures of subjective well-being are valid, and that they accurately capture the concepts that they claim to measure, namely, an overall evaluation of life or the experienced moods and emotions of an individual over a period of time, then it follows that such measures can be used to provide information on the relative contribution of different factors and circumstances to a person's well-being; this is albeit with some limitation due to both measurement error and the fact that a person's subjective perception of their well-being is not necessarily quite the same thing as their overall well-being. Nevertheless, measures of subjective well-being can be used to help identify what factors are critical aspects of people's well-being.

Overall, much literature on this subject exists, some as early as 1917 (Kinloch 1917), on the key theme of well-being. In Science Direct, the first paper relating to quality of life dates back to 1969 which already discussed assessment thereof using technology (Jantsch 1969). Both well- being and quality of life were studied given their interchangeability in many areas as well in the domain of Computer Science.

2.5.4 Quality of life

Quality of life (QoL) is diverse and comprises a variety of societal or individual perspectives and a range of applicable theoretical models and academic orientations. Liu (1976) suggest that 'quality of life' is a term used to replace 'general welfare' or 'social well-being'. However, there seems to be little consensus about what QoL is. There are as many quality of life definitions as there are people, due to individual differences in what people find important (Liu 1976). The World Health Organization defined quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (World Health Organization 2004). According to Dodge et al. (2012) quality of life is a dimension of well-being rather than an all-embracing definition.

Quality of life has been the subject of numerous studies, as shown in a search of the Web of Science, a multidisciplinary database that contains high impact research journals from around the world. The term appeared 767,224 times in relation to all fields, in a search conducted on 3rd of July 2015. The research area with the greatest number of publications related to this term is Oncology with 10.858% (23,985); some papers in this field have as the aim the assessment of patients' quality of life during their treatment or thereafter. The second greatest frequency is Neurosciences Neurology (10.149%) and General Internal Medicine (8.384%). The research field of the Classics had the lowest number of publications about Quality of Life with 0.001% (1 record). The year with the most records about the subject was 2013 (396 records), representing 9.148%, followed by 2014 (380 records), and 2012 (358 records). Table 2.1 shows the search results from other data sources, reflecting how extensively the term is used in the academic domain.

Table 2.1: Results of an exploratory search on 03/07/2015 using the term 'quality of life' across all fields.

Base	Number of results	oldest paper
Web of Science	767,224	1959
MEDLINE	211,448	1959
Science Direct	300,917	1945
Scopus	324,391	1947
LILACS	11,759	1985
IEEE Xplore	1,797	1970
PsycInfo	55,865	2006

A sub-concept in this area is that of health-related quality of life (HRQoL) that comprises aspects of overall quality of life that clearly affect health, and is related to physical and mental health perceptions and their correlations over time. Measurement of HRQoL has the potential to help determine the burden of preventable disease, injuries and disabilities and can provide new insights between HRQoL and risk factors (Taylor 2000).

2.5.5 Assessment of quality of Life

The World Health Organization has developed questionnaires for use in quality of life assessment. These questionnaires are well-known and well-used to measure QoL in research from different countries, using three distinct versions: the first is the WHOQoL-100; the second one is a briefer version, WHOQoL-BREF (WHOQoL Group 1998); the third is a specific version that focuses on older people WHOQoL-OLD (Halvorsrud, Kalfoss, and Diseth 2008). In addition, another questionnaire that focuses on elderly adults was developed by University College London in 2003, known as the questionnaire model CASP-19 (Hyde et al. 2003). The WHOQoL-100 was developed from a pilot study in 15 centres across different countries, including data from about 4,500 subjects, feedback from which led to the selection of 100 questions (World Health Organization 2004). The WHOQoL produces a multi-dimensional profile of scores across six domains: physical; psychological; level of independence; social relationships; environment; and spirituality/religion/personal beliefs. In addition, there are 24 QoL sub-domains. The WHOQoL-BREF is a cross-culturally valid assessment of QoL, as reflected by its four domains of physical, psychological, social and environmental. Finally, the CASP-19 questionnaire was developed based on a 19-item scale to measure the needs satisfaction of QoL in early old age (aged 65–75years), focusing on 4 domains: control, autonomy, pleasure and self-realisation (Hyde et al. 2003).

Numbeo, a database of user-generated content, has presented the ranking of Quality of Life Index by country once a year since 2012, increasing to twice a year from 2014. This Index is an estimation of quality of life using an empirical formula. In this formula, the highest weight allocated by the group was to pollution with the second highest importance given to safety; health, traffic and purchasing power were also considered (NUMBEO 2015). In this index, Switzerland, Denmark and Germany had the highest indices for the first semester of 2015, while Ukraine, Egypt and Venezuela showed the lowest level in a ranking of 57 countries; the United Kingdom was in 16th position and Brazil 51st (NUMBEO 2015).

The LEIPAD (De Leo et al. 1998) is a subjective assessment questionnaire specifically designed to appraise quality of life in the elderly. Its name is an acronym deriving from the first two of the three most involved universities: LEIden (the Netherlands), PADua (Italy), and Helsinki (Finland). The project has been conducted under the auspices of WHO EURO.

Another example of a specific instrument is the Rotterdam Quality of Life Questionnaire for Heart Transplant Recipients, which is a brief disease-specific instrument that measures quality of life in heart transplant patients (Jeu et al. 2003). Related to HRQoL, there are some other instruments that use measurement, for example, the SF-36, which is a 36-item scale measuring physical, functional, and psychological well-being, satisfaction and social relationships (Schulz et al. 2012).

2.5.6 Quality of Life Technologies (QoLT)

Another term used in this field is Quality of Life Technologies (QoLT), that focus on design technologies that impact the quality of life of people who use them. Assessment normally includes objective and subjective measures of domains such as emotional health, life satisfaction, work productivity, and the cognitive function (Schulz et al. 2012). Cooper (2008) defined this as a technology designed to maintain or enhance the health, functioning, and independence of older and disabled individuals. QoLT covers a broad range of applications including assistive technology, telemedicine, telemonitoring, telehealth, e-health and gerontechnology and includes intelligent systems capable of detecting what a user is doing and providing assistance as needed (Schulz et al. 2012).

The University of Pittsburgh, USA has The Quality of Life Technology Centre that has a focus on improving QoL and enabling elderly adults and people with disabilities to live more independently. This centre is jointly run by Carnegie Mellon University and the University of Pittsburgh (Quality of Life Technology Center 2015). The technology purpose here is primarily related to the use of robots, as detailed in a paper presented at AT-EQUAL (Advanced Technologies for Enhanced Quality of Life) in 2009 (Lefeber 2009; Lobontiu and Loisance 2009; Mahmud, Hawellek, and Valjamae 2009; Munteanu et al. 2009). The AT-EQUAL are meetings that aim to bring together people from different backgrounds to present/demonstrate new techniques, and to discuss future avenues using technology to enhance quality of life (Advanced Technologies for Enhanced Quality of Life, 2009).

A systematic analysis was conducted to understand the state-of-the-art in-use technologies to monitor well-being and quality of life. The search included the interchangeable use of both terms and used databases from general areas and Computer Science, Psychology, Nursery and Medicine; the results are shown in Table 2.2 and Table 2.3. The criteria for the first search were ("well-being" OR "wellbeing" OR "well being") AND "monitoring*" AND ("ubiquitous" OR "pervasive"). The criteria for the second search were "quality of life" AND "monitoring*" AND ("ubiquitous" OR "pervasive". The literature dates from 1990 to 2015, considering that Ubiquitous Computing emerged from 1989. The results are presented separately using the terms quality of life and well-being, to show how both terms have a large amount of applicability in science papers. As described in the section 2.5, this term is much-used in many areas, therefore, to find research which relates more to the aim of this project, further terms were added to the search to narrow down the results. Even with these combined terms, the database IEEE Xplore brought many results, and it was identified that most were conference papers, with 84% of the results relating to well-being (14,786 conference papers), and 89% to quality of life (21,525 conference papers). This proportion of papers can be explained because conference papers are important in the Computer Science field, and IEEE is an association that organises conferences for electrical and electronic engineering, telecommunications, computer engineering and allied disciplines. This search shown in Table 2.1 was conducted between 23rd and 24th September 2015.

Table 2.2: Results in databases using the following criteria to explore the work related to monitoring and the use of ubiquitous or pervasive technologies from 1990 to 2015. Criteria: ("well-being" OR "wellbeing" OR "well being") AND "monitoring*" AND ("ubiquitous" OR "pervasive")

Database	Search criteria	Number of results
CINAHL	TITLE-ABS-SUBJ	3
SCOPUS	TITLE-ABS-KEY	110
Web of Science	TOPIC	21
MEDLINE	TITLE-ABSTR-KEY	22
PsycInfo	TITLE-ABS-KEY	12
ASSIA	ALL INDEXES	2
Science Direct	TITLE-ABSTR-KEY	8
IEEEXplore	MATADATA ONLY	17,525
LILACS - Bireme	TITLE-ABS-KEY	0
Scielo	ALL INDEXES	0

Table 2.3: Results in databases using the following search terms to explore work related to monitoring and use of ubiquitous or pervasive technologies from 1990 to 2015: "quality of life" AND "monitoring*" AND ("ubiquitous" OR "pervasive")

Database	Search criteria	Number of results
CINAHL	TITLE-ABS-SUBJ	1
SCOPUS	TITLE-ABS-KEY	124

Table 2.3: Results in databases using the following search terms to explore work related to monitoring and use of ubiquitous or pervasive technologies from 1990 to 2015: “quality of life” AND “monitoring*” AND (“ubiquitous” OR “pervasive”)

Database	Search criteria	Number of results
Web of Science	TOPIC	27
MEDLINE	TITLE-ABSTR-KEY	31
PsycInfo	TITLE-ABS-KEY	7
ASSIA	ALL INDEXES	2
Science Direct	TITLE-ABSTR-KEY	7
IEEEXplore	MATADATA ONLY	24,149
LILACS - Bireme	TITLE-ABS-KEY	0
Scielo	ALL INDEXES	0

Table 2.4: WHOQOL-BREF domains

Domain	Facets incorporated within domains (WHOQoL Group 1998).
Physical health	Activities of daily living
	Dependence on medical substances and medical aids
	Energy and fatigue
	Mobility
	Pain and discomfort
	Sleep and rest
	Work Capacity
Psychological	Bodily image and appearance
	Negative feelings
	Positive feelings

Table 2.4: WHOQOL-BREF domains

Domain	Facets incorporated within domains (WHOQoL Group 1998).
	Self-esteem
	Spirituality / Religion / Personal beliefs
	Thinking, learning, memory and concentration
Social relationships	Personal relationships
	Social support
	Sexual activity
Environment	Financial resources
	Freedom, physical safety and security
	Health and social care: accessibility and quality
	Home environment
	Opportunities for acquiring new information and skills
	Participation in and opportunities for recreation activities
	Physical environment (pollution / noise / traffic / climate)
	Transport

The databases LILACS - Bireme (Latin American and Caribbean Centre for Health Sciences Information[1]) and SCIELO (Scientific Electronic Library Online[2] - a database conceived for developing countries, established in Brazil) was considered due to being founded in Brazil, as this could have identified additional papers; however, a

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[1] https://www.paho.org/en/bireme

[2] https://www.scielo.org/

search produced no results. Regarding cultural differences, the most appropriate instrument identified is proposed by World Health Organization (WHOQoL Group 1998); this model is illustrated in Table 2.4, and shows the four domains and the facets incorporated within these domains. In this table, it is possible to see that the domains presented here have similarities with Figure 2.2 that presents the five domains related to quality of life. The similarities identified are around the domain for 'Material well-being and development activity' which is covered in the 'Environment' domain in this instrument. Furthermore, 'Emotional well-being' in this instrument is defined by 'Psychological' and 'Social well-being' whereas in this table it is defined as 'Social relationships'; the first 'Physical well-being' in this table refers to 'Physical health'. There are slight differences in the facets incorporated within domains in this comparison between Table 2.4 and Figure 2.2; however, overall a significant number of similarities are evident. In this study, Table 2.4 serves as a base for the empirical studies. Moreover, due to identifying the overlap between these two instruments, some scenarios or kinds of data collected in this study through a sensor or self-report can also be based on Figure 2.2.

2.6 Technology Acceptability

As regards the field of Human-Computer Interaction (HCI), digital health studies are a growing area of interest (Ford, C. E. Connelly, and Meister 2003; Fang et al. 2016; Patel, Kannampallil, and Kaufman 2015; Shaw et al. 2015; Zapata et al. 2015; Zheng and Weir 2016). The design of human-centred technologies aims to address the end user's needs. In respect of technology acceptance, many studies have used a well-known framework that measures factors that affect the intention of technology acceptance proposed by Davis, Bagozzi, and Warshaw (1989). The technology acceptance model (TAM) is based on two theoretical constructs that are fundamental determinants of technology acceptance: perceived usefulness (PU or U) and perceived ease of use (PEOU or E).

The TAM model proposed by Davis is an adaptation of the Theory of Reasoned Action (TRA) where adaptations to the basic TRA approach were made, based on these goals for TAM that explain the determinants of computer acceptance that is general, capable of explaining user behaviour across a broad range of end-user computing technologies and user populations.

Figure 2.3 displays the Technology Acceptance Model (TAM) by Davis, where we can identity six different factors as well as the perceived usefulness (U) and perceived ease of use (E) that are primary relevance for computer acceptance behaviours (Davis, Bagozzi, and Warshaw 1989).

The factors incorporated on TAM can be defined as:

- External variables: such as demographic variables, influence perceived usefulness(U) and perceived ease of use (E)
- Perceived usefulness (U): is defined as the prospective user's subjective probability that using a specific application system will increase his or her job performance
- Perceived ease of use (E): refers to the degree to which the prospective user expects the target system to be free of effort
- Attitudes towards use (A): is defined as the user's desirability of his or her using the system (Malhotra and Galletta 1999).
- Behavioural intention (BI): is predicted by attitude towards use (A) combined with perceived usefulness (PU).
- Actual use: is predicted by behavioural intention (BI).

In the work of Venkatesh et al. (2003) the authors used the TAM model as a base to expand and with the aim to unified a model, in this version social influences, facilitating conditions as well experience, gender and age are considered. This a

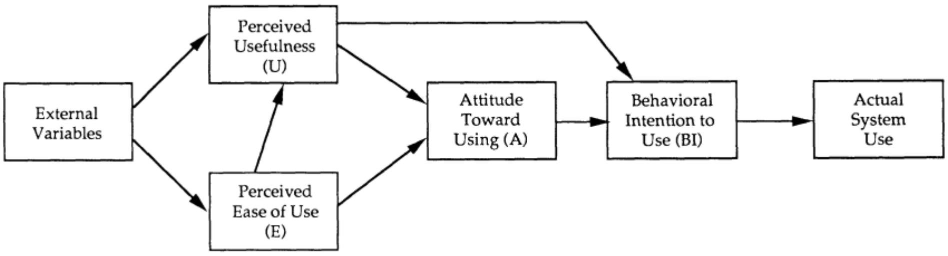


Figure 2.3: Technology Acceptance Model - TAM. Source: (Davis, Bagozzi, and Warshaw 1989).

unified model is called the Unified Theory of Acceptance and Use of Technology (UTAUT). This model had the aim to bring a unified model what could help the research that are confronted with a choice among a multitude of models and find that they must “pick and choose” constructs across the models, or choose a “favoured model” and largely ignore the contributions for a review and synthesis in order to progress towards a unified view of user acceptance (Venkatesh et al. 2003)

Specifically, in the health domain Kim and Park (2012) proposed a model that integrates the TAM model proposed by Davis along with antecedents and health-related constructs such as perceived health threat, health beliefs and concerns, health status and health attitude and behavioural beliefs (that are substantially affected by a perceived threat, perceived usefulness, and perceived ease of use). This model is called the health information technology acceptance model (HITAM).

In the work of Renaud and Biljon (2008), a triangulation of the quantitative findings from literature with the qualitative findings from their study led to a set of interlinked acceptance factors and adoption phases presented in a model called the Senior Technology Acceptance and Adoption model for Mobile technology (STAM).

Especially regarding a model of acceptance that considers privacy, Li et al. (2016) brings hypothesise that users’ decisions to adopt healthcare wearable devices are determined by their trade-offs between perceived privacy risk and perceived benefit (privacy calculus). And the author argues that studies about health information technologies (HIT) adoption should not only focus on technology acceptance but domains as privacy issues considering the higher risk in this field regarding to health data. Figure 2.4 presents the research model proposed in this study.

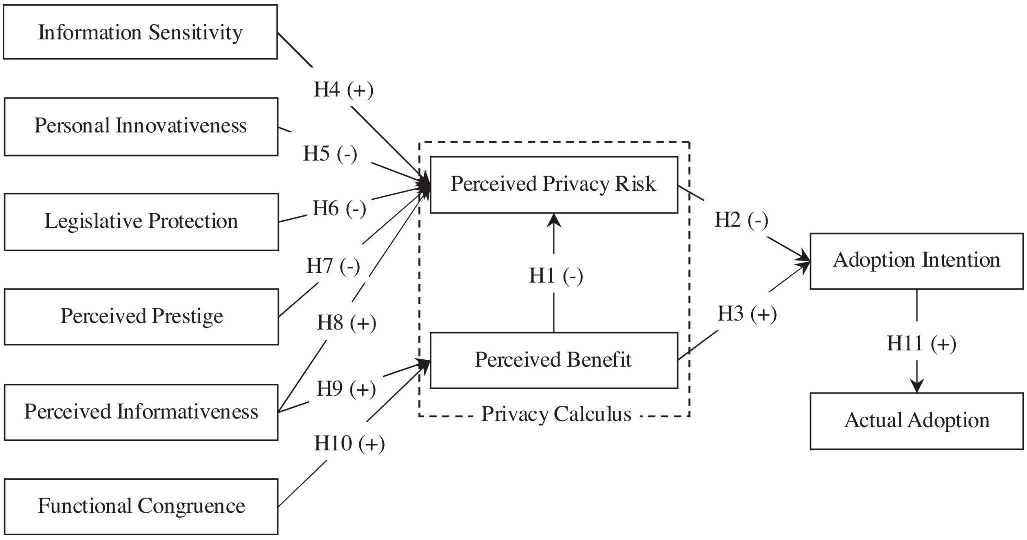


Figure 2.4: The research model - Privacy Calculus. Source: Li et al. (2016).

Considering that up to now, none of those models presented here does consider the concept of Trust it was seen the need to bring a model that addresses this construct for this research. It was identified in the work of Connelly (2007) the model of pervasive technology acceptance model (PTAM) that is an extension of the TAM model, but considering the particularity of pervasive computing that introduces an entirely new set of issues related to trust, considering that pervasive computing environments often gather very intimate and personal data about its users. In this context emerges the need for trust in the application.

The TAM and the other models here presented are used in this thesis, not with the aim of testing those models, rather as a base for understanding the findings from the first and second studies regarding factors relating to technology acceptance and adoption.

A study by Nadal, Doherty, and Sas (2019) argues that research into technology acceptability refers to individual's perception of a system before use; considered more important than adoption, this is a multi-phase process that begins with an individual's decision to adopt and then achieve persistent use. This claim is justified especially in the health domain, considering that the intrusiveness of technologies could lead to users refusing to even try any. The study observed that the use of the terminologies acceptability, acceptance and adoption in HCI have been used interchangeably and the TAM is used in studies that explore any of these terminologies. This result was observed through a systematic review focusing on literature published in the two previous years on how the concepts of technology acceptability, acceptance and adoption are referred to and measured in mobile health.

According to Renaud and Biljon (2008) technology adoption is a process which begins with the user becoming aware of the technology, and ending with the user embracing the technology and making full use of it. As aforementioned, in the health domain, the question of technology acceptance is even more important, as the possible intrusiveness of technologies could lead to patients' refusal to try them.

In this research, the terminology used is technology acceptability that focuses on exploring acceptability of a system before first use. However, given that terminology is used interchangeably in the area of HCI and that there is a close relation between these terminologies, literature on technology acceptance (after use, as defined by Schade and Schlag (2003)) and adoption have also been considered in this research.

2.7 Human-centred Design

Human-centred design (HCD) is an approach to product development and problem-solving that emphasizes understanding and addressing end users' needs, preferences, and context. By incorporating user feedback and experiences throughout the design process, HCD aims to create solutions that are effective, accessible, and inclusive (Bazzano et al. 2017a).

Some fundamental principles of HCD are empathy, co-creation, iterative design, and inclusivity. Empathy is at the core of HCD, enabling designers to understand better the users' needs, emotions, and perspectives (Giacomin 2014). By actively listening, observing, and engaging with users, designers can better understand their target audience and create solutions that resonate with them. Co-creation involves collaborating with users and stakeholders throughout the design process to ensure that their input and feedback are incorporated into the final solution (Sanders and Stappers 2008). This collaborative approach helps to create solutions that are more likely to meet users' needs and expectations and fosters a sense of ownership and investment in the solution. Iterative design is a process of continuously refining and improving a solution based on user feedback and testing (Buchenau and Suri 2000). This approach allows designers to identify and address issues early in development, leading to more effective and user-friendly solutions. Inclusivity in HCD involves considering the needs and preferences of diverse user groups, including those with varying abilities, cultural backgrounds, and socioeconomic statuses (Steen, Manschot, and De Koning 2011). By designing for inclusivity, solutions can reach a broader audience and have a more significant impact.

The human-centred design uses methods and practices such as contextual inquiry, rapid prototyping, and usability testing to support the principles above. Contextual inquiry gathers user insights through observation and interviews in the users' natural environment (Holtzblatt and Beyer 1997). This approach provides valuable insights into users' behaviours, motivations, and challenges, which can inform the design process. Rapid prototyping involves creating low-fidelity representations of a solution to quickly gather user feedback and iterate on the design (Rudd, Stern, and Isensee 1996). This approach enables designers to explore multiple ideas and refine their concepts based on user input before investing significant time and resources in development. Usability testing evaluates a solution's effectiveness, efficiency, and satisfaction by observing users as they interact with it (J. Nielsen 1993). This feedback can help designers identify areas of improvement and ensure that the solution meets users' needs and expectations. By employing these methods, designers can create low-fidelity prototypes to quickly gather user feedback and refine their concepts before investing significant time and resources in development. Furthermore, usability testing ensures the solution meets users' needs and expectations by evaluating its effectiveness, efficiency, and satisfaction.

HCD has been used in healthcare to improve patient outcomes and experiences by designing solutions that address the unique needs and context of patients, caregivers, and healthcare professionals (Chen, Neta, and M. C. Roberts 2020). Examples include the development of user-friendly medical devices, patient-centred care environments, and healthcare apps. By designing solutions that address the unique needs and context of patients, caregivers, and healthcare professionals, HCD can contribute to better healthcare experiences and overall well-being.

2.8 Related Works

Czaja et al. (2006) found that older adults are less likely to adopt technology compared with younger adults; however, this study further highlighted that not using computers or the internet puts older adults at a disadvantage, considering that technology has the potential for increasing the quality of life of older adults. Further, this research takes into account that technology can support problems with "social isolation, foster linkages to family and friends and facilitate the performance of essential activities such as banking and shopping. The Internet can also enhance educational opportunities for older adults and enable them to take a more active role in their own health care" (Nadal, Sas, and Doherty 2020). This work presented some reasons why older adults do not go online including cost, lack of skills, lack of interest, and concerns about information security.

The American Association of Retired Persons (AARP 2011) stated that one reason for the resistance to mHealth by seniors is caution about sharing personal health information. Further, that this "must be addressed as mHealth stakeholders aim for wider acceptance of mHealth solutions for independent living". Furthermore, regarding concerns over security and privacy, a more recent AARP report (AARP 2019) found that this concern is an issue for Americans over 50 who do not place much trust in institutions keeping their personal data safe. The AARP report showed that of those aged 50 and over, only one in four trust online retailers, the federal government, and telecom service providers, among others. Nevertheless, the same report highlighted an increase in the use of technology among Americans aged 50 and above. Moreover, it noted that the computer is in use by 91 percent of this population with smartphones used by 83 percent. Therefore, this report suggested that the assumption that older individuals rely less on technology than others may becoming increasingly inaccurate.

In the study by Kao, Nawata, and Huang (2019), it is argued that society has benefited from the convenience provided by IoT-based wearable fitness trackers; however, few studies have explored the factors influencing adoption, users' awareness, acceptance, and full utilisation of such technology. Furthermore, one of the most concerning issues currently is the large attrition rate among consumers no longer wearing their device. Current business models are built on technology marketing and therefore are clearly not succeeding in matching technology to consumer needs. Previous studies have either focused on the technological features or adoption potential of wearable devices. Yet, little is known about the elements leading to their adoption in general, and specifically, the attrition of wearable fitness trackers.

A study by Mitzner et al. (2010) explored the use and attitudes of older adults towards technology with positive and negative attitudes reported; given that more positive than negative attitudes were noted, the authors concluded that the results contradict stereotypes that older adults are afraid or unwilling to use technology. Furthermore, a workshop conducted by Villalobos Zuñiga and Cherubini (2017) encouraging the development of interest in technology among the ageing population, argued the importance of developing specific design guidelines alongside a study of the desire of the elderly to embrace technology, potential benefits and technology adoption barriers.

In research by Fox and Connolly (2018), it was found that while many older adults have access to m-health,they are currently excluded and require careful consideration by technology organisations and researchers. The study provided recommendations for narrowing the m-health digital divide through inclusive design and educational efforts to improve self-efficacy, develop privacy literacy, and build trust, thereby ensuring that older citizens are both capable and willing to adopt the technology.

In research by Vaportzis, Giatsi Clausen, and Gow (2017) a focus group was conducted using a generic qualitative design applying thematic data analysis; emergent themes related to barriers, advantages, concerns and scepticism. Similarly, results of a study by Simblett, Matcham, Siddi, Bulgari, Barattieri di San Pietro, et al. (2019) presented barriers to and facilitators of engagement with mHealth technology for remote measurement based on analysis of focus group data that was collected in three countries; it was found that providing guidance on ways to promote the design of cross-cultural mHealth tools was needed.

The main contributions of this research are to explore the facilitators and barriers in using sensor technologies by older adults, identifying the factors influencing their acceptance to embrace this technology in their lives and respecting aspects regarding the personal data collected and data shared in this context. For this PhD research, it is important to highlight that the concept of acceptability relates to technology acceptance and refers to individual's perception of a system before first use. However, it was identified that acceptance sometimes refers to adoption in the HCI field.

Chapter 3

Materials and Methods

3.1 Introduction

This chapter presents and discusses the methodological approach adopted to understand and address older adults' needs, perceptions, and concerns to inform the design of technology (sensors, software, and data sharing) that improves acceptability. Understanding and involving users in technology design and using their feedback as a guide for improvement decisions is a core feature of user experience. Hence, the choice of the human-centred design process to guide our data collection. This methodological orientation, arguably pragmatic and phenomenological, has a well-established tradition in research and industry in projects involving HCI (Coulton and Lindley 2019; Liam Bannon 2011; Stephanidis 2001; Bannon and Kaptelinin 2000). It is important to highlight that HCI focus has expanded significantly and is not so much based on human-computer interaction, rather on human activities that are mediated using computers. Further, it can be seen that the human-centred design represents only one aspect of HCI interdisciplinary research programmes that re-specify the nature of the relationship between people and technology (Liam Bannon 2011).

The human-centred design (HCD) approach driving this work is defined by ISO 13407:1999 (ISO 1999) as one that focuses on making systems usable; a multi-disciplinary field that incorporates human factors and ergonomics knowledge and techniques. Furthermore, according to Bazzano et al. (2017b), the tools used in HCD may overlap with user-centred design (UCD), an expansion of the field which encompasses applications beyond human-computer interaction and which has been adopted more widely to indicate a design process that is focused on the preferences and needs of the users of a service or product. Since the emergence of this field, participatory research methods have been adopted more widely and across other fields. Bazzano et al. (2017b) suggest that human-centred design or design thinking, focusing on empathy, context, ideation and iteration, appears well-suited to addressing population health issues. The last decade has seen increasing examples of design thinking in global health.

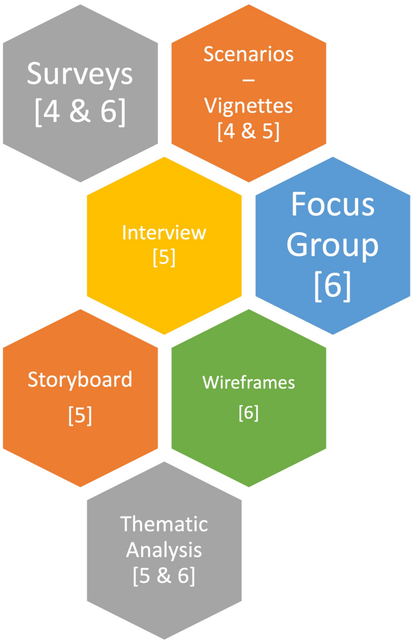


Figure 3.1: Methods used throughout this research, highlighting the respective chapters. Source: author.

Considering that the design of human-centred technologies aims to make systems usable by addressing the end user's needs and that, as aforementioned, this area takes into account that such needs are multifaceted, this study found the need to narrow this further and navigate the research towards an aspect seen as key to understanding the user's needs. Therefore, this research focuses on users' impressions of technology before the first use, which is the concept of acceptability. To understand the acceptability of the technologies certain models evaluated in the literature, such as model TAM, HITAM and STAM are applied in this research. A decision was made to use the TAM model as a base for understanding the findings from studies one and two regarding factors relating to technology acceptance and adoption.

The following sections present the methods used in this study including their strengths, limitations, and relevance, with an overview provided in Figure 3.1.

3.2 Methods

This research employed a mixed-method approach, combining quantitative questionnaires and qualitative interviews, followed by thematic analysis, to identify potential barriers to and facilitators of older adults' engagement with wearable devices and trust in sharing data collected by such devices. All methods were applied with full consideration of the research questions and based on a human-centred approach.

This research involved two studies, conducted in 2016 and 2019, respectively. The first study (see Section 3.3), including participants from Brazil and the United Kingdom (UK), aimed to explore user's opinions about adopting existing and hypothetical devices. It comprised an initial questionnaire followed by a 90-minute, face-to-face interview exploring a broad range of aspects; the second study (see Section 3.4) comprised a focus group addressing more specific questions with UK participants. The mix of nationalities in study one was merely incidental as this research did not aim to explore cultural differences, rather this reflects findings from a period during which the researcher was located in Brazil. Furthermore, as discussed later, no significant differences were found in the analyses based on nationality; hence, study two involved UK participants only.

During the interviews and focus groups, participants were fully informed about the purpose and nature of the study and informed consent was obtained prior to data collection (see Appendices D, E, F, and G). Participants were made aware of their right to withdraw at any point, and all names and identifying information were removed from transcripts to ensure confidentiality. Data was stored securely on a password-protected computer, and questionnaires were stored in a locked cabinet. Ethical approval for both studies used in this thesis was granted by the University of Nottingham's Ethics Committee within the School of Computer Science.

The following sections describe the methods applied in this research project. Section 3.2.1 discusses the thematic analysis method used to explore the qualitative data collected in both studies. Section 3.2.2 describes the interview technique used in study one. Section 3.2.3 describes the surveys and questionnaires used in both studies. Section 3.2.4 outlines the focus group applied to collect data in study two. Finally, section 3.2.5 presents the low fidelity prototype.

3.2.1 Thematic Analysis

This research methodology exploits the human-centered design process to understand older people needs, abilities and requirements in relation to wearable devices and sharing personal health data. To address the need for understanding of participants' views, extensive data was collected through questionnaires, interviews and focus groups. Once the data was available, however, there was a need to choose and apply an analytical method that would allow identification of major topics within the dataset. This research therefore applied Thematic Analysis (TA) due to its effectiveness as a research method in identifying, analysing and reporting themes or patterns present within a data set, therefore generating further understanding about a phenomenon. Simply put, it is defined as a way of seeing, in that what is seen through thematic analysis does not appear to others, even when observing the same information, events, or situations Boyatzis (1998, p. 4). Furthermore, this method is used as a process for encoding qualitative information. Encoding requires an explicit "code" (e.g. a list of themes). A theme is a pattern found in the information that could at least describe and organise possible observations and at most support interpretation of aspects of the phenomenon. The compilation or integration of a number of codes in a study is often referred to as the codebook.

There are two approaches to generating themes: inductive and deductive. In study one themes were extracted from the interviewee transcripts using the inductive method, instead of deducting the themes from theory and prior research. In study two both approaches were applied with the code initially being built based on the focus group's transcription. However, after generating a codebook based on the first three focus groups, it was evident that there was an overlap with the study one codes; hence, the adoption and emergent extension of the study one codebook for study two. The next chapters present and critically analyse these and newly observed themes.

Braun and Clarke (2006) suggest thematic analysis is a method 'in its own right' that provides a flexible approach to coding and analysis of data. In this research, thematic analysis delivered a rich, complex and detailed account of the older adults' different perceptions related to sensor-based technologies. This analysis was initially conducted using paper-based thematic analysis, then changed to using a software version. NVivo was used to support the coding process of the fully transcribed interview data from both study one and two.

3.2.2 Interview technique

Study one included a semi-structured interview with participants. A semi-structured interview is an in-depth interview in which respondents answer open-ended questions. This type of interview may be utilised extensively as an interviewing format with an individual or sometimes even with a group (Corbin and Strauss 2014). In this study, the interviews lasted on average 43 minutes, allowing around 15 minutes for each one of the three presented scenarios.

The objective was to understand the types of personal data that older adults are comfortable providing and being shared. Further, it aimed to investigate participants' attitudes towards pervasive technologies and potential implications regarding privacy. Data was collected in two countries, England and Brazil. As aforementioned, although it was not the study's aim to evaluate the impact of cultural differences in participants' characteristics, some quantitative results were presented by country to observe this feature.

The interviews followed a semi-structured interview guide, a schematic presentation of questions, topics, or needs to be explored by the interviewer, used to achieve optimum use of interview time. This approach serves the useful purpose of exploring the views of many respondents more systematically and comprehensively whilst keeping the interview focused in the desired direction. For each scenario presented to the participant, a set of questions were asked by the interviewer; the three scenarios were presented in random order to minimise extraneous effects. The session was audio-recorded for later transcription and thematic analysis.

Interview participants received scenarios on an A4 worksheet containing the storyboards and a written scenario - specific stories used to present information and evoke participants' opinions and perceptions. According to Carroll (1997), scenarios are an informal narrative description, a way of demonstrating a story, and a starting point for discussion with users. Scenarios can have four different purposes: to illustrate the use of a system, to evaluate the functionality of a specific system, to design system attributes, and ultimately to test a theory. Scenarios can be designed, for example, to include detailed, lengthy processes or to portray storyboarded representations of interactions with the product, and can vary in scope and scale. Researchers can use scenarios to explore potential issues when using proposed technology, sensor-based devices and to identify implications of the data before adopting the technology.

Specifically, the scenarios presented in this thesis were vignettes - short descriptions of a single event. Considering that many technologies that comprise the Internet of Things are yet to be realised, vignettes were used in both studies in this research. This methodological approach is considered a useful tool for exploring the behaviours observed in response to technologies, before they become widely available. Hughes (1998) suggests that, "Vignettes are valuable... as they recognise the socially situated nature of individual behaviour and provide participants with an opportunity to discuss aspects of their own lives". Further, it is noted that an important consideration in using vignettes is how people draw upon various sources in their own lives to interpret and relate to the vignette. Considering that detachment from the real world could be considered a limitation, research highlights that even though there is a challenge in defining absolutely how a response to a vignette might align with a response to a situation in the real world, there is considerable evidence of the validity of data gathered through vignettes.

Storyboards were used to present in the style of a vignette in the three different scenarios, which are discussed in the Storyboard section below. In study two, wireframes were used in the vignette style to explore two scenarios; both studies used personas in each presented scenario. The decision to use personas was made to motivate participants to engage with the scenario and bring the hypothetical situation closer to them. The persona method brings benefits that simple data aggregation does not offer. First, the personas descriptions "help project participants identify with users and think of these instead of themselves. And they provide all participants in a project with the same understanding of who the end-users are." (L. Nielsen 2019). Second, their use allows designers to focus on the designs for a small set of specific users. By putting a human face on the generic user, personas can introduce empathy into the design process, which can, in turn, improve the functionality of the product for the user. Moreover, using personas "makes it possible to get an idea of what the user will use the product for, and in what future situation or context it will be used." (L. Nielsen 2019).

The use of storyboards using pictures and text to present a vignette was proposed to exercise control over the level of detail presented to participants. Further, it is a relatively quick and cheap method to administer, which is a practical characteristic of an industrial design setting. The sections 3.3.1, 3.3.2, and 3.3.3 detail the elements of the three storyboards used in the scenarios to stimulate participants to voice their perceptions.

3.2.3 Surveys and Questionnaires

Questionnaires, also known as surveys, are commonly adopted in scientific research to collect users' data, objective interpretations, attitudes or opinions either in quantitative or qualitative form (Sharples and Cobb 2015). This research applied quantitative questionnaires in both studies. Surveys can contain different question formats, such as check boxes, ranges, rating scales or open-ended queries. The choice of format varies according to the type of answer expected by the researcher. Check boxes or ranges are commonly used in demographic questionnaires, such as when personal information about gender or age, is required. In contrast, rating scales are frequently used to collect participants' subjective opinions. They are appropriate for asking participants to make judgements about something, such as how difficult a task is (Rogers, Sharp, and Preece 2011). One of the most frequently used types of rating scales is the Likert scale. Likert scales (Likert 1932) are designed so that participants select their level of agreement to an individual statement, i.e., "The message made the intention of the other driver clearer". The scale from which participants should choose their level of agreement is usually anchored with verbal descriptions with the two extremes of the scale being, for example 'strongly disagree' and 'strongly agree'. The other points in the scale may contain verbal descriptions such as 'agree', 'disagree' or numerical values. The number of response levels used in any rating scale varies widely, with some scales using an odd number of options to allow a neutral status in the middle. This research employed different types of surveys in both studies. One of the surveys used a pre-existing questionnaire by the World Health Organisation about Quality of Life (WHO-QoL). This questionnaire has been widely tested and validated in several studies and countries. Furthermore, other questionnaires were used in this research to collect additional quantitative data on participants' familiarity with the technology and general demographic data.

The WHO-QoL is a quality of life assessment that can be applied cross-culturally. The version used in this research was the WHOQoL-BREF, and comprised six general questions and twenty-six questions related to the four domains of life quality: physical health, psychological health, social relationships, and the environment. The twenty-six questions comprised closed questions using a Likert-type 5-point response regarding the participant's feelings over the past two weeks. Permission was obtained by the WHOQoL Group that developed the assessment before using in this study. The full assessment is available in Appendix A.

3.2.4 Focus Group

Thematic analysis of the results from study one led to a follow-on study (study two) exploring a low fidelity prototype using wireframes in a focus group (results reported in Chapter 6). A focus group is a group interview approach that involves using a group of appropriate participants, which is flexible in approach and can be used to assess a wide range of features associated with a system or device, including user opinions and reactions.

The focus groups, comprising 35 participants, took place at Nottingham Central Library between July and August 2019 and was run with six cohorts on three different days with two sessions in parallel each day. Each cohort had six or seven participants plus one facilitator. The focus group comprised four phases: pre-survey, two scenarios, collaborative design, and post-survey and the total duration, including a ten minutes break, was around 2 hours and 45 minutes. Each group was presented with two scenarios and had approximately fifty minutes to explore these via group discussion.

The workshop comprised three parts: first, it began with the team greeting participants and answering questions related to the study, including any related to the consent form. Consent forms were sent to participants via email the day before the focus group. Pre-survey and health monitoring questionnaires were also handed out to participants. The pre-survey aimed to capture participants' opinion about the focus group topic before any explanation or group discussion. This task elicited a reflection about the subject and provided varied opinions and feelings. The first part of the focus group ended with an introductory presentation about the PhD research, study one, and the Horizon Digital Research Group. In the second part the scenarios were presented, with a ten minutes break in-between. Each session applied the scenarios in a different order to reduce extraneous variables in the study. The third part included a co-design activity with ten minutes for reflection. During this initial activity, participants were encouraged to improve the App's design to reflect their aims and to share concerns regarding data sharing; thereafter, the group reflected on the task during a ten-minute discussion.

A post-survey questionnaire was completed after each focus group. All focus group sessions were audio and video recorded; in case of doubt, the video was used to identify which participant was talking, as sometimes, with audio only, identification may not be possible considering the number of participants in each cohort.

3.2.5 Low Fidelity Prototype – wireframes

A low-fidelity prototype was used in study two to explore the intricacies involving the trade-offs of data sharing and privacy in sensor-based technologies with the potential for contributing to enhancing people's health and well-being. Low fidelity prototypes are a valuable tool for exploring a concept in comparison to a high-fidelity prototype

(Rudd, Stern, and Isensee 1996). The conventional use of low fidelity prototypes is to investigate early ideas about what functions a product might have and how the user might perceive it with a view to evaluating design alternatives, depicting concepts and screen layouts rather than a user's interaction with a system. Further, these prototypes demonstrate the general look and to some extent, the interface's feel; they do not aim to detail how the application operates (Rudd, Stern, and Isensee 1996).

A decision was made to focus on a mobile app and display the app via sketches using wireframes (Brown 2010). Wireframes are a schematic or low-fidelity software interface, intended to primarily demonstrate functionality, features, content, as well as user flow. Wireframes may function as an interface specification for products such as computer applications, web and mobile sites, and any products requiring some form of human-computer interaction. Wireframes were chosen for this study as the main focus is what a screen does and not what it looks like.

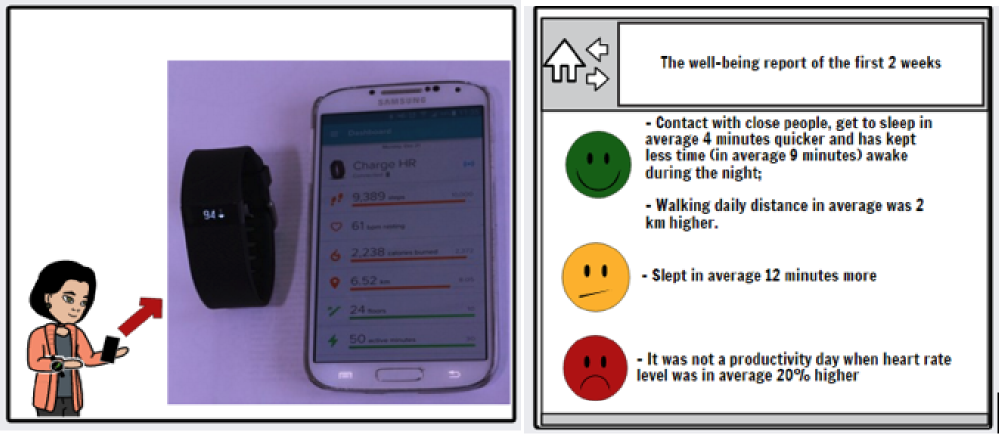
The use of a mobile app presented in the scenarios in wireframes was chosen based on the results of a study by Umemuro (2004) that suggested that participants using a touchscreen device were less anxious compared with those using a standard keyboard device. This result is crucial considering that based on the findings of Czaja et al. (2006), computer anxiety predicted lower use of technology. Therefore, to minimise barriers due to interface usability, it was decided that wireframes would be used to depict a device with touchscreen feather in the scenarios. Additionally, the results from study one showed that more participants had mobile phones with a touchscreen feature, in this case, a tablet, than other technologies.

3.3 Study one details

This study aims to contribute to the overall thesis objectives of identifying the factors that affect the acceptability of sensor-based technology to address the individual needs of older adults regarding using their data to monitor physical and mental health. Specifically, this study uses three scenarios to guide interviews with the study's participants about acceptance of sensor-based technologies and willingness to share personal data. The scenarios involved sharing data with different groups, such as family members, healthcare practitioners, organisations, and places visited. This study was conducted through semi-structured interviews using the vignette technique (results are reported in chapters 4 and 5). The vignette was adopted to show hypothetical scenarios outlined below, using current and near-future pervasive technologies to identify differences in respondents' reactions to the same information. The specific objective of this study was to begin an exploratory analysis of the participants' perceptions about sensor-based technologies adoption and sharing of health data with third-party entities. This objective is closely related to this thesis's goals, i) identifying factors that affect acceptability in using sensor-based technologies to monitor health and well-being in different contexts, and ii) investigating factors that affect the willingness to share personal data collected by sensor-based technologies with other individuals, groups, or organisations. Also, this study provided the basis to develop more in-depth activities in the scenarios and focus groups presented in study two.

3.3.1 Scenario A - Fitbit plus self-reported well-being diary

This scenario describes a healthy, middle-aged persona, around 60 years old, wearing an existing wearable device (see Figure 3.2 and Appendix D). This is a Fitbit fitness tracker that she received as a gift from a family member. The persona combines Fitbit use with self-report to monitor mental well-being. The Fitbit is a wristband, and the model presented to the participants was the Charge HR that collects data such as heart rate, daily walked steps, distance, floors climbed, active minutes, calories burned and sleep tracking.



The well-being report of the first 2 weeks

- Contact with close people, get to sleep in average 4 minutes quicker and has kept less time (in average 9 minutes) awake during the night;

- Walking daily distance in average was 2 km higher.

- Slept in average 12 minutes more

- It was not a productivity day when heart rate level was in average 20% higher

Figure 3.2: Scenario A aims to explore acceptability of a) usage of an existing wearable device; b) usage of self-reporting; c) monitoring mental well-being, and d) sharing information with family members and friends. Source: author.

3.3.2 Scenario B – A set of wearable devices

The second scenario describes a persona with a chronic respiratory condition that finds it hard to breathe and by choice uses a set of wearable devices (see Figure 3.3 and Appendix D). In this scenario, the person is a middle-aged male (50 years old) using a set of wearable devices comprising three elements: a Velcro fastening on the neck and arm, and a wristband; these devices are represented as blue dots on the storyboard. The sensors collect the following data: respiratory rate, blood pressure, blood glucose, body temperature, electrodermal response, sweat rate, continuous heart rate, calories burned, floors climbed, active minutes, daily distance walked, time sleeping and location.

3.3.3 Scenario C - Indoor sensor

The final scenario presents a persona with indoor sensors at home (see Figure 3.4 and Appendix D). The person is an elderly lady (73 years old) who is not physically active, due to feeling occasional pains in her knee and shoulder and struggles with depression. The sensor has been installed in her house by her daughter, who is the person with access to the data collected. This device can detect the temperature

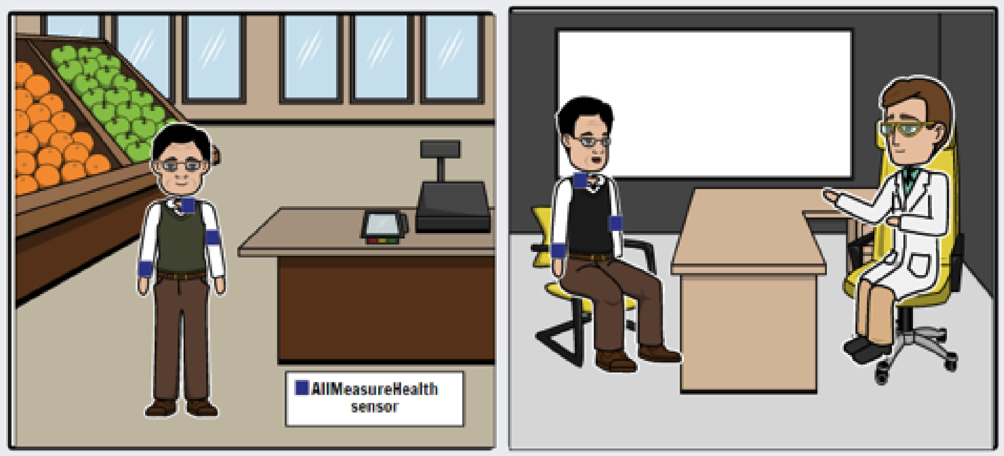


Figure 3.3: Scenario B explores a) acceptability of using a set of wearable devices; b) what kind of data people are more interested in having collected, and c) attitudes towards sharing the data with third parties. In this case, sharing data with a physician, organisations and places visited was explored. Source: author.

inside the home, time spent in each room of the house, time spent on the same activity, and time sleeping. Further, it can detect static activities such as reading, using a computer, watching TV and motion activities like cleaning, cooking or walking around the house.

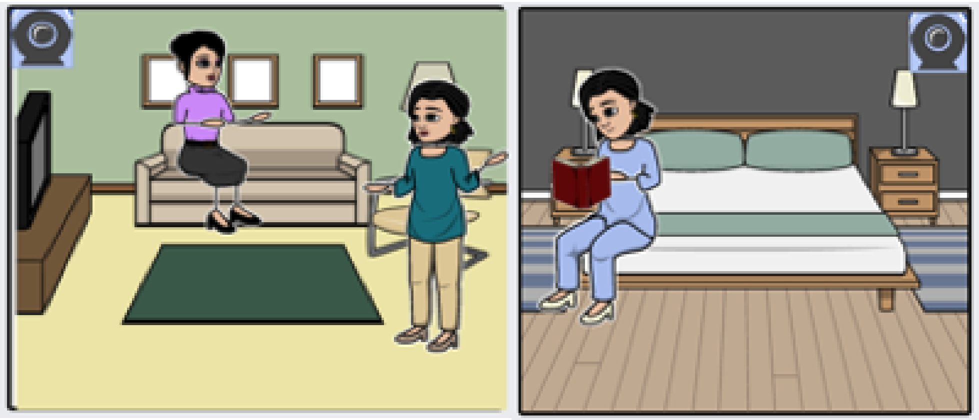


Figure 3.4: Scenario C explores acceptability of a) having an indoor sensor; b) a third person accessing the user data and making decisions, and c) sharing the data with the healthcare system. Source: author.

All storyboards were created with StoryboardThat [1]. Appendix D contains all scenarios and the storyboards.

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[1] https://www.storyboardthat.com/

3.3.4 Recruitment and Ethics

Participant recruitment was through direct contact and paper-based advertisements and leaflets circulated within public spaces. Recruiting from the University was avoided in order to draw upon a diverse background of participants. The study was approved by the School of Computer Science Research Ethics Committee.

3.3.5 Introducing the Participants

Participants were categorised into four groups by age in order to identify possible age differences as well as by country; whilst identifying cultural differences was not a particular focus of this study, a balance of participants from each country was sought. The groups were 1) Middle-aged Brazilians (from 45 to 64 years old) 2) Elderly Brazilians (from 65 years old); 3) Middle-aged British (from 45 to 64 years old) 4) Elderly British (from 65 years old).

Table 3.1: List of participants of the first study.

Gender	Education	Country
Female	Tertiary	Brazil
Male	Primary school	Brazil
Female	Secondary school	Brazil
Female	Tertiary	Brazil
Male	Tertiary	Brazil
Female	Tertiary	Brazil
Female	Primary school	Brazil
Male	Tertiary	Brazil
Female	Secondary school	Brazil
Male	Secondary school	Brazil
Female	Tertiary	Brazil

Table 3.1: List of participants of the first study.

Gender	Education	Country
Male	Primary school	Brazil
Male	Secondary school	Brazil
Female	Tertiary	UK
Male	Tertiary	UK
Male	Tertiary	UK
Female	Tertiary	UK
Male	Tertiary	UK
Female	Tertiary	UK
Male	Tertiary	UK
Female	Secondary school	UK
Male	Secondary school	UK
Female	Tertiary	UK
Male	Tertiary	UK
Male	Secondary school	UK
Male	Primary school	UK
Female	Tertiary	UK

The thirteen participants from Brazil were interviewed between January and February 2016, and the 13 UK participants between March and April 2016. In Brazil, there were three middle-aged males (between 45 to 64 years old), four middle-aged females, three elderly males (65 years old and above) and three elderly females. In the UK, there were four middle-aged males, three middle-aged females, three elderly males and three elderly females. All participants came from different professional backgrounds with varying levels of education; Table 3.1 shows the level of education and gender in both countries.

3.3.6 Interview structure/protocol

For each scenario, participants were asked to respond to a series of open and closed questions about how they might react to the device, what data they were interested in being collected, how they might respond to results from the data collected, with whom they would want to share the data and their general opinions on the technologies presented.

The study lasted around one hour in total; the interview itself lasted approximately 45 minutes divided into around 15 minutes for each of the three scenarios presented based on the four domains. First, participants read the Project Information Sheet and the Consent Form and those in agreement, signed the latter. The interviews were audio-recorded and transcribed for data analysis. Specifically, the semi-structured interview used storyboards to present three vignette scenarios, presented one at a time with interviews taking place at the end of each scenario. An overview of the processes involved in preparation for the interview is presented in Table 3.2.

Table 3.2: Description of the personas.

Name	Description
Personas:	Design of three main personas to represent the final user of a wearable device and two additional personas to explore the acceptability of access to the data and decision to install an indoor sensor by another person that it is not the main user.
Storyboards:	Design of storyboards using Vignette techniques, illustrating hypothetical situations in which the three sensor-based devices are used.
Illustrative material:	Production of material used to illustrate the storyboards at interview.

Table 3.2: Description of the personas.

Name	Description
Translation:	Material was translated into Portuguese for interviews conducted in Brazil.

A within-subjects study was conducted where all three scenarios were presented to participants one after the other; however, the scenarios were presented in a different order for each participant with the aim of counter-balancing and minimising extraneous variables that may influence a specific device, such as the factor of fatigue during the study and/or experience of having been presented previously with another technology. Moreover, a full overview of the scenarios is available in Appendix D.

At the end of the interview, the WHOQoL-BREF (World Health Organization 2004) questionnaire and survey were handed to participants.

3.3.7 Pilot Study

A pilot study was conducted with three participants, two females and one male, details of which can be found in Appendix D. This showed that the use of the vignettes and scenarios and questions were clear for participants during the interviews; thus, no changes as a result of the pilot were needed for the final study. However, during the pilot study, it was noted that the two female participants stated that the persona in Scenario B may have reacted to the physician's phone call due to their gender. Considering this observation was made by both participants, it was decided that a balanced number of male and female participants would be best, to reduce possible extraneous variables due to gender perceptions. Another change as a result of the pilot related to the general questions posed at the end of the interview regarding the amount of time new technologies were used and for how long they had been using this technology. Instead of asking this question verbally, it was decided that this would be better incorporated into a post-survey form of four questions.

Chapter 4 presents the results from the quantitative surveys methods used in this study and Chapter 5 presents the results from qualitative aspects this study.

3.4 Study two details

Study two contains two scenarios with a persona called Adam, who is 70 years old and healthy. He is concerned about his high blood pressure and arthritis. The study one results indicated that users were interested in high blood pressure and arthritis data, hence their choice of the low fidelity prototype, to which participants could relate. In the first scenario, the persona chooses to share the data with the UK healthcare system, the NHS, and in the second scenario, the persona shares data with companies.Each participant was given an A3 worksheet containing the written scenarios and the wireframes. Additionally, an A4 worksheet with the key questions and space for notes was given to participants. The lead facilitator read the scenarios aloud and then allowed 5 minutes for participants to reflect or make notes. Further details regarding each scenario are presented in next sections. The objective of this study was to delve deeper into participants' perceptions about adopting sensor-based technologies and sharing health data with third-party entities. Building on the insights from study two, which informed the development of scenarios and topics for our focus groups, the author structured this investigation in alignment with the two main objectives of the thesis. First, the author aimed to identify the factors that affect acceptability in using sensor-based technologies to monitor health and well-being in different contexts. Second, the author sought to explore the factors influencing the willingness to share personal data collected by these technologies with other individuals, groups, or organisations. To address these objectives, the specific research goals, R01, R02, R03, and R04 were developed.

- RO1: To identify the factors that affect acceptability in using pervasive technologies to monitor health and well-being when applied to different contexts.
- RO2: To identify the factors that affect users' trust in sharing personal health information with other individuals or organisations.
- RO3: To identify the factors that promote the willingness for data sharing and desirable outcomes expected by the user.
- RO4: To determine the factors in the design of sensor based-technologies that affect technology adoption by the user.

3.4.1 Scenario 1 - Sharing data with healthcare services

The first scenario describes the persona, Adam, choosing the first on-screen option, 'Data Sharing' which is part of the Health & Pharmacy option, then selecting the NHS option and finally, choosing the opportunity to share the data with this organisation (see Figure 3.5 and Appendix K for the complete scenario). It is important to note that in these screens, two options, namely, 'Pharmacy' and 'Medical Health Insurance', can be explored and a further option of general 'Companies' in the second scenario. The companies presented in the second scenario are from various sectors, including department stores, supermarkets, food shops and other retail businesses; therefore, it explores a different type of context (relating to RO1).

The first scenario included five initial questions, plus one additional question related to another wireframe introduced in the middle of the discussion. These other wireframes aimed to offer participants options to display the privacy policy and shared data. Table 3.3 shows the connection between research objective, study question, and themes from the first and study two.

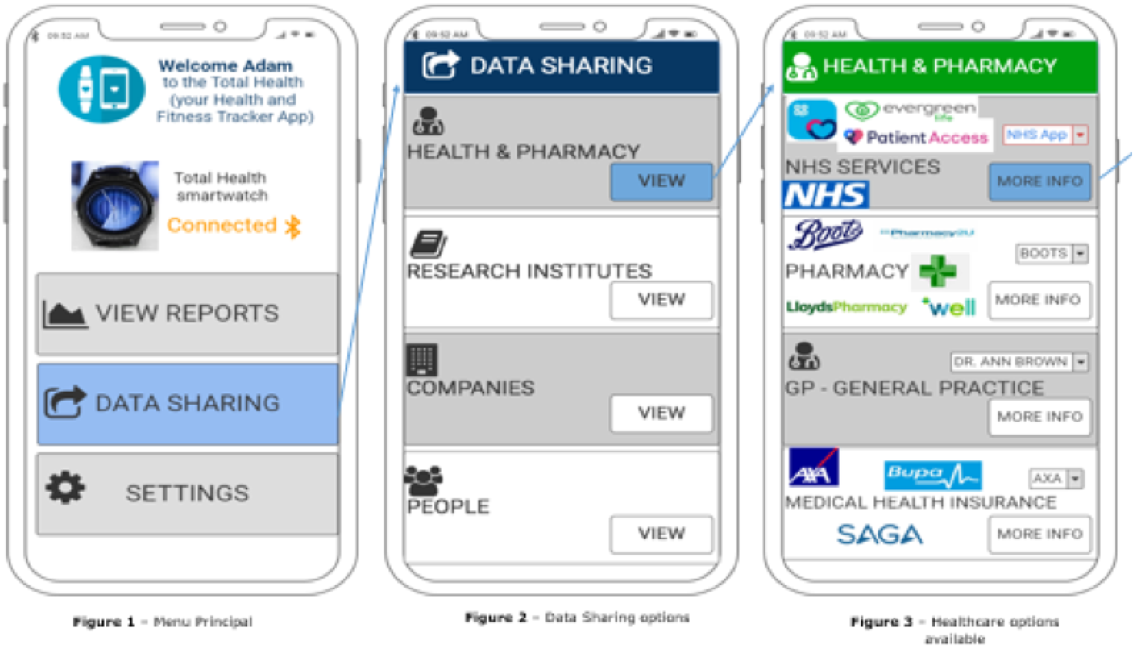


Figure 3.5: Example of wireframes used in study two - Scenario 1. Source: author.

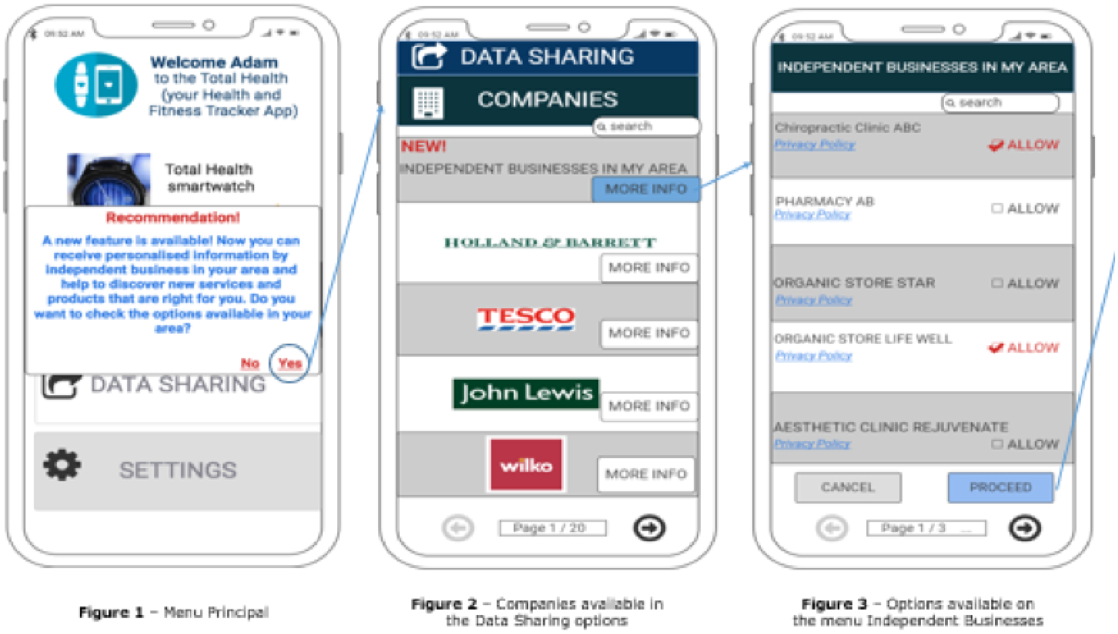
Table 3.3: Relation between Research Objectives and questions explored in the focus group for the study two - Scenario 1.

Research Objective	Illustrative question in the workshop	2nd study Theme and sub-themes related	Related theme in the first study
RO1 RO2	Would you like to have your health data collected as described in the scenario? If yes, would you like to share this data? With who? If no, any reason in particular?	Theme 1: Data-related factors (Sub-themes: Data Collected; Data use; Data sharing)	Theme 2: Data-related factors
RO2 RO4	2) In Figure X, Adam saw some information about what is going to happen with his data after sharing it before deciding. What do you think about the information displayed on the screen?	Theme 1: Data-related factors (Sub-themes: Data sharing; Data use, privacy Policy) and Theme 2: Technology related factors (sub-theme: Recommendations; App Design)	Theme 1: Technology related factors Theme 2: Data-related factors
RO2 RO4	3) What do you think about this alternative way that the information is displayed on the screen?	Theme 1: Data-related factors (sub-theme: Data sharing, Data use, Privacy policy) and Theme 2: Technology-related factors (sub-themes: Recommendations, App Design)	Theme 1: Data-related factors Theme 2: Technology related factors
RO3	4) What do you think about the follow up from the NHS that happened in the scenario? Do you think this is a good approach?	Theme 1: Third parties related factors (Sub-themes: Motivations for data sharing; Outcome Utility Theme 2: User-related factors	Theme 1: Data-related factors Theme 2: User-related factors
RO3	What would you expect in exchange for sharing your data with the NHS?	Theme: Third party related-factors (sub-theme: Motivations for data sharing and Outcome Utility)	Theme 1: Data-related factors Theme 2: User-related factors

3.4.2 Scenario 2 - Sharing data with companies

In the second scenario, the persona chooses to share the data with companies (see Figure 3.6 and Appendix L). This scenario contains five questions and one additional question regarding an alternative wireframe related to the screen about displaying what would happen when you allow a company to have access to your data, and which way of displaying the information would be more transparent and trustworthy.

Table 3.4 shows the connection between research objective, study question, and themes from study one and Two.



A new feature is available! Now you can receive personalised information by independent business in your area and help to discover new services and products that are right for you. Do you want to check the options available in your area?

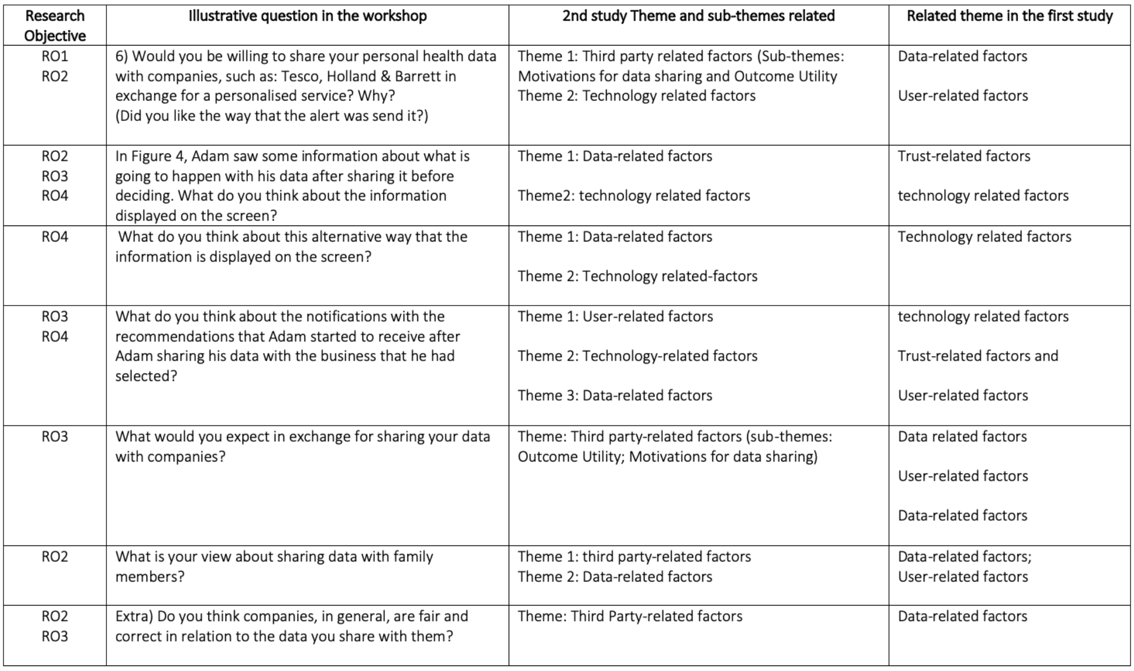
Figure 1 – Menu Principal

Figure 2 – Companies available in the Data Sharing options

Figure 3 – Options available on the menu Independent Businesses

Figure 3.6: Example of the wireframes used in study two - Scenario 2. Source: author.

Table 3.4: Relation between Research Objectives and questions explored in the focus group for study two - Scenario 2.



Research Objective	Illustrative question in the workshop	2nd study Theme and sub-themes related	Related theme in the first study
RO1 RO2	6) Would you be willing to share your personal health data with companies, such as: Tesco, Holland & Barrett in exchange for a personalised service? Why? (Did you like the way that the alert was send it?)	Theme 1: Third party related factors (Sub-themes: Motivations for data sharing and Outcome Utility Theme 2: Technology related factors	Data-related factors User-related factors
RO2 RO3 RO4	In Figure 4, Adam saw some information about what is going to happen with his data after sharing it before deciding. What do you think about the information displayed on the screen?	Theme 1: Data-related factors Theme2: technology related factors	Trust-related factors technology related factors
RO4	What do you think about this alternative way that the information is displayed on the screen?	Theme 1: Data-related factors Theme 2: Technology related-factors	Technology related factors
RO3 RO4	What do you think about the notifications with the recommendations that Adam started to receive after Adam sharing his data with the business that he had selected?	Theme 1: User-related factors Theme 2: Technology-related factors Theme 3: Data-related factors	technology related factors Trust-related factors and User-related factors
RO3	What would you expect in exchange for sharing your data with companies?	Theme: Third party-related factors (sub-themes: Outcome Utility; Motivations for data sharing)	Data related factors User-related factors Data-related factors
RO2	What is your view about sharing data with family members?	Theme 1: third party-related factors Theme 2: Data-related factors	Data-related factors; User-related factors
RO2 RO3	Extra) Do you think companies, in general, are fair and correct in relation to the data you share with them?	Theme: Third Party-related factors	Data-related factors

3.4.3 Recruitment and Ethics

Participants were recruited through existing links, connections and organisations with whom the researcher worked or had come into contact with, such as members of the University of Third Age (U3A), previous participants of other projects in Horizon and Human Factors Research Groups and activities from UnBias and ReEntrust projects, as part of the Horizon Digital Economy Research at The University of Nottingham and others institutions. In addition, participants were recruited by contacting those that took part in previous workshops in the first study of this research and through paper-based advertisements and leaflets circulated within public spaces such as the Central Library, Age UK Nottingham and Nottinghamshire and Nottingham Community and Voluntary Service (NCVS) in Nottingham city centre. In addition, flyers were used to advertise the focus groups to members of the general public who fell into the age category of 65 years and upwards, by placing them in popular and accessible locations around Nottingham city centre (Age UK, NCVS and the Central Library) (see Appendix H). As with the first study, the University was avoided in order to sample a more diverse background of participants. The study was approved by the School of Computer Science Research Ethics Committee. Participants received a voucher after the focus group, and due to confidentiality purposes, participant's data were anonymised and they were referred to in the study using an identification number (e.g., P1, P2).

3.4.4 Introducing the Participants

Thirty five participants in total took part in study two, aged 65 years and above, with the oldest participant being 84 years old. Figure 3.7 below presents the age range of participants. Of the 35 participants, 57% (20) were aged between between 65 and 69 years old.

Following the three life stage subgroups presented in Little (2014), the older adults

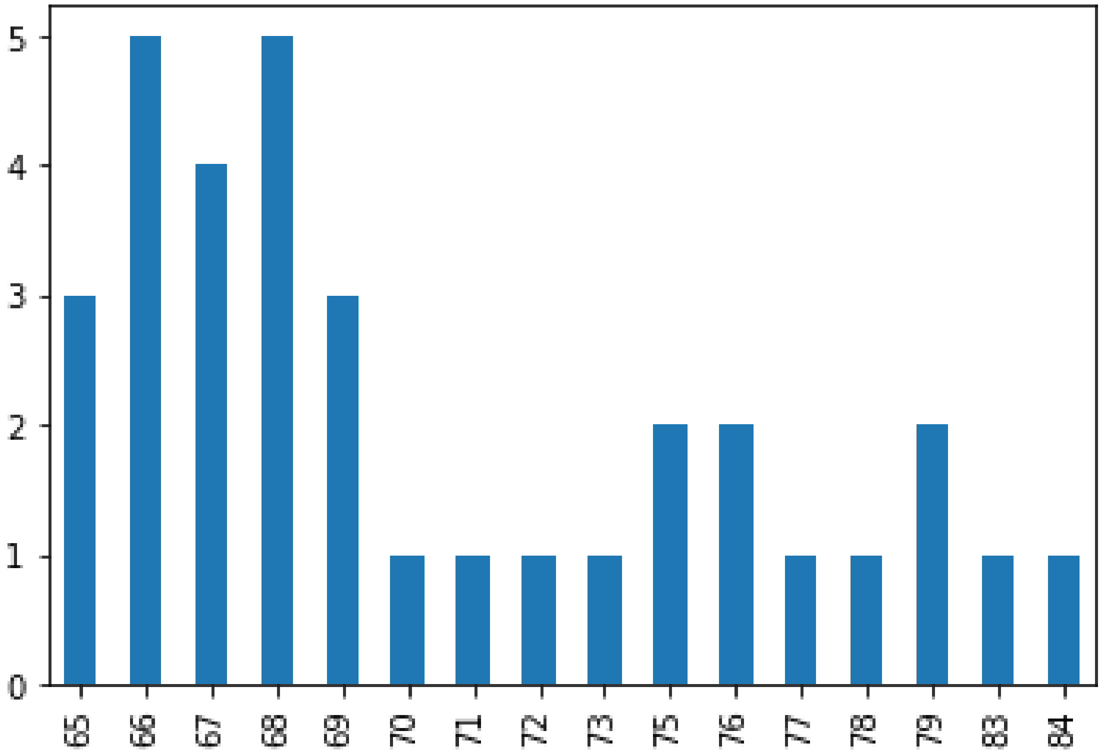


Figure 3.7: Number of participants per age in study two. Source: author.

were divided according to young-old (approximately 65–74), middle-old (ages 75–84), and old-old (over age 85); thus, in this study 68% participants were young-old and 32% middle-old.

As in the first study, a balance between female and male participants was sought in this study, with 17 males and 17 females. One participant did not provide gender information.

Participants came from different professional backgrounds and levels of education as shown in Figure 3.8.

Table 3.6 below presents an overview of key information for each of the thirty-five participants including number id, focus group number, age, gender, education level and the first scenario presented.

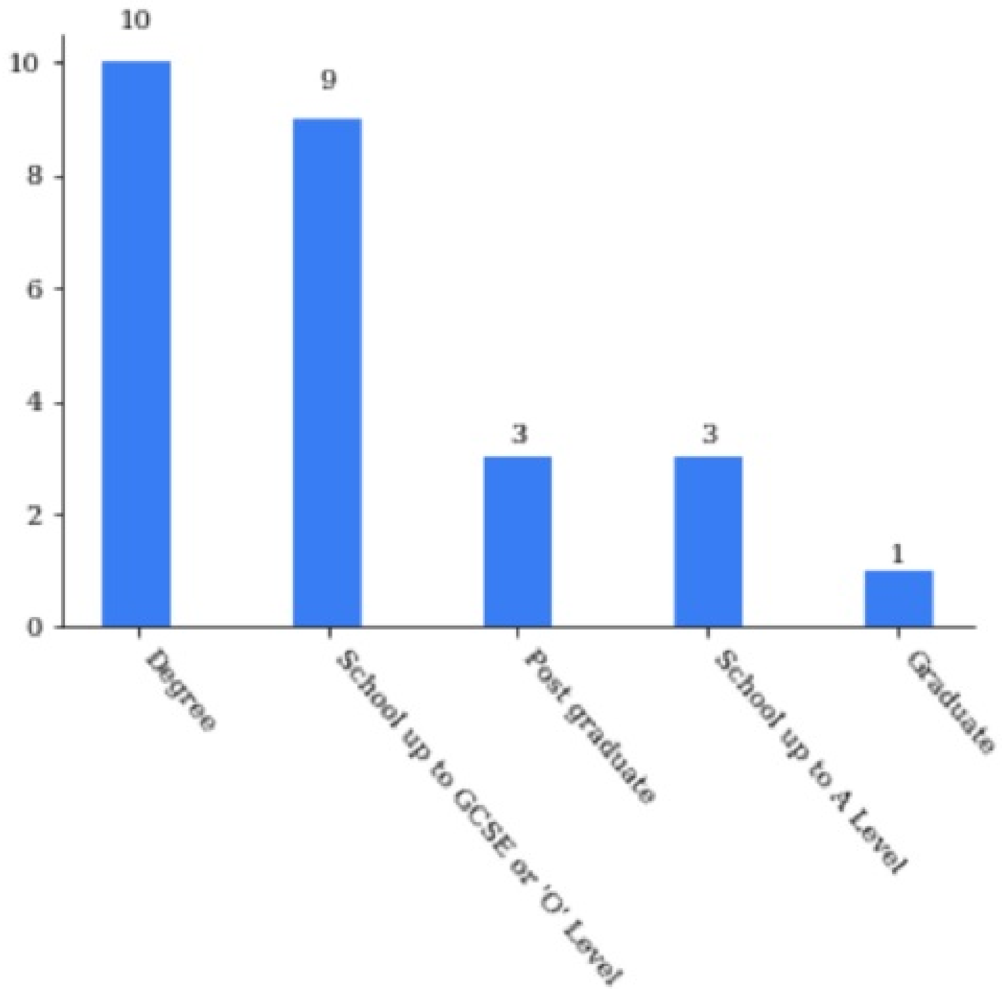


Figure 3.8: Participants' education level in study two. Source: author.

Table 3.6: List of participants in the study two.

Id	Group	Age	Gender	Education level	1st scenario presented
P1	G2	83	Female	Graduate	1 - NHS
P2	G2	68	Male		1 - NHS
P3	G2	75	Male	School up to GCSE or 'O' Level	1 - NHS

Table 3.6: List of participants in the study two.

Id	Group	Age	Gender	Education level	1st scenario presented
P4	G1	73	Male	School up to GCSE or 'O' Level	1 - NHS
P5	G1	66	Female	School up to GCSE or 'O' Level	1 - NHS
P6	G1	67	Female	Post graduate	1 - NHS
P7	G2	66	Male	Degree	1 - NHS
P8	G1	68	Male	Degree	1 - NHS
P9	G1	79	Female	Degree	1 - NHS
P10	G2	65	Female	Post Graduate	1 - NHS
P11	G1	70	Male	School up to GCSE or 'O' Level	1 - NHS
P12	G2	79	Male		1 - NHS
P13	G3	66	Female		2 - Co.
P14	G3	68	Female	School up to A Level	2 - Co.
P15	G3	66	Male	School up to A Level	2 - Co.
P16	G4	68	Female	Post Graduate	2 - Co.
P17	G3	76	Male	School up to GCSE or 'O' Level	2 - Co.

Table 3.6: List of participants in the study two.

Id	Group	Age	Gender	Education level	1st scenario presented
P18	G4	78	Male	School up to GCSE or 'O' Level	2 - Co.
P19	G4	69	Female	Degree	2 - Co.
P20	G3	66	Female		2 - Co.
P21	G3				2 - Co.
P22	G3	67	Male		2 - Co.
P23	G4	68	Female		2 - Co.
P24	G4	67	Male	School up to GCSE or 'O' Level	2 - Co.
P25	G4	77	Male		2 - Co.
P26	G6	65	Female	Degree	2 - Co.
P27	G6	65	Female	Degree	2 - Co.
P28	G5	69	Male	School up to A Level	1 - NHS
P29	G5	69	Female	Degree	1 - NHS
P30	G5	75	Female		1 - NHS
P31	G5	72	Female	Degree	1 - NHS
P32	G6	67	Male	Degree	2 - Co.
P33	G6	76	Male	School up to GCSE or 'O' Level	2 - Co.

Table 3.6: List of participants in the study two.

Id	Group	Age	Gender	Education level	1st scenario presented
P34	G6	71	Female	'School up to GCSE or 'O' Level	2 - Co.
P35	G5	84	Male	School up to A Level	1 - NHS

Two scenarios were explored with participants: Scenario '1 - NHS': explored data sharing with the healthcare system; Scenario '2 - Co.': explored data sharing with companies. These scenarios were chosen to investigate the intricacies of the issue relating to data sharing, privacy and receiving personalised content with the aim of contributing to improving health care services.

The focus group took place on 26th July 2019 for groups G1 and G2. Thereafter, on 30th July 2019 groups G3 and G4 participated in the focus group. Finally, the last focus group session took place on 8th August 2019 with groups G5 and G6.

3.4.5 Structure of Focus Group

The structure of the focus group was carefully designed to support discussion around aspects of potential use of data collected by the wearable devices, with a focus on the research objectives in the study two. Focus groups took place on three separate days, each day comprising two separate participant groups (3 workshops X 6 groups) with between 5 to 7 participants in each group and a total of 35 participants. Each focus group study contained three parts. The first part began with greeting the participants and answering any questions they had related to the study and gaining signed consent. Pre-survey and health monitoring questionnaires were also completed by each participant, followed by an introductory 10-minute presentation on the PhD research, study one and the Horizon Digital Research Group. The decision to conduct a pre-survey is supported by Bernard, Wutich, and Ryan (2016) who suggest that focus group participants should complete a short questionnaire about the topic beforehand to begin the discussion; this starts participants' thought process and provides various opinions and feelings about the topic.

The second part was a presentation of the scenarios with a 10-minute break between scenarios. Scenarios were presented in two ways: Scenario 1 was presented to one half of the cohort whilst Scenario 2 was presented to the other half. This process was adopted to achieve a counterbalance, thus, reducing extraneous variables. A series of open-ended questions about participants' perceptions were used to guide the discussion in each group. The facilitator read the first page of the scenario aloud after which participants could follow using the printed version to-hand; participants were therefore asked to read individually the first page of open-ended questions and were given 5 minutes for them to reflect on them.

For each scenario 45 minutes of discussion was planned. After the initial reading and reflection period, the session began with the facilitator asking the first question, then discussion, followed by the second and further discussion, at which point the additional wireframes were introduced; these represented an alternative way of displaying the information and participants' perception towards these was discussed. Next, the facilitator read aloud the second part of the scenarios and again, participants were asked to reflect for five minutes on two final questions before group discussion was resumed. Participants were then given a short 10-minute break, with refreshments and snacks, before proceeding to presentation and discussion of the other scenario following the same protocol.

Participants provided useful insights into design factors which were of interest and importance to their specific user group. These factors included usability, interaction, acceptance, aesthetics and how easily the device fits into their everyday lives.

Finally, part three of the focus group was completion of the post-survey by participants, the results of which are described later in the Results section of this chapter.

The whole process took two hours and forty-five minutes with each focus group audio and video recorded. Video was used to aid transcription and to identify, in case of doubt, which participant was talking, as sometimes audio identification alone might not be possible considering the number of participants in each cohort.

An overview of the processes involved in the focus group preparation is presented in Table 3.7:

Table 3.7: Overview of processes involved in preparation for the focus group.

Step	Description
Scenarios	Design of two scenarios using Vignette style to explore intricacies of issues relating to data sharing, privacy and receiving personalised content through use of sensor-based technologies.
Persona	Design of a main persona to represent the final user of a wearable device.
Wireframes	Design of wireframes being presented to illustrate hypothetical situations in the use of a wearable device app.
Illustrative material	Production of material used to present the scenarios and illustrate the wireframes.

As aforementioned, a within-subjects study was conducted where all participants were presented with both scenarios. However, for half of the cohort, Scenario 1 was presented first and for the other half Scenario 2 was presented first with the aim of achieving counter-balance and to minimise extraneous variables including potential influence of fatigue during the study and/or the experience of having been presented with another technology previously. A full overview of the scenarios can be found in Appendices K and L.

Scenario 1 presents a persona using a wristband wearable device, accessing the Mobile App data sharing option and selecting 'Share Data with the Health Care System', in this case the NHS; Scenario 2 presents the same persona using the same wearable device as described in Scenario 1, however, this time when accessing the Mobile App, they choose the option 'Data Sharing with Companies'. At the end of each focus group, the WHOQoL-BREF questionnaire (World Health Organization 2004) (see Appendix A) and post-survey were completed by participants.

3.4.6 Pilot study

A pilot study was conducted with four participants, two females and two males. The results of the pilot study showed that use of the Vignette scenarios and corresponding questions were clear; however, it revealed that the number of questions was too high with the overriding perception that this left insufficient time for the group discussion. Therefore, the number of questions was reduced to allow for more discussion time.

Another informed change was made to the questions asked by the facilitator which participants did not have to-hand; it was felt that some participants did not have time to reflect. To avoid this situation in the official study, a printout of the questions was provided to each participant prior to the discussion, along with sufficient independent reading time, to support their reflection.

A final change resulting from the pilot feedback related to the sequence of scenario presentations in the first and second part, as this was felt to require longer reading time and that if conducted in smaller parts, this would be more dynamic and result in participants being less likely to experience problems in retaining information about the sequence.

With these changes made as a result of the pilot study feedback, it was felt that the official study would run more smoothly and present more time for discussion to meet the overall aim.

Chapter 4

Study One - Findings from the surveys

4.1 Introduction

The methodological approach of this project, human centered design, places the user in the center of the design process, as an active player that expresses interests and priorities, comments and criticisms of the product throughout the conception and development processes. In the context of this project, it is important to understand the characteristics of the interviewers and focus groups participants, to enable their comments, opinions and reservations to be disentangled from gender and age factors; hence, the need to inspect the participants' profile through simple descriptive statistics as shown in this chapter.

In line with the findings from studies by Czaja et al. (2006) and Mitzner et al. (2010) it was also assumed in this research that older adults' relationship with technology is much more complex than that stereo-typically suggested as simply being afraid and unwilling to use technology. Thus, the research objectives of this first study were as follows:

1. To identify the factors that affect acceptability in the use of pervasive technologies to monitor health and well-being, when applied to different contexts and using different types of sensor-based devices
2. To identify the types of information older adults would be willing to have collected from their wearable devices and from indoor sensors in houses and public spaces, such as airports, hospitals
3. To identify the type of third party with whom older adults are willing to share their data (family, friends, physicians, research groups, public and private companies)

4.2 Quantitative Results

The following section presents the findings of the data analysis comprising responses to the questionnaire applied in Study One, participants' technology user and preferences profile, and some results from the thematic analysis, beginning with analysis of the WHO – Quality of Life (WHOQOL-BREF version) findings.

4.2.1 Quality of Life Questionnaire findings

The WHOQOL-BREF is a more concise version of the Quality-of-Life Assessment developed by the World Health Organization. This questionnaire is used to measure Quality of Life in different countries reflected in four domains: physical health, psychological factors, social relationships, and environment. Facets incorporated within the domains are: 1. Physical health - activities of daily living, dependence on medical substances and medical aids; energy and fatigue; mobility; pain and discomfort; sleep and rest; work capacity; 2. Psychological factors - body image and appearance; negative feelings; positive feelings; self-esteem; spirituality / religion / personal beliefs; thinking, learning, memory, and concentration; 3. Social relationships - personal relationships; social support; sexual activity. 4. Environment - financial resources; freedom, physical safety and security; health and social care - accessibility and quality; home environment; opportunities for acquiring new information and skills; participation in and opportunities for recreation/leisure activities; physical environment (pollution / noise / traffic / climate); transport (WHOQoL Group 1998).

The t-test was applied to check for a statistical difference between the average scores of the Brazilian and English groups. Although identifying cultural differences was not a focus, these were checked to verify the assumption that there were no significant differences between the Brazilian and British participants. A null hypothesis means that both populations are equal, and an alternative hypothesis is the true difference where it is not equal to 0. The t-test showed no significant statistical differences in the scores for physical, psychological and social (see table 4.1) as opposed to the environment domain where the English group had an average score of 79.64 compared to 72.33 for the Brazilian group.

Table 4.1: t-test results for assessing statistical difference using 95% of interval confidence between average score of participants, grouped by nationality.

Domain	t-statistics	degrees of freedom	p-value
Physical	1.19960	25	0.24160
Psychological	0.51649	25	0.61010
Social	-0.14106	24	0.88900
Environmental	-2.15630	24	0.07087

The t-test was also applied to assess the statistical difference among participants grouped by age. Again, the results showed no significant statistical difference among the domains other than that of environment (see Table 4.2).

Table 4.2: t-test results for assessing statistical difference using 95% interval confidence between average score of participants, grouped by age.

Domain	t-statistics	degrees of freedom	p-value
Physical	0.65611	25	0.5177
Psychological	-0.03907	25	0.9691
Social	-1.02640	24	0.3149
Environmental	-4.31330	25	-4.31330

Quantitative analysis of the dataset was complemented by an exploration of the distribution of scores given to groups based on a combination of nationality and age (see the following figures, starting with 4.1). This is included to illustrate at a glance the distribution of domain-wise scores.

4.2.2 Results from survey and closed questions during interview: Participant preferences and use of technology

The following sections present and describe the general profile of participants' use of technology, at the time of interview, and their preferences for the ubiquitous technologies presented in the scenarios. The preferable way to visualise report generates through the sensor device, the kind of data collected that might be interesting for them that was gained from a closed interview question.

As aforementioned, although identification of cultural differences was not a key aim of this study, the assumption that there were no significant differences between countries was tested. No significant differences were observed; however, interesting qualitative differences were noted in relation to participants' experiences as sum-

Figure 4.1: Distribution of scores of all participants grouped by four domains of WHOQOL-BREF questionnaire. Source: author.

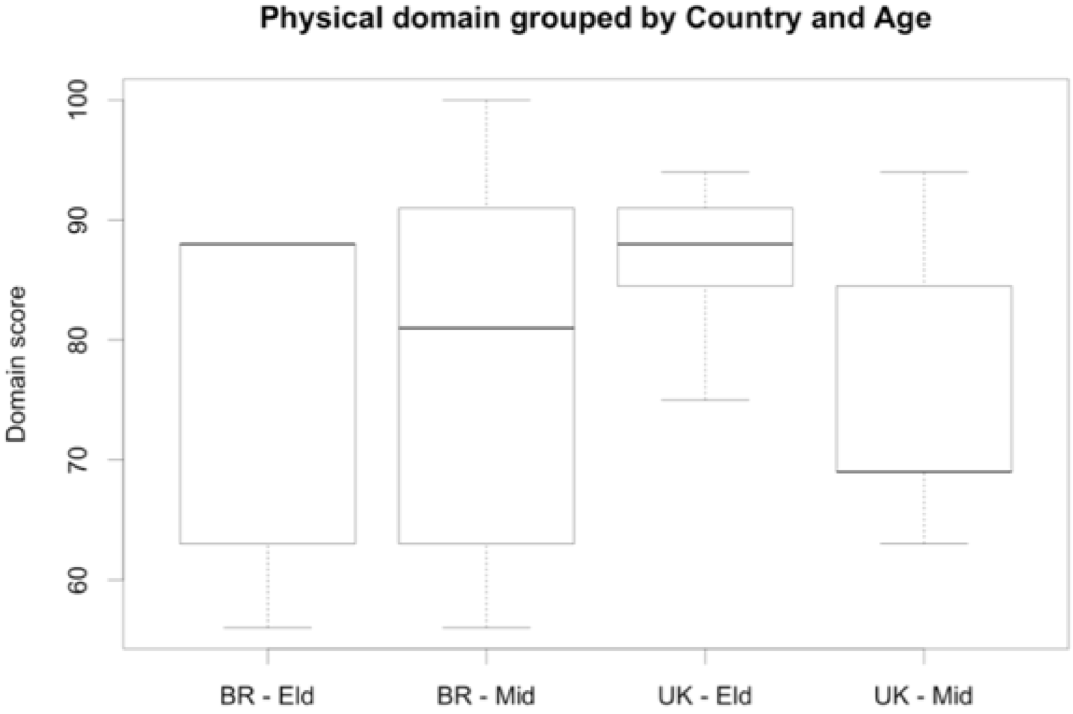


Figure 4.2: Distribution of scores in physical domain of all participants grouped by nationality and age. Source: author.

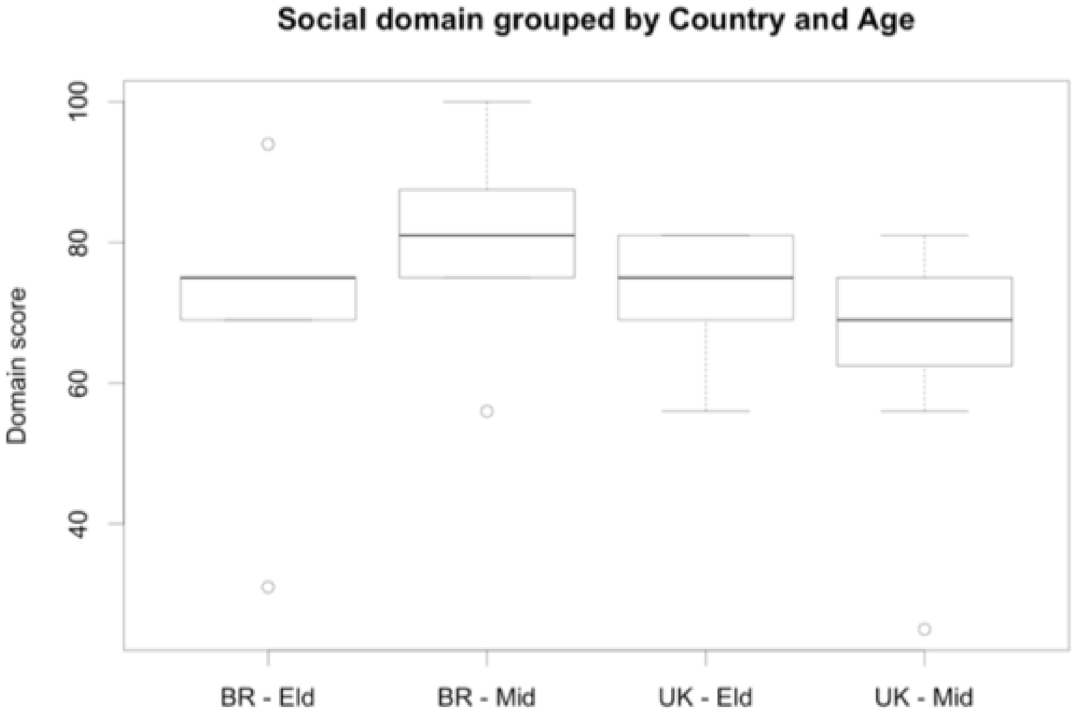


Figure 4.3: Distribution of scores in social domain of all participants grouped by nationality (Brazil –BR, United Kingdom - UK) and age (Elderly, above 65 years, and middle age, between 45 and 64 years old). Source: author.

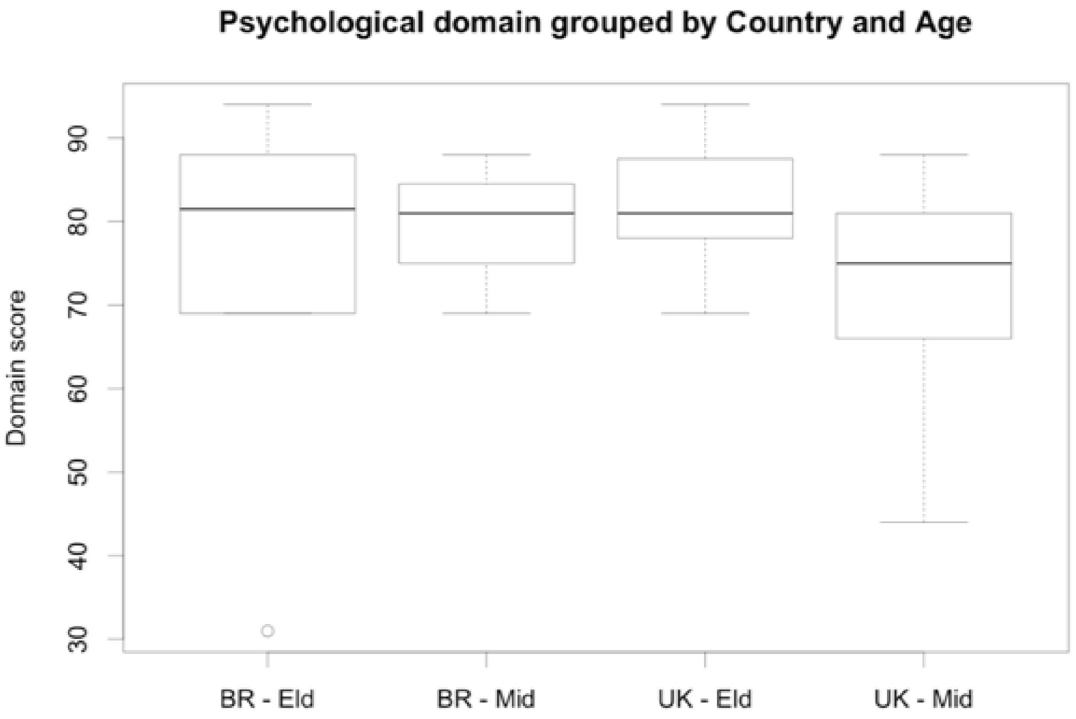


Figure 4.4: Distribution of scores in psychological domain of all participants grouped by nationality and age. Source: author.

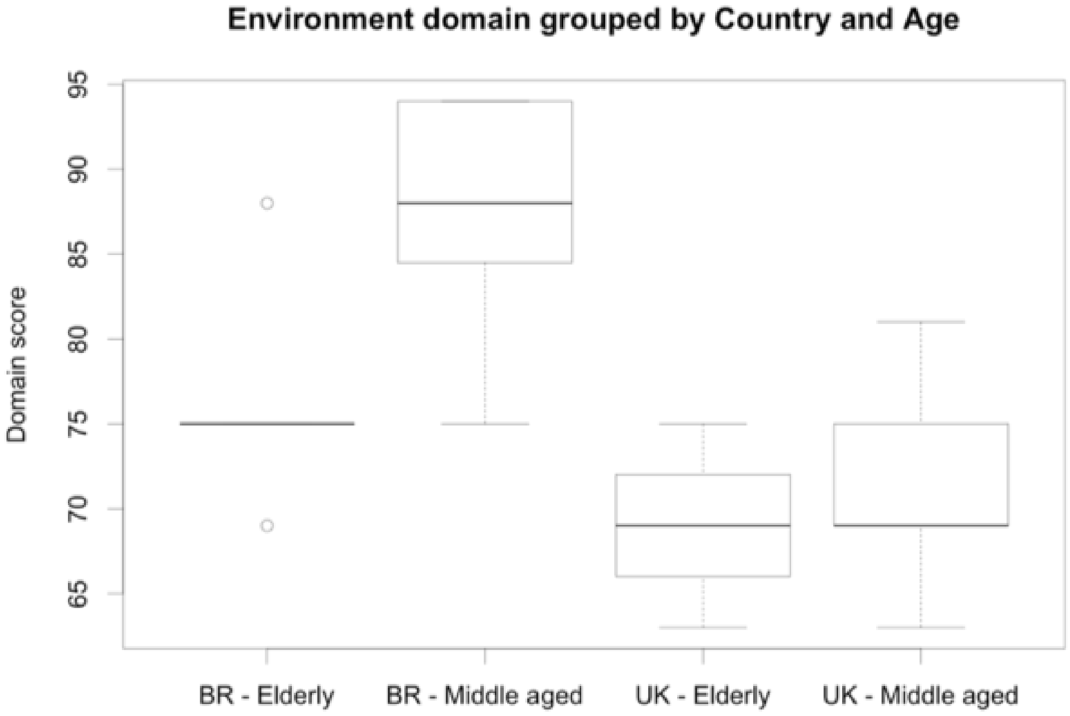


Figure 4.5: Distribution of scores in environmental domain of all participants grouped by nationality and age. Source: author.

marised below.

4.2.3 Brazilian female middle-aged group (4 participants)

For the middle-aged female group, preferences for the most interesting sensor were split between the indoor sensor 'Home Sense' (2/4) and the Fitbit (2/4). However, they were unanimous in their view that the least interesting device was the set of wearable devices by 'AllMeasureHealth' (Scenario B) (4/4), and the measurements they were most interested in were blood sugar level and body temperature (2/4). There was no agreement on the least interesting measurement collected. All participants used computers, and only one did not have a smartphone. Daily digital technology use was between 1 and 3 hours (2/4), up to a maximum of 5 hours (1/4). Technology use began from 5 years ago up to 10 years ago (2/4) (2/4). The preferred method of keeping a diary was using a webpage (2/4).

4.2.4 Brazilian male middle-aged group (3 participants)

In contrast, the middle-aged male group held different opinions; each of the participant's found one of the four devices the most interesting; meanwhile, the least interesting devices were 'Home Sense' (2/3) and 'All Measure Health' (1/3). The measurement of most interest for this group was blood pressure (2/3); however, there was no agreement on the least interesting measurement. All participants used smartphones, which was the most popular technology, and one did not use a home computer. However, he was the only participant that was already familiar with and had used the Fitbit in Brazil. The daily average use of digital technologies ranged between 1 and 3 hours (2/3). Participants began to use technology from 5 to 30 years previously. Use of the smartphone app was the preferred way to complete a diary in this group (3/3).

4.2.5 English female middle-aged group (3 participants)

This group found the Fitbit the most interesting device (2/3) with the least interesting being the indoor sensor ‘Home Sense’ (2/3). The measurement they were most interested in collecting was minutes being active (2/3). There was no consensus on the least interesting measurement to be collected. All participants used computers, and only one did not have a smartphone. Furthermore, one participant already used a Fitbit. Daily digital technology use varied between participants from 1 to 7 hours. When technology use started varied from ten to more than thirty years ago. Finally, the preferred way of keeping a diary was via a webpage (2/3).

4.2.6 English male middle-aged group (4 participants)

In the middle-aged male group, there was unanimous agreement that the most interesting sensor was the Fitbit (4/4) and the least interesting device was the indoor sensor ‘Home Sense’ (4/4). This group were most interested in measuring three areas: heart rate (3/4), calories burned (3/4) and blood pressure (2/4). However, there was no agreement over the least interesting measure to be collected. All participants used computers and smartphones. One of them was familiar with using a Fitbit and was currently using a smartwatch. Daily digital technology use varied between participants from 3 to 9 hours. The time they started to use technology also varied, ranging from 10 to more than 30 years ago. The preferred method of keeping a diary was split between a webpage (2/4) and a smartphone App (2/4).

4.2.7 Brazilian female elderly group (3 participants)

This group agreed unanimously that the most interesting sensor was the Fitbit (3/3), and the least interesting device was the ‘All Measure Health’ (2/3). The three measurements they were more interested in collecting were: Blood pressure

(3/3), sugar level (3/3) and electrodermal response (2/3). Furthermore, two of the three participants found no measurements of less interest, highlighting that all would be of interest to them. All participants used computers and smartphones and the daily digital technology use ranged from 1 to 3 hours. Moreover, their use of technology began a maximum of 10 years ago. Finally, their preferred way of keeping a diary was through a smartphone App (3/3).

4.2.8 Brazilian male elderly group (3 participants)

Among the elderly male group, the most interesting sensor was the Fitbit (2/3), and the least interesting device was the hypothetical wearable device 'All Measure Health' (2/3). Two measurements they were more interested in collecting were blood pressure (3/3) and blood sugar level (2/3). As for the female group, two of the three participants noted that all measures would be of interest to them. All participants used a smartphone, and one did not use his home computer. The daily use of digital technology varied between participants from 1 to 5 hours. Time using technology varied, from 5 to up to 30 years ago. Finally, the preferred way of keeping a diary was using a smartphone App (2/3).

4.2.9 English female elderly group (3 participants)

Similar to the Brazilian elderly group, this group considered unanimously that the most interesting sensor was the Fitbit (3/3). The least interesting device was the indoor sensor 'Home Sense' (2/3). Two measures they were more interested in collecting were identified as activity minutes (2/3) and calories burned (2/3); respiratory rate was of least interest (2/3). Only one participant did not use a computer or smartphone; however, she used a tablet on a daily basis. Daily technology use varied from 1 to 7 hours with use of technologies beginning from 5 to 30 years ago. Finally, the preferred way of keeping a diary was via a webpage (2/3).

4.2.10 English male elderly group (3 participants)

The English male elderly group, as with both the Brazilian male elderly group and British female elderly group, unanimously considered the most interesting sensor to be the Fitbit (3/3), and the least interesting device was the set of a hypothetical wearable devices ‘All Measure Health’ (3/3). Two measures they were most interested in collecting were blood pressure (2/3) and blood sugar level (2/3). Two of the three participants expressed interest in being able to measure for all factors. All participants used a computer or laptop; however, two did not use a smartphone (2/3). Daily digital technology use varied between participants from 1 to 5 hours. Further, the point at which they began to use technology varied from 15 to up to 30 years ago. Finally, the preferred way to keep a diary was through a webpage (2/3).

4.2.11 Overall findings

Although is not the aim of the study to explore cultural differences, some anecdotal differences in the experiences of participants were identified. English participants used technology for more hours per day and some already had experience with wearable technologies. Regarding measures of most interest to the British group, it appears that those related to fitness were more relevant (calories burned, heart rate and active minutes). However, for Brazilian participants, health measures were considered more interesting (blood pressure, blood sugar level, and body temperature). Further, the preferred way to complete a diary was using a web page for both English and Brazilian participants, although a smartphone app was also highly considered in Brazil, particularly in the male middle-aged group. In the Brazilian elderly group, participants used a smartphone more than a computer, compared to the British participants; conversely, the use of a computer was more common than a smartphone for the British participants. This result explains the rationale behind Brazilian participants selecting a smartphone app as the best way to complete a diary, while among the English participants, this would be via a web page. It was possible to identify that in both the middle-aged and elderly British group, participants began using technology years earlier, particularly when comparing the female groups in Brazil and England (maximum 10 years in Brazil; maximum 30 years in England). Daily technology use in hours in the female groups evidenced further differences (up to 3 hours in the Brazilian group; up to 7 hours for the British group). However, the male groups had similar daily technology use time in both countries (from 1 to 5 hours). All things considered, it seems reasonable to assume that the acceptability of the Fitbit device was higher as participants could visualise the device working during the interview. The fact that the other scenarios did not include a real device that could be touched and whose functions could be tested may have affected participants decisions in relation to device preference and acceptance.

Chapter 5

Study One - Findings from the interviews and focus groups

5.1 The coding process

To address the research objectives below of this first study conducted, as presented in Chapter 1, and again below, thematic analysis of the interview transcripts was used.

1. To identify the factors that affect acceptability in the use of pervasive technologies to monitor health and well-being, when applied to different contexts and using different type of sensor based devices
2. To identify the types of information older adults would be willing to have collected by their wearable devices and from indoor sensors in houses and public spaces, such as airports, hospitals
3. To identify the type of third party with whom older adults are willing to share data (family, friends, physicians, research groups, public and private companies)

The author had the opportunity to attend a two-day workshop on Thematic Analysis held in Newcastle. This training was vital as it offered initial experience of working with this analytical approach. Following the workshop, it was decided that initial coding would be more beneficial in a paper-based format. However, when the new interview coding was complete, and the study results began to be compiled, it was noted that this process would be challenging due to the number of interviews, codes, and the amount of paper needed in total. After coding, all 26 interviews were then transferred to NVivo. Eventually, the improved process of code retrieval, considering the number of interviews involved, proved worthwhile. However, the number of nodes and codes were still a challenge. With the arrival of a new supervisor to replace two previous supervisors that had left the University, this was a critical moment in supporting this stage of the work. It was agreed that work on a preliminary codebook would begin, with the aim of representing factors influencing the acceptance of health-monitoring technology.

The coding process was a singularly isolating endeavour, enhanced by the support of a new additional supervisor joining the supervision team during the third year of study, with whom some of the nodes were discussed. Word choice and sense-making of the data were challenging, resulting in the interview codes being adjusted three times.

The analytic procedure of coding followed the process of familiarising oneself with the data, generating initial codes, searching for themes, reviewing, defining, and naming themes. Coding meetings with the supervisors took place, to refine and form a codebook. The development and use of a codebook is a valuable way to test how data is interpreted, as well as ensuring rigour within research (K. Roberts, Dowell, and Nie 2019). Appendix P presents the preliminary codebook generated.

The final version of the codebook in accordance with the suggestion of the new supervisor, involved creating notes for three of the interviews, making it possible to see that these constituted a summary of the key factors covered by the interviewees; thus, this preliminary codebook was used to code the remaining 23 interviews. However, whenever a new code emerged, this was added to the initial codebook.

This was an important stage, considering the challenges faced as regards word choice and thematic analysis of the data for the first time. This third codebook was broader than the two previous versions, with an extensive list of nodes, comprising in total some 2,296 quotes and 28 sub-themes by the time coding of all interviews was complete. The aim of this coding was to be comprehensive, ensuring all topics were discussed, so emerging themes could be observed, rather than forcing pre-established categories into the data. Moreover, with 28 sub-themes it was essential to reflect on the commonalities and differences thereof; thus, it was decided to group them into clusters as broader themes, with the 28 themes effectively becoming sub-themes. As a result, three overarching themes were added that encapsulated the 28 sub-themes: trust-related factors, user-related factors, and technology-related factors. These are presented in the next sub-section.

During analysis, it was decided that coding would be done mostly at sentence-level considering that the context was important for this research and as a result, sometimes a quote was relevant to several themes. It can be seen, therefore, that the themes and sub-themes are not mutually exclusive, rather they overlap with each other, sometimes interrelating so closely that the boundaries become somewhat blurred. Given that the themes emerged from the data, this reflects an inductive approach to the analysis.

5.2 Technology-related factors

The technology-related factors cluster encapsulates the codes related to participants' opinions of the three devices (Fitbit, Indoor Sensor and the set of Hypothetical Wearable Devices) presented separately through the scenarios and encompassing the following topics:

- Features and functionalities: range of operations/functions of the device as highlighted by participants during interview
- Warranting alerts: situation and perception of participants about how an alert would be useful
- Metrics: the kind of measurement participants were interested in being collected by the devices.
- Wearability: characteristics related to the wearability of the device, predisposition related to wearing or using the device.
- Contextual metric data: data collected using self-report diary to measure mental well-being and preferred way of filling out this diary (mechanism preference).
- Data representation/report: preference for the kind of report to visualise information collected. Opinions related to self-report combined with fitness tracker data.
- Technology preference: preferred kind of wearable device.

Figure 5.1 illustrates codes regarding technology-related factors. The sub-themes are discussed in detail in the next sub-sections.

5.2.1 Wearability

Related to the theme of technology-related factors, one of the encapsulated subtheme codes is wearability. This sub-theme refers to the features that promote devices being worn on the body as an accessory or implant or even incorporated into clothing. From the three scenarios presented, two included wearable devices (Scenario A: activity tracker Fitbit and Scenario B: set of a hypothetical wearable devices to collect health data). Scenario C related to the Indoor Sensor, to which

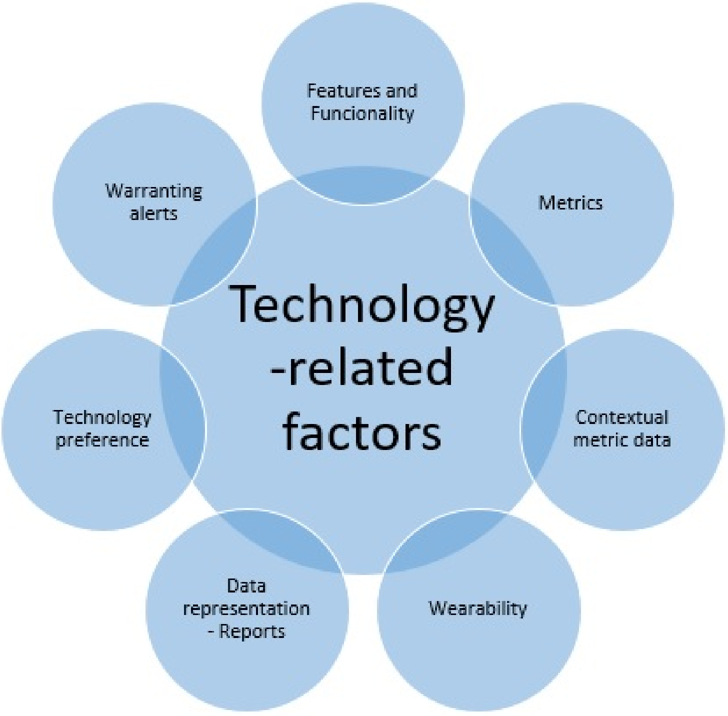


Figure 5.1: Conceptual map of themes identified in the data and related to the cluster: Technology-related factors. Source: author.

the topic of wearability does not apply. This section aims to explore participants' impressions of wearing the set and its features for collecting health data. Further, it explores the impression of wearing a currently available technology device for fitness tracking, in this case, a Fitbit.

Participant statements were tagged with the code 'wearability', for instance, when they referred to whether they would consider the device as acceptable for wearing, or when they mentioned conditions that would make the device acceptable for wearing. Of the 26 participants, it was observed that 17 expressed opinions about wearability aspects, most of which were focused on the set of hypothetical wearable devices (45 quotes) rather than the Fitbit (7 quotes). As the actual Fitbit was presented to the participants during the interview, it was already anticipated that this device would be more acceptable considering that people could observe this device working. This may explain why fewer comments on wearability related to the Fitbit. Furthermore, some participants had used a Fitbit in the past or were still using one or other similar wristband technology, such as a smartwatch (1 participant in Brazil: 3 participants in the UK). Moreover, this wristband looks like a gadget that people are already used to seeing in daily life which was reported during the interview as one of the factors in support of the wearing the device. This is consistent with Davis, Bagozzi, and Warshaw (1989) theoretical construct that is fundamental for technology acceptance: perceived ease of use (PEOU).

Meanwhile, the set of hypothetical devices was only presented through the Storyboard; this raised some questions related to aesthetics, workings and level of comfort, mainly given the location of the sensor on the neck presented in this scenario. Participants highlighted that a device positioned on the body could severely restrict the potential adoption of such wearable devices. This may by extension suggest that more than one device is perceived as not easy to use, following Davis, Bagozzi, and Warshaw (1989) fundamental determinants of technology acceptance. This is despite the higher measurement capability of the technology (that could enhance perceived usefulness) compared with wearable devices currently available on the market. The restricted potential uses of the device as suggested by participants were: using it only for a period of time; only wearing the device when needed, and using it if there is a health condition that justifies wearing it.

Overall, in this respect, seven factors were found to influence wearability: 1) aesthetics, 2) third-person reactions 3) practicality, 4) comfort level, 5) usefulness, 6) awareness, and 7) wearing duration. These factors are presented in detail in the next sections.

Aesthetics

Three participants (1 from Brazil; 2 from UK) commented on the aesthetic aspect of the set of wearable devices. One participant raised questions in relation to its size:

> *Yeah, I don't know [about] the size of these devices. (BR-15).*

Further, there were some queries about the design:

> *So, what would it look like? Like a plaster or something? (UK-19).*

Comments were also expressed about how discreet the device would be when worn:

> *Yes, it looks a bit like a watch, it looks a bit like something, like a pedometer, so it's something that would be acceptable but might make people say, what is that? Why are you wearing that? Yes. (UK-20).*

Other concerns were noted regarding third-person reactions, as discussed in the next sub-section.

Third party reaction

Connected to the aesthetic aspect, three participants (2 BR and 1 UK) voiced concerns about the sensor being accepted by a third party, particularly, that wearing it may cause embarrassing situations:

> *I do not need to use five different devices, [the Fitbit] it's better, even for when you go out to work, people will look at you, they will discriminate against you for wearing that ... "Look, the guy over there is done for. He's dying". (BR-8)*

> *This is going to be visible to people, right? It would bother me. So, people might ask, "What have you got there?" "What did you do to your neck?". (BR-15)*

Specifically, the device on the neck was of the greatest concern, as this may cause embarrassment:

> *I see here that one is worn on the neck ... I'm discreet. I am so uncomfortable with people staring at me' (BR-15)*

> *Because if you think of it on the neck, that sounds quite intrusive but if it's sitting on the neck, then that would be okay but you would worry about it being visible, whereas the wrist band is something you can cover up and people's health you tend to want to keep private, you don't want people to know that you're being monitored or what have you. (UK-20)*

The possibility of the device being worn under clothing attracting unwanted attention and similar questions from others were also raised, in that this might mean more user restrictions related to their outfit:

> *Today I'm wearing a long sleeve t-shirt, right? But I usually wear sleeveless, even in winter. Just a little bit of sunshine and I'm taking my clothes off ... 'Cause it's very rare for me to feel the cold, right? (BR-15)*

Alternatively, it was suggested that it may be seen as an accessory similar to one already recognised and worn, such as a wristband:

> *The most important thing for me is that the wristband is like a watch, right? (BR-15)*

Practicality

One of the main concerns about the set of wearable devices was the fact that more than one device should be worn at the same time; this was seen as an issue by six participants (4 BR; 2 UK):

> *But the three [devices] there, each one will have a function. So all would be showing, I don't think you can use just one, right? (BR-15)*

One participant suggested that he would find wearing more than one device annoying:

> *Velcro on the neck, Velcro on the arm and a wristband, no, I'd get fed up with that." (UK-26)*

In addition, it was considered potentially difficult to remember it had to be worn, or to be motivated to wear all devices:

> *If there was one device that could collect all these data, that would be good. But, in this situation, you might get confused about whether you had switched it on or not... (BR-07)*

During the interview, preference was investigated for a set of wearable devices that provided more capability (more measurement types) even if it meant the need to wear more sensors rather just one device which would offer fewer measurement types to the user. Most responses showed that participants preferred a combination of the two scenarios: to wear only one device, but with greater measurement capability:

> *What could be done here is to encompass everything into one - the watch that does it all. (BR-15)*

> *Just one of the three. Well, I mean, I'd imagine if it were all-in-one, it would be better, wouldn't it? (UK-29)*

It was suggested that wearing more than one device could cause irritation to the user, given its over-complicated nature; therefore, the Fitbit was seen as a good solution taking in to account the practical aspect:

> *Reading what's actually written here, I'm not sure where it would sit, . . . If using it was fiddly and irritating, my patience with it would be pretty limited. In other words, putting complicated bits of plaster on would be irritating. This is why I was impressed with this thing that you call Fitbit, because it's easy. And if you remember I was very fussy about it being easy to use. If it's not easy to use or if it's irritating to use I don't want to know. (UK-27)*

The inconvenience of not being used to checking it was raised by participant UK-27, who did, however, also express a willingness to try the device:

> *I would prefer not to have both my arms with things on. And if I had... so I don't know, I haven't thought about it much, if I have to push my sleeve up to look at it, that might be a nuisance. So it may be that I might just guess, because I haven't tried it. I probably would end up being happy to wear it on the other arm, so I could look at it easily, I'd have to get used to it... (UK-27)*

Comfort level

The level of comfort was highlighted by six interviewees (3 BR; 3 UK) as a factor affecting the acceptance of wearing the set of wearable devices:

> *I would look like a robot. I think one is okay, but three isn't. That's too much. (BR-10)*

The fact there is more than one device was seen as something that would impact on acceptance of wearing it:

> *If it's just one, I'll use it, no problem, you know? I would get up; I would put it on and go for a daily walk, that's it. Even though I'm already used to wearing a watch, I'm usually monitoring myself at times. (BR-10)*

However, one participant, who saw the usefulness of wearing the set, mentioned the key factor would be comfort:

> *As long as they weren't in the way and were comfortable to wear, to me it wouldn't be a problem because they have to monitor different parts of the body to get different measurements. (UK-28)*

Similarly, it was felt that the device worn on the neck was the most unacceptable from a comfort perspective, given its restrictive nature:

> *Sticking the thing on my neck I might not be too keen on that, but... no, I mean, I couldn't... that kind of thing, it would show. (UK-21)*

> *I wouldn't be inclined to do that unless I was actually having a problem. So, if I was aware I had a problem, then I'd say, okay I need to look at this. But as long as I'm feeling okay, that I'm breathing fine, I wouldn't want to walk around with a thing stuck on my throat. (UK-19)*

Finally, it was considered most acceptable if the device was similar to something already worn and with which people were familiar, such as a watch; therefore, the Fitbit was preferable given its similarity to wearing a watch. This is one of the reasons why the Fitbit, chosen by 20 of the 26 participants, was seen as the most interesting device.

Usefulness

Five participants (2 BR; 3 UK) raised comments about perceived uses that would justify or motivate the decision to wear it. These included health/medical or personal reasons:

> *I like the information on the wristband because I'm interested in that. This feels.. I could see this being useful for somebody who is ill or has a known condition that needs monitoring from a safety point of view. So, if you know somebody's perhaps got a heart condition or you know somebody's got diabetes or whatever. But if I'm relatively fit and healthy, why would I want all of this? (UK-30)*

However, for one participant, the use of a set of sensors might indeed improve measurement accuracy:

> *The more sensors the machine has, from a health point of view, the better it's going to be. More information, more medical information means you're going to arrive at a more accurate diagnosis of what is ailing the patient. (UK-18)*

Whether participants were aware of the particular use of each sensor and the extent to which there were interested or saw the usefulness of the data collection, was investigated:

> *I understood why you had one around his neck, one on his wrist, because they need that to be able to...what's the word..compare the..? ...maybe the heart rate measured through here and there and it's a good comparison and ensures the system is working properly. A lung capacity one would be a good one for me, because I need to improve my lung capacity. (UK-28)*

Using the set of devices was perceived as acceptable if needed for health reasons:

> *If I had his disease, I would wear it. But I don't have his disease as far as I'm aware, so I wouldn't. (UK-23)*

Finally, additional concerns were observed in the Brazilian group about the price of the device:

> *First, I'd like to know the price. Because that's my first concern, but of course, I want this. If I could have a device like that, it would be mainly because I have high blood pressure. (BR-13)*

Awareness

As regards perceived usefulness, two participants wanted to know the purpose of each sensor and what data each particular sensor was responsible for capturing, in order to justify wearing them.

> *But from what I've been told here, I don't know what it does, this thing on the wrist, because he didn't explain what each one does, did he? It's just the three of us here who do all this. So, if we knew what it all does, like on the wrist this does this, and this does that, that'd be good. Like, the pulse is the response to stress, anxiety and heartbeat. That'd be great, you know. (BR-15)*

As aforementioned, the device on the neck prompted more questions among participants:

> *So, how do you read this device? [the device on the neck] Is it stuck on? (BR-15).*

> *It doesn't actually explain what... The thing on the neck for instance, what does that actually do? (UK-19)*

Wearing duration

Five participants felt that the set of wearable devices was justifiable for use over a short time period, or for a specific time of day (3 BR; 2 UK), otherwise it was seen as impractical:

> *I think so, for a short length of time, I think. I mean, ...you're not going to be able to move as freely, probably, if you've got this device on. (BR-17)*

Regarding the Fitbit, two participants stated that they would like to continue using it, though they see the necessity of wearing their usual watch as well.

> *I would feel slightly odd, having a little black thing on here, but I think I would soon get used to it, I think I would be happy to wear one. I would not substitute my normal watch with it. So, I like my normal watch, and on reflection, I would not like to wear two on one arm, because I'd get really annoying trying to get at the one a bit higher up my arm. So, there we are. (UK-27)*

Participant 23, in particular, emphasised that if he needs to wear his regular watch as well as the device, he would restrict Fitbit use to a specific period of time:

> *I don't think I would want to wear that all day, frankly. It doesn't look particularly... you can't wear an ordinary watch as well, can you? You won't want both on your wrist. (UK-23)*

The importance of the user having control over the device and the option of deciding when they want to wear it, was mentioned:

> *I think that I would not want to wear it every day particularly, only if I chose to. I would want control over it. Because to some extent, I think if you said, I'm going to wear this every day, it has control over you and I wouldn't want that, I don't think. So, I would be interested in the things that it can do but not everything. I certainly wouldn't bother to wear it at night. (UK-26)*

To summarise, the key findings as regards wearability are: 1) Wearing multiple devices caused more concerns among participants, who seemed to be more comfortable with the use of a wrist-worn device (Scenario A) rather than a set of devices, even if this meant that more data would be collected (Scenario B). This preference may be explained by the fact that wrist-worn devices are technology currently available on the market and that participants regard these as gadgets that people are already used to seeing in daily life. Therefore, wearing it would not be an issue, as is familiar, therefore others would not likely comment on it; thus, this may reflect a fear of being discriminated against or stigmatised for using the device. 2) Use of the set of devices was seen as justified when there was a medical or health-related need to wear the set.

5.2.2 Contextual metric data

The sub-theme Contextual Metrics emerged from participants' comments regarding the data from the report presented in the scenario, which was a combination of data gathered by the Fitbit and the self-report diary. This theme was mainly observed as a result of question D in Scenario A (see Appendix D): Would you consider subjective aspects such as life satisfaction and people's feelings important when evaluating well-being or would objective measures collected through the Fitbit be enough?

This sub-theme was observed in the comments of 24 participants of whom fifteen demonstrated a positive attitude towards the measures to be collected or for the report that used a combination of the data gathered by the Fitbit and the self-report diary. Nevertheless, it was observed that nine participants had no interest or found no use in the subjective data and/or report generated by the self-report. Some reasons as to why participants found the self-report diary interesting are evidenced in the comments below. Participant UK-27 suggested that using the information gathered by the self-report could support their choice of activities, which in turn could improve user well-being:

> *I've just embarked on an NHS-funded fitness thing, I know it's true, that what I do, whether it's meeting people or whether it's exercise or diet, or alcohol, I know that all those things will affect my mood, and I am interested, subject to my natural laziness. I can believe that. And I think knowing that, may help you do more useful things. (...)*

Further, participant BR08 felt that information shown in the report could improve user awareness. From the moment she began to focus on aspects provided by the device, she expressed interest:

> *Wow, this is cool. It has improved here, it has not been very good here... (BR08, A)*

Participant BR13 felt positive about the use of the self-report; however, if this were to be used for a specific period, they would need know the reason for use:

> *I would find it interesting knowing what the goal is, whether you are going to have to do this the rest of your whole life or you are going to*

> *do it just one time to monitor your behaviour ... How do you say? Your biorhythm, right? So, if it were to be done for a while, for example, a week, to evaluate it during that week, we could even take a moment and take in this information: my day today was great, today was terrible, today I felt very hot, or today I had such and such a difficulty. So, that kind of information would have to be passed on, right? So, I couldn't spend my whole life giving this kind of information, because it would take a long time, wouldn't it? (BR13, A)*

Participant BR14 commented on the self-report being potentially used for specific aspects of concern or interest to the user:

> *I think it is all reasonable, very much down to whether you need something. Like sleep, a questionnaire like this is good. I think that if you take certain aspects that you feel are not right, then you can complete your questionnaire about the particular aspect that needs investigating. Well, I think that we have to make an assessment if it's better just with this one (Fitbit), one time you might think "Ah, I think I'll just leave it at that", and then, you might suddenly think, "Now I want to analyse it more deeply. We will see". (BR14, A)*

Regarding the question about using the data provided by the Fitbit plus the self-report data, participant BR10 commented that the use of both would provide a better overview:

> *No, I think that putting the two together, both the device and us evaluating ourselves would be very good. I think it would be ... Then it would be complete - one would complete the other, don't you think? (BR10, A)*

Regarding the nine participants that did not see the usefulness of self-report, it was observed that different related aspects were raised. Participant UK18 felt the information provided would show what the user already knows, even though they might try it out for a while:

> *I would do it out of curiosity, but that's it. I mean, I wouldn't go out of my way to spend time each and every day for the rest of my time, to gather information say, look, if you sleep more you're going to be less stressful. I know that already. But out of curiosity say, to check, say one particular month when I've got more time to spend. Let's say, I go off, I'm off on holiday. Just to have, to do something different, you know, have some fun with this gadget. (UK18, A)*

Participant UK20 similarly noted that the information provided by the self-report would not show anything that the user was not already aware of:

> *Because I can kind of get the idea that if you do exercise or some exercise, then it does improve your well-being, because you've got more oxygen floating about and you're a bit more aware. If you're sat watching television all the time, obviously you're not as healthy in your mind or body, so there are certain kind of things that you're generally aware of and I don't think it would tell me more than that, to be honest. (UK20, A)*

Participant UK19 mentioned that he would use it out of curiosity if the app was free:

> *I mean, if this app came out, I would give it a go, but I'm, I'd have to be convinced it would be... I'd try it out of curiosity, but I don't, at the moment I don't think it's something that I'm missing. [...] But I would give it a go if it was there and it was free, and I could just add it in, I'd try it, yes. (UK19, A)*

Finally, participant UK24 raised the concern that use of the self-report could cause the user to spend time reflecting about negative aspects:

> *...on that, I think you would be spending more time thinking about how you feel, yourself, and I sometimes think if you delve into too many psychological reasons as to the way you feel, it's not really good for you. I think it's best to try and, if you've had a bad day, put it behind you and start again. ...because, I think, with that many things happening on the news, you can have a bad day before you've even started. So, I think, at my age, you've just got to... You can't afford to spend too much time thinking... (UK24, A)*

To sum up, it was observed that there is a willingness among interviewees to use the self-report, due primarily to it bringing user awareness about activities for well-being support. However, it was further observed that some aspects such as use over a period of time, and the App being free would facilitate use. For those participants who did not see the purpose in its use, it was observed that the main reason was that the report data would not bring any information that the user was not already be aware of, as well as the diary requiring time to complete, time which might be spent reflecting negatively on the day.

5.2.3 Features and Functionalities

The sub-theme Features and Functionalities explores observations relating to participants' comments about features and functionalities that they would or would not like to have on the device. This theme was not observed in response to a specific question, rather during comments regarding features and functionalities that emerged during the interview. Responses were observed in the comments of seventeen participants. This theme is related to the sub-theme Warranting Alerts considering that one of the features commented upon by participants related to receiving alerts.

Participant BR08 mentioned that he would like to have some alerts from the device in case of variation and one possibility was that the device showed the alert when the user charged it up:

> *This type of equipment, usually it uses batteries, and the batteries need to be recharged. ...then quickly, they could, at that moment, perhaps, if it needs charging daily and they're about to charge it up, then they'd have to look at it just before, and he might have see some notification saying "Look, this is red. That item is missing here". For example, if it monitors physical activity, heart and hypertension, anything in red would show what was missing. So, it would give a warning signal. (BR08, B).*

Regarding data sharing with the airport, participant BR08 added that the device could share the information whenever something was irregular:

> *This can even collect the information, but it could only divulge it in the case of ... Like, "Oh, he's hypertensive, but it's green, his heartbeat is showing as fully green, it's fine". Nothing is said. It's red, or, he went into the bathroom and is taking too long, and the security officer checks, "Look, it's showing a very low heart rate here." Saves lives, right? Saves the patient's life. (BR08, B).*

Participant UK18 expressed an interest in having the option of receiving a short message service (SMS) which would serve as a reminder:

> *What I would do, Elaine is I would give the patient the option to stop the texts if they think they are not really needed. But I would also give the patient the option to change his mind and start receiving notifications again. It happens nowadays, in our day, at our age, ...when you receive text messages and they tell you, if you want to unsubscribe from these messages, go to this link on the internet and unsubscribe. (UK18, B).*

Another feature recommended by participant UK18 was to offer options that could be switched on or off by the user:

> *I think the best way to deal with this, Elaine, is to have all the features listed down, all the features and then inactivate those features which you do not feel are relevant to you. (UK18, B).*

Similarly, participant UK19 commented on having the option to turn off alerts:

> *Well I've got the ability to decide which information comes through on the equipment. So if I can set the settings then I'd be happy with it. I've got, you know, 1000 things coming through every second, but if I'm able to turn it off and turn on, you know... (UK19, B).*

Participant UK-27 did not see the need for measurements to be taken continuously, rather simply in a more routine way:

> *My point is that I don't need continuous blood pressure monitoring because if I'm worried about it, or somebody tells me I ought to be worried about it, then I can measure it. Not automatically without needing it. Blood sugar, I've just mentioned blood sugar just now. [. . .] And a continuous measurement of these things is over the top, but a way of getting it done intermittently on a sensible basis, I could do with. So, if somebody invented a device that said, you should have your blood glucose measured three times a year, measure it and enter it into here and we'll put it in a graph. In other words, technology but not technology which I'm sort of in charge of. I'd like to be reminded to do something and what to do, and the measurements made to be recorded. I don't think I need it continuously. (UK27, B)*

Participant UK26 raised the concern that the device needed to be calibrated so as not to send alerts for all data variations:

> *I would hope the machines are not so very sensitive that they pick up the very fact that you've been caused to jump because somebody said boo behind you. It sounds as if it might and I think, I think maybe, such a machine, such a device could be over-sensitive. You know, I would like the chance to say, be quiet, like you can satnav, you know. I know which way I want to go. (UK26, B)*

Participant BR13 would be interested in an indoor sensor that could monitor, for example, how much water the user had drunk during the day:

> *If this device recorded, for example, if an elderly person is inside the house and if this device recorded the times that she drank water and the amount of water that she drank, it would record how much water she'd taken in during the day, and this measure, this measurement collection, over time would show a person's better performance, mental and physical performance. So, it would be ... in that case, it could be very important, couldn't it? (BR13, C)*

This participant further suggested that the indoor sensor could also be used to monitor negative behaviour, sending a warning to a third person that had access to the data:

> *... imagine the behaviour of different people in a house, a person living alone or an old couple, what their behaviour is like, how they live together, if it's friendly behaviour, the device shows a green light, or if it's hostile behaviour where the two fight, he hits her, the device shows a yellow or red light. (BR13, C).*

To sum up, it was observed that the user would like the device to offer a range of options including turning alerts on or off whenever desired, and appropriate frequency of monitoring as a feature, over which the user had control, as this might be determined by the personal circumstances or condition of the user. Finally, alerts from the device were seen as a useful feature, again with the option for the user to turn on or off as desired.

5.2.4 Data Representation

The sub-theme Data Representation relates to participants' opinions about the two presented methods of data visualisation collected by the wearable device in Scenario A, namely, a chart and the use of a graphic resource (faces and colours) plus descriptive interpreted information.

Table 5.1: Participants' preferred way of seeing report generated by combination of wearable device and self-report.

Preferred data representation method	Number of participants
Charts	5
Graphic and descriptive information	12
Both ways	8
No interest at all	1

It was observed that a minority of participants would prefer to see the report represented only by a chart, as with the bar chart presented in the scenario; the preferred method would be to either have a combination of the chart with graphic resource or just the graphic resource and descriptive information, as indicated by the responses of twelve participants.

One factor identified and reflected in the responses below in support of the graphic resource was that it represented an intuitive format in which the data could be displayed.

Participant BR08 felt that graphical resources would attract more attention whereas charts would be viewed as more technical:

> *What is described. Just like that first little text, I said, right? Green, red, yes? Because that catches your eye and it's easier. Wow, it drew attention here. Then from the moment I consider the chart, it becomes very formal, very technical. So, the statistician here who would like to see the graph. (BR08, A)*

Further, participant UK20 mentioned that graphical resources would be easier for user interpretation:

> *Descriptive, because I think although you might work out the chart, you can't assume that the person is familiar with how charts work, that is very business-orientated, whereas if it's descriptive, it's a bit easier to digest. (UK20, A)*

However, this participant noted a preference for the use of other resources, rather than emojis to bring more formality to the report:

> *I don't particularly like smiley faces though, that's a bit kind of ... I don't know, it takes away the importance of it, it's a bit too child-like, I don't know though, you could probably include some visual clips or visual symbols to make it look more attractive, but I just don't like the smileys. Sorry. (UK20, A)*

In contrast, participant UK22 suggested that the use of smiley faces would leave a positive impression on her, adding a somewhat personal approach:

> *I like visual, I love colours and visual. This is nice but it doesn't feel as personal [chart], somehow that [smiley face] is almost like a little text message and it's more personal.*
>
> *Yes, but I can imagine for a lot of people the other one would be good, but for me, I like a bit of that, it doesn't feel too serious then. (UK22, A)*

Among the reasons for not choosing the chart, it was observed that participants felt it to be impersonal and technical:

> *I don't like charts, its like going back to school (UK17, A)*

> *Yes, I'm not very good on those sorts of things. Wasn't very good on graphs when I was at school. (UK24, A)*

As can be seen in Table 5.1, eight participants mentioned that they would like both forms of data representation (chart and graphical resources plus descriptive interpretation), given that it was mostly for the participant to select whichever option they felt most relevant/preferable at that time and, that one way of representing the data could complement another. Participant BR05 commented that as the graphic resource includes descriptive information, this is already an interpretation of the combination of data collected between the sensors of the wearable device and therefore the self-report already reflects an opinion and in the bar chart, the data would be free of correlation:

> *Both, because then, this first graph here refers to an opinion already formed, and here, you would form an opinion [bar chart] (BR05, A)*

Further, participant BR12 mentioned that having the two ways of representation would bring more effective information to the user:

> *With these you have better parameters, don't you? (BR12, A)*

A similar comment was made by participant BR07.

> *The chart complements what I'm describing, because I can demonstrate it in charts if there are more people: "Oh, that day when she spent two more hours with the family", then you show it here and the chart will only give you a record of the number of people who used it, in that case. You can do a graphical comparison (BR07, A)*

To sum up, it was observed that the graphical resource plus description were preferred by participants as a data visualisation format considering the readability and practicability this would bring. However, having the chart to complement this information was also felt to be important.

5.2.5 Metrics

The sub-theme Metrics concerns participants' opinions regarding the metrics collected by the set of wearable devices in Scenario B. Question A: "Would you like having many measurements available, such as monitor respiratory rate, heart rate, blood pressure, electrodermal response, sweat rate, blood sugar level, body temperature, distance walked during the day, continuous heart rate, calories burned, floors climbed, active minutes, time sleeping and location?", and B: "Is there any specific measurement that is of interest to you? Which measurement(s) is/are not necessary or not of interest?", explored metrics that participants are interested in or do not wish to be collected. Table 5.2 shows the most and least preferred metrics.

This sub-theme relates closely with Purpose of Use from the theme User-related factors and Health Conditions considering that subject to certain health conditions, participants may have a specific interest in one metric. All twenty-six participants in this study raised comments regarding the metrics.

Table 5.2: Participants' most and least preferred metrics

Id	Most interesting measurement	Least interesting measurement
4	Blood sugar level, body temperature	Blood Pressure
5	Depends on your interest and condition	Depends on your interest and condition
6	Heart rate	Calories burned
7	Blood sugar level, body temperature	Respiratory rate
8	Blood pressure	All are of interest
9	Respiratory rate, blood pressure, blood level, electrodermal response, calories burned	body temperature
10	Heart rate, calories burned, time sleeping, blood pressure	All are of interest
11	Heart rate, blood pressure, blood sugar level, calories burned, time sleeping	Active minutes, distance walked during the day
12	Respiratory rate, blood pressure	Blood sugar level, body temperature, electrodermal response
13	Blood pressure	All are of interest (wants even more)
14	Blood pressure, sugar level, electrodermal response	All are of interest

Table 5.2: Participants' most and least preferred metrics

Id	Most interesting measurement	Least interesting measurement
15	Blood pressure, blood sugar level, body temperature, electrodermal response	All are of interest
16	Blood pressure	blood sugar level
17	Electrodermal response, blood sugar level, calories burned	sweat rate
18	Blood pressure, heart rate, calories burned, time sleeping	location
19	Distance walked during the day, heart rate, calories burned, active minutes	Body temperature, time sleeping
20	Active Minutes	Electrodermal response
21	Electrodermal Response	blood sugar level
22	Calories burned, floor climbed, activity minutes, sleeping	Respiratory rate, body temperature, sweat rate
23	Blood pressure, blood sugar level	Sweat rate, calories burned
24	Heart rate, blood pressure, blood sugar level	Floors climbed, respiratory rate
25	Participant withdrew	Participant withdrew
26	Distance walked during the day, calories burned, active minutes	location, time sleeping
27	Blood pressure, blood sugar level	Alcohol level in blood and shares this information
28	Heart Rate, Distance walked during the day, calories burned, active minutes	Electrodermal response, sleep pattern
29	Blood pressure	All are of interest

Table 5.2: Participants' most and least preferred metrics

Id	Most interesting measurement	Least interesting measurement
30	Distance walked during the day, active minutes, time awake	Respiratory rate, heart rate, sweat rate, body temperature

It was observed that measurements tailored specifically to the health conditions of the user would be of interest, as suggested by participant BR07:

> *The respiratory rate, in my case, for example, would not be relevant, because I don't have any pre-disposition, but if I had, it would be ... wouldn't it, ..., yeah? If I wanted to capture what I was feeling if I had a blood pressure problem, that would be more for this purpose, wouldn't it? As required. (BR07, B)*

Similarly, BR08 was interested specifically in having blood pressure collected due to need:

> *Yes, in my case, it would be hypertension because I am hypertensive. (BR08, B)*

Further, when questioned which he felt were irrelevant measurements being collected, this participant saw relevance in all measurements with the aim of raising user's awareness to their general health condition:

> *No. I think they are all important from the moment it was identified that the equipment allows me to have access to this type of information ... We never go to the doctor constantly, do we? So, if you had equipment that*

> *can practically give you an accurate answer to what is happening to you, it could save your life. I think it is very important. (BR08, B)*

Similarly, participant BR13 mentioned that he liked all available measurements in the device and that more would also be useful. When then questioned if he could give an example of what other data he would like, the participant suggested collecting data that could support advance detection of diseases common among older adults:

> *More, more ... I don't know, the elderly person who is compromised? Compromised due to osteoporosis. If that device measures the level of ... err, like bone density. If that device identified your bones as becoming porous, then you might easily get a fracture. (BR13, B)*

Participant BR16 suggested that some metrics do not need to be collected all the time considering those where there is no considerable variation, therefore, these couldn't be collected occasionally:

> *I think there is. There are conditions which don't change instantly, overnight. It changes, but changes slowly, and you don't need to use equipment constantly to monitor blood sugar. Like, high blood pressure doesn't need it. Like here, blood pressure is necessary, it changes a lot. No, there are many things here that may not be the case, Which are not things that ... if you had a monthly follow-up, that'd be enough. I believe that ... (BR16, B)*

Similarly, participant UK27 commented on not seeing the need to monitor blood pressure continuously, as it is easy to monitor in other ways:

> *My point is that I don't need continuous blood pressure monitoring because if I'm worried about it, or somebody tells me I ought to be worried*

> *about it, then I can measure it. Not automatically without needing to. (UK27, B)*

It was observed that the some measurements, such as sleep pattern, were considered as useless by some (UK26) yet quite useful by others (BR06):

> *I have had before now a little thing that measured how many steps I've taken in a day but I ought to do that again, I suppose, so the distance walked and the active minutes, certainly. The time sleeping, I know very well how much I sleep, I don't need to measure it. (UK26, B)*

> *I even think that I ... the most I want to do is monitor my sleep! (BR06, B)*

This difference in perception might be justified by the specific conditions or concerns held by each participant in relation to their health or personal interests.

In sum, it was observed that participants were most interested in the collection of measurements of blood pressure, heart rate and sugar level; however, the same measurement could be deemed highly interesting for one participant and completely useless for another, the difference being justified by the purpose of use and health conditions or personal interests of the individual.

5.2.6 Technology preference

The sub-theme Technology preference refers to participants' opinions on preferred device when considering the limitation of measurements in comparing one device and a set of devices, as explored in question C Scenario B (see Appendix D): Would you prefer a device with more capabilities (more measurement types) even if it means more sensors around your body, or would you prefer having just one device with fewer measurement types?

This sub-theme relates closely to Purpose of Use from the theme User-related factors and Health Conditions, considering that on the subject of health conditions, participants could be specifically interested in one metric and or more receptive to wearing more than one device. Further, it has a close relationship with the theme Wearability, as it was observed that good wearability aspects would directly influence preference, and finally, with the sub-theme Usability with respect to practicability of use.

Twenty-three participants expressed their preferences of which five participants felt it would depend on the health condition or personal interest:

> *Depending on the need, it would provide the necessary, with two functions or more. If needed. If needed, I would use it more. (BR04, B)*

Similarly, participant UK20 would use the three devices only out of necessity, and that the user should be clear on which is the most important to be worn:

> *If I was somebody with a progressive disease, it sounds like its more serious, it's very serious so perhaps he is somebody who needs the three devices, but in a way you kind of need to prove why you need the three. What are the three doing? Has it been explained to him what each of the things are doing, or is he just doing it because the doctor told him? (UK20, B) (...)*

A similar requirement was raised by participant UK24 regarding the health condition as justification for wearing one or more devices:

> *Well, it depends on the state of my health. Say if I was in poor health, and I couldn't get about, say for people who are wheelchair-bound, who*

> *cannot get the exercise and that, probably it would be better to monitor more of their... Just to see how they're getting on. (UK24, B)*

Participant UK30 suggested that having both devices available would be desirable, subject to user needs, in that the simpler one might be used to collect less data, as presented in Scenario A or that the other devices be used to collect more data, as presented in Scenario B.

> *I think it would be a good idea to have both options available on one device, but I think for most people what you've got on yours, the fitness stuff, would be interesting but not crucial, Whereas if somebody's ill then you probably do need, for some people, their blood pressure, their heart rate, for medical reasons. So in terms of a gadget, I suppose you'd want, it would be useful to almost have like, version A which is just for your average person who wants to monitor their health and wellbeing, and a version B that you, or potentially like an upgrade or an extra app or something that you could then add for somebody who actually had a condition. (UK30, B)*

Participant UK18 would prefer equipment which meant using fewer devices that collected less data to keep it simpler and more practical:

> *I think I would go for simple, keep things simple, okay? Essentially, when you look at health in a person, it's really what keeps, what keeps people healthy is really essential things, like are you eating the proper food, are you getting enough sleep? So, I would go for the keep things simple idea. (UK18, B)*

Further, participant BR05 mentioned that he would need to test the devices first to be able to establish a preference between then:

> *They offer you a chance, don't they? First possibility A. Then, possibility B, you have a greater multiplicity of options, but then you ask: "But how am I going to test it if I don't have a complete evaluation?". I have to test it first so there is no preference yet. This is the first problem, to establish preference you would have to have prior knowledge, wouldn't you? (BR05, B) (...)*

Participant BR08 commented that he would prefer a combination of collecting more measurements as with the set of devices presented in Scenario B, but that it should be more practical to wear, like the one device presented in Scenario A. Further, the use of more than one device raised the concern of being stigmatised:

> *It is, in fact, what we always prefer ... useless equipment that provided us with more information. I believe, if it can really provide more information, and it is... I don't need to use five different pieces of equipment. It is better, even if you to go out to work, people will look at you, will discriminate against you for being... Suddenly, someone sees it, "Oh, the guy over there is finished. He's dying". (BR08, B)*

Similarly, participant BR09 added that a combination would be better and using less equipment more desirable, mainly from a comfort perspective:

> *Oh ... This is difficult, isn't it? This sticker on the neck is very weird, right? The one on the arm, the bracelet, is interesting, yeah? No, I would prefer to have more information available and less ... less equipment. A bracelet that did all this is still going. Oh yes. But imagine going to cover your body with little things just to identify how your health is, it sounds a little mad, doesn't it? I'd prefer one with everything. (BR09, B)*

Participant BR13 added that wearing it would depend on necessity and this could reduce with time, therefore the importance of a customisable device should be a key consideration by designers:

> *Look, it depends on the situation ... For the man with a respiratory problem, this device around his neck is of interest. It's more sensitive to recording what's going on, isn't it? So, it would be important that a sensor treats each type. (BR13, B)*

To sum up, it was observed that sensor preference relates to factors such as good principles of wearability and practicability without, where possible losing options for data collection. Thus, participants mostly desire a combination of less equipment and more data collected. However, if this is not possible or in the case of a specific need, the use of additional devices would be acceptable.

5.2.7 Warranting alerts

The sub-theme Warranting Alerts emerged from observing participants' opinions relating to the option of receiving alerts from the device. This theme was mainly noticed in responses to questions I and J in Scenario B (Appendix D) as regards lack of alerts and participants' perceptions of whether this function was needed or of use.

- I: Would you like the device to warn you about some situations such as high or low blood pressure, for example? Or would it bother you and you would prefer to check yourself if the pressure is low or high?
- J: In situations where you have more awareness such as reduced physical activity during a week, would you like to receive alerts on this, or would you feel uncomfortable?

This sub-theme is closely related with the Features and Functionalities theme, which considers an alert as an additional function in the device explored in this scenario. This sub-theme was observed in the responses of twenty-five participants, who viewed alerts as either a good resource or were neutral. No responses regarded availability of an alert as unnecessary.

Reasons presented in favour of the alert by thirteen participants suggested that this would bring awareness and/or would help track potential health hazards. Participant UK28 commented about the awareness that the alert would bring to the user:

> *I think a bleep or something with a little message would be wonderful. I certainly wouldn't be against that. If that means it's...it wouldn't have to be connected to a central computer, it will just have to be programmed for the individual, and we have the technology to be able to do that. And if you get a little bleep or red light, whatever it takes to get your attention, saying your blood pressure is getting high: careful what you're doing or you've only done 6,000 steps today and you usually do 10,000, no problem with that information coming through because it's still contained within the privacy of his programme. For me, personally, it would be good. (UK28, B)*

Further, participants BR12 and UK21 suggested that they would like to see alerts only for essential information:

> *This alert would be good if it were measuring the level of your blood pressure and it went up too much, or the sugar level went up ... for that kind of alert. Pay attention! See the doctor - that kind of alert. Not just anything. Just the most important. (BR12, B)*

> *If it was two… if there was too much information then I'd get irritated*

> *but if there was something I can just glance at it and know, yes, and delete it, then that would be totally fine. (UK21, B)*

For participant BR04, alerts could make the user aware of the need for treatment:

> *It's interesting because the patient is not always aware that a certain treatment has to be done. So, so, the alert would help to them to become more aware of what they really need. (BR04, B)*

As regards frequency, two participants suggested that this could be daily. Participant BR07 mentioned that a daily alert could help track potential hazards in the user's diet or behaviour:

> *It would be interesting at the end of each day, in that case, wouldn't it? "Today blood pressure in the morning started at 9/11, then increased to 12", because when you make that little map, you can monitor the pressure, you have to report what you ate, what time you ate, if you drank water, then this device can store this data, and then at the end of the day, it can show it: "No, you didn't drink enough water today"; "You ate a lot of sugar", according to whatever it has collected. (BR07, B)*

Similarly, BR10 shared the opinion that the alert could be used to help track potential hazards to the user's diet:

> *It would be good. Because then you would evaluate ... For example, you eat lunch, then the device shows a lot of salt, the pressure changes, so you will see that the diet is not right, I must look at what the device is warning me about. I think it would be very important for people to know what's going on. (BR10, B)*

One suggestion for the way in which an alert could be sent, noted by participant BR08, involved the alert coming from the device itself, which makes it practical and could occur when the user comes to charge the device:

> *If you receive an alert ... Let's suppose, it is sent via e-mail, you will see it and think "I won't look at it now", see what I mean? But if the the equipment has to be charged up or removed, when they go to remove it, they'd look and think, "Oh, this function is red. Something is wrong". (BR08, B)*

For participant BR11 this kind of alert would be acceptable if related to personal health data:

> *they (companies) would keep sending lots of information, several messages, so many of these messages would end up bothering you and you wouldn't value them. So, value them. For health reasons, it is still a more personal thing, so, on the one hand, it does not stop the worry of invasion of privacy, but, on the other hand, it is something that relates to the health of that person. So, it would be acceptable, wouldn't it? (BR11, B) (...)*

It was observed that 4 participants would like to have alerts as an option that could be switched on and off. Participant UK20 further questioned who would have access to this alert, suggesting that this should be solely for the user unless the user gives access permission to another person:

> *I would give it as an option, so that the alert should only really go to him, or unless he nominates somebody to receive the alert, if it's his wife, if it's a condition that is serious and needs monitoring and perhaps he wants somebody else to receive this, but it should also be able to switch*

> *off, because in the end it's his health, and he hasn't been told to wear this device, it's his choice, so he should have the option. (UK20, B)*

To sum up, it was observed in this sub-theme that the alert is seen as a useful resource and therefore would facilitate acceptability, given its potential usefulness in promoting tracking and user awareness of issues relating to behaviour, diet or a point at which there is a need to seek advice or treatment from a health care professional.

The findings from this sub-theme of technology-related factors provide an understanding related to the first research objective of identifying factors that affect acceptability in the use of pervasive technologies to monitor health and well-being, affected by a range of operations and functions that the technologies brings, the alerts that devices could send to users and to others, the characteristics related to wearability and the kind of wearable device. Related to the second research objective, identification of the types of information older adults would be willing to have collected is subjective dependent upon the type of measurement going to be collected, the type of method of completing the self-report and the kind of report to be generated.Based on these findings it is possible to identify that these permeate the concepts of the user seeing the usefulness and their perception of ease of use from TAM model of acceptance by Davis. Considering that the health information technology acceptance model (HITAM) is an integration of the TAM model with antecedents and health related constructs, in this model, it can be seen that the sub-theme Metrics is related to the health status and health beliefs and concerns that the participants expressed. The findings from the sub-themes Wearability, Contextual Metric Data and Technology Preference are related to the HIT Self-efficacy proposed by HITAM, which encapsulates the objective usability of the technology. As mention in the literature review, this study does not aim to test the technology acceptance models available in the field, however these four models introduced in Chapter Two are used to identify how these models contribute in this research in the process of understanding the factors relating to technology acceptance.

5.3 User-related factors

The main theme User-related factors encapsulates nine sub-themes related to participant opinions on the following topics and their basic definitions:

1. Actionability of data: attitudes in response to the data
2. Agency: (in-)ability to take action
3. Behaviour change: things that do or do not influence people's behaviour
4. Cultural knowledge: situations raised that are culture-specific
5. Experience: situations that the participant has experienced in the past
6. Health conditions/self-awareness: health-related aspects raised and attitudes towards prevention
7. Purpose of use: identification or not of reason for technology use
8. Mechanism preference: identifying participants' preferred way of completing the self-report on wellbeing
9. Routines: habits and routines in daily life
10. Technology attitudes: views and reactions towards technological devices

Figure 5.2 illustrates these themes, which are presented in detail in the next subsections.

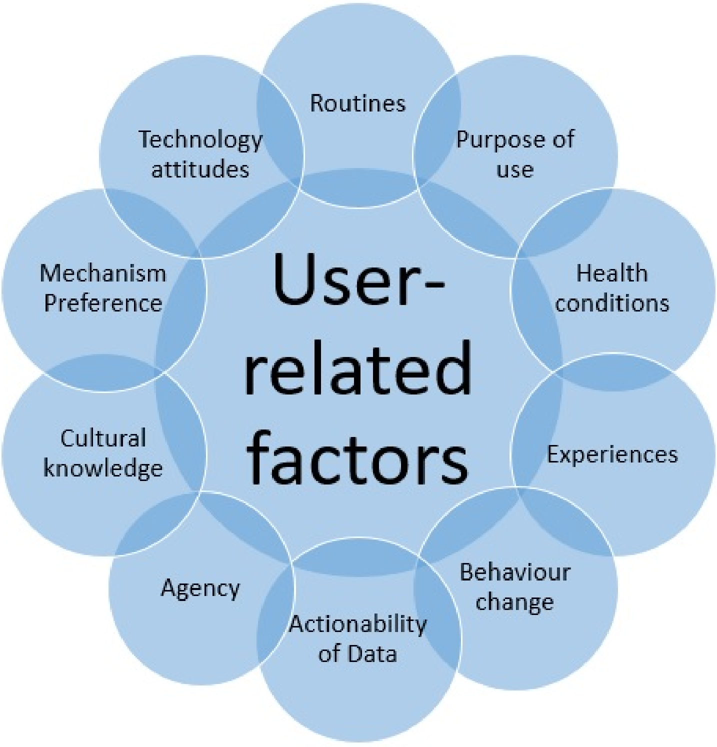


Figure 5.2: Conceptual map of themes identified in the data and related to the cluster: User-related factors. Source: author.

5.3.1 Actionability of data

This sub-theme refers to how the participant might respond to the data in the event it showed some significant change in a health measurement collected by the device. This contributes to an understanding of acceptability of the device and this sub-theme was observed in the comments of 25 out of 26 participants. Further, this sub-theme emerged from the analysis of Scenario B presented in the Methodology chapter which aimed to explore user reaction/behaviour in response to data variation provided by the device to the user, the extent to which the user might trust that data, and the first action that would be taken in this event; for example, if an increase in blood pressure was observed over a couple of days, even if the user did not experience any discomfort. For this specific sub-theme, there is an anecdotal difference between Brazilian and British participants, and it is unclear if nationality has an impact or if indeed factors such as age, socio-economical background, underlying health conditions and other confounding factors could be impacting this potential difference.

It was observed that in the event of the device indicating that something needs attention, Brazilian participants' responses would be to check the data with a specialist by booking an appointment with a physician. This was observed in the responses of 10 out of the 13 Brazilian participants, as shown below:

> *If there is a change? I would look for a doctor. Book an appointment. Yeah, to clear up any doubt. (BR04, B)*

> *Seek medical help. Seek medical help, because perhaps one time, it shows you have high blood pressure, if the device is wrong, the doctor will tell you. If it's right, the doctor will tell me that too. And [the device] being right, generates action, and being wrong is a relief. That is the point. (BR05, B)*

In contrast, for British participants faced with the same situation, their first reaction would be either to allow some time for observation (5 of 13 British participants) or to reflect on what they might have done differently to cause a variation and to try to resolve it themselves (4 of 13 British participants). Then, if the variation persisted and they considered it important enough, they would book an appointment with a doctor:

> *I would let, I would let time pass first and keep a mental note of the information. I would let a few days pass, okay, because A, the doctor is a very busy person so, what's the expression? It's like applying, going straight to the doctor each time, it's like using a high-power drill to drill a small hole. You know, you only use it, go to the big man when you have serious concerns that something is wrong. (UK18, B)*

> *My immediate reaction would be to be slightly alarmed, I suppose, and then I would stop, and I think I would stop and think carefully through what I'd been doing, what might have caused this difference. Then, I'd be very hesitant about going to the doctor, unless it specifically said, you know, if it shows something, a dramatic change, so I certainly wouldn't rush, I don't think I'd rush to the doctor. (UK21, B)*

From the demographic data presented in Table 1 it can be seen that participants' existing health concerns were noted. In total nine participants mentioned a concern regarding some aspect of their health (6 Brazilian participants: BR04, BR05, BR06, BR08, BR10, BR14 and 3 British participants: UK24, UK27 and UK29).

One factor that could justify the difference could be whether the participant has private or public health insurance. Data from a survey in Brazil in 2018 (1) shows that among classes A and B, the percentage of people with private health insurance is 55 per cent, while for classes C, D and E 23 per cent have private health insurance. In contrast, in 2015, an estimated 10.5 per cent of the U.K. population had private voluntary health insurance (2). Even though this source does not specify by class, it is noted that even in those classes with less private health insurance in Brazil, the percentage is still double that of the UK (23 and 10.5 per cent, respectively). In this situation, the reaction to book an appointment could be viewed differently considering the pressure that the user feels their own health care system is under, as illustrated in the quote below:

> *Do I want to rush up to my hard-pressed GP, and they are hard-pressed, and say, doctor, doctor, I'm wearing this machine and it's telling me that my systolic blood pressure is 20% more than it should be, or whatever? Do I want to do that? I would do it if it were enough, if there was a big enough variation from normal and it lasted for a bit, I would. But I wouldn't do it straight away because I don't want to be classed, either*

> *by myself or my doctor, as a pain in the neck, another phrase for you. A worry well, I don't want to be a... So, it's more complicated than a simple answer. It depends on you, your relationship to your GP, how much you believe what you're being told, whether you think it's serious or not etc. (UK27, B)*

Another related point of note which may play a role in the way a participant reacts, are differences in the health service. In Brazil, the way in which you book consultations works differently from the UK. Those with private insurance in Brazil can book an appointment directly with a specialist without the need to be referred by a General Practitioner (GP), as is the case in the UK. However, this difference between healthcare systems is only one factor. Other factors could influence the difference observed in the reaction between Brazilian and British participants, including socio-economic background and underlying health conditions among participants that were not examined in the study.

5.3.2 Agency

The subtheme Agency refers to the perceived (in-)ability to empower the user to take action in lieu of or in response to the device in this research and was observed in the responses of eleven participants. It was found that being in control was one factor that would facilitate acceptability of the sensors. Participant BR05 commented on the relationship between privacy concerns and being in control, and the perception that wearing the device suggests they do not have full control but they acknowledge that relinquishing access for one aspect might be acceptable:

> *So, it is like this, it's a simple question: why are you afraid to use technology? So that's the question, isn't it? We use technology and what technology can do for us, because it lets us always be the master of our situations as desired, however, this information can change accordingly.*

> *No, it's not an invasion of privacy. Because then, I see that this doesn't take total control of your life, it controls only a part of the normal, everyday activities you do. (BR05, B)*

However, a barrier to acceptance of the indoor sensor due to the perception of lack of agency, was observed in the response of participant BR09:

> *I don't know about that, no, because I think it's a control, isnt't it? It's a control. This business of being in control, I don't like being controlled. I like to stay as long as I can in one place and go somewhere else without having to stop like that and think, oh no, I have to stay another 20 minutes here. No. You often want to be home alone all day, it's great, isn't it? By your choice, right? As long as you don't have any health problems as a result, yeah? (BR09, C)*

A further concern was observed regarding lack of agency due the kind of details collected by the data:

> *But it doesn't have to be so detailed, otherwise you would be controlling the will of the elderly person too much, but you don't have to let it ... give them a watched freedom. (BR04, C)*

Participant BR15 commented that he would not be worried if the physician had access to the data due the agency he would have anyway:

> *In the case of ... People sometimes get comfortable, like me. I was a walker, right, who walks is a walker. Now I'm accommodated. So, I think that in this condition, the doctor can even speak, but I'll go if I want, right? You know? It is not because he is saying that I am going. I'm not in the mood, kind of walking now. "Ah, but you have to go", "yes,*

> *but whenever I feel like it, I will". That's how I feel now, don't I? When I feel like it, I'll go. (BR15, B)*

Further, participant UK19 raised concerns regarding a third party taking the decision to install the sensor:

> *The fact that it's installed by her daughter seems to be like making Claire [main persona] less of an autonomous, independent person. Do you know what I mean? (UK19, C)*

Thus, it was observed that concerns regarding Agency closely relate to the subtheme of Consent, discussed in the section on Trust-related aspects and reflected in the comment below:

> *For me it's about personal autonomy, okay? Now if the mother is very happy for her daughter to do it and it's been agreed and they've discussed it, fine. (UK19, C)*

Similarly, participant UK27 raised the concern regarding agency and consent unless the decision was made by a trusted person:

> *It depends on what one's going to do with the data, which we come to later on don't we? If I were, as I've known some people, 95 years old, I would be very glad probably, to have such sensors in case I fell down or got locked in the toilet, or whatever, or fell out of bed, I've done that anyway, at my age. It would be useful to have a sensor, but I would not want to give up that much privacy until I knew I needed these sensors, and that would be my decision, unless I was so ill, somebody who cared for me, like my children or my wife, had to take the decision for me. (UK27, C)*

Lack of agency concerned participant UK28 in that it would also be a barrier to data sharing with the doctor:

> *Personally, I wouldn't. I would just rather go the doctor and say that over the last few days there's been a bit of a problem. Sort it out; I don't particularly want you to be having to monitor me all of the time. If I'm capable of doing it myself, I'll do it myself. (UK28, B)*

It was observed that the sub-theme of Agency is influenced by other aspects such as consent, level of detail of the data collected and the person who will have access to the data. Further discussion of this sub-theme can be found in the section on Data Sharing.

5.3.3 Behaviour change

The sub-theme related to behaviour change refers to situations prompted in the scenarios that could promote or influence a behaviour change in the persona; these situations were used to explore participants' perception about this change, whether this change was seen as positive or negative and therefore facilitate or hinder acceptability of the sensors and data sharing as a consequence. This topic was observed in the comments of 16 of the 26 participants and was prompted on two different occasions during the interview. Firstly, in Scenario B, (for more information, see Section 4 on Trust-related aspects) regarding the consequences of data sharing with the physician in response to a call from the doctor to the main persona and how the doctor's orientation might influence behaviour change. Secondly, in Scenario C, that explores the consequences of behaviour changes observed by the daughter of the main persona - here the question asked was whether this change could be seen as a warning sign by the daughter and even justify the decision by her (as a third party) to install the indoor sensor. It was observed that the call from the doctor was seen by participants as a good resource used as a means of influencing a behaviour change, as reflected in the quotes below:

> *Yes, I'd like him [the doctor] to tell me off! I would walk, exercise, try ... to change it. (BR04, B)*

> *I think it would definitely be an advantage, you know. Definitely an advantage, the person being alerted to another situation that's occurring, that he's not aware of, yes? So, this monitoring allows that. Undoubtedly an advantage. (BR11, B)*

> *If I'm told something and I do what I'm told, yes, from the doctor's point of view. If the doctor tells me to do it, I do it. (UK29, B)*

> *I would change my behaviour if I thought it would make a difference, you know[...] I would prefer an alternative to, you know, another prescription. (UK17, B)*

However, regarding Scenario C and the change of behaviour that occurred with the main persona who is an active person, and for whom over the last weeks the sensor was registering a low level of activity, the participant's perception of whether this was a signal for concern or not varied, as can be seen in the quotes below:

> *Well, it could be many factors, couldn't it, I mean, she's 73, she's getting old, you know, just the outdoor factors could influence, the weather could be the influence, the dark days, it could be rainy or cold, she mightn't want to go out, so those kinds of things could be influencing her. (UK17, C)*

> *I think yes, we usually go through this type of change. It might not be because of a disease; you're no longer in the mood for ... sometimes it's*

> *something you're fed up of doing, for example, "Ah now I'm going to stop doing this for a bit", so you leave that alone for a while, it's not a disease. (BR15, C)*

> *Yeah. It seems to me that she was discouraged from maintaining the pace of life she had. But I think it's normal, at that age it's normal for this to happen. Don't let yourself get depressed, but it is normal to make these changes. (BR12, C)*

Participant BR16 pointed out that this change in behaviour could be important and as such it would be useful to report it to the doctor and to use the data collected by the sensor to support this:

> *I think it has changed; it is indicative of some problem she has. It relates even more to depression, which is more common nowadays. A person doesn't change just like that. Based on this ... with the changes she gave, she only installed it after she saw that her mother didn't want to leave. To be able, even if you go to take her to the doctor, she says: "Oh, she is like this and that... Her behaviour is like this and that. (BR16, C)*

A willingness to use the device was observed for the purpose of monitoring behaviour changes that could raise a well-being concern:

> *I think it's about the symptom, which allows you to monitor whether the person has had ... this change. I think this is a useful thing, yes. And having this information helps, in this case, it is a person, apparently, alone. (BR11, C).*

Based on the above comments, these seem to indicate that reporting an issue to a health professional based on the data collected by the device would more likely influence a behaviour change in participants than an observation of a family member regarding the low level of activity. However, another factor that could have an influence here is a health condition that was different in each scenario. Scenario B has a persona with chronic respiratory disease, whereas in Scenario C, the main persona has episodes of depression; therefore, the perception of the ups and downs that depression can bring could influence the participants' perception of the usefulness of the data collected due to the subjectivity this could bring.

5.3.4 Cultural knowledge

It was observed that seven interviewees commented on specifics about the way the sensor might work in relation to the culture they are accustomed to in the country in which they live. As a result, the sub-theme: 'Cultural Knowledge' emerged. One observation from the comments of two participants related to concerns about data sharing with the public health system, given that they do not see the government as a trustworthy institution:

> *Because of our government, for example, you see, it is a government that ... is capable of wanting to take advantage of the information by saying it has an initiative of ... Or, for example, you see, until now it hasn't ever issued equipment like this, so starting today if we have to use this equipment in such cases, it will cost so much for the people ... No, it will not cost anything, as in the end, we will pay. You can say "No, starting today, you will have the equipment". Then you will get a piece of equipment like this put it in all houses without asking ... So, with the government in Brazil, I don't think so ..., I think I wouldn't want to share it with the government. I think it should be linked more to family or to someone directly connected to that person where the equipment is. (BR08, C)*

> *Because you see, in Brazil [the information] is misused a lot too, isn't it? So, I'm going to share something ... here the character talks about the mother, and I'm going to reveal something about my own mother's life through a device that doesn't give me confidence that the data will be kept confidential or they'll be safe. A third person could take advantage and, suddenly, use this data to commit a crime inside my mother's house, couldn't they? (BR12, C)*

Second, is the suggestion that data sharing with an institution may lead to that information being used for commercial purposes in Brazil:

> *I think that always sending data ...talking about Brazil. I'm talking about Brazil. Certain types of information you shouldn't discuss openly, because it could be used for other types of ... for other purposes… for another purpose, other than to try to save your life or minimise any eventuality regarding the patient's health. What could that kind of information be used for? Such as ... "Man, you have diabetes, you have hypertension, I'm going to sell you some medicine ..." ...here in Brazil, you know how it works, don't you? (BR08, B)*

For participant UK26 use of the sensor does not seem such an advantage as he would prefer that people used an alarm device already available in the UK rather than the sensor presented:

> *I think if I had somebody close to me who was in a vulnerable situation, I would, most certainly want them to wear one of the alarm buttons, either on their wrist or around their neck. They work very well. I'm sure you're familiar with them. They work very well because if they're pressed even by error, somebody's there straightaway at the end of the phone and I've known where it's saved people's lives, somebody having a*

> *stroke got one recently and was able to press the button, somebody was there so quickly. So, I think if there's an emergency, then it's worth it but to monitor every minute, no. (UK26, C)*

As can be seen, the comments relating to this theme are concerned with the question about data sharing and in this case, willingness to share with an organisation, either public or private, that may not be trusted, or that may use the data for an inappropriate purpose; other familiar ways considered more efficient and less intrusive than the indoor sensor were preferred by participant UK26.

5.3.5 Experiences

During the interview, seventeen participants expressed situations that they had experienced relating to how technology use may or may not help, incidents that occurred to other people or that they had heard about, all of which were added to the sub-theme Experiences. It was observed that for five participants, these experiences contributed to acceptability of the device if they can see the usefulness. Participant BR04 expressed that the usefulness or purpose of use in the daughter having access to the data collected through the sensor was the ability to act immediately in the event of an emergency, and this was related to news that she had watched on TV:

> *Realising what's happened, the daughter already calls for help, she also goes personally to help, and if she stayed there, as happens in lots of cases, the person dies instantly or even gets sick and carries on for another two, three days without ... There was a 45-year-old woman , here in Paraná. A grandmother, a new grandmother, wasn't she? 45 years. She was with her seven-month-old granddaughter, while her daughter spent three days working as a maid in a house far away. The daughter rang again and again, the mother didn't answer, then she asked her relatives*

> *to go there to check on her, or she left her job and went to see her, and when she got there, she called the Fire Department to open the house, the woman was dead, and the child was miraculously safe, after three days without eating. The woman had been dead for three days. I mean, she had a health problem, a stroke or a pulmonary embolism, something like that, ... So, in such a case, technology could only help, couldn't it? (BR04, C)*

A similar experience that would facilitate acceptability of the device was a situation that happened with the mother of one participant UK23:

> *My mother collapsed a few years ago and was there overnight, on the floor, and we only found out by chance because my sister happened to go the next day and found her on the floor. Certainly, it would've been useful if the sensor had alerted us to the problem. The same thing could happen to me that happened to my mother, and if somebody were told that I was unconscious on the floor, it could be useful. (UK23, C)*

Another element observed here related to the question about whether the participant could see themselves getting used to wearing a device even when sleeping (Scenario A, see Appendix D). Participant BR08 mentioned that he had to wear a device for 24 hours to detect blood pressure level as a necessity; therefore, seeing the purpose of use would facilitate getting used to the wristband device:

> *That part is fine. So much so that, for example, the day I went for a medical examination, they asked me to keep this little thing for 24 hours, like a box on the side of my body, to work with it, sleep with it there so I could see the pressure thing, things like that, my sleep and everything, so I stayed. I stayed for those 24 hours because I knew it was a necessity.*

> *Likewise, this thing, I found this 'speedbit' interesting ... Fitbit, right? (BR08, A)*

Participant UK26 already had an experience of using a device that worked well in the past, and therefore did see the purpose of using the indoor sensor presented in this scenario:

> *I think if I had somebody close to me who was in a vulnerable situation, I would, most certainly would want them to wear one of the alarm buttons, either on their wrist or around their neck. They work very well. [...] I got one recently and was able to press the button, somebody was there so quickly. So, I think if there's an emergency, then it's worth it but to monitor every minute, no. (UK26, C)*

In sum, it was possible to observe that participants used their experience to justify using or refusing to use the sensor technology presented. It was noted that most found these technologies useful due to experienced situations in which technology could have helped them or other people. However, in contrast, if they had already experienced using different technology that seemed better (in this case due to being less invasive) as observed with 2 participants, this would be a barrier to seeing the usefulness of the sensor presented.

5.3.6 Health Conditions

The sub-theme Health Conditions relates to comments observed from participants where health conditions were exposed. It was observed that eight participants mentioned something related to a health condition during the interview. Half the participants referred to their own health in general and the other four participants related that acceptability of use of the sensor-based device would depend on whether there was a health condition that justifies its necessity, as can be seen in the quotes below. Participants BR09 and UK23 mentioned a health condition when asked about acceptability of a third person having access to the data collected by the indoor sensor in a hypothetical situation:

> *If it's a matter of being sick, some serious problem, yes, I think it's relevant. [. . .] only if I had a disease. Ah, it gets boring, doesn't it? It seems that the person is being monitored, watched. (BR09, C)*

> *You could say Claire [main persona] has, she's struggling with depression, so she does have a medical problem. Again, if you have a medical problem, information needs to be collected, which doesn't need to be collected if you're fit and healthy. I think I'm fit and healthy. (UK23, C)*

For participant BR11, acceptability of sharing the data with the doctor and receiving a doctor's call as a result of that data sharing, as discussed in the Data Sharing subtheme, was a concern. However, if there was an associated health condition, this participant felt it would be a good resource:

> *Look, at first, it scares you to know that you are being monitored at this level with someone reaching out and interfering, it seems that ... although there is an objective, it's like an invasion. It has got to get to the point where I am so afraid that, once again, I would choose it based on the level of health that I had, if I had a very strong commitment to an aspect of my health, which needed greater support or was a type of illness which needed monitoring, I think ... If it was something that would enable me to maintain a good level of health, then maybe it wouldn't even be necessary. But I think it's important for people who need more monitoring, for them, it would be a very good thing. (BR11, B)*

It was observed from the comments that the sensor-based devices were seen as more invasive, and that in the event of a health concern this would justify use or data sharing, and this relates significantly with seeing the purpose of using the device, which is presented in the next section.

5.3.7 Purpose of use

This sub-theme describes situations observed in the interview where participants raised comments regarding being able to see (or not) a purpose in them using the device, what the advantages were, and the usefulness or lack of purpose of use detected in the technologies presented. It was identified that this sub-theme is a prevalent factor in the acceptance of a sensor-based device as reflected in the comments of all twenty-six participants that took part in this study.

Key facilitators for seeing a beneficial purpose of use in the devices are shown in Table 5.3 below:

Table 5.3: Key facilitators of acceptability: reported beneficial purpose(s) of use. Column Total indicates the number of participants.

Factor	Description	Total
Age	The factor of being older was observed as being a facilitator of acceptance	5
Health condition	The factor of having a health condition that could be improved or monitored by the device would be a facilitator to acceptance	11
Lifesaver	The factor of seeing the possibility of the device in helping in an emergency would be a facilitator to acceptance	2

Table 5.3: Key facilitators of acceptability: reported beneficial purpose(s) of use. Column Total indicates the number of participants.

Factor	Description	Total
Person living alone	The factor of a person living alone would facilitate acceptance of the indoor sensor	8
Provides better information	The factor of bringing more precise information to the specialist or a third party would be a facilitator to acceptance	2
Remote or distance locations	The factor of being in a remote location or far from other people that care about you would facilitate acceptance of the indoor sensor	1
Self-awareness	The factor of bringing self-awareness to the user would facilitate acceptance of wearable devices	2

This section presents key findings as to facilitators for purpose of use supported by relevant participant extracts. As can be seen above, one aspect identified by 11 participants related to Health Condition, discussed in the next section.

For participant BR04, a health condition for a person who lives on their own would be a factor supporting purpose of use for the indoor sensor:

> *I think that in the case of Clarice, 73 years old with health problems and living alone, I would install it. With a younger healthy person - only if the person lives alone. I think it's useful that they have communication with someone. (BR04, C)*

As regards acceptability of the decision of a third party to install the sensor, age and living alone were mentioned as contributing factors:

> *With the purpose that the daughter gave, yes, because it could happen that she [main persona] gets sick, has a heart attack, has a health problem and is left without assistance. So, she's being monitored, like this, especially with her daughter working, even from a distance, that in this case, as she works, she cannot be there, so even from a distance, then, it's beneficial. It's useful. (BR04, C)*

Further, participants BR08 and BR10 mentioned that the age of the main user would be a contributing factor in seeing the purpose of use of the indoor sensor:

> *Look, I, if I were in a situation like this, a person alone like that, I would be glad to have it, you know? Especially if it were my parents, for example. Although they are 1,500km from here, I would like to have that kind of information, you know? Because with people that age, alone at home, the risk of an accident is high, the risk of you being sick, stumbling, falling, and getting hurt is greater. So, anything that can monitor movement, movement like that, I think is very feasible. (BR08, C)*

Participant UK22 saw the purpose of using the indoor sensor to monitor her mother due to distance:

> *I think it's really useful and I'm thinking about my own mother, who lived far away and so she had some carers in, but what happened in between, and I could only see her at the weekends, so this would have been really valuable for me, same as the daughter is in this situation. (UK22, C)*

Furthermore, participant UK24 saw the purpose of using the monitor with her mother who has dementia:

> *I changed my mind in that scenario. That is a good idea. Yes. Especially because someone can't be with her all the time [...] Yes. I think, under those circumstances it would be a good idea. Because in a different scenario, as my mum had dementia. And, of course, with a monitor like that, I would be able to know when she'd eaten, because she was adamant that she'd eaten when she hadn't eaten, and things like that. So, although I wouldn't want the knowledge to be widespread, it would help in as much as if someone's very depressed and they can't think straight, it's a similar scenario to someone who has dementia who actually thinks that they have eaten when they haven't eaten, you know? Because, sadly, the carer doesn't always go in on the day when they are supposed to, you know? And so that would've been easier, while my mum was living on her own, to be able to... I could perhaps have detected things a bit earlier, but who knows? You don't think your mum's going to have dementia, do you? But, yes, when I look back at it, that would've been a good idea for me, yes. (UK24, C)*

In contrast, participant UK30 raised a concern regarding the paradox of finding the indoor sensor intrusive and yet, finding it useful if she was in the position of the daughter as presented in the scenario:

> *Now I wouldn't want it, I'd see it as intrusive. If you, if I did have ill health and I acknowledged I'd got the ill health, then it would be one way of monitoring, I suppose, your activity levels and what you were doing, but I still would feel uncomfortable, I think. Knowing that something was monitoring what I'm doing. I'm sure it would be very helpful to monitor it, but if it was me as the subject, I don't know that I'd prefer. If I was the daughter, I'd probably find it very helpful, but if it was me being monitored, I don't think I'd like it. (UK30, C)*

Participants BR24 and BR14 further mentioned age and health conditions as factors supporting purpose of use of the indoor sensor and the necessity to act quickly in the case of a health issue, otherwise, using it would be seen as overreaction:

> *Only in extreme cases. The mother has passed that age, is already 73 years old and as such, she needs it, and at that age they could be having, for example, heart attacks, or a very serious problem with blood sugar suddenly rising, or another time blood pressure dropping, there is no control. I think that there should be something to monitor 24-7. What's more, if the mother lives alone all the time, as the daughter works far away, she can come later. So, I think it's fine. [BR24]*

> *You really need it, not for any specific reason, just because it's a little bit like that, staying there for a few hours, that's not necessary. We all have to have common sense. You have to know your limits, you shouldn't overreact too, should you? If I were that overanxious daughter who always wanted to know how everything is and was always thinking that if I didn't take her to the doctor that day, she would die. Yeah, I'd be being kind of paranoid (BR14, C)*

Participant BR10 showed willingness to have the indoor sensor for herself because of her age and that the device could potentially bring the feeling of being safer at home:

> *I thought it was a very good thing [the daughter's decision to install the indoor sensor]. Of course, monitoring and knowing what people are doing, I think that for this age it is already very important, isn't it? Because she could fall in the house, couldn't she? And then there's no help, no one, is there? So, if she is being monitored, then she herself might feel more confident that someone is monitoring what she's doing*

> *or what is happening inside her home. I think that when we get older and we live alone, we will feel a little insecure. So, with this sensor, you would feel safer, you would know that someone is watching what you're doing. (BR10, C)*

For participant BR09, having a health condition would be the only justification for installing an indoor sensor. Otherwise, they felt that other monitoring methods would work better than the sensor:

> *With a healthy person, say, a son, cousin, brother-in-law, whoever the relative is, I think there must be another way to communicate with the person at least once a day, "Hi, how are you? Okay?". It's done. You know it's okay, isn't it? At night the same thing, "Hi, good night. Good night. Good night", he didn't say good night, he disappeared, he disappeared there is nothing to worry about. (BR09, C)*

Participant BR05 similarly commented that having the opinion of a specialist would be advantageous to the user in the case of sharing data collected by the set of wearable devices with the doctor:

> *When we undergo this evaluation, [. . .] by a third party, naturally you'll adopt a better attitude towards yourself and better behaviour, for more peace of mind, wouldn't you? (BR05, B)*

Further, participant BR09 mentioned that this device could bring key supplemental information for the doctor during the appointment:

> *I think the equipment is good because we often forget some things that have been going on, don't we? I think so. The equipment is good for this. Some moments you feel something, you don't remember everything*

> *all the time, especially when you are talking to the doctor. And if there is equipment that can create a picture, that would be good, wouldn't it? (BR09, B)*

Related to the Fitbit, it was observed that the purpose of use was seen in the measurements that this device collected which would facilitate the user's acceptance and growing accustomed to the device:

> *It wouldn't bother me [to use even when asleep]. I would use it. Because I think it's good since it monitors so many things, blood pressure, how long you slept, I think this is wonderful, I do. (BR10, A)*

Participant BR13 commented that the possibility of increased self-awareness would be an advantage in using the Fitbit:

> *It would be interesting, for example, to walk for 40 minutes and know how many calories I lost, and get home, eat pasta and know how much I gained. In that sense, I think the device would be great. (BR13, A)*

Further, he added an example of how it would be useful for people to be aware of the movements that they make in their home that otherwise would not be feasible:

> *Because there was once a survey, which I read, which said that a woman doesn't go out for a walk, but that she sometimes walks 10km, 15km inside the house, going here and there, on the go ... Sweeping, going backwards and forwards etc. Covers 10km a day. Something that you'd never even imagine even if you had a ruler in your hand measuring it all, right? I walked 5m there, plus 10m here etc. And the Fitbit would record that automatically, that technology would be, like, wonderful. (BR13, A)*

The same participant further added that the device could help to prevent silent conditions and thus, the possibility of acting in advance:

> *My heart has to keep beating until the end of my life. And if the Fitbit picks up any problems with my heart, it will tell me to see a doctor. [...] The device could acknowledge that the heart is having a problem and beep, give an alert. And it goes, it consults and says: Look, your heart has a chance of having a myocardial infarction? Or, you have a problem with your head, from having a stroke. If there is, in the future, a device that by tracking your body, will alert you to this condition, wow, it would be wonderful. Because how many people die suddenly? And why? Because, the problem was already there, but no human picked this up. (BR13, A)*

When asked about getting used to using the device all day every day, participant BR16 commented that the use of the Fitbit for a long period would only be acceptable if necessary:

> *I think there must be a need. A need to use it, and then I would use it permanently, no problem, I'd get used to it. But would I use it permanently without having a need, I don't think so, for me I don't think there is much point... (BR16, A)*

And later, when Scenario C was presented, it was observed that this participant saw the purpose of use in this situation due to the main persona having a health condition that justified the need:

> *Yes, this is already a different scenario. He has a progressive disease, I mean, he has to use it ... Everything changes, if you need to use certain equipment, you will have to get used to it. [...] I would only use it if I had a problem, like Peter [main persona]. There has to be a need to use such a device. So, I would not like to use it. (BR16, C)*

Furthermore, this participant added that he could use it for some time to see the results and how the device would work:

> *Wouldn't keep it permanently. No, but I'm curious. I could use it for three days, a week to see how my body works ... Like, this equipment that records a lot of things here and monitors things. I could, and for that reason, I'm curious. (BR16, C)*

Regarding the self-report used to monitor well-being as presented in Scenario A, it was observed that some participants did not see a purpose in this, and therefore, some would not be willing to use the device:

> *This, for me, at the moment is more difficult, just because of what I was talking about before [would depend about his health condition], of being monitored, of following this daily. This idea of having your emotional and physical state being assessed, I don't know, this sort of information, I wouldn't have much interest in doing that, no. [...] Yeah, the idea of my day being excellent, my day being terrible, my day being reasonable, like, this thing about giving me this information, like that, I don't really like that, no. (BR11, A)*

It was observed that reported purpose of use of the device is a key factor affecting acceptability, as presented in Table 5.3 and evidenced in the participant statements. Therefore, this may extend to Perceived Usefulness (PU), which in this case would be a key factor for the acceptance of the indoor sensor about which more comments were noted and coded as Purpose of Use; this could be due to the sensor being seen as more intrusive than the other two wearable devices presented in Scenarios A and B.

The next section about mechanism preference presents participants' preferred way of completing the diary.

5.3.8 Mechanism preference

The sub-theme mechanism preference relates to the question to participants about a preferred way to complete the self-report presented in Scenario A. Options presented to participants included receiving a call similar to the one described by the main persona in the scenario, having an App on the smartphone or using a webpage. Table 5.4 presents the preferred method selected by participants:

Table 5.4: Participants' preferred method of completing self-report.

Mobile	11
Call	4
Webpage	7
Mobile App or Webpage	2
All options	1
Other (SMS)	1

Twenty-four responses were received to this question. As can be seen in Table 6, the preferred way of completing the self-report was through the use of a mobile App, chosen by ten participants. The reasons presented for this method were convenience and practicality that the App would bring, as reflected in the extracts below:

> *I'll do it through the phone, because you always have your phone with you and if you've got half an hour at work or on your way home in the evening, if you're not driving or something, you can sit and do it that way. Because it's instant, as opposed to going home and saying I really don't need to put my computer on today; why should I bother just for filling in one form? Smart phones now you can do most things on them if you understand how. (UK28, A)*

In addition, participant BR05 commented that the call could come at an inappropriate time:

> *I think so, on smartphones, because of the convenience, right? Because it can generate a phone call at that time and if you are busy with some-*

> *thing and can't answer, for example. With the mobile phone, it would be simpler ... (BR05, A)*

Participant BR14 related that the smartphone is easier than using the computer, but raised the concern regarding data should the smartphone be stolen.

> *I think that between the computer and the cell phone, on the cell phone better for me, because I have difficulty using a computer, so it'd be easier on the cell phone. Only I keep thinking about something else, if you put your data on your cell phone and it's stolen, whoever takes your cell phone, they can use some of your data in some malicious way? Huh? It has all your data too. So, it's something to think about. You have to see how feasible it is to wear it, or how far you have to have your notebook where you put it. You'd then see what the questions are and answer them on it. (BR14) (...)*

Participant UK18 expressed that the call option would be seen as invasive, and the best way would be through a webpage:

> *I don't like the thought of someone calling me. I don't like it. It's too invasive. It's too invasive. For a situation like this, I would go for desktop. Desktop. See, with a mobile, I like reserving the mobile for ... Calls or messages, or late at night for example, if I can't sleep I can watch YouTube, put some YouTube videos on it without having to switch on the desktop because it's inappropriate. (UK18, A)*

Although for participant UK22, if the call was seen as a personal tool, she would be more inclined to answer that:

> *The thing about somebody coming and questioning you would mean that you would make time to do it... The journal on the mobile, yes that's*

> *okay. And on the computer, so they're all fine but these two, nobody is going to be affected if I don't do it, but if I thought somebody was coming, then you... Or call you then because it becomes personal then I think the person would be more inclined to do it. (UK22, A)*

To sum up, the App followed by the webpage were the preferred methods of recording the self-report data, given their convenience and practicality. The call prompted the most contradictory responses with some participants seeing it as invasive and others finding it more personal.

5.3.9 Routines

The sub-theme Routines relates to comments raised during the interview about participants' habits and specifically about one question exploring acceptability of wearing a device 24 hours a day as presented in Scenario A; this asked if the participant believed they would get used to the device and whether they would use it when asleep. This sub-theme was observed in the comments of twenty-one participants and relates to Purpose of use. If the participant sees a purpose to using the device and added it to their routine, this would not be seen as a barrier as reflected in the comments of participant BR12:

> *I think it arouses interest in the device and how it works, and it's for our well-being, even for us to get to know ourselves better, isn't it? I think it would be easy to remember to use it every day. (BR12, A)*

Similarly, participant UK30 added the importance of the device being comfortable:

> *If I was interested, I would wear it. As long as it was comfortable. (UK30, A)*

Participant UK20, however, did not see the device becoming part of his routine as he did not see a purpose of use for himself:

> *If it was something like that, I'd wear it, put it on just as you put on a wristwatch. You wouldn't think about it, but I don't know that I would feel I would get a great deal of benefit from it, because I know how much I walk. I walk quite a lot and I know how much water I drink, I know what I eat, so I'm kind of conscious of those things without being reminded by them, yes. I don't feel I need [...] unless if I was having, if I felt I had a health issue that would benefit from this, then I wouldn't, no. (UK20, A)*

As regards nighttime wear, participant UK19 commented that use during the night would be a problem as this is normally when it would be charged:

> *The only thing about sleeping is I tend to charge it while I'm sleeping. So, if you're wearing it then I have to find a special time in the day to charge it. So, I just take it off, charge it, and then the next morning put it back on. That's why I don't wear it to sleep really. (UK19, A)*

One device feature that would facilitate getting used to it relates to the aesthetic aspect. If similar to wearing a watch to which participants BR10 and UK24 were already accustomed, using a device such as a Fitbit would not be seen as a problem:

> *I would use it, no problem, you know. I would get up, put it on, go on my walk and that's it. Because I'm used to wearing a watch, I'm always controlling my time. (BR10, A)*

> *I think, yes, it's just like wearing a wristwatch, really, isn't it? [...] I would wear it when I was sleeping, because that information would be*

> *quite interesting because, like, maybe... I do have restless nights, and it would be interesting to see how many times you toss and turn in the night. Because, sometimes, you can wake up in the morning and you feel worse than when you went to bed, with all the tossing and turning. (UK24, A)*

However, for participant UK28, using the device at home would not be seen as necessary, therefore it would be used outside only:

> *My difficulty would be wearing it in the evening and overnight, because as soon as I get home, I take my watch off as a force of habit. I don't need it in the house, so I don't wear it in the house; I wear it when I go out. (UK28, A)*

Similarly for participant BR14, he would not use it indoors, as with his use of a watch, adding that he would like to wear it from time to time and not for long periods:

> *Look, let's say I replace it with a watch. I always wear a watch. I just don't use it all the time at home because I have a wall clock that I keep checking, but I never go out without it, even if the computer shows the time, I like the watch, you know. So, I think that if I start using it, I get used to it, that I go from there, I have control of it, I get into using it that way. But I also think it doesn't have to be permanent. I'd use it for a long time, see how I get on, then take it off for a while too, then go back to it. So intermittently. (BR14, A)*

5.3.10 Technology attitudes

The previous sub-theme Routines revealed comments during the interview about participants' attitudes towards new (digital) technologies. This sub-theme emerged mostly due to one specific question that explored how the participant saw themselves with regard new technologies use, namely, were they excited or conservative when it comes to new technologies. Scenario A, question A (Appendix D and presented below) asked: How would you respond to a new technology device? Do you consider yourself excited to test out new technologies? This sub-theme was observed in the comments of twenty participants and is related to the sub-theme Purpose of Use. Five participants said that they consider themselves more cautious/ conservative when it comes to trying new technologies. For participant BR08, the cost of new technologies is a factor that affects them being more conservative:

> *In terms of technology like that, I'm a little conservative, you know. I'm a little conservative. So, in the beginning ... Even for financial reasons. Everything's about technology, that each passing day is being ... it's being launched, it's being perfected here, so even for financial reasons, I look at this and I think it's cool. I know something about it, but I wasn't committed to purchasing it myself because of the cost. That's why I say that I'm a little conservative. (BR08, A)*

Resistance to change was further highlighted by participant BR10:

> *We are always resistant to new changes, aren't we? So, we just [accept] with great insistence, otherwise, we are resistant to new things. (BR10, A)*

As regards difficulty in using new technologies, it was identified as a factor that influenced being more conservative for participant BR14:

> *Well, to tell you the truth, I'm more conservative. Because even with a computer, I have no interest in learning. I took a course, but then, since I didn't have a computer, I didn't apply it as soon as I'd learnt it. I got the certificate but I didn't use it. I lost all that. And since then, I have not recovered that knowledge. (BR14, A)*

A further seven participants commented that they see themselves as neither conservative nor excited. Lack of digital literacy would be a barrier to enjoying new technologies, as reflected in the comments of participants UK30 and BR09:

> *In general, I like technology to do what it's supposed to do. A lot of the time I would be scared that I don't really know what it's doing, and as long as it does what I want it to do and it works and does what I need it do to, it's great. But as soon as it crashes or it goes wrong, and I just think, oh I don't know what's wrong with it. So as long as it works. (UK30, A)*

> *These new technologies usually leave me a little like this ... as you say, like this, hesitant, right? It is not that I'm conservative; I like it. But I have some difficulty in understanding it properly, so the explanation has to be very detailed so that I can understand how it works, and can do things without being afraid of, say, using the device incorrectly, right? Handling the device. I am afraid of handling it. (BR09, A)*

In addition, participant BR13 commented on the lack of digital literacy, though sees that the technology is helpful and has a clear purpose of use:

> *Look, when the computer arrived ... Today I am semi-computer-literate; I am not good. I know a little. But I felt it was necessary for me to keep up to-date because otherwise I would fall behind and be ignorant. So, I*

> *bought a computer, it beat me, even to this day its beaten me ... But I think technology is something that is here to stay and to help humanity. Because everyone ... the overview you use, from supermarket bar codes, from the travel agents selling airline tickets, technology supports us everywhere. (BR13, A)*

Lack of face-to-face connection was seen as a barrier to use of new technologies for participant BR15:

> *When it comes to this I am more like Ana [main persona], kind of reluctant to consider it. Because there is not much privacy in dealing with this business. It's just like a mobile phone nowadays...isn't it? Mine is there to answer calls and send a message because there is this Facebook thing today, I don't have any of that. Because I can't communicate like that, you know. I'd rather not be talking when I'm not with the person. If I'm supposed to talk to someone without actually seeing them, I don't know. I don't know what I'd say in that situation. (BR15, A)*

Four participants mentioned that they find themselves excited about using new technologies, though a lack of digital literacy was observed as an issue of concern for UK28 due to the complexity some technologies present:

> *I get slightly excited, but technology sometimes gets way above me. Because I don't use a lot of technology. I don't think I do, but we all have the technology without realising it. It wouldn't deter me; it wouldn't put me off, as long as I can play with it to get an understanding of it. Some basic instructions. For example, I bought a new laptop at Christmas. No instructions; totally different to the laptop I had before. I'm still struggling to find my around some of it because it was such a big difference from the old one, I had to the new one and a different company, so the*

> *whole set up is different. And without some form of a manual in English or simple English, I would say, without using technical jargon, which I wouldn't understand, that wouldn't be a problem. If they just said press this button and this should show and press...not starting using abbreviations and things like that. That's one of my bugbears, when people use abbreviations because they know what they're talking about, but you haven't got a clue. So, I've no problem with trying new technology. I quite like to play with it. (UK28, A)*

In sum, as can be observed in the above comments that participants' opinions were divided, perceiving themselves as conservative, or excited or provided an alternative definition for their attitude towards technologies. However, one factor common among all these categorisations was the level of perceived complexity seen by participants in the use of new technologies, which contributed to their lack of digital literacy and represented a barrier to acceptance of the new technology.

The findings from this theme of user-related factors address the first research objective of identifying factors that affect acceptability in the use of pervasive technologies to monitor health and well-being; this is affected by the way that user´s respond to the data, concerns about not being in control of the technology, situations that the user´s have experienced in the past, health-related aspects and the others sub-themes that were categorised in this theme.

Based on these finding it is possible to identify the underlying concepts of perceived usefulness (PU) and perceived ease of use (PEOU) from TAM model of acceptance by Davis, mostly in the sub-theme of purpose of use. However, for the sub-theme related to experience, the HITAM model is a better fit considering that factors of HIT Reliability refers to reliability that can come from either direct or indirect experience with technology. The sub-theme health conditions/self- awareness is another factor that relates to factors of Health Status and Health Beliefs and Concern that are present in the HITAM model.

5.4 Theme Data-related factors

The main theme Data-related factors encapsulates ten sub-themes that are related to participants' opinions regarding the following topics and their definitions:

- Privacy: comprises comments about the desire to keep data private from others. This sub-theme also encompasses considerations on mechanism to control how the personal data is collected, and about measures to protect from unwarranted interference.
- Trust/Confidence: comments regarding the trust in or feelings or beliefs about reliability of the data collected through use of sensor based-devices.
- Security: concerns regarding the physical and digital integrity of the data.
- Boundaries for sharing: explores the facilitators and barriers that participants express regarding data collected by sensors to be shared with others.
- Intimacy: comments regarding feelings of being exposed or privacy invasion.
- Technology not warranted: expressions of caution regarding use or usefulness of the technology to monitor or assess the user.
- Warranting invasive tracking: circumstances that warrant certain monitoring despite its potentially invasive character.
- Consent: expressions of need for consent of the main user of the device, such as to collect or share data.
- Responsibility: responsibility of physicians regarding the data collected by the sensors shared with them.
- Data sharing: statements comprising facilitators and barriers to allow access to the data collected by sensor by third parties (family members, physician, the health care system and places visited) in different contexts.

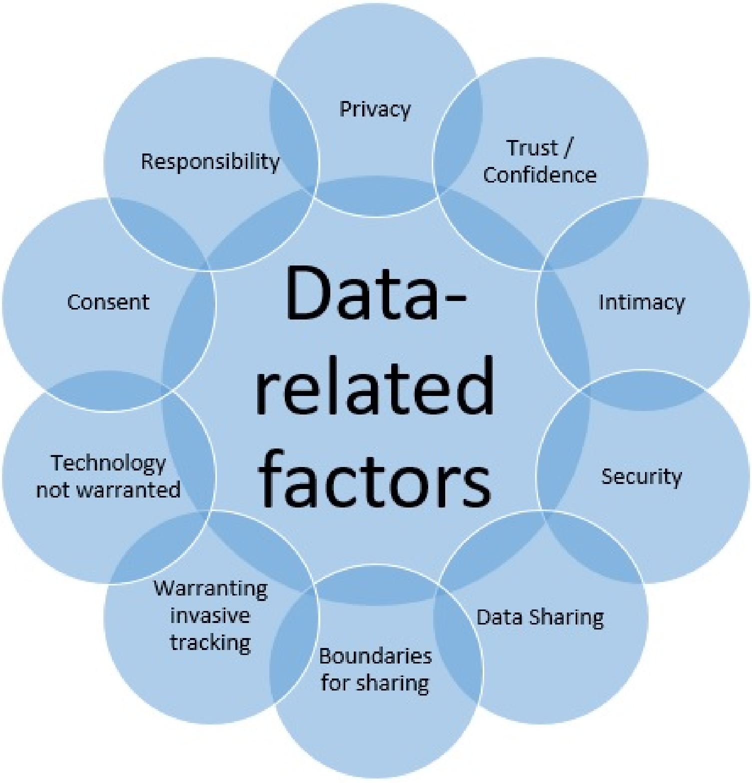


Figure 5.3: Conceptual map of themes identified in the data and related to the cluster: Data-related factors. Source: author.

Figure 5.3 illustrates the codes related to trust-related factors. The next sub-sections present these sub-themes in detail.

5.4.1 Privacy

The primary sub-theme Privacy in this cluster relates to the desire to keep data private from others, comprising statements regarding the mechanisms for control-

Theme	Primary sub-theme	Secondary sub-theme
Data-related factors	Privacy	Agency (n=5) Anonymity (n=1) Context and place matters (n=6) Discretion of device (n=1) Health conditions (n=3) Overall value security (n=1) Traceability (n=3)

Table 5.5: Secondary sub-themes related to privacy. N = number of participants who made related statements.

ling how your personal data is collected, and measures to protect ourselves from unwarranted interference. This sub-theme comprises eight secondary sub-themes of factors that would affect acceptability of use of the technologies presented that can be seen in Table 5.5 below, as described in the following sections.

It was observed that the device that predominantly raises concerns regarding privacy was the Indoor Sensor, followed by the set of wearable devices. First, one factor noted as facilitating acceptability relates to its potential impact on human agency (e.g., User-Related Agency theme), such as whether the user is able to choose if and when to use such a device that collects this kind of personal data. This can be observed in participant UK27's comment:

> *It would be useful to have a sensor, but I would not want to give up that much privacy until I knew I needed these sensors, and that would be my decision unless I was so ill, somebody who cares for me, like my children or my wife, had to take the decision for me. (UK27, C).*

Further, one participant stated that if the data collected was anonymous, this would for them facilitate accepting data sharing:

> *I think in this particular scenario where she has had the sensor in the house and it has been monitoring her, and then if it's going to be of any value, yes, share the information, if it's anonymous, okay. (UK26, C)*

Another factor noted was the context of the data being collected or shared, and the place where this occurred. For example, the data being shared with the airport collected during the time when the persona was in the airport toilet was seen as intrusive as can been observed in the quote below:

> *No, it's intrusive, completely intrusive, because he's in a public place and unless he signs to say he wants his data being accessed everywhere, then*

> *why should anybody else need to know about it? I can see the benefits in that if maybe he wasn't feeling well, and maybe something bad could have happened in which case he would be grateful, but at the same time his personal details and his health condition is his own business and his doctors. It doesn't belong to the airport or anybody outside that unless he gives express permission. (UK20, B)*

Further, with regards to context, prior decisions such as whether the user had agreed for the data to be collected and shared affects acceptability, as participants UK23 and UK28 commented:

> *And if she doesn't want her daughter to know, it's a little bit sneaky for her daughter to put these sensors in to spy on her. It's like putting a camera in the room without telling somebody and spying on what they're doing. You shouldn't do that. (UK23, C)*

> *I'd say possibly a bit invasive unless he knows the situation. As it says there, Peter has been working very hard, so he hasn't got time for the extra physical activities. If the doctor is not aware of that and he thinks he's just getting lazy and that's going to increase, maybe a phone call, at most, like he did, but ask the right questions first before you make the assumptions. (UK28, B)*

However, it was observed that for some participants who raised concerns about privacy, if they could see an overall value to the data collected, then this would influence its acceptability:

> *My immediate reaction was a bit negative but then I can see the point of it. You know, it could be actually quite helpful to Claire to know that that is actually what she's doing. (UK21, C)*

Again, for UK30, agency, such as being able to decide on a case-by-case basis, would be essential as observed in the comments regarding sharing data with the airport:

> *To me it's a bit like telling everybody on Facebook what you had for dinner, you know, the world does not need to know. But there might be situations where it would be helpful to have that kind of back up, but I would want to decide where that was and it would only be situations where I thought, actually that is a bit risky. So maybe I would want that safety net. (UK30, B)*

Participant UK28, and two further participants voiced concerns regarding traceability of the data, and who would be able to access it:

> *Who is going to monitor and who is going to see it? It's the, like I said, Big Brother feeling. Who is going to be allowed to see this? If it's just her daughter, then her daughter talks to her and reports it to an authority, that's fine because it's just kept within the family. But if it's going into an institute or something with hundreds of others and people are analysing and lots of people are seeing this data, although it might be anonymous, eventually they're going to find out and to me it's a bit intrusive. (UK28, C)*

Concerns regarding privacy and security were also observed in the comments of participant UK18:

> *So instead of having money, people have some kind of chip in their arm or whatever, like you are mentioning, and they will know exactly what the status of, what that political status of the individual is. It may not be a medical status; it could be a political status. (UK18, B)*

Discretion

As discussed earlier in the section on Wearability (see Section 5.2.1), the discreetness of the device would have an impact on the decision whether or not to use it. Concerns were raised about the set of wearable devices regarding how discrete it would be as this might bring about awkward situations, where normally the user could keep their decision and the wearing of the device itself private.

> *I'm always discreet. I get it, I look at it, and I keep it to myself, because it's my problem, and also if I am ill or not. I don't ask questions. Now on this subject, I don't know, I feel kind of, like, it's an invasion (BR15)*

Participant UK20 raised the same concern in response to the description of the device, especially for health conditions:

> *You would worry about it being visible, whereas the wrist band is something you can cover up and people's health you tend to want to keep private, you don't want people to know that you're being monitored or what have you. (UK20, B)*

Participant UK21 further illustrated the pros and cons of the indoor sensor as a visible, indiscreet surveillance device, which would lead to him not accepting it; however, he saw that the data collected could raise self-awareness, therefore might help in the case of facing a health problem, such as depression:

> *My immediate reaction was one of surprise that there was such technology available and might be used and it felt a bit like big brother is watching you and felt intrusive. So, my immediate reaction was a bit negative and then, but I can see the point of it. You know, it could be actually quite helpful to Claire to know that that is actually what she's doing, she's*

> *living a depressed life and if it's pointed out . . . these are the facts about it, she might actually go and alter her lifestyle a bit, get some exercise and get out, yes, so a very negative response to start with and then well... yes... (UK21, C)*

Similarly, participant UK21 seemed annoyed by the data collected through the indoor sensor and felt the device to be invasive.

> *I'm not sure I would like people to know exactly how long I've spent in bed and how long I've spent sitting doing nothing or whatever, I think that was what it was. [...] You can see that that would be important, but it's an invasion of privacy in a sense, isn't it? (UK21, C)*

A similar attitude was observed with participant UK26 who described being tracked by the indoor sensor as disturbing, for which one solution might be data anonymisation:

> *I wouldn't like every moment to be monitored in my life that is then shared with others who are, her daughter who does know her but others who don't. Every movement. . . Big Brother is watching you. I still wouldn't be comfortable with it. It's too intrusive [...] if it's anonymous, okay. (UK26, C)*

Overall Value

In the case of the set of wearable devices, although participants perceived it as intrusive, one participant UK21 saw an overall value for the device, as a result of which, they would be willing to share the data with the airport due to potential benefits in that situation:

> *Yes, I suppose it's all right, but it's a bit intrusive but on the other hand, if he did have a nasty turn and it enabled somebody to come and help you, whatever the situation was then fair enough. Perhaps having to explain yourself to somebody would perhaps be a bit annoying, especially if they were intrusive or pressing, and you didn't really want to be pressed but on the whole, yes, that would be okay, yes. (UK21, B)*

5.4.2 Trust/Confidence

Another sub-theme identified during the interviews and observed in the comments of 24 participants was Trust/Confidence. Trust/Confidence in this research refers to comments regarding trust or the feeling of or belief in the reliability of the data collected through sensor based devices. One of the main questions used to explore this situation was with regards to participants seeing data in the report that was in contrast with what they were feeling. One example situation was when the report showed high blood pressure and the user was feeling very well; However, other example situations were given.

In general, it was found that confidence in the device would be impacted by the following factors:

Alignment with user expectations

Three participants raised comments regarding the report shown by the device presenting unexpected data, as one example below shows:

> *I will probably trust the data if it confirms what I know. So, if I know I've been in a stressful meeting and then I'd think, yes, you're probably right machine because I've had a stressful time and yes, I'm not surprised it's up. Well done, machine. You know what I know. If it was showing it*

> *was up and I couldn't think of any reason why it was up, I wouldn't do anything immediately I don't think. (UK30, B)*

It is possible to detect that alignment between user expectations and data could be a facilitator of trust in the data that is being displayed to the user.

Growing with time

Three participants commented on confidence in the device dependent upon length of time used:

> *If I've been using it for a while and I've adapted to it, and I see that the results are good, and then suddenly, something negative appears, then it would not be the device, it would be me. (BR10, B)*

Calibration

Another factor to emerge regarding the device being checked or calibrated in case of any discrepancy with how the user was feeling, would be a factor impacting on user confidence in the device; this was raised by 5 participants, as one example suggests:

> *Well, I could, perhaps, doubt it because I'm feeling well when it's showing something, which can sometimes be some 'deregulation', or similar, couldn't it? So, it'd be interesting to check the device, if it was working, how it could be fixed, or if I was the problem? (BR14, B)*

Further, one participant mentioned that it might be checked using other equipment:

> *Well, I would have to have it measured by a different technology to know if it was correct or not. (UK2, B)*

Similarly, participant BR12 mentioned that the data could be compared with other types of tests to see if the device was precise or calibrated:

> *The equipment gave me a measurement of what was happening to my organism. And I did a blood test, there, for example, in the lab, it would also give me other results, wouldn't it? It's matching, it's not matching ... (BR12, B)*

Checked by specialist

Another factor observed in the comments of 5 participants which would build confidence in the device was if the report could be checked by a specialist in case the data presented any variations:

> *Seek medical help, because in a specific situation, say I have high blood pressure, if the device is wrong, the doctor will tell me. If it's right, he'll tell me that too. (BR05, B)*

> *Oh, yes, I trust it: if it tells me something, then I must say it's right, so I'd make an appointment and see my doctor. (UK29, B)*

Being recommended by a trusted person

Three participants suggested that confidence in the equipment would be connected to whoever had recommended the device, as illustrated by participant UK22's comment:

> *How would I feel? Yes, that's the big thing, it would have to be by somebody that you totally trusted, so if it was your son or daughter, then I would totally trust. I've got children and I would totally trust that it*

> *was for my best interest, and as long as I gave consent, then I would be happy for that, but I would not probably be as comfortable if it was a social worker, or somebody like this because I might think that they make a decision that I'm not happy with about my ability to live independently. And there's a bit of a fear as well nowadays, for people of my age that younger people will make assumptions about how we can cope and make decisions that we don't want. (UK22, B)*

Based on experience

It was observed in some statements that confidence in the device would be impacted by users' previous experiences with technologies:

> *I think the more familiar people are that these are quite normal things to have, then they won't be fearful of them, but people are fearful of the unknown. (UK22, B)*

Limitations of the device

Six participants noted limitations as a factor that could affect their confidence in the device:

> *There can be variations and I'm not sure. I'll make an appointment with the doctor, but I have suspicions. Because the equipment is reliable. Because it changes, it is very sensitive, to any other magnetic field, whatever form, it changes. (BR16, B)*

> *Because of course, machines, technology can be faulty. But initially, if it's been working correctly, I would suppose that it was still working correctly. But then it becomes a balancing act, you know, is there something*

> *that needs investigating or is it the machine? Do I need to investigate myself or the machine? (UK26, B)*

Reputation

One participant BR07 related that the device's reputation would be a factor impacting on confidence in the device:

> *For example, I would book (an appointment), because if I already have this device, before I buy it, in this case, I would have done some research, if there is any type of complaint. if the device is well received, if it has already come with some issues ... So, before I buy this device Ill go through this process, I'd do some research, so I would be more or less sure of what it would be giving me, you know? (BR07, B)*

Unconditional confidence

It was observed in 6 participants comments that they would have unconditional confidence in the data presented by the device:

> *Yes [I would trust the data report], otherwise there's no point in wearing the device, I don't think. You're not going to trust, it's like having a satnav and it tells you where to go and you think, no I'm not going that way, I'm going another way. (UK22, B)*

> *I'd trust the data, yes. That's telling you, isn't it – it's telling you there is something either going wrong or is likely to go wrong. (UK29, B)*

5.4.3 Security

The theme Security refers to concerns regarding physical and digital integrity raised by three participants as illustrated in the four quotes below.

Organisation Reliability

Participant BR12 was concerned that the data collected through the indoor sensor could be used to practice crime, and questioned reliability of the organisation that would be sharing this data:

> *I'm going to expose my mother's life to an instrument that doesn't give me assurance that the data will be confidential, am I? It's got to be safe. A third person can take advantage and suddenly use this data to perpetrate a crime in my mother's home, couldn't they? (BR12, C) (...)*

The fact that the indoor sensor provides data that relates to a person's routine inside their home environment raised concerns regarding security:

> *A person sleeps at a certain time, and watches television at a certain time, what the person does in every moment, leaves the house, does not leave the house? Hence there's the question of security, I think, not only the personal health of the individual. (BR12, C)*

Further, the indoor sensor was likened to a similar device which has already been used to detect abuse by caregivers in care homes:

> *they install in nursing homes and that sort of thing to see what is going on, but it's not to see how the patients are behaving, it's to see how the caregivers are treating them, you know, it's not with that in mind, really, sadly. (UK17. C) (...)*

For participant UK18 information about the position or location is something that threatens security:

> *But my concern, serious concern is location information that the computer and... by which I mean the persons who are in control of the information that the computer is gathering can use that location information of various people to their detriment if they are evil people. (UK18, B)*

5.4.4 Boundaries for sharing

This sub-theme explores expressions of facilitators and barriers to data sharing, identified by 10 participants and illustrated in 19 quotes presented in this section. These quotes identify 5 factors that impact willingness to share data, namely, anonymity, personal data, remote circumstances, perceived benefit and setting options.

Anonymity

Two participants raised concerns related to anonymity of the data as a factor impacting on their willingness to share the data. Both participants mentioned this concern in the scenario regarding the indoor sensor device and sharing the data with the healthcare system. For participant BR07 sharing the data was seen as useful for a behavioural analysis so he would be willing to share this information provided it was anonymous:

> *Collect the data, so input if she stays three hours in the room, don't type identity..., the person knows who the person is, but say: "The person of 73 years usually her behaviour..." which will give a behavioural analysis. (BR07, C)*

In addition, identification of the person would be seen as a privacy breach:

> *As long as she isn't identified, "Oh, you need to know?"; "Oh, the mother of that person ...",do you know what I mean? (BR07, C)*

Furthermore, sharing data with the healthcare system was seen as potentially improving care and therefore a willingness to share existed in these circumstances:

> *If it were totally anonymous, then it could be shared to build up information then that could help other people. But it would have to be totally anonymous. I wouldn't want my information going, just being on general display, even though they say it's restricted. Once it gets online, anybody can hack into it. There's that opportunity. But if it's anonymously done, then that's...it's just a case number, no names because then that would be fine as long as that were... (UK28, C)*

Personal Data

Another factor observed as impacting acceptability and willingness to share was the type of data, namely, personal data; thus, restrictions might need to be put in place. Participant UK18 highlighted his concern specifically about location data:

> *If I decide they need to know my location in order to fetch me, that's different, obviously. What is of concern is this automatic location information". (UK18, B)*

Further, participant UK28 commented on the sensitive nature of information regarding health conditions that are both personal and private, access to which he felt others should not have:

> *...if they're [his parents] suffering from depression they're not going to want the whole world to know. They're not the one you can discuss it with." (UK28, C)*

Participant UK17, whilst seeing a purpose in sharing the data for health reasons, suggested such data was so personal that it would be invasive if it included too much detail, such as on which places were visited as shown in the scenario about sharing data with the airport:

> *...too invasive. It's a bit too invasive even though, you know, he could've been dead in the toilet, but it's a bit too invasive for me (UK17, B)*

A similar restriction was found in participant UK26's comment that the kind of data shared with the airport was too personal to be shared with that organisation:

> *If somebody notices that you don't look well and says, are you alright? That's kind. If somebody is intervening because they've received information about you that is very personal, I think I would resent that too. I wouldn't want anybody else to be receiving that information. (UK26, B)*

Remote Circumstances

A further factor noted regarding justifying data sharing with places visited, was the remoteness of the location, as commented upon by three participants. Participant BR14 supported data sharing from a remote place as useful:

> *Yes, when you are in a place, for example, where there is no one around. It sometimes happens that you're passing by a street or go into a place where there is, in a little part of the shopping mall where there's almost no movement, some stores sometimes don't have much custom, you're passing, and suddenly you feel bad, nobody sees you, I think that's the case, right? (BR14, B)*

However, for participant UK18, even when in a remote place, he did not see the purpose of sharing location data with places visited as other options would work better without the need for such data sharing:

> *That is not, that's not a problem because wherever I was if I knew that something was seriously wrong and I was about to collapse, all I would have to do is dial 999. Problem solved. There is no need for anybody to know my location automatically. (UK18, B)*

Participant UK24 felt that remoteness of location was not the issue, rather the action taken following the data sharing with the location, that was more invasive:

> *But it's ... Anybody could walk in then, couldn't they? You know, so, I think it's difficult. I think it's good if it saves someone's life, but if it embarrasses you and there's nothing wrong, and ... But I think then you've got to make that mind up. (UK24, B)*

Perceived benefit

It was observed that some participants perceived a benefit of sharing data in certain circumstances; however, it can be difficult to judge whether the benefits outweigh the concerns about data sharing, as participant UK23 suggested regarding assessing whether a person needs help:

> *Well, what is 'some time'? If he's there for two or three hours, then it's good that somebody has come to see that he's okay. If he's there for half an hour, perhaps he's waiting to be sick or something. You don't want somebody banging on the door if you're waiting to be sick. But if you're there for two or three hours, it's quite good given that he has a medical problem, that somebody is taking some trouble to see if he's all right. (UK23, B)*

Regarding sharing data with places visited, participant UK28 further mentioned seeing no benefit, rather that this should be more for personal control:

> *... in the situation that there are a lot of people with these devices on, it's not going to be just one person, is it? How are they going to monitor that? What are they going to use the information for? I don't believe that it should be for general use. If it's just for Peter for monitoring himself, like I would on mine, and being able to put it on my laptop and compare it with graphs and everything, that would be fine. (UK28, B)*

Being able to trace with whom the data would be shared was a useful option voiced by participant UK20:

> *I would want to know what they would do with it, what are their plans to do with the data, what are they looking for, and if it looks like something that would be beneficial to my mother or father, then I would ask my mother or father whether they were happy to share it, because it is data protection, it's a form of data protection, so yes. (UK20, B)*

Setting options (sharing specific data)

Two participants raised the question regarding sharing certain types of data. Participant UK18 would not want location information to be shared, but was willing to share other data collected with his physician:

> *As I say, Elaine, my only concern is location. That is the only unacceptable piece of information that I would be completely uneasy about. [...] And indeed, you don't really need location information from the medical point of view. (UK18, B)*

Similarly, participant UK19 pointed out that sharing specific data with the physician would be acceptable:

> *if I'd had a particular problem and knew that, and I gave information to the doctor about that problem and he phoned about something else like... activity level, I mean, people do have lazy days. Do you know what I mean? And that fact that if I'd got a lazy day and the doctor phoned me and said, why haven't you walked? That would feel intrusive. (UK19, B) (...)*

5.4.5 Intimacy

Another sub-theme identified in the cluster of data-related factors is that of Intimacy. This sub-theme refers to situations in which participants would feel exposed or an invasion of privacy. These comments related in the main to the indoor sensor scenario. Participant BR08 raised concerns about how the device would measure activity and if in the form of a camera, would be rejected:

> *But I wouldn't like to have a camera, no. If I could have it without the camera, no problem. (BR08, C)*

Participant BR13 commented about the feeling of data being collected in private situations by the indoor sensor:

> *Look, there are some private moments which might not be of interest for example, constant use of this sensor could show, for example, how many times I have sex, or that I never have sex, and in that sense, it'd be becomes embarrassing. (BR13, C)*

Further, another barrier to using the set of wearable devices, was that there was some data the user would not like to be collected if it were to be shared:

> *I don't think I care about much else. They can... Oh, I do occasionally drink too much. At the moment I'm trying to be and succeeding in being really rather good at this. I like whisky, and given the chance, I will drink too much whisky. If we were measuring that I could be embarrassed. (UK27, C)*

Three participants viewed the situation of sharing data on locations visited as invasive, especially given this may be a private/personal space:

> *It's a bit too invasive even though, you know, he could've been dead in the toilet, but it's a bit too invasive for me. I would find it a bit invasive at this moment in time for me, I think, if I was in the toilet and suddenly somebody came, where are you...? (UK17, B)*

> *He obviously wanted a quiet ten minutes to himself, and you can't get that in an airport. Sometimes if you go into the toilet and you sit in the cubicle you haven't got people around you all of the time and you can just calm yourself down. To have somebody come..., banging on the door, you're going to get wound back up again. And the stress level will go through the roof. Even though they're showing their concern, personally I wouldn't have liked that. I would have been very upset with that because I'm trying to calm down because I'm stressed out. (UK28, B)*

> *I think again, this is a position where if he had received the information himself, he knows he doesn't feel so well, but nevertheless, he's waiting to see if he feels better. And as it transpires, he does feel better, just something brief. I think to have somebody else intervene and say, are you all, right? And you say, you know, I don't need this, I just, I'm sorting myself out. It's not, it's not just somebody noticing you, it's somebody receiving the information. If somebody notices that you don't look well*

> *and says, are you all, right? That's kind. If somebody is intervening because they've received information about you that is very personal, I think I would resent that too. (UK26, B)*

5.4.6 Technology not warranted

This sub-theme concerns participants' expressions of caution regarding the use or usefulness of technology to monitor or assess the user. This further relates to the sub-theme Purpose of Use in the Theme User-related factors and the Privacy sub-theme. Comments supporting this sub-theme were observed in the discussion of eleven participants, some of which are presented below.

Participants UK20 and BR09 commented on the importance of maintaining face-to-face contact as well as using data from the indoor sensor, being maintained by the daughter when monitoring the daily life of her mother in Scenario C:

> *So, it's very minimal information and would or shouldn't be relied upon and shouldn't replace people visits, for example, that would be my worry but at least she's moving around. I think it's a reasonable idea, it can't be replaced by going out and having people visiting, because then you can be sure about the person's health, but it does provide a little bit of information, and if there's nothing else then that's something. (UK20, C).*

> *I think talking is more practical, isn't it? Although conversations today are more difficult, they are more difficult, each person has a certain view of things. But if you have a certain affinity, you can see it. After all, they might be a daughter and a mother, or a son and a father, or a relative, right? (BR09, C).*

Furthermore, participants UK26 and UK28 commented on their fear about the lack of privacy that the indoor sensor would bring:

> *I wouldn't like every moment to be monitored in my life that is then shared with others who are, her daughter who does know her but others who don't. Every movement... Big Brother is watching you (UK26, C).*

> *I'm quite a private person. It's almost like, for me personally, a Big Brother scenario but I can see the benefits of it when somebody gets a little bit older and their health deteriorates a little bit physically and mentally, and without realising they are spending too much time at home alone. (UK28, C).*

Other comments related to this theme have already been explored in the Purpose of use theme, such as the benefits that justify the use of technology. In general, conditions that would facilitate acceptability of the device are if the device were used as one tool among others, not as the only source of information, if it did not replace face-to-face contact, and if there were mechanisms in place to protect people's privacy.

5.4.7 Warranting Invasive tracking

The sub-theme warranting invasive tracking emerged from comments related to participants' confirmation of circumstances where monitoring might be acceptable despite the feeling of invasiveness that the device might bring. This sub-theme relates to Purpose of Use in the theme User-related factors, considering that if the purpose of use is not clear, a stronger sense of invasion and rejection of the device may be more likely. Further, it is related to the sub-theme Data Sharing in this cluster. This sub-theme was observed in the comments of nine participants. The factor most observed regarding invasiveness was the feeling of being watched, as commented upon by seven participants.

For participant BR09, when questioned about acceptability of the indoor sensor and her opinion about a third person, in this case, the daughter having access to the data, was linked to the feeling of being watched:

> *Only if I had a illness. Ah, it gets annoying, doesn't it? It seems that the person is being monitored, watched. No, it's a weird thing. I don't know. I think ... It's like having a little camera over there, "No, you sat down. You got up. You smiled". Damn, that's weird! No, even if I had to use it here I know that it's has that level of control ... But this should be private. (BR09, C)*

Similarly, participant UK26 raised a concern connected to the invasive nature of the tracking and data sharing:

> *I wouldn't like every moment to be monitored in my life that is then shared with others who are, her daughter who does know her but others who don't. Every movement... Big Brother is watching you. (UK26, C)*

Despite seeing a purpose and usefulness in the data being shared with the daughter, this participant later added:

> *But I think it's too intrusive, too intrusive, really. Yes, even for, even for close relations, to know that. I would not be comfortable with it at all. (UK26, C)*

For participant UK21, whilst the purpose of tracking was evident, this still felt like an invasion:

> *My immediate reaction was one of surprise that there was such technology available and might be used and it felt a bit like big brother is watching you and felt intrusive. So, immediate reaction was a bit negative and then, but I can see the point of it. (UK21, C).*

It was observed that the context and location where the data is being collected also has an impact on the sense of invasion. For participant UK30, in a public place like an airport, there is no need for the wearable device:

> *I can see why in theory it's a good idea, but I could, I might be okay with it if I was going up a mountain, or if I was going in the back of beyond where there are no human beings who could monitor it. Because if actually then you did have an illness, or you were, had a dodgy heart or whatever it might be, you are putting yourself at risk and actually it's a bit of a lifeline to somebody who would then be able to respond. But in an airport, that's full of people, to me if feels like, well can't a human being monitor if I fall, collapse in a heap? Or if I'm looking hot and sweaty or... I just think in somewhere busy where there are people, again, it's too 'big brother's watching you'. (UK30, B)*

To sum up, it was observed in this sub-theme that factors that represent a barrier to acceptability of the sensor-based device were related to the sense of being watched. The feeling of invasion of privacy, the context in which the data is collected and who has access to the data would play a part in moderating this factor.

5.4.8 Consent

The sub-theme Consent was observed in participants' comments relating to the expression of need to obtain the consent of the main user of the device to have data collected or shared. This topic was mainly observed as a result of two questions in Scenario C, relating to the decision by the daughter to share the data with the healthcare system:

- In your opinion, should Andrea share her mother's data with the health care system? Could it be a good decision? Why?
- Do you think, Andrea, the daughter, has the right to decide to share the data? Could it be considered that the mother, Claire, is very vulnerable and might not be sufficiently familiar with the technology to make the decision about whether or not to share the data and the daughter may take the decision?

This sub-theme relates closely with Purpose of Use from the theme User-related factors considering that if the participant sees the purpose of use, this will facilitate giving consent to use the device. Further, actionability of data is connected with this sub-theme considering that it depends on what the user expects to get in exchange for data sharing. Consequently, the data sharing sub-theme also relates to this sub-theme. Comments regarding consent were made by twenty-two participants. Of these, eight mentioned that consent from the main user would be a pre-requisite for having the sensor installed and the data collected and shared; some of these comments are presented in this section.

> *For me, the important thing is that Claire agreed to it and that it wasn't just Andrea putting it in because she hasn't got time to visit, as she may be far away. (UK20, C)*

Participant UK23 commented on the need to have consent from the main user independent of who owns the house:

> *Only if her mother consented to it. I'm assuming it's her mother's house, so she definitely needs her mother's permission to install something in the*

> *house. And even if it's Andrea's house, she ought to have her mother's permission because the devices are specifically intended to spy on mother, which she should only do with her mother's consent. (UK23, C)*

The fact that the main persona could have a lack of capacity was raised in the comments of six participants.

Participant UK21 felt that agreement with the main user is a pre-requisite; however, he sees that there could be cases where people that are more in need would be rejecting the technology:

> *If she knows there's no question that it's okay, if she can sense it and agree, but then the person who actually doesn't agree is probably going to be the person who will benefit most from having it installed and you know, if it's sent through to the doctor and so on. (UK21, C)*

Participant BR08 commented that age would be a factor for another person to become responsible for an older adult and in this case this person would be able to take decisions such as in the scenario presented, to share the data with a family doctor:

> *I think so. I think so, why? Because the mother is already at an advanced age, many things, as much as the mother doesn't agree, I think that the daughter becomes responsible for her. I think that all of a sudden, from … Let's say, 65 years old, that is practically retirement age in Brazil, I think that the daughter, or the son, whoever it is, becomes responsible for the elderly, for the father and mother. So, I think you have a right. (BR08, C)*

On the other hand, two participants mentioned the lack of agency raised in the scenario as can be seen in the quote below and the fact that installation by the daughter whilst seemingly kind, makes the person less autonomous and independent.

Participant UK22 raised concern about assumptions that the younger generation could make the decision:

> *I've got children and I would totally trust that it was for my best interest, and as long as I gave consent, then I would be happy for that, but I would not probably be as comfortable if it was a social worker, or somebody like this because I might think that they make a decision that I'm not happy with about my ability to live independently. And there's a bit of a fear as well nowadays, for people of my age that younger people will make assumptions about how we can cope and make decisions that we don't want. (UK22, C)*

The need for consent was further observed in the comments relating to Scenario B in response to the question about participants' perception regarding the call that the doctor made to the main persona about his recent low level of activity (Scenario B, question H). However, for participant UK20, the consequences of giving agreement to access the data need to be made clear:

> *I think it should have been discussed when they had the consultation, it should have been discussed that when the doctor assesses the data and information, what happens next? Does he want to know, does he want feedback from the doctor if it's not life-threatening or something? (UK20, B)*

Similarly, in response to a question in Scenario B (see Appendix D) about data sharing with locations visited, participant UK20 stressed the need for consent to be made very clear by the locations collecting the data:

> *It's intrusive, completely intrusive because he's in a public place and unless he signs to say he wants his data being accessed everywhere, then why should anybody else need to know about it? I can see the benefits in that if maybe he wasn't feeling well, and maybe something bad could have happened in which case he would be grateful but at the same time his personal details and his health condition is his own business and his doctors. It doesn't belong to the airport or anybody outside that unless he gives express permission. (UK20, B)*

To sum up, it was observed in this sub-theme that consent would be a pre-requisite for acceptability, mainly for the devices that were reported as more intrusive, such as the indoor sensor or data sharing with the doctor and places visited in the case of the set of wearable devices. Lack of mental capacity is a topic that presented diverse opinions; middle-aged participants perceived age as a potential factor, whilst older participants raised concern regarding assumptions that could be made by younger people.

5.4.9 Responsibility

The sub-theme Responsibility emerged from observation of participants' comments regarding the responsibility of the physician as regards the data collected by the sensors. This topic was mainly observed as a result of questions in Scenario B regarding the possible benefits of allowing the data collected to be accessed by the physician, and the physician then getting in contact with the patient by phone as a result.

- Do you believe the data collected through the wearable device could provide the doctor with better information about the patient and treatment or would it be the same if the doctor called the patient and asked about how the patient felt?

- What is your opinion about the call? Do you think Peter has reason to feel under pressure due to the doctor's call?

This sub-theme relates closely with that of Health Conditions from the theme User-related factors in that having a health condition was one factor observed as contributing to acceptability. Further, this may directly influence seeing a purpose of use, therefore the sub-theme Purpose of Use is also closely related. Furthermore, the sub-theme Data Sharing from this cluster also relates, considering that this data would be shared with the physician.

This topic was observed in the comments of twenty-one of the twenty-six participants that took part in the study. The call from the doctor was regarded as an advantage by twelve participants, as indicated in the quotations below:

> *I think it shows that the doctor is really concerned about the patient, doesn't it? So, I think it's cool. (BR06, B)*

> *Ah, I would like that because the doctor is worried about me. Regardless of whether I'm a patient, he's worried about the person, right? Then I wouldn't be upset. (BR07, B)*

> *In my case, I would be extremely pleased to receive a call from the doctor to give me any information, or it there was a change in my blood pressure, or my heartbeat. Why? Because he, with the equipment there, he is monitoring me, he is seeing what is happening to me. (BR08, B)*

> *I thought it was very good. I really should do it. I think this is very important. Because then, there are people who only take action under pressure, so, he, in the way he called, he knows that the doctor is checking everything he is doing. It doesn't look like it didn't matter. No, it matters,*

> *and the doctor is concerned with what is happening. Isn't he? (BR10, B)*

Three participants expressed that they did not like the call that the main persona received from his doctor. Participant UK24 felt that the call was intrusive:

> *Is that his doctor's being nosy? Yes. So, no doubt, he will be like everyone else, he'll say, oh, thank you for the advice, now I'll do what I want to do. (UK24, B)*

Further, participant UK27 commented that the appropriate time to talk with the patient would be during the periodic review and not through a call:

> *If you have, as we do in this country but it's only annual, if you have periodic health reviews, I think it's entirely reasonable for the doctor to say, look Bob, you've been giving me the data and you just aren't taking enough exercise in my opinion. It's up to you, old chap, if you want not to. I'm advising that you should. I don't mind being told that. If he starts ringing me up and saying, have you acted on my advice? I don't want that. So, there's a limit to how much I want to be pestered, bothered by the doctor. (UK27, B)*

Moreover, five participants raised comments that calls should be made in moderation and in specific situations. Participant UK19 raised the concern that the call should be made for sensible reasons, considering relevance, frequency and in accordance with clear rules:

> *It depends possibly on the doctor actually. You know, if I got the feeling that every three seconds the doctor was phoning me just because I've, you know, I ran across to get a bus and oh your heart rate's gone up. You'd*

> *be going, for goodness's sake, because it feels again that you're sort of being controlled. [...] So that would annoy me. I would think, look, exactly, I think that's the point. If it had been, if I'd had a particular problem and knew that, and I gave information to the doctor about that problem and he phoned about something else which... Activity level, I mean, people do have lazy days. Do you know what I mean? And that fact that if I'd got a lazy day and the doctor phoned me and said, why haven't you walked? That would feel intrusive. (UK19, B)*

Participant UK26 commented on the perception of the call varying, depending on how the participant is feeling, but needed to be used only in cases of absolute need:

> *If I felt it would be... it would depend how I was feeling, I think. If I was feeling unwell and the doctor called and said we're receiving information that so-and-so may be wrong, then I would be happy with a telephone consultation about it. I'm not sure that I would immediately want to be told that, you must be doing so-and so. It sounds very, a bald thing, if you like, you know, that you just must do this without the gentle discussion that I feel that a doctor needs to be giving, unless there's an absolute need. (UK26, B)*

Further, participant BR15 suggested that the advantage of the doctor using the data from the wearable device was to target patients that needed more assistance:

> *What I'm noticing here that it's good. It's like, like, the doctor doesn't need to have a full clinic. So, he's just working on the computer. He's monitoring what's going on? With his patients, let's say. He might say "Peter is fine, isn't he?". He's monitoring and in a little, while he checks on me, "Oh, Mr. (participant's name) is not doing well". Then he calls me: "Come to the clinic because there's a problem etc, I can see it here".*

> *And I think that would be more ideal, wouldn't it? Because otherwise, if I wasn't well, I'd go to the doctor's clinic and someone else arrives at the same time, or there are a lot of people there, and it's like a health centre. See what I mean? This is a good point. (BR15, B)*

For participant BR16 any doctor with access to the data has the duty to ask for tests to be carried out in case the data collected from the device presents some variations:

> *That he will ask, he has to ask (additional tests). Otherwise, he is not doing his job. And another thing you can't be sure of. Indication, it's an indication, but it is not a certainty. It is an indication that you have to find out, you always have to find out with more sophisticated ones [tests]. (BR16, B)*

Regarding the question as to whether the data collected through the wearable device could be used by the doctor to provide him/her with information about the health of the patient and thus, could replace the doctor checking up on or asking how the patient is doing, seven participants felt both were needed; the doctor should check the data and also question the patient about their condition and how they are feeling.

Participant BR08 thought that the doctor should also request additional tests to double-check results:

> *I think that would be the case, I would provide the doctor with the equipment so that he could have access to the information, but I also believe that the doctor, as a doctor, would ask me. What have you been doing? What are your habits? Do you run? Do you walk? Do you exercise? What do you eat? Do you drink alcohol? Do you use drugs? Understood? Do you smoke? Then, all the information the doctor asks - so,*

> *based on that and with information that the equipment will provide, the doctor can then make a diagnosis, can't he? He will probably ask me for some tests to confirm that the information is correct or not. (BR08, B)*

To sum up, it was observed that this sub-theme is a facilitator for acceptability of the wearable device as participants saw the responsibility of the doctor to act or to check the data if he has access to it; thus, data access would implicate the doctor's responsibility. However, this data analysis and actions need to be conducted in a sensible manner to avoid becoming intrusive to patients. It was also observed that participants see the data as a tool to help the doctor, but that this should not replace the usual doctor-patient discussions or requesting of further tests if needed.

5.4.10 Data Sharing

The sub-theme Data Sharing is a key sub-theme in this study considering that this topic was explored during all three scenarios presented, as regards acceptance of data sharing in different contexts, and permission for access by different people, such as family members, physician, health care system and locations visited. All twenty-six participants expressed their perception regarding data sharing in the range of aspects presented, and as a result, this sub-theme comprises 641 coded quotes.

It was observed that this sub-theme relies on the type of third-party having access to the data, and this is presented in this sub-section. However, some factors highlighted at the beginning of this section are considered more general and do not rely as much on the type of third-party having access. Therefore, this sub-theme presents factors that influence the decision or acceptance of data sharing, namely: (1) Promoting awareness and/or support in the case of care needs; (2) Control; (3) Anonymity; (4) Trust; (5) Context and Place matters; (6) Purpose of Sharing; (7) Data Security; (8) Invasiveness; and (9) Type of third-party access (as mentioned below, this factor is at the core of concerns regarding data sharing).

Promoting awareness and/or support in case of care needs

Data collected by the sensors is seen as a good way of being aware of what is happening to your health, a good way to support health, and that the data provided would support predictions:

> *When you go on a weekend walking or go out and about, you consult the weather forecast: Will it rain today or not? So, if you have an idea of the current situation, the measures are much healthier, you prepare much better, don't you? That's the way it looks. (BR5, B)*

Participant UK22 commented that the government could use that information to decide if a person needs a caregiver:

> *That if too many well-meaning people have information, they might just decide that it couldn't be independent. (UK22, C)*

Control

One aspect that would influence the decision to share data, is the extent to which the user has control to act or make this decision. Participant BR5 commented that the user would have control over the outcome and if assistance is not needed, they can simply decide not to respond:

> *If you're not doing anything wrong, you're ... if you're not trying to hide anything from anyone, it doesn't matter, does it? You own the situation; you're there. On the other hand, he identified it there, the security officer knocks on the door, and I'll tell him, "No, officer, I'm just drunk. I drank too much wine; it's okay." Perfect, it's done. (BR5, B)*

The user may want to keep control over the data being collected and pause that when desired. For participant UK27 the data should not be sent automatically, rather should be shared at the discretion of a person acting in the interest of the user if the user is not able to do so themselves:

> *If there was an intermediary (Not goes automatically), who was human, as opposed to a machine, and acting in my interests, like a son or daughter, or still fit wife, then I would be happy for the information to go to the NHS. If there was no such intermediary, I would not at all be happy, oh wait a minute, unless I was living on my own, and I had, or somebody had given permission for that information to be transmitted. But if people do, if I had one of these pendant things, that was monitoring my activity, if I'd given permission to, or I'd agreed to wear it, and suddenly it was being transmitted that I was on the floor instead of upright, I would be happy for that to be transmitted. Because then somebody would come round to my house and save me from the position, the situation I found myself in. (UK27, C)*

Similarly, participant BR15 mentioned the need for a person close to the user to have control over data sharing:

> *If it were to improve the health system it would be interesting, because our health care system is broken. And I guess I don't even know if it would work, but that would be a good idea. The health care system has access to this. ,like the person there, but there has to be someone responsible for that too, like her daughter. (BR15, C)*

One aspect that would impact on control is consent previously given and its potential consequences in allowing access to the data. For participant BR8, when the main persona decided to use the device, he implicitly consented that the data would be available for the physician to follow on with a phone call:

> *Peter changed the equipment, he began to give the doctor the freedom to monitor his situation, when he changed the equipment to allow the doctor to follow the situation, his daily life, with that, he gave the doctor autonomy to be able to contact him. So, I think there is a big privacy issue, right? (BR8, B)*

Another aspect highlighted by participant UK23 was the freedom for the user to withdraw whenever needed:

> *If Claire is happy to be a guinea pig for research, that's fine. I'm a guinea pig for research today. I can get up and walk out if I want to. (UK23, C)*

Anonymity

This refers to remaining anonymous to avoid situations in which people, such as neighbours, friends and so on, could identify you:

> *As long as she's not identified (BR7)*

Participant UK28 expressed concern about the data not identifying the person. If it were totally anonymous, then it could be shared to build up information that could help other people. However, it would have to be completely anonymous:

> *I wouldn't want my information going, just being on general display, even though they say it's restricted. Once it gets online, anybody can hack into it. There's that opportunity. But if it's anonymously done, then that's*

> *... it's just a case number, no names, because then that would be fine as long as that were. (UK28, C)*

Trust

This aspect relates to having trust in those parties who would have access to the data that would influence willingness to share data. Participant BR08 expressed concern about the data collected being used by other companies in an inappropriate way, e.g., to sell services or products:

> *Certain types of information you cannot get from talking about it, because this can be used for another type of ... for other purposes. It will be used for another purpose, not to try to save life or to minimise any eventuality regarding the health of the patient. Sometimes you can use this kind of information for example ... "Man, you have diabetes, you have hypertension, you know what, I'll sell you some medicine ..." It's out of the ... Here in Brazil, you know how it works, right? (BR8, B)*

Sharing the data with a doctor was seen as one aspect to facilitate data sharing given that this professional is a trusted person. Opinions were given by 5 participants to justify the data sharing with a healthcare professional, as can be seen in the comments below:

> *In that case, I would make it available to the doctor. Because the doctor is the person who can give you what you need ... How do you talk like that? The recipe, some information like that, for you to improve on what is in the equipment here. [...] So he is the most capable person to have information. The equipment helps. (BR08, B)*

Having a trusted relationship with the doctor, was also raised as a factor influencing the decision of data sharing with the doctor, as observed in two Brazilian participants' comments:

> *I think yes I would have to share with the doctor as long as it was your trusted doctor who had always supported you. (BR09, B)*

> *I believe it depends on the level of health that the person has, you know. So, if I had a bigger need for follow-up, I would not doubt that. And going through the doctor usually there is a relationship of trust with the doctor, as I have with the doctor who accompanies me today, I would have no doubt that he would monitor me, you know? (BR11, B)*

Two participants viewed the call from the doctor as invasive:

> *So that would annoy me. I would think, look, exactly, I think that's the point. If it had been, if I'd had a particular problem and knew that, and I gave information to the doctor about that problem and he phoned about something else which... Activity level, I mean, people do have lazy days. Do you know what I mean? And that fact that if I'd got a lazy day and the doctor phoned me and said, why haven't you walked? That would feel intrusive. (UK19, B)*

> *Yes [it's invasive], I do because he's got a good reason for not doing the exercise. He knows that he needs to do it. And I think that I would go along with him, not liking the call because of the pressure it's putting on. (UK26, B)*

Lack of trust in the healthcare system was raised as a reason for unwillingness to share the data with this organisation:

> *Because you see, well, in Brazil, it is used a lot of bad faith too, is not it? So I'll expose ... here [the main persona] speaks of the mother, and I'm*

> *going to expose my mother's life to an organisation that does not give me confidence that those data will be confidential there, right? You'll stay safe. A third person can take advantage of and suddenly enjoy this data to practice some crime inside my mother's house, right? (BR12, C)*

However, for participant UK21, trust in the NHS not to share the information further supported their willingness to share data:

> *Yes, and I can't see that any information is going to leak out so yes, I don't have a problem with that, yes. (UK21, C)*

Context or place matters

For participants BR9 and BR16, privacy was also dependent on the location of the user. It was seen that the airport was more acceptable as a location for data sharing given the factor of being more vulnerable in this space. On the other hand, school was seen as a more private space by participant BR16:

> *It depends on the location, doesn't it? It depends on the place because at an airport you are travelling, so that's what I imagine, right? If you are at the airport, you are collecting someone or you are going on a trip, it is important. But at school, when anything happens ... school is a more private place, I think. I don't know if it's because the idea I have of school is different? But school is a very private place. Very specific, it's not your home, but it's private, there are 70 people who would instantly know of a boring situation? You know. That's the question. That the person could also be having a bad time in the bathroom, could really be a seriously urgent case, yes, if it detected that it was a case of a vital signal, but a problem of a lighter thing ... I think it's necessary to have a kind of control there. At what point, right? (BR9, B)*

Whilst participant BR16 felt the airport was a good place to have the sensor, the same did not apply to other places:

> *Yeah, I said I'd like it at the airport because it's a case of you're going to travel, there could be a problem, now at the market, whilst shopping etc, it'd be too much (BR16, B)*

However, in contrast, for participant UK20 sharing data with the airport was seen as completely intrusive and consent would only be given for data to be shared with the physician:

> *No, it's intrusive, completely intrusive, because he's [main persona] in a public place and unless he signs to say he wants his data being accessed everywhere, then why should anybody else need to know about it? I can see the benefits in that if maybe he wasn't feeling well, and maybe something bad could have happened in which case he would be grateful but at the same time his personal details and his health condition is his own business and his doctors. It doesn't belong to the airport or anybody outside that, unless he gives express permission. (UK20, C)*

The Indoor Sensor was seen as invasive by participant UK24. However, if they could see a purpose of use, they would be willing to accept it:

> *If I was in his position, I think it creates stress, yes. Because you know you're not very well, if people have given you information like his doctor about how much exercise he should do and when he's on a particular medication, either increase or decrease it, and so just verbally telling him that should be enough. He's either going to do it or not, but to have a device that's forever over shadowing you, when he's made a decision not to follow the doctor's advice, so I just feel it's overkill that. Yes,*

> *three things being checked, he's got no flexibility or choice. And every move is being monitored, but he did know when he took these devices on that that's what was expected of him, so you know, he made his decision for that. (UK24, C)*

The situation in which the physician gets in contact with the patient to talk about their data was seen as inappropriate:

> *could guide him later. Since he has already booked an appointment ... But calling now, I mean, that's really not right. (BR16, B) (The doctor)*

For participant UK28, the physician needs to know the full situation before making assumptions regarding the context:

> *I'd say possibly a bit invasive unless he knows the situation. As it says there, Peter has been working very hard so he hasn't got time for the extra physical activities. If the doctor is not aware of that and he thinks he's just getting lazy and that's going to increase, maybe a phone call, at most, like he did, but ask the right questions first before you make the assumptions. (UK28, B)*

For participant UK26, the call from the doctor was seen as inconvenient:

> *I do because he's got a good reason for not doing the exercise. He knows that he needs to do it [. . .] I would go along with him feeling cross. (UK26, B)*

In contrast, for participant UK18, this situation was seen as appropriate and non-intrusive:

> *I wouldn't mind if I was the patient because I know the doctor knows... he's been studying this sort of thing for years. I know instinctively that it's not because he wants to intrude on my privacy. I know instinctively, hey, this man means well, you know? He's telling me, look, you're in danger. (UK18, B)*

Further, participant UK27 raised a concern that being measured by a set of wearable devices could cause embarrassment:

> *I like whisky, and given the chance, I will drink too much whisky. If we were measuring that I could be embarrassed. (UK27, B).*

Regarding the data being shared with the airport, this prompted concern from participant UK28 as regards it being a private moment which was disturbed unnecessarily. Thus, how to approach this kind of situation would be key:

> *I was concerned when I read that one, I must admit. He obviously wanted a quiet ten minutes to himself and you can't get that in an airport. Sometimes if you go into the toilet and you sit in the cubicle you haven't got people around you all of the time and you can just calm yourself down. To have somebody come in on the bank banging on the door, you're going to go straight back up again. And the stress level is going through the roof. Even though they're showing their concern, personally I wouldn't have liked that. I would have been very upset with that, because I'm trying to calm down, because he's stressed out. I suppose it's also how it's actually done. If you've got two burly security men coming in and banging on the door, you're going to...obviously they're worried because you haven't moved for so long. But there could be more reasons for that. And as long as...if they're hooked up to your monitors, they can see there's nothing wrong with you. So why are they banging on the door? Unless*

> *they suspect you are up to something no good and then you're going to get stressed because that's what you're thinking. If they're monitoring you just because you haven't moved, not a problem if you're still healthy and all of your readings are okay. (UK28, B)*

For participant UK30, data collected using the set of wearable devices would be justified in the case of it being in a remote area where it would be difficult to contact people in the event of an emergency. These circumstances would justify the invasion of privacy that this data collection represents:

> *I can see why in theory it's a good idea but I could, I might be okay with it if I was going up a mountain, or if I was going in the back of beyond where there are no human beings who could monitor it. Because if actually then you did have an illness, or you were, had a dodgy heart or whatever it might be, you are putting yourself at risk and actually it's a bit of a lifeline to somebody who would then be able to respond. But in an airport that's full of people, to me if feels like, well can't a human being monitor if I fall, collapse in a heap? Or if I'm looking hot and sweaty or... I just think in somewhere busy where there are people, again, it's too big brother's watching you. (UK30, B).*

For participant UK30 some information should not be shared such as personal information of only one specific person:

> *I don't like the idea of... I don't even like people walking down the street having a conversation on their phone that everybody can here. I just think, I don't need to know, thank you. So anything that unnecessarily, to me that would be the last resort. Rather than a, let's make this standard. To me it's a bit like telling everybody on Facebook what you had for dinner, you know, the world does not need to know. But there might*

> *be situations where it would be helpful to have that kind of back up, but I would want to decide where that was and it would only be situations where I thought, actually that is a bit risky. So maybe I would want that safety net. Do that make sense? (UK30, B)*

Participant UK23 raised concerns regarding inter-personal data being collected through the indoor sensor in that this data could be being collected from someone who did not make the decision to install the sensor or is not the owner, rather someone else who lives there; thus, they may not be aware nor have agreed to what is going on:

> *And if she doesn't want her daughter to know [person that stays at home], it's a little bit sneaky for her daughter to put these sensors in to spy on her. It's like putting a camera in the room without telling somebody and spying on what they're doing. You shouldn't do that. (UK23, C)*

Purpose of sharing

For one participant, being monitored and having a third person interfering, in this case, the physician, was seen as acceptable only if they have a health condition that necessitates it:

> *See, at first, it scares me to know that it is being monitored at the level where the person arrives and interferes, it seems that ... although the goal is one, it's like an invasion. It's at that point that I become so afraid, once again I would choose this based on the state of my health , if I had a strong commitment to a health aspect, like a disease that needed a greater or determined follow-up, I suppose ... If it was one aspect that I was going to be able to maintain for good health, then maybe it's not even necessary. (BR11, B)*

For participant UK30 the indoor sensor would be acceptable if there was some health condition that justified the data been collected:

> *If you, if I did have ill health and I acknowledged I'd got the ill health, then it would be one way of monitoring, I suppose your activity levels and what you were doing, but I still would feel uncomfortable I think, knowing that something was monitoring what I'm doing. (UK30, C)*

Data security

Security was one factor raised participant BR12 regarding the data collected through the indoor sensor:

> *It's because of the person in the house. The person sleeps at such and such a time and watches television at a certain time, what the person does at any given moment, leaves the house, does not leave the house, hence there is the question of security, I think, not only personal health. (BR12, C)*

On the other hand, data sharing with the Government was seen as positive, if the personal data is secure:

> *It's the population in that age group that will come to have data like that. I think that given the security of the people whose data will be collected there, I think that would be interesting, that the government may have important data there for this age group, as people lead to life, right? (BR12, C)*

The vulnerability of having data collected by a device that could be easily stolen, such as a smartphone, was also seen as a concern by participant BR14:

> *But I keep thinking about something else. If you put your data there on your cell phone and it's stolen, someone takes your cell phone, can't someone use some data in a fairly scary, malicious way? Huh? It has all that too. So it's something to think about. You have to see how feasible it is to put it inside, or to what extent you have to have your notebook near where you put it. (BR14, A)*

Invasiveness

The indoor sensor raised concerns regarding the personal life of the subject, as it was installed in a private place:

> *Look, some part of private time that might not be interesting, for example, the constant use of this sensor could show,, how many times I have sex, or I never have sex, and in that sense would become annoying. (BR13, C)*

However, if the indoor sensor does not detect private activities, then it would be acceptable for this participant:

> *Then, it would be a device that would invade the person's privacy. Providing you don't disturb the person's privacy, that's fine. (BR13, C)*

If the data collected was not seen as private, then this would be willingly shared with the healthcare system:

> *It's not a subject that impacts on a person's privacy, is it? It's not a subject that will denigrate the image of that person, rather inform data that serves the person's well-being. (BR13, C)*

Use of a camera if the indoor sensor incorporated this device was seen as invasive:

> *But I'd not want to have a camera, no. If I could have it without the camera, that'd be okay. (BR8, C)*

The indoor sensor was also seen as an invasive device by participant BR13 though this could be used initially as a trial:

> *I do not think it [the indoor sensor] would take away privacy. It's for the experience, right? To measure behaviours, especially in the elderly. (BR13, C)*

The indoor sensor was seen as useful whenever the user has a disease that justifies needing the system, otherwise it was seen by participant BR9 as an intrusive device:

> *Only if I had some disease. Otherwise, it's boring, isn't it? It looks like the person is being monitored, watched. (BR9, C)*

It was not seen as a privacy issue when the doctor calls the patient to discuss their data, if the user has authorised the physician to access the data:

> *Well, it's a difficult situation there, isn't it? In fact, it's not an invasion of privacy, but he also has to not feel pressured, right? If he passed authorisation to the doctor monitoring him, he'd already know that. If he knew this, he wouldn't feel offended, "Okay, doctor, I know that. But let's do it. Let's do it, okay". (BR9, B)*

Type of third parties having data access

This sub-section concentrates on the specifics of sharing data with third parties explored in this first study. Factors previously presented generally in this sub-section (e.g. awareness, trust, control) relate to any type of third party. Here these are more specifically related to particular types of third party:

Healthcare system

Sharing data with the healthcare system was seen as a benefit for older adults, therefore, participants saw the purpose of data sharing with the healthcare system, as reflected in the comments of 9 participants, and a subsequent willingness to share this information with this third party was observed:

> *The data sharing, in this case, was seen as a possibility of understanding more deeply the needs to be met regarding the factor (1) Promote awareness and/or assist in case of care needs. Yes, to know more about the needs of the elderly, is it not? What they need at this age. That is an age at which many face much loneliness, don't they? (BR04, C)*

Participant BR07 mentioned that this sharing would bring benefits for this age group of acting upon various health conditions:

> *More to report about people in this age group, to monitor if they have the same behaviour, to see if they have any type of illness that may be the same for others. That's the case here, she may have a touch of depression, but not necessarily. Sometimes she may have another problem. (BR07, C)*

Further, it was seen as a way of providing more resources for the government to help this age group:

> *In my opinion, I think so, because it would be a way for the government to see what is happening to older people. It would be a way for them to also know more about the elderly, the life they are living, and how it is,*

> *the way it is. I think it would be very good, for my part I think it would also be good to help the government see what the situation is like with the elderly. (BR10, C)*

At the same time as seeing the benefits of data sharing with the healthcare system, concern was expressed regarding the security of data:

> *Even because they'll get data when one person connects with another after he retires, after a certain age, there will be data like that on the population in that age group. I think that given people's security data will be collected, I think that would be interesting, that the government may have important data there for this age group, as people lead their lives. (BR12, C)*

Participant BR13 commented that if the cost of the sensor was reasonable, it would bring valuable data for research:

> *It's wonderful because at some point in the future it'll be possible to manufacture these types of sensors in their billions, it would be affordable for everyone ... I predict that. Because I cannot see a future for a factory making these sensors if these sensors are going to be expensive. It has to be an accessible sensor for everyone to enjoy the benefit. And since few people are using it, but have precious data, for research it would be very interesting to add to this research the behaviours of those who have it so that ideas could be gained from there ... (BR13, C)*

Participant UK29 related data to be shared with the health care system to the data that he already provided in part to the National Health Service (NHS) from time to time and was therefore unwilling to share further data:

> *Well, for a start, these... I get... about two a year from NHS forms about 50 questions on. And that's asking you about everything... How you're feeling, you know, what... they... a lot of information, you know, they keep asking... they ask you, and they ask you nearly the same questions every time. (UK29)*

> *Just keep ticking them, and filling them in. It says it helps them and it says... you know, and so you just fill it in and send it back. But it says... I mean, a lot of people says: oh, well, I had one and throw it away. I said: well, why throw it away? I said: it takes you what: half an hour to fill it in; why not fill it in? (UK19, C)*

Participant BR14 similarly commented on how he could see similarities with what is already happening with the private insurance care he holds:

> *I'll tell you, I have Unimed (private health insurance company in Brazil). Unimed, in addition to being able to do tests, go to the doctor, everything, within their program, they have another program of care with nutrologists, with people who attend the health side, with health aids, and a once a month they call us to find out how things are, mainly people who, like me, have diabetes, high blood pressure, these sorts of cases so they always stay with the person, causing a lot of problems. They have a girl every month in charge of supporting certain people. So, there are several attendants who keep the person's record, and then they want to know how we feel, if we are always going to the dentist, if we have flossed, if we are eating sweet things, i.e. our sugar levels. Any exam reports you can do, you know? They want to follow all the tests for that problem of yours. Then they follow. It is still a thing of the past. It's just over the phone because that kind of sensor is not yet being used. (BR14, C)*

Furthermore, participant UK17 highlighted that the data shared would help to provide a better overview providing more resources to help older adults:

> *Yes, it probably is, it would be good to share with the healthcare system just to, you know, they'd get a broader picture of what's going on kind of thing, maybe, and it might help them to put in better caring or think from something new to help that age group or something. (UK17, C)*

Participants raised comments about benefits perceived from the government having access to that data. For participant BR04 the government could use the data to help the wider public:

> *So it is important that you provide possible health information because the government, having access and interest, can help. (BR04, C)*

Participant UK22 raised the point that the government could use that information to decide if a person needs a caregiver:

> *That if too many well-meaning people have information, they might just decide that it couldn't be independent. (UK22, C)*

Participant BR09 stated that if it provides better control over an illness, they would be willing to share the data:

> *If the mother agrees, because she is sick and this was done to be able to carry out this control, how the disease is evolving if it's not evolving, I think it is good to share. (BR09, C)*

Participant UK26 further added that he saw the purpose but would not be willing to share the data:

> *I think in this particular scenario where she has had the sensor in the house and it has been monitoring her, and then if it's going to be of any value, yes, share the information, if it's anonymous, okay. Yes, I think that's possibly what I would say about that. If it's already happened and it's already been functioning for a couple of weeks, then the information may be of value to others who might be considering using it and then also, as it says, you know, for assessing that person's own situation. But if anybody asked me if I wanted one, the answer would be no. (UK26, C)*

Similarly, participant UK30 saw the benefit in the use of the indoor sensor, but expressed resistance to sharing the data as they would feel uncomfortable with that:

> *So I think the actual, the principle of it and the idea of monitoring somebody's behaviour to then provide a service for them, and potentially develop services for other people in similar situations, I think in theory is a very good idea. But I fundamentally would still feel very uncomfortable myself if it was me that was being monitored. So I think that would be the only reservation I would have. It's very easy to say that would be very helpful for the NHS or to develop programmes of care, but I, my only reservation would be that's fine as long as you don't put one in my house. (UK30, C)*

Participant UK27 raised the concern that willingness to share would depend on his interests, as sharing the information could have a downside:

> *Oh well I'll tell you a bit about it, amoral, about something, and if to give the information would damage either my interests, my family's interests, or my pocket, I might suppress the information. If I was pretty sure, I knew I was ill, and it might... I don't need life insurance any more, I*

> *don't need it. I'm too old to need it. But if I were younger, I would not want to use that information that would damage my chances of getting insurance. (UK27, C)*

Traceability of the data was raised as a factor that could impact acceptability of sharing the data:

> *Yes. But, as well, to know where the information is going to go and what's going to be done with it, you know, where it's going to end up (UK17, C)*

Participant BR05 expressed concerns about people being unable to get to each other easily, therefore, taking care of themselves through use of the sensor would be useful:

> *But that's generating a situation of little communication, is it not. Very small families, people with no time to show interest for others, because sometimes it involves travelling and the person is taking care of his life in another location, and it's not like being there every day, my sister, my father, with my brother, with such a person. But I have an interest in knowing more or less if there is anything wrong, I can ask for some help, I can contact a friend, an ambulance, or something, if I don't know what to do. It's a form of care, isn't it? (BR05, C)*

Although a level of discomfort with the indoor sensor was observed, participant BR05 expressed his willingness for data sharing:

> *So, my baby monitor will always do that? In this respect, I am totally in favour [sharing data health care system]. (BR05, C)*

For two Brazilian participants, distrust in the government would be a barrier to sharing data with the healthcare system:

> *Because our government, for example, like this, is a government that ... This kind of information is capable of wanting to take advantage of the information to say that it had an initiative of ... Or, for example, like this, from here little he launches equipment so, from today we will have to put the equipment in such cases, it will cost the people so much ... No, it will not cost anything, and in the end, it's us who will pay. You can say, "No, from here on in, you will have the equipment." Then go get a piece of this equipment and put it in all the houses without bidding ... So, with the Brazilian government, I do not think ..., I think I should not share with the government. I think it should be more linked to the family or someone directly attached to that person who owns the equipment (BR08, C)*

Therefore, sharing with a physician would be more acceptable for this participant:

> *So I guess it's hard for you to share this with the government, your see? I think I should perhaps share it, if it happened like this, with a family doctor, you know, information, that a person is suddenly more able to give, and could not share with the government. I think it would be like this, I reckon. (BR08, C)*

Further, participant UK24 commented that willingness to share data with the physician would be more acceptable rather than the NHS considering concerns regarding data leakage:

> *That is difficult because I think it would be interesting to share the information with the doctor that you're going to get help from, but if it goes on a widespread system throughout the NHS, it's once again, isn't it? Your private... But anyone who goes to the doctor, their information is on the computer. So, you can go from one department to another and they*

> *can pick up your information, what is wrong with you. And, I think if it stays within the right people... But, because, I sometimes believe there was supposed to be a private – I forgot to mention that because I've forgotten – all your details are kept private, the Data Protection Act. But I don't think that works these days because you seem to get telephone calls, and how on earth did they get my number, you know, so... But, I think, if it's all done discreetly, yes. (UK24, C)*

The above comment from participant UK24 compares with that of participant UK21 presented earlier reflecting an opposing perception of NHS data protection; thus, this opinion is not unanimous, rather variable. Similarly, it was observed that some Brazilian participants would be happy to share data with the Brazilian healthcare system, but others expressed their distrust in the organisation underlying their restrictions on sharing data with the government as can be seen in the comments of participant BR12 regarding concern about data security:

> *If there is security for that. Now, if I'm going to expose the life of a person in the home to an instrument that does not give me confidence, then I don't (BR12, C)*

Concern was raised that the information could be used to practice an act of crime:

> *Because you see, well, in Brazil it's used in a lot of bad faith too, isn't it? So I'll expose ... here the character of the mother, and I'm going to expose my mother's life to an organ that does not give me assurance that those data will be confidential there, right? You'll stay safe. A third person can take advantage of and suddenly take this data to practice some crime inside my mother's house, right? (BR12, C)*

Furthermore, this same participant raised concerns about the sensitivity of this data, that due to being personal in nature, there are questions regarding security:

> *It is because it is the privacy of the person in the house. The person sleeps such time, and the person watches television such time, what the person does in every moment, leaves the house, does not leave the house, does it? Hence comes the question of security, I think, not only the personal health of the person (BR12, C)*

Data sharing physician

Offers support to the doctor

Regarding sharing data with the doctor, most participants (14/26) commented that the data collected through the sensor-based device could provide support to the doctor and was seen as a facilitator, mostly by the Brazilian participants (10) compared with 3 British participants, who expressed opinions representing mainly the middle-aged group (6 middle-aged participants and 4 elderly participants). Some examples of opinions are presented below.

Participant BR05 suggested the benefit of analysis input of a person outside the circle:

> *Sharing is ideal because sharing with the person outside your direct environment will tell you: Look, something is wrong, do you want to check it out? Would you like to...? It's much healthier if the person ... because many people develop pathologies that could have been prevented, and such monitoring would be in that sense, wouldn't it? Specifically, here, it's a really healthy that the person has this possibility to submit to it. (BR05, B)*

For participant BR09, historical data would be an important tool considering that the patient may forget events that happened when reporting to the doctor:

> *I think the equipment is good because we often forget some things that*

> *we've been through, right? I think so. The equipment is good for that. Sometimes you feel something, not every time you remember everything when you are talking to the doctor. And if you have equipment that can keep historical data, that'd be good, right? (BR09, B)*

For participant BR11, the device could provide a real doctor-patient follow-up:

> *I believe so, because nowadays, in my case, after I leave the doctor, I am practically on my own. And whenever I come back, usually a year later, he asks me for tests to be able to say something later. If he has this monitoring, it is something like that, already different and there is really monitoring, right? We say: "Ah, the doctor accompanies me", but, in part, when I go there, he accompanies those minutes that I am there. So, here, there would be a real follow-up. (BR11, B)*

A similar observation was raised by participant UK30:

> *And he will have to rely on my memory of, you know, whatever it was and how you are feeling and blah, blah, which is obviously notoriously unreliable. (UK30, B)*

Participant UK27 suggested that the data provided could evidence that additional care might be needed:

> *Oh, I would love the doctor to be able to see the facts. I mean, I've been fussed about my coughing for about a year or more, two years maybe, and I moaned about it, complained about it before. They don't seem to do anything. (UK27, B)*

For participant UK30, the reason to seek a doctor's opinion would be because they are concerned enough about their health and data collection would therefore be an important tool for the doctor:

> *If I was in the position where I was concerned enough to have taken myself to the doctor then I would give them the data because otherwise the doctor's going to ask you, and I hope he would ask you as well as just read the data. But then he's got your perception of it and he's got the data. Either your perception and the data will marry up or there could be a discrepancy. But if I was concerned enough to have gone to the doctor, then what the doctor does need is data. (UK30, B)*

However, participant BR07 highlighted their preference for showing the report in a paper-based version to the doctor:

> *It would be nice to show the doctor because sometimes when I'm interpreting, I don't have the technical knowledge he has, do I? I'd rather take a printout and show it to him. (BR07, B)*

Purpose of sharing with physician

In total, eleven participants, ten of which were British, saw a purpose in sharing the data with the physician. Therefore, an unconditional willingness for data sharing with the physician was observed for some participants (5/11 (BR04, UK29, UK22, UK21 and UK18)), with the other half of participants having some conditions for data sharing with this health professional:

> *Well, it will be interesting to see it. I wouldn't want it shared unless I had a particular reason. He has a pretty good reason to share it with his doctor. That's different. (UK23, B)*

Participant UK19 raised concern about access to the data being seen as intrusive if all the data collected was shared:

> *I wouldn't want to give just generic data about everything I do, because it's not just health. I mean, they can also find out about, you know, sort of lifestyle patterns and that sort of stuff. And that to me would seem too intrusive. I wouldn't want to give just generic data about everything I do, because it's not just health. I mean, they can also find out about, you know, sort of lifestyle patterns and that sort of stuff. And that to me would seem too intrusive. (UK19, B)*

As reflected in this last quote from participant UK19, control was highlighted during the interview by 7 participants; thus, this code is seen more as a barrier to sharing data with the physician in the context presented, especially regarding the outcome of data sharing with the physician during the call that the main persona receives from the doctor to discuss activity level. Participant BR14 commented that they would share data only from the specific period needed:

> *to a limit, too, until the doctor felt, "No, now it's all good, you can stop sharing it with me." When you feel a difference, you come and speak with me. (BR14, B) (I would share)*

Participant UK24 noted that he would keep the data private and consider sharing only in case of need:

> *I think I would've... I probably would keep it private. And if he says, oh, your blood pressure has gone really high, then I might consider saying, well, I'm monitoring this and then I might do. (UK24, B)*

Participant UK27 raised concerns regarding the impact that the data could have on health insurance companies:

> *I might wish to conceal from my insurance company, for example. I might suspect I've got a serious illness and decide that I would sooner just carry on and hide it. I might do. So I have to make the decision as to whether I share it. It's like in. (UK27, B)*

Participant UK23 commented that the persona should interrupt the data sharing if the outcome was not what the patient expected from the doctor. However, they pointed out that the responsibility of the doctor would be higher in the event of detecting some threatening situation and then not taking action:

> *(...) if this information is coming to the doctor, then the doctor can see a problem and does nothing about it, the doctor could be in trouble. So the doctor has to respond in some way. And if Peter doesn't like that, he should stop sharing the information with the doctor, it's very simple (UK23, B)*

Sharing data with organisations and places visited

Regarding the situation of sharing data with the airport as described in the scenario, several recurrent topics were raised regarding context, reflected in the comments of 12 participants. It was important for participants to understand the context of the persona and the location where the data was to be shared. During the interview, it was possible to identify a dilemma in participants' rejection of sharing data with places visited and seeing it as a benefit in the situation described, as can be seen with participant UK24:

> *this is really difficult because... No, in a supermarket it's different, isn't it? Because if you're going to pass out, you'll fall on top of someone, won't you? It's only if you go into the private toilets, you see, yes. And I do know someone who was a volunteer helper at the hospital and went to the toilet and had a heart attack in the toilet. (UK24, B)*

For participant UK17 the situation would depend on the needs of the person wearing the device:

> *Well, it's a bit too invasive, really, but, you know, if he was vulnerable, it depends on the person, if they were very vulnerable, like, if they were very old and fragile or, you know, and they had a terminal illness or something, but they went out for a day, then I think it has to look at the individual, really, and see. (UK17, B)*

Participant UK24 raised the concern that this could cause embarrassment in some cases:

> *But it's... Anybody could walk in then, couldn't they? You know, so, I think it's difficult. I think it's good if it saves someone's life, but if it embarrasses you and there's nothing wrong, and... But I think then you've got to make that mind up. (UK24, B)*

Participant BR12 similarly raised concerns about embarrassing situations that could happen when there was no need:

> *has the good side that the person did not go well [...] But at the same time, if the device detects, let's say, a very momentary situation, say, the heart beats too fast for a reason, so you get a scare or that it gives a beep, then I think it's not good, because then, let's say, it's in the middle, it's in the street among the people. Won't it bother people? (BR12, B) (...)*

The sensitivity of the device was also a worry raised by participant UK26:

> *I wouldn't want anybody else to be receiving that information. I would want to know it myself if it's anything that's going to register on the machine. And I would hope the machines are not so very sensitive that they pick up the very fact that you've been caused to jump because somebody said boo behind you. It sounds as if it might and I think, I think maybe, such a machine, such a device could be over-sensitive (UK26, B)*

Nevertheless, participants BR04 and BR06 viewed the outcome from sharing data with the airport as positive considering the context described in the scenario:

> *It's good because just like he's there alone at the airport, he's heading for a trip, isn't he? He was feeling bad. If he was already on the flight and he needed care, there wouldn't be any, would there? So, the important thing is that he was alerted, and that someone saw this ... (BR04, B)*

> *I think that, for example, if you suddenly start to get sick and this is being monitored, you can be rescued in time, can't you? So, I think it's cool. (BR06, B)*

The fact that the persona is alone was an additional factor highlighted as positive interaction by participant BR07:

> *Oh, I found it interesting, because then, sometimes I find myself alone, I have nobody, so I start to feel ill, for example, in the bathroom here, in this case, there was only him in the bathroom. I think it's interesting. (BR07, B)*

However, it was further observed that sharing some types of data would have some restrictions:

> *Not necessarily sharing vital signs, but like my device sends information that shows I'm not doing well. No need to talk ... (BR07, B)*

Locations with which the data is going to be shared was seen as a restriction by participant BR14:

> *Well look, then you would also have to see what locations, right? Not for all locations. Because in the case of supermarkets, you're surround by people, if you feel sick you may fall over on your side, whoever is nearest to you there will help you, ask if you need any help, or anything. (BR14, B)*

Participant (BR14) added that being in a particular place isolated from others would be one reason for the data to be shared and then for help to be sent to the person:

> *Yes, when you are in a place, for example, where there is no one around you. Perhaps you are passing a street where there's noone, or go somewhere, in a certain part of a shopping mall that has almost no movement, some stores sometimes have little movement, and you suddenly feel unwell, but no one notices, I think so, if it's like that? (BR14, B)*

Further, the airport scenario was seen as a sensitive situation by participant BR16, who, as a result, was more willing to accept data sharing:

> *Yeah, I said I would like to at the airport because it's a case of if you're going to travel and you have a problem, at the market, or when shopping etc, it's a lot. Then you can't do it anymore. After a little while, you get upset and never leave home because you know that everyone ... In the case of a trip, so much so that you even have travel insurance. (BR16, B)*

Purpose of sharing with organisations

For eight participants it was evident that they saw the purpose of data sharing with organisations, and thus, their willingness for data sharing was observed, as can be identified in the following quotes:

> *It would be very good. Because suddenly, even more so when you are an older person, you may feel ill, have low blood pressure, or diabetes, or something, and no one even knows what's going on. If you are being monitored, then use that means you have to help us, right? (BR10, B)*

Participant BR13 saw data sharing of this kind of data as a potential lifesaving feature:

> *A miracle. Because, look, if it was such a sudden attack, it could be a threat from a CVA [(Cerebral Vascular Accident)], it could be a heart attack, couldn't it? Then, as quickly as it arrived, it passed, but if it had been a more serious illness, he would have been saved by this device. (BR13, B)*

Participant UK29 saw in this situation the possibility of having a faster rescue:

> *Yes, yes. Like I say, if everybody... if everybody knows, then the quicker... if anything happens to you then they can get you off to hospital, can't they. (UK29, B)*

The fact of being alone was another characteristic that would influence willingness to share:

> *Sometimes you're in a bathroom and no one else comes at that time, and you can't say to them, "Look, I'm feeling sick," or something, can you?*

> *So, you're alone in a place, suddenly you are there without conditions, and it occurs in the place where you are, especially so, in a busy place, like the airport, I think it's very good. (BR14, B)*

A similar observation was mentioned by participant UK22:

> *Personally, I think it's a good thing, especially how terrifying it must be to have a heart attack and you're in the loo and nobody knows, you're in the airport and you don't know who to contact, and it was something that you were fearful of anyway, it was just, if he's wearing all these devices, then he knows he's not a well man and for me, I think that would be a secure thing. I think that would be good (UK22, B)*

Invasiveness

For 8 participants (5 British; 3 Brazilian) the situation of data sharing with locations that you were visiting was seen as invasive.

Total monitoring

> *I keep thinking that individually it can be a good thing, but there is no doubt that this system is taking care of the individual, you know? Taking care of the individual, I think it is knowing that you are being watched and, in a way, it is something that's a little scary, but it seems to be a trend. (BR11, B)*

> *It's a bit too invasive. It's a bit too invasive even though, you know, he could've been dead in the toilet, but it's a bit too invasive for me, I think. (UK17, B)*

> *If somebody notices that you don't look well and says, are you all right? That's kind. If somebody is intervening because they've received infor-*

> *mation about you that is very personal, I think I would resent that too. (UK26, B)*

Participant UK30 raised the concern of feeling exposed, even though they could see the benefits; however, one requirement would be to have control over the data:

> *I just think in somewhere busy where there are people, again, it's too big brother's watching you. To me it's a bit like telling everybody on Facebook what you had for dinner, you know, the world does not need to know. But there might be situations where it would be helpful to have that kind of back up, but I would want to decide where that was, and it would only be situations where I thought, actually that is a bit risky. So maybe I would want that safety net. (UK30, B)*

Do not see the purpose of sharing with organisations

Another barrier to data sharing was not seeing the purpose or need for sharing data with organisations and places visited as observed in the comments of six participants (all British).

Participant UK18 commented that he could easily ask for help in any location, even the more remote ones, so there was no need for data sharing:

> *Whether I'm in an airport, whether I'm in a national park, whether I'm camping out, if something is wrong, all I have to do is dial 999. Even if you are in the mountains, you can still dial 999 and say, mountain rescue, please. (UK18, B)*

Participant UK27 could not visualise a scenario where this should happen:

> *I just think it's unrealistic. Airports can measure things. For example, if the sensor was in the airport and if there was a device that instantly*

> *measured your skin temperature, they were considering that for monitoring people who might be coming back with Ebola fever or something like that. I don't have any problem with that. But that's not data that I've got about me that could be shared with the airport. (UK27, B)*

A similar observation about not envisioning the scenario happening was raised by participant UK28:

> *in the situation that there are a lot of people with these devices on, it's not going to be just one person, is it? How are they going to monitor that? What are they going to use the information for? I don't believe that it should be for general use. If it's just for Peter for monitoring himself, like I would on mine, and being able to put it on my laptop and compare it with graphs and everything, that would be fine (UK28, B) (...)*

Sharing data with friends and family members

Regarding this theme, it was observed that for this to be a facilitator, data sharing would have to be with specific family members close to the main user. Some of the comments listed below reflect that purpose of use of the device would be an important factor in facilitating acceptability of having the data collected and sharing it with family members.

Participant BR14 highlighted that with access to data from the indoor sensor, the family member could help the main user to overcome health problems:

> *I think so, especially in the case of depression. That the person has to be motivated to act to be able to release... [...] But, I think that as a measure of the person taking action and what it's going to do for the person who's in trouble, I think it's important. (BR14, C)*

However, for the same participant (BR14), should they see the purpose of sharing the data as acceptable, in this case, sharing the data with family members could bring undesirable outcomes. Therefore in the case of sharing the data collected by a smartwatch with his son, this was seen as a barrier:

> *Then it would be a case of picking up and going to the doctor and saying to him: "Look" ... I check this report, one day I'm like this, or like that. And it would be, got it? Didn't share with the son, because I think that at this point it wasn't much use to me. I would just be bothering and worrying him in this case. "Dad's not well and I don't know why." It's not like that either. In this case, you monitor and see every day what happens to you, when you see that it's happening regularly, you have to look for someone who will help you there. (BR14, A)*

Similarly, participant UK18 highlighted that sharing data with family members could cause unnecessary worry for relatives:

> *One, there is a possibility that might get people worried about her health status, okay, and I don't like fuss. I don't like the thought that my family members are fussing or getting worked up about my health. You see? (UK18, A).*

Participant UK24 would restrict the data sharing to only one specific person as they did not see the purpose of sharing the smartwatch data with others:

> *Well, I might share it with my sister, but I wouldn't, you know, I wouldn't really want to be telling other people, because I don't really think that other people would be interested. (UK24, A)*

However, participant UK23 expressed a willingness to share the data with a family member, though raised the concern about privacy on the Internet:

> *I wouldn't mind my wife seeing it. Anything that is on the web can be seen by somebody. There's no such thing as privacy on the web. So even if you keep it private, it's not completely private. (UK23, A)*

Nevertheless, in the case of the data from the indoor sensor, the purpose of sharing was seen as more acceptable in that situation:

> *Yes, I think you need someone else's help when you're depressed, don't you, really? I think so, because I think it's very difficult for people to come out of a state of depression on their own. It's very difficult. (UK24, C)*

In contrast, for one participant, having the data checked by a family member in the indoor sensor scenario was viewed as an uncomfortable situation:

> *This issue of depression is a difficult question, isn't it? But for a healthy person, if that person choses to do this, to have control of herself, so that she knows more or less how her life is, yes. Now, to be controlled by a son or any relative, I wouldn't find that very interesting, no. (BR9, C)*

Participant UK22 saw that the smartwatch could improve her motivation for doing an activity and that she would like to share this achievement with family:

> *Well, she doesn't have a personality like mine, because I couldn't not tell my son. Especially if it is something really good, I'd be telling him all the time, oh, you wouldn't believe how much I've walked today, yes, especially if that was the person that gave me the gift, I would be talking to them a lot about how well it's improved my life, yes. So...I would share it. (UK22, A).*

A similar opinion was observed with participant UK28 about the willingness to share non-specific data rather than positive achievements with family members:

> *If it's a positive response on Fitbit, why not shout about it? Say thank you for the Fitbit; that's really good, great. Look what it's showing me; I can do this and I've done that. I would say it's...maybe keep the actual information on the computer private, but certainly discuss it with the family. Yes, I had a really good day today and it shows it on there; look at my charts. Be positive about it. (UK28, A)*

On the other hand, the purpose of use of having access to the data collected on his parents by an indoor sensor was seen as useful by participant UK20. Considering their age and previous experience it was considered that use and access to the data collected would have benefits; thus, it represented a facilitator for the acceptance of data sharing:

> *It's a good point, because my parents are in their 80s and they are not well, both of them and my father had a stroke a couple of years ago, and I do have concerns about their health and my mum was very active, but she has problems with her knee and her back now, so her mobility has got much less, so it's different when you've got two people because they are obviously looking after each other in a way. My mum is looking after my dad, but if there was only one of them, then at least I would have a bit of information about what they were doing and that they were actually moving about and not... for example, my father if he has a fall, he lays on the floor and how long does he lay there for? You know, so it does provide a little bit of information, so yes possibly. (UK20, C)*

A similar opinion was observed in the comments of participant BR13 who felt that the data collected by the indoor sensor would be valuable for the family member:

> *I found it fantastic Because if there were any hidden problems, the daughter wouldn't know, she could have found her mother dead at home. And*

> *with these different behaviours, these are beginning to catch her attention and possibly this call is a warning to her to help her mother change this behaviour, "Look, you have to walk more. You have to leave because otherwise, you will have depression, you will start to feel isolated, you will be alone, you will feel sad, and so on." So have contact with people. I think the moment the device showed the mother's behaviour, such behaviour was very useful. (BR13, C)*

Similarly, participant UK29 expressed that due to personal experience, access to the data collected by indoor sensor data was seen to contribute to the purpose of use:

> *Oh, yes, yes. In fact, I've even told my brother to get something like this, because he lives on his own and he's... he's of a... he's collapsing and he doesn't know what's happened. And, you know, he gets up with bruised heads and bruised arms and legs. He's even fell down out on the street a couple of times, you know. (UK29, C)*

Participant UK21 also saw a purpose in sharing the data collected by a smartwatch, however, his personal decision would be to keep the data private:

> *I suppose, I would probably keep it private as well myself, but actually I think it probably is a good thing, a good idea to share it with those that you're living with so that they can respond to what's going on, yes and what's affecting your, my well-being, yes, so a lot to be said for sharing it, but when it came to the crunch, I might just keep quiet (UK21, A)*

For participant BR16 data sharing with family was seen as acceptable for the main user in terms of getting support from loved ones in both situations explored in the storyboards, and with the use of the smartwatch as can be seen here:

> *Share with the family at least [...] It's no use having a problem, that's not good, it's good to warn someone, share it. I think I'd have to share it. (BR16, A)*

In a similar way, this participant saw a purpose in the data collected by the indoor sensor being visible to the daughter:

> *And her here, as she can't be at home all the time with mom, she installed this. I think it's the right thing, she is taking care of a person who is already 73 years old and who has no desire anymore. So, she detected here that she was suffering from depression, I think already. [...] she's taking care of her mother here. I would do the same. (BR16, C)*

Participant BR10 saw the positive aspects of data sharing in the smartwatch scenario:

> *Because I think there's no problem sharing and other people knowing how she's doing, how she's feeling, if she's alright or not. It's good to evaluate ourselves, but it's also good to see someone else because sometimes there are things that we do not understand, that other will see. (BR10, A)*

The point that the data from the indoor sensor was not seen to impact on the privacy of the person was raised by participant BR13:

> *Because it's not a subject that impacts on a person's privacy, is it? It is not a matter that will blacken the image of the person rather it provides information that serves their well-being. I think in this sense, the daughter did very well, showed that she has more than love, has dedication and concern, doesn't it? (BR13, C).*

One important aspect of data sharing observed by five British participants was that it would be within the control of the main user to decide whether or not to share the data. For participant UK20 it was seen that the user should have control and ownership of their own data:

> *It's entirely up to her, every individual it's their own data, their own information, so if she feels that her son can help her or she wants to learn more and she does, or she needs help interpreting, then, by all means, share it, but she has the right to decide. (UK20, A)*

For participant UK27 the choice of sharing or not was seen as connected to whether the main user felt this was beneficial to them:

> *I think I could be encouraged to share, I think I could be encouraged to learn this is worth sharing, I think I could see for myself it's worth sharing, but I'll decide. (UK27, A)*

Conditions that would promote sharing, as observed in some quotes, were if there was some health problem or that it was practical for specific people:

> *If they were ill and there was some concern that actually this data would help monitor what, you know, they might need or what might help them, yes. But it's whether the person that is being monitored feels happy about it (UK30, C)*

Participant UK28 pointed out that trusting those with whom the data was shared was not the issue, rather the disposition of the person to help:

> *It would probably only be a partner or my daughter, because they're the only ones that live close to me.[. . .] It's not that I don't have friends I*

> *would trust, it's just that they are similar ages and they probably wouldn't be able to do anything in that relation, so...my daughter would be the only one. She lives close by and she manages me sometimes. (UK28, C)*

A similar comment was observed by participant BR08 for whom sharing data with a person with whom they were close would be the most acceptable way:

> *There would be no need for me to share with other people. Unless, for example, like this, for example, my wife. My wife is my partner, if I had such an app, she would probably have one on her smartphone, so she would want to know about mine and I would want to know about hers. In that case, yes. (BR08, A)*

Fear of being judged or stigmatised, was a factor raised by participant BR07 that would restrict their data sharing:

> *In my case, at first, I wouldn't share it because there are people who don't have the knowledge, and will think: "Wow, why are you doing this? What made you do this?". At first, I wouldn't speak to anyone either. (BR 07, A)*

Another factor observed as a barrier for sharing this kind of data with friends and family related to the aspect of Privacy and was raised by 5 participants:

> *I'd be a bit hesitant about revealing what was being shown by this, I think I might just be... I might not want to admit that I'd spent quite so much time sleeping or doing things if I was depressed, yes. (UK21, C)*

Participant BR13 raised concerns regarding the sensitivity of the information collected by the indoor sensor:

> *Look, then some part of private time might not be interesting, for example, the constant use of this sensor could show how many times I have sex, or I never have sex, and in that sense, it becomes embarrassing (BR13, C).*

For participant BR09, there were mixed feelings regarding data sharing:

> *Yeah, it's pretty complicated, isn't it? Because there's something there that's very private, very private. But it is also good to share some things at times, isn't it? (BR09, C)*

A similar mix of feelings was observed with participant UK27:

> *I don't think such information should be transmitted unless you are of an age, and in a certain circumstances where you need that, but I certainly can see that knowing how long Clare [main persona in this scenario] was in her bedroom, would be very useful. Because if somebody spends all day in bed, or in their bedroom, I certainly would agree, they're in a sad state and need help. (UK27, C)*

To sum up, this sub-theme has provided reflection on factors that could facilitate data sharing or collection in specific situations, such as threat to life, being far away from others, or being in a remote location. Factors related to who would have access, and if the person or the organisation is trustworthy would all influence acceptance. It was observed that willingness to share the data with the physician was more likely, compared to data sharing with places visited and this would often be conditional upon seeing a purpose of use that would benefit the user.

Regarding purpose of use, having a health condition is a factor that would facilitate data sharing considering the benefit that the user could identify in this situation.

In general, a trade-off was observed with sharing data to gain some benefit in exchange, and this would depend on the perceived usefulness that would justify doing so. Therefore, the challenge for data sharing is be to understand what that trade-off may be, and identifying what uses the user requires to stimulate data sharing in an acceptable way for the end user.

The findings from this theme of data-related factors provide evidence to address the first and third research objectives of this first study by identifying the factors that affect acceptability in the use of pervasive technologies specifically in the emergent themes related to privacy concerns and security. For most of these factors in this study no constructs in relation to previously discussed models were identified as being applicable to analysis of the findings. Therefore, the search for a model that could help in understanding the findings was investigated in the literature, whereby the pervasive technology acceptance model (PTAM) proposed by Connelly (2007) was found, in which the concept of trust is presented, and further, a model by Li et al. (2016), that helps in understanding the trade-off related to data and the benefits that participants are seeking, which could justify data sharing by what they propose as 'privacy calculus'; this refers to individuals' decisions to adopt healthcare wearable devices being determined by their risk–benefit analyses - if an individual's perceived benefit is higher than perceived privacy risk, the person is more likely to adopt the device.

5.5 Summary and next steps

This chapter has presented a set of sensitising overarching themes and their subthemes that emerged from the interviews comprising factors that facilitate, moderate, and pose barriers to the acceptability of sensor-based technologies to support health and well-being. These themes group into three main technology-related clusters providing important information to address the first research objective of identifying factors that affect acceptability in the use of pervasive technologies and respond to the second research objective by identifying factors regarding the type of information older adults would be willing to have collected and these factors were seen as related to Health Status and Health Beliefs and Concerns. The user-related theme identifies additional factors also in response to the first research question that affect acceptability and in this moment referent to the user. The last theme related to data-related factors helps address the third research objective by identifying the type of third party with which older adults are willing to share. It was identified that the majority of factors were related to privacy, security and trust concerns and it was observed that there is a lack of literature addressing privacy and security concerns regarding the acceptability of technologies in an e-health context, with only a few extant studies employing privacy calculus theory to examine individuals' health information sharing behaviours. Taking into account that wearable devices generate higher level of privacy risk, individuals' decisions to adopt healthcare wearable devices would involve a highly salient privacy calculus in which users may face a trade-off between perceived benefit and perceived privacy risk (Li et al. 2016; Xu et al. 2009).

As anticipated from the literature and validated throughout this study there is a complexity of understanding around the acceptability of sensor-based technologies.In general, the construct that has more impact on the acceptability of technology is the core principle of the TAM model that relates to perceived usefulness and perceived ease of use.However, it was possible to identify that no unique model of technology acceptance exists in current literature that can address all the factors identified in this study and therefore more than one model is adopted in this study to understand these factors.

Considering the complexity of the topic, it was decided that data sharing and these factors would be further explored in a second study into acceptability of data sharing and the benefits that the user would be expecting to motivate them to share their data with third parties.The next chapter 6 discusses the results of two scenarios presented to older adults in the focus groups, which together provide additional material that further probes into the facilitators, mediators and barriers to acceptability of the aforementioned technologies. Thereafter, Chapter 7 presents a detailed discussion, drawing out the key facilitators, mediators and barriers to acceptability, and guidelines intended to support the future design of sensor-based technology, addressing particularly the factors that affect acceptability of such technology by older adults.

Chapter 6

Study Two - Findings from the focus groups

6.1 Introduction

Chapter 5 presented the outcomes of study one, describing facilitators and barriers to the acceptability of wearable devices. Among the finding were discussions about seeing the purpose of use and respecting privacy and trust. However, study one lacked a device or prototype that could give participants more practical scenarios; hence, the design and execution of a second study to probe further into acceptability factors related to specific design choices. This study's goal was to identify further potential facilitators and barriers to acceptance pertaining specifically to the role of access to the data collected by third parties such as retail companies, health care services and family members due to the predominance of this theme in the previous study. Study Two aimed to identify these facilitators and barriers through themes and sub-themes,using a low-fidelity prototype of a wearable device App since Fitbit was a popular device among participants in Study One. This prototype helped explore the factors influencing participants' willingness to share personal data.

Qualitative data was collected in group discussions, transcribed, and analysed using thematic analysis. As a result, a fourth overarching theme emerged, alongside confirmation of the previous three: (1) User-related factors, (2) Data-related factors, (3) Technology-related factors and (4) third-parties related factors. These four clusters comprise 35 factors (sub-themes) which aside from furthering understanding of the facilitators and barriers to acceptability of sensor-based health technology are discussed in relation to their implications for design. Further, these are discussed in terms of their relevance to design work, how the interface could promote participants' willingness for data sharing and potential for use of the data collected.

These themes are grounded in data gathered during six focus group sessions of between 5 and 7 participants per group and a total of 35 participants. The focus groups were conducted in three events held during July and August 2019 in the Central Library in Nottingham, UK. Finally, quantitative data was collected using surveys during the focus groups, with the aim of understanding the demographic data of participants that took part in this study.

6.2 Results

6.2.1 Descriptive statistics of surveys

The following section presents the findings of the data analysis of the three surveys used in this study, two at the beginning of the focus group and one post-survey.

Pre-survey findings

The aim of the pre-survey was to identify participants' use of digital technologies, the purpose behind any Internet use, use of Apps, trust in the data collected and the decision to install a new App. Furthermore, this pre-survey included demographic data on age, gender and education level, as shown in Section 3.4.4.

Related to the use of technology it was observed that the majority of participants use Smartphones (28/35), with use of laptop, computer, tablet being very popular. Devices such as 'Alexa' that could support independent living were less popular as can be seen in Figure 6.1 below.

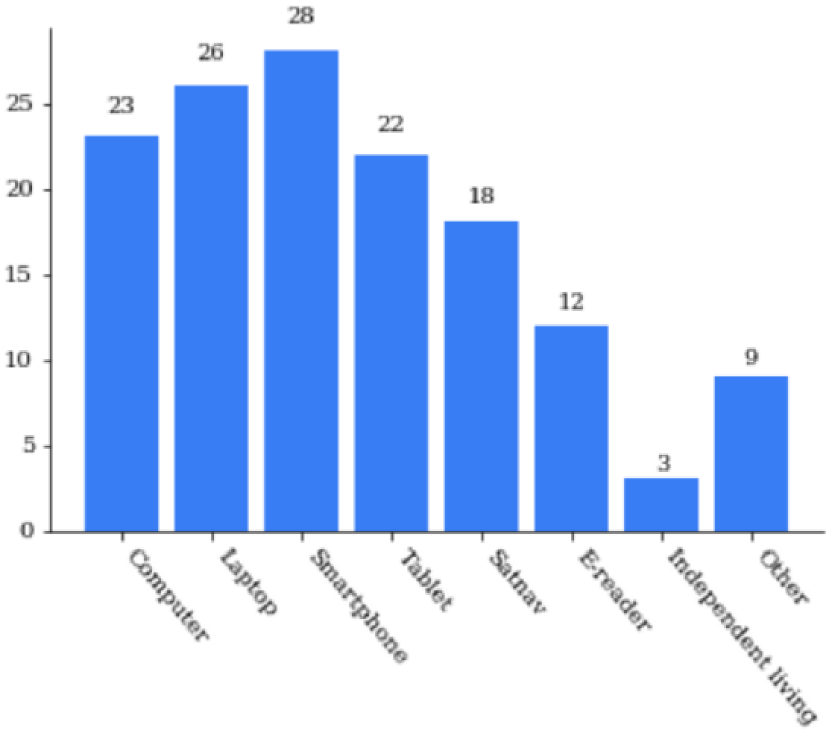


Figure 6.1: Participants' use of digital technologies. Source: author.

In relation to the above, Figure 6.2 presents the amount of daily use of digital technology.

Another question asked in the pre-survey was how long participants had been using new digital technologies (see Figures 6.1 and 6.2).

The final three questions on the pre-survey related to trust and the results are presented in Figures 6.3, 6.4 and 6.5.

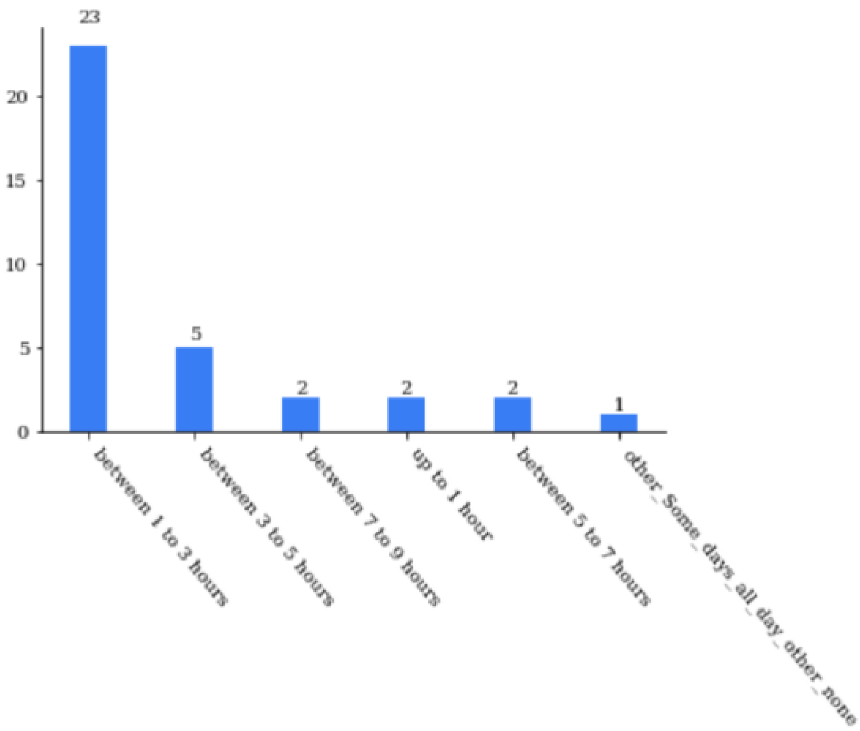


Figure 6.2: Hours of use of digital technology. Source: author.

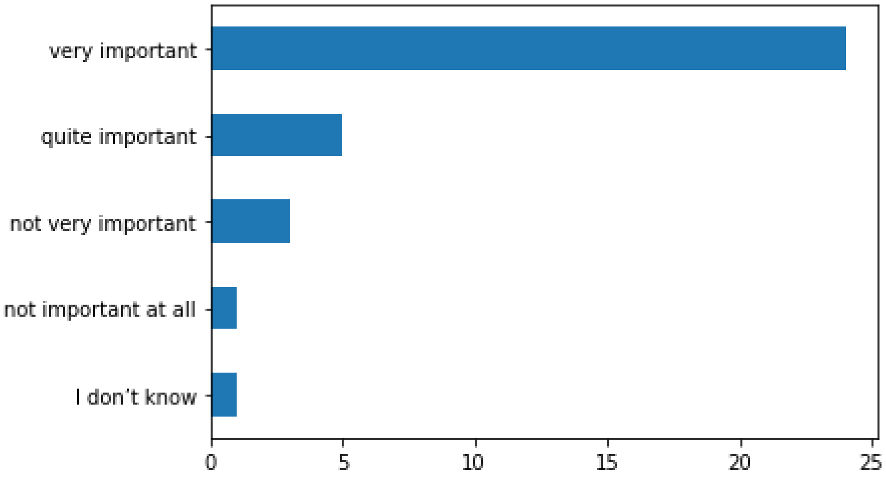


Figure 6.3: Number of participants answering the question "How import is TRUST in how the data collected is going to be used, in your decision to use new technologies devices?". Scale: Very important, Quite important, Not very important, Not at all important, and I don't know. Source: author.

Health monitoring Questionnaire findings

This short questionnaire comprised four questions (see Appendix O) with the aim of identifying health concerns and interest in health-related information among participants. Figure 6.6 presents the health conditions about which participants reported

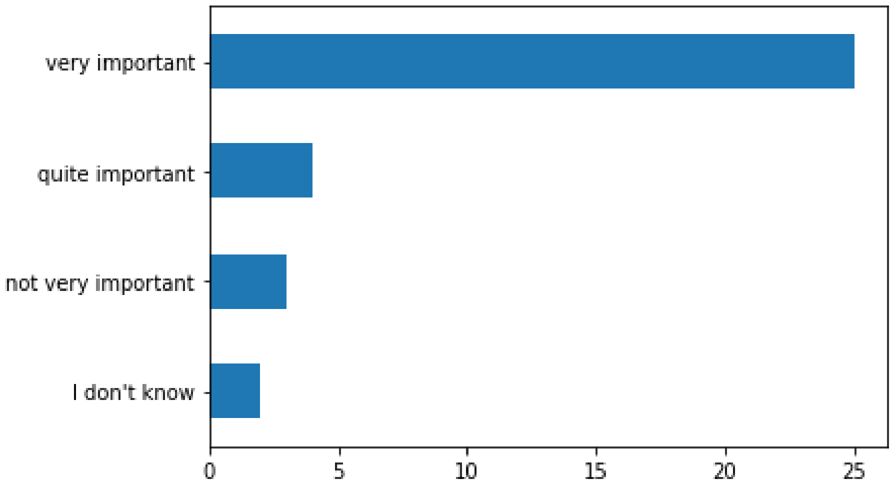


Figure 6.4: Number of participants answering the question “How import is TRUST in your decision to download a new App or to use a new service online?”. Scale: Very important, Quite important, Not very important, Not at all important, and I don't know. Source: author.

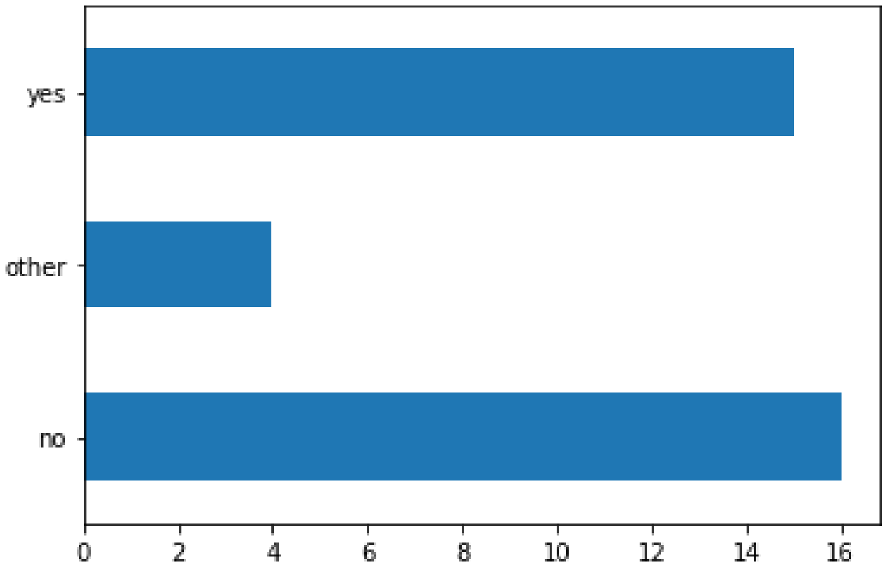


Figure 6.5: Number of participants answering the question “Have your ever stopped using a device, App, or online service because you didn't trust how the data used?”. Scale: yes, other, and no. Source: author.

concern,in which it can be seen that issues related to cholesterol level and arthritis were the most selected.

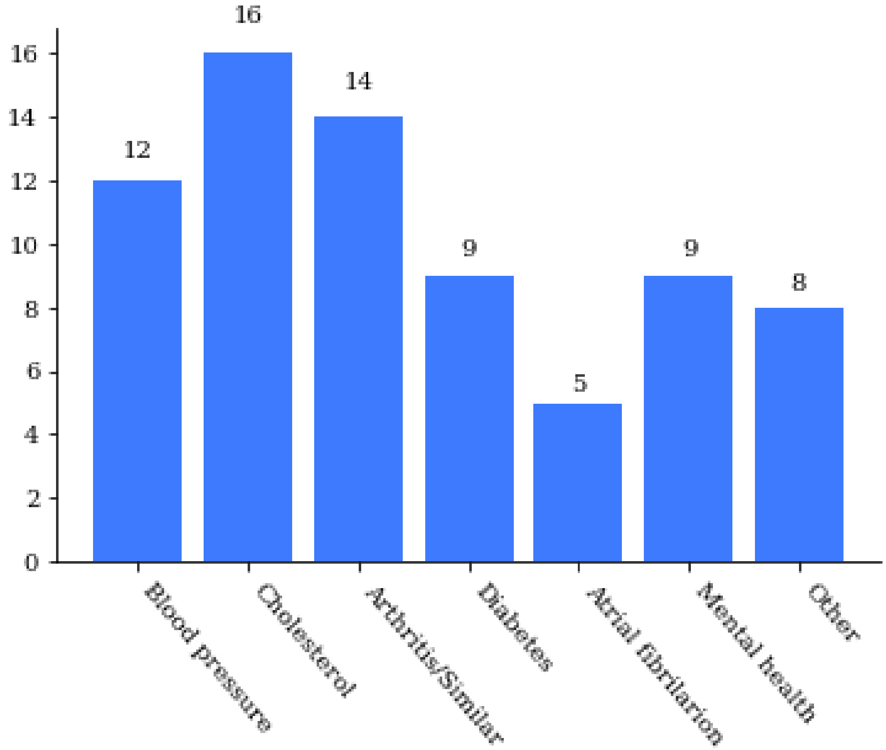


Figure 6.6: Number of participants answering the question "Are you concerned with any of those conditions?". Source: author.

Post-survey findings

The aim of the post-survey was to collect opinions about the data collected by the wearable device, concerns related to online data and feelings related to well-being. The full survey can be found in Appendix N. In relation to the type of data collected through the sensor, it was observed that the most important were heart rate (20 extremely important), blood pressure (17 extremely important), and glucose level (11 extremely important) as presented in Table 6.1. In contrast, of least importance was location.

Table 6.1: Participant's answers to the question "Which type of data collected through the sensor device would be more important to you?" in a 7-point Likert scale from 1 = not at all important to 7 = extremely important.

Data type	1	2	3	4	5	6	7
heart rate	3	1	3	3	1	3	20

Table 6.1: Participant's answers to the question "Which type of data collected through the sensor device would be more important to you?" in a 7-point Likert scale from 1 = not at all important to 7 = extremely important.

Data type	1	2	3	4	5	6	7
blood pressure	4	1	1	3	5	3	17
respiratory rate	4	2	1	6	9	4	7
glucose level	4	5	5	5	2	1	11
step count	5	3	3	9	2	4	8
distance	4	3	6	6	4	5	6
type of activity	7	1	5	6	5	4	5
sedentary time	8	4	3	7	2	4	4
calories burnt	1	4	4	9	6	2	8
sleep data	6	1	3	6	3	4	8
stress level	4	2	3	6	5	3	8
location	13	2	4	4	2	3	3

Table 6.2 presents the result regarding participants' feelings about their use of technology over the last month. The analysis indicates the most negative feelings were anxious, powerless, apathetic, paranoid, disempowered, and low mood; in contrast, general experiences in the use of digital technologies were reported as very positive. The analysis further indicates that positive feelings such as pleased, safe, and in control were reflected in the highest selected 'Often' option. These findings suggests that this group of participants presented very positive feelings regarding the use of new technologies.

Table 6.2: General experience using digital technologies during the last four weeks before the focus group. The table shows the number of participants per feeling and per the following scale: 1 = Never, 2 = Very rarely, 3 = Rarely, 4 = Sometimes, 5 = Often, 6 = Very often, and 7 = Always.

Feeling	1	2	3	4	5	6	7
High mood	6	3	1	13	5	3	2
Anxious	10	4	6	9	2	1	1
Pleased	1	2	0	10	12	3	5
Powerless	14	4	3	5	2	3	1
Safe	2	3	3	6	10	4	5
Apathetic	16	5	4	3	3	1	1
Paranoid	22	3	5	2	0	0	0
Tracked	9	5	2	6	5	2	3
Disempowered	14	4	4	6	1	2	1
Creative	3	3	3	14	6	3	1
Calm	0	2	1	12	7	7	4
In control	0	1	2	9	10	6	5
Empowered	3	2	5	8	6	7	1
Low mood	14	10	1	7	0	0	0
Annoyed	10	1	7	7	4	3	0
Powerful	6	5	7	8	3	3	0

6.3 Qualitative findings

6.3.1 The coding process

Considering the learning curve during the coding process in the first study, and researcher experience gained from helping with the codebook used in the ReEntrust project as part of the Horizon Research Group, though complex and detailed, this study's coding process ran more smoothly. The focus group discussed several topics during the time available which was used to gather the majority perception of the App Design presented using the wireframes alongside opinions regarding the scenarios presented in the study.

Supervisor guidance on codebook definition was important in helping to clarify some points of uncertainty around researcher data interpretations. The coding process began by using a bottom-up approach, with inductive coding, without any theme or code in mind. On completion of coding of the first three focus group transcripts, a meeting took place with the supervisor to present the preliminary codebook. Appendix Q presents the preliminary codebook generated. Although a bottom-up approach was used, it was noted that researcher bias could have influenced the preliminary codebook. Therefore, to reduce such bias, a supervision meeting presenting the preliminary codebook was essential. During this meeting, similarities in the codes from the first study were identified. This was expected, considering that the second study was designed to further explore some of the topics that emerged in the first study. During the discussion, it was agreed that the similarities in themes and sub-themes of the first study would be equally presented in this second study and therefore a mixed bottom-up and top-down approach would be adopted in the process of coding for this second study. As a result of this decision, changes were applied to the preliminary codebook. Moreover, this second version of the codebook was applied to the first three focus groups and adjustments made. Finally, the remaining three focus groups were coded using this revised version, adding newly emerged themes and sub-themes as needed. Thus, it should be noted that a mix of deductive and inductive approaches was used in this second study.

6.3.2 Data-related factors

Thematic analysis confirmed the familiar main theme Data-related factors, and gave rise to 11 sub-themes. Figure 6.7 illustrates the sub-themes relates to data-related factors. The definitions of each sub-theme are as follows:

Figure 6.7: Conceptual map of sub-themes identified in the data and related to the main theme: Data-related factors. Source: author.

- Data collection: comments related to the data being collected by the wearable device presented in the study or other technologies.
- Data protection: comments related to the process applied or that should be

applied in order to safeguard data, and comments regarding General Data Protection Regulation (GDPR) adopted in the UK.

- Data sharing: comments regarding data access by third parties or the act of sharing data with third parties (family members, healthcare system, retail business and others).
- Data use: comments regarding how data will be used.
- Invasive Tracking: comments regarding feeling around intrusive nature of data collected by the device or the device itself.
- Data Privacy/ Privacy: comments on the desire to keep away from others or to maintain seclusion as noted in the first study. This sub-theme also includes data privacy, the right to have control over how personal data is collected and boundaries to protect from unwarranted interference.
- Privacy Police: comments regarding the Privacy Police. This concept was used in the wireframes as a way to promote discussion and to explore how data could be presented in a way that facilitated greater user confidence. Alternatives ways to present privacy policy and options were therefore shown in the focus groups.
- Data Security: concerns regarding the data being protected from unauthorized access.
- Technology not warranted: caution over use or the usefulness of the technology presented.
- Transparency and Traceability: comments on the process of data flow, clarity of the process, and perceptions around a lack of transparency.
- Trust: comments regarding the feeling of trust or confidence in reliability of the data collected.

Data collection

This sub-theme relates to participants' comments on the data being collected by the wearable device presented in the study or other technologies, and was observed in all six groups. This sub-theme strongly relates to Purpose of Use, given that if the participant sees a purpose in using the technology, consequently they are more open to having data collected. Further, this relates significantly to Third Parties as regards who will have access to the data collected.

Participants expressed that they would like the data collected because they could see the purpose:

> *Surely the first point is whether we would like it collected. And yes, I would quite – I would find it quite interesting. I mean, I'm not concerned about sharing at the moment, I just think it's a good idea to do it. I'd quite like one of these little things. It would be a really interesting concept. (P1)*

However, concerns regarding the accuracy of the device would be one factor that would impact the willingness to have data collected:

> *I think the other one on the sleep pattern, I'm not – I don't think those Fitbits or any device measures that accurately [. . .] It's telling me I had, you know, I had light sleep from two until four and I know I was sat reading my book. (P2)*

The type of data collected was also found to directly affect data collection:

> *They'd be useful to the same extent that any other information would be useful [other than sleep pattern], like your blood pressure, whatever, it would be use. (P2)*

The type of data collected was explored during the post-survey, details of which can be found in the section on descriptive statistics 6.2.1.

Another concern raised that would influence the willingness to have the data collected related to who would have access to the data in the case of data sharing:

> *Yeah. My immediate concern would be, I don't have any problem with data collection, it's who is collecting it and for what purpose. I could just split it into two, which is I would be more than willing for any data whatsoever to go to companies that are for the good of people's health, NHS. Okay? But commercial organisations is a different matter (P17).*

Finally, if the participant sees the purpose this would facilitate their willingness to have the data collected:

> *But if what's normal for you suddenly changes, that could be indicating there's an issue or a problem and I think it's more having this data over a period, you know, like even you – your sort of heart rate, your pulse, if over a period is suddenly changes, becomes erratic or, you know, becomes higher or whatever, it's an indication something's happening. So I think gathering the data's useful. (P28)*

To sum up, factors that facilitate acceptability of the data being collected are: (1) type of data collected, (2) accuracy of the data collected, (3) control over who would have access to the data collected and (4) seeing a purpose in having the data collected.

Data protection

This sub-theme relates to participants' comments about the process that is or should be applied to safeguard the data, and comprises comments regarding General Data

Protection Regulation (GDPR) adopted in the UK. This sub-theme is strongly connected to Privacy, Privacy Policy and Security, as these sub-themes relate to user protection concerning the personal data collected. Additionally, it relates to the theme Third Parties and who will have access to the data, and its impact on the data protection.

Regarding data sharing with companies, one participant mentioned that even with data protection regulation he does not feel in control of who will have access to the data:

> *The new data protection laws would say that these companies cannot share that data and must keep it safe, so there's a lot of – in the data protection. But the minute you tick a box saying, you know, it's okay to share that data with somebody else or with a – particularly a company like Tesco's, etc., which, you know, are going to use it to sell you things, you've opened the floodgates from personal experience (P28).*

Further, participants P34 and P26 mentioned that Data Protection gives the user a guarantee of which data will be collected and used; however, that it is unclear what happens with the data if that company ceases to exist:

> *Absolutely. And unless you put forward some sort of personal request with the Data Protection Act or something, you have really no guarantee that they are limiting themselves to that data and that data only. So for me, it's a whole black hole that I wouldn't be comfortable with. (P34)*
>
> *Such as what happens to the data when the company ceases to function. Before I had a Fitbit, I had some sort of tracker with a company that then failed to continue producing them. (P26)*
>
> *Yes, yes. (P34)*

> *And I had all my data on there, in the Cloud on there. Where did it go? I couldn't access it anymore, so where is it? (P26)*

To sum up, it was observed that Data Protection is a facilitator as the user sees that data collection has been regulated and this provides some guarantees, although in this study, participants' concerns were also observed around Data Protection not providing the feeling of user control over what happens to the data, which, in turn, could impact on trust and well-being.

Data Use

This sub-theme relates to participants' comments regarding how data will be used by third parties. It was observed that participants raised concerns regarding lack of control and security issues over the data shared. This sub-theme is mainly related to the sub-themes of Security, transparency and traceability and Trust in the data.

In the comments of participants P5, P6 and P11, feelings of lack of control and lack of traceability were observed:

> *. . . in whose hands personal information will end up in. And also will the information be available forever, never to be deleted. (P5)*

> *It still doesn't say what they're – what they're gonna do. I mean they might send you products that you might want to – to purchase. Doesn't tell you what they're gonna do with that data. (P6)*

> *Does it – there is a little comment on most – I – with the data that we will not share this data with anybody else or anything. (P11)*

Participant P7 raised a point regarding what he would require from the healthcare system to reduce feelings of lack of control:

> *I think I'd like to see a statement from the GP and the NHS, for a start off, what is the – what are they going to do with that data. (P7)*

To sum up, it was observed that the use of data raises concerns among participants about data security and lack of control in relation to who will have access to the data, and what the data will be used for.

Invasive Tracking

This sub-theme relates to participants' comments regarding feelings around the intrusive nature of data collected by the device or the device itself. This sub-theme was observed in discussions about Scenario 1 and participants' perception of the NHS follow-up after data sharing with this organisation begins.

Participant P10 noted concern regarding usefulness of the outcome and the user feeling exposed to unwanted content:

> *It just feels intrusive wearing it all the time. I think the first part is... but then it starts bombarding you further down, making appointments and all that sort of stuff. (P10)*

Participant P18 commented on the feeling of lack of agency in this situation:

> *I think it's too much information, I don't like being told what to do. (P18)*

Further, this concern regarding feeling under pressure due the outcome of data sharing was seen as an invasive by participants P23 and P32:

> *And perhaps, you know, one follow-up would be fine. But then to carry on and carry on would become intrusive. (P23)*

> *Because the second one asks him to contact, it doesn't say, you may like to contact, but it is pushing it too – it's getting intrusive, isn't it? (P32)*

To sum up, it was observed that the feeling of being under pressure, that could be associated with lack of control regarding usefulness of the outcome, the amount of unwanted information and lack of agency discussed in this scenario presented a barrier for participants to accepting the device.

Data Privacy and Privacy

This sub-theme relates to the desire to keep away from others or to maintain seclusion as noted in the first study. This sub-theme also includes data privacy, the right to have control over how personal data is collected and boundaries to protect from unwarranted interference. This theme is mainly related with the sub-themes Invasive Tracking and Privacy Policy

Participant P33 highlighted his perception that concerns over privacy is higher nowadays, impacted by the feeling that third parties hold significant data about individuals:

> *The problem here too is you've now got technology that will know more about us than we know about ourselves. And yeah, we're all – the other – that's one side of it. And the other side is we're absolutely obsessed with privacy these days, we don't want anybody to know anything about us at all. I mean, years ago, you had absolutely no privacy at all, you even had to share the same blooming toilets and things like that. (P33)*

Participant P2 voiced his perception that by taking the decision to share data, this implied that as a result there is a lack of control over and traceability of the data which compromises data Privacy:

> *Well, yeah. We're talking about data privacy, aren't we? And whatever, you know, if you're considering sharing your data you want to be certain where that data is going beyond who you're sharing it with, if it's going anywhere. (P2)*

This participant further expressed thoughts related to a Privacy Policy that could bring protection to the data:

> *But based on experience – well, you just – because you see these things, you get right down, when you read sometimes privacy policy, you get right down to the very small print, it says, your data will be shared with third parties. (P2)*

The next sub-theme details participants' perceptions of the Privacy Policy; however, in this sub-theme, these were expressed as barriers to the use of data currently in relation to Privacy.

Privacy Policy

This sub-theme explores participants' perceptions regarding the Privacy Policy. The wireframes used in this study displayed different ways that the Privacy Policy could be presented to the user. In total, four different ways were explored in the focus groups using the wireframes with the aim of promoting discussion on how data could be presented in a way that facilitated greater user confidence, and alternatives ways to present privacy policy.

Discussion of comments regarding organisation and readability of the Privacy Policy is included in the theme Technology related factors; however, here this sub-theme perceptions in relation to adherence, confidence and feelings about policies regulations in general are detailed.

Participant P4 expressed his view that a privacy policy does not protect the data:

> *Well, a – everybody has a privacy policy, don't they? I mean how – how many organisations have – have been hacked? You know, Marriot Hotel has had 300 and so million of – of their people's information stolen. Companies like Equifax have been hacked, and so on and so on and so on. They all get hacked somewhere down the line. TalkTalk have been hacked. (P4)*

For participant P8 the Privacy Policy can create a barrier in some situations that could compromise justice being served in the investigation of criminal offences:

> *. . . because I'm very irritated with these privacy policies because I had a – a friend who got assaulted and then they – the – they reported to the police and the police dealt with the person that assaulted and then the police wouldn't give the guy the – the – the name of the person that assaulted him so the lawyers couldn't process the case. So these privacy policies are getting a – pretty ridiculous now. (P8)*

Similarly, participant P7 commented on the Privacy Policy potentially compromising justice being served:

> *And then, you know, they've got commercially trained lawyers to get round, you know, the privacy policy. (P7)*

Further, participant P11 suggested that the fact that the Privacy Policy is displayed in small font does not motivate the user to read it, rather that there is insecurity that this could used against the user:

> *Going back to your point, it's the small data at the bottom that do we really – everybody read it? No. (P11)*

> *But they put it there and then they come back to you and they say, "Well, you should have read that." (P11)*

Participant P18 added that going through Privacy Policies is not part of his general practice:

> *How often do you read privacy policies? (Laughs) I never read them. (P18)*

To sum up, it can be seen that participants' perceptions of the Privacy Policy do not promote data privacy or data security, considering that there is a lack of trust regarding how this data will be used and how the policy itself offers data protection by, for example, providing guarantees that the data will not be used against the user.

Data Security

This sub-theme relates to the concerns regarding the data being protected from unauthorised access. This sub-theme is mainly related with Data Privacy. It can be observed over the mainly states that are going to be highlighted here, the overall concern of participants is regarding the use of the data primarily by people to whom the user did not give access, therefore there were observed restrictions regarding of the use of partners.

Participant P28 mentioned the concern regarding agreeing to share data with one company but then receiving content from others:

> *I – I think there is, isn't there? The new data protection laws would say that these companies cannot share that data and must keep it safe, so there's a lot of – in the data protection. But the minute you tick a box*

> *saying, you know, it's okay to share that data with somebody else or with a – particularly a company like Tesco's, etc., which, you know, are going to use it to sell you things, you've opened the floodgates from personal experience.(P28)*

The inconvenience and feeling of lack of control over data sharing was highlighted by this participant again in another comment:

> *And – and the ads bit as well because, again, with data protection, the minute you sort of okay something, that opens the floodgates and I think certainly for us and probably all of us have ex – experienced nuisance phone calls constantly, because of our age, people trying to sell us insurance plans, I mean death plans, want to look at our finances for our old age and everything and half these people are just trying to get their hands on what savings you've got. And we – we now don't fill in anything, do we? (P28)*

Participant P34 stated his perception of lack of warranties provided by the companies:

> *P34: Absolutely. And unless you put forward some sort of personal request with the Data Protection Act or something, you have really no guarantee that they are limiting themselves to that data and that data only. So for me, it's a whole black hole that I wouldn't be comfortable with.*

To sum up, it could be observed in this sub-theme that participants expressed concerns and perception of lack of control and warranties when agreeing to their data being shared.

Data Sharing

This sub-theme is key to this study, as with the first. Due the complexity of this sub-theme, this second study explores further data sharing with a variety of parties discussed in the first study. Therefore, in this second study a new theme was added: Third-party related factors. This section discusses data sharing in general, meanwhile the specificity around accessibility to the data by a specific third party is explored in Section 6.3.3 (Type of third party). Thus, this sub-theme relates clearly to Third party-related factors, mainly 'Type of third parties', 'Trust', 'Purpose of Use' and 'Data Use'. The type of third party seems to have an impact on the decision or willingness to share data. Furthermore, trust is another factor that impacts on the disposition towards data sharing. Identifying purpose of use appears to impact on the inclination to share data. Finally, how data will be used is a further factor that could facilitate willingness for data sharing. These factors are discussed in this section.

This sub-theme was observed in the comments of twenty-seven participants and in all six groups that participated in this second study, with 112 coded quotes. One factor identified that would affect willingness to share the data would be who would have access to the data, namely, the type of third party.

For participant P6 sharing data with companies would be a restriction as he does not see a purpose in doing so, as evident in his comments:

> *... that would concern me, not about sharing with health and pharmacy or research institutes or people, my family, I would strongly be very worried if I saw the third one about companies. (P6)*
>
> *... why would companies want it? (P6)*
>
> *Mmm, why— (Facilitator (F))*
>
> *Because they want control. (P4)*

> *Yeah. But that would be – that would be – that would be a huge red alert. That would be a red light, you know, in my mind. I probably wouldn't take data sharing ... (P6)*

It was further observed that trust in a company would facilitate willingness for data sharing as can be seen in the comments of participant P28:

> *It could be used, like everything, isn't it, it could be used for good to help keep you healthy, but it can also be used on the other side for somebody that wants to make profit out of insurance, etc. (P28)*

The outcome quality of sharing data would be another factor influencing willingness for data sharing:

> *But no, no, this is coming from information we've given to Holland and Barrett, and I think that's very different. I think that is the thing, it's information creeping round the system in a way that's not directly relevant. (P32)*

A further concern raised about data sharing relates to use of data and the perception that this data could be used against the user:

> *I think also if you're of working age, those of us here are retired so we don't have to worry about getting a job and being interviewed, but as you say, if this information is part of [15:53] want you to share your health condition and that becomes part of it, it could – it could actually sort of put someone in a – a – a less favourable position although they could be doing all the preventative things ... So it – it – where it gets to be shared can really affect people's lives, couldn't it? (P31)*

Participant P18 further highlighted that they would not like family members to know what they were doing:

> *No way at all, everybody would worry about how much I'm drinking, how much I'm sleeping, how much I'm doing. So I don't want them to know (laughs). (P18)*

Another factor raised relates to confidence in sharing data and being in control of that data and with which parties this is or is not shared:

> *I'd be quite happy to share it, but I would want to know that it wasn't going beyond there. (P2)*

> *But as far as that's concerned you don't know who those other people will go on to share it with. (P19)*

> *You see, I have an opposite view, If I'm happy to share it, my view is, with the NHS, yeah, have it, please have it. If it's beneficial to you, fine. As long as you're not going to share it with people I don't want it shared with. But I'm not bothered about the wider community or anything else really (laughs) I'm just think – my view would be, as long as I know it's being kept private and it's – if it's helping somebody or some – you know, me or anybody else for that matter, then that – I'm fine with that. I'm not bothered about feedback or anything else. (P2)*

One factor observed that would facilitate data sharing would be if the user sees a benefit as participant P10 explained:

> *I think I'd – personally I'd be happier to share that with my GP rather than the NHS as a big, wide organisation. I think they're most likely to actually look at it and – it would more benefit to you. (P10)*

Participant P19 mentioned that the benefit could be the time the user could save:

> *That's what I was thinking. I wouldn't mind sharing, but it depends, with reservations, because it can be quite time saving. And as you say, if a new product comes around, you know, you might become aware of it quite early on. (P19)*

To sum up, factors that would affect acceptability of data sharing would be (1) the type of third party that would have access to the data; (2) outcome use; (3) seeing a benefit; (4) use of the data, and (5) having confidence in the third party. These factors are further explored in the theme Third-Party-related factors presented in the next subsection.

The findings from this theme data-related factors provide factors to address the first research objective (RO1) to identify the factors that affect acceptability that are impacted by the data collected by the device, the data protection to try to safeguard the user, and the intrusive nature of the data collected by the device itself. In this theme it was observed that answers to the second research objective (RO2) regarding identifying the factors that affect the decision for sharing data emerged from the participant´s comments regarding data access by third parties.

As regards the third research objective (RO3) with the aim of identifying the factors that promote the use of the data collected, these were observed in the data protection sub-theme of the General Data Protection Regulation (GDPR) topic in participants comments regarding promoting the safe use of the data, and concerns regarding the user being in control over the personal data to reduce the perceived risks.

The findings here are closely related with the TAM model regarding the Perceived Usefulness and with the Privacy Calculus model regarding to the legislative protection such as GDPR Privacy Policies and the Perceived Privacy Risk and Perceived Benefit, how the higher the Perceived Privacy Risk the great number of barriers mentioned by participants with the use of those technologies.

6.3.3 Third party-related factors

The main theme Third party-related factors encapsulates 9 sub-themes related to participant opinions. Figure 6.8 illustrates the codes related to Third Party-related factors. The descriptions of sub-themes are presented next.

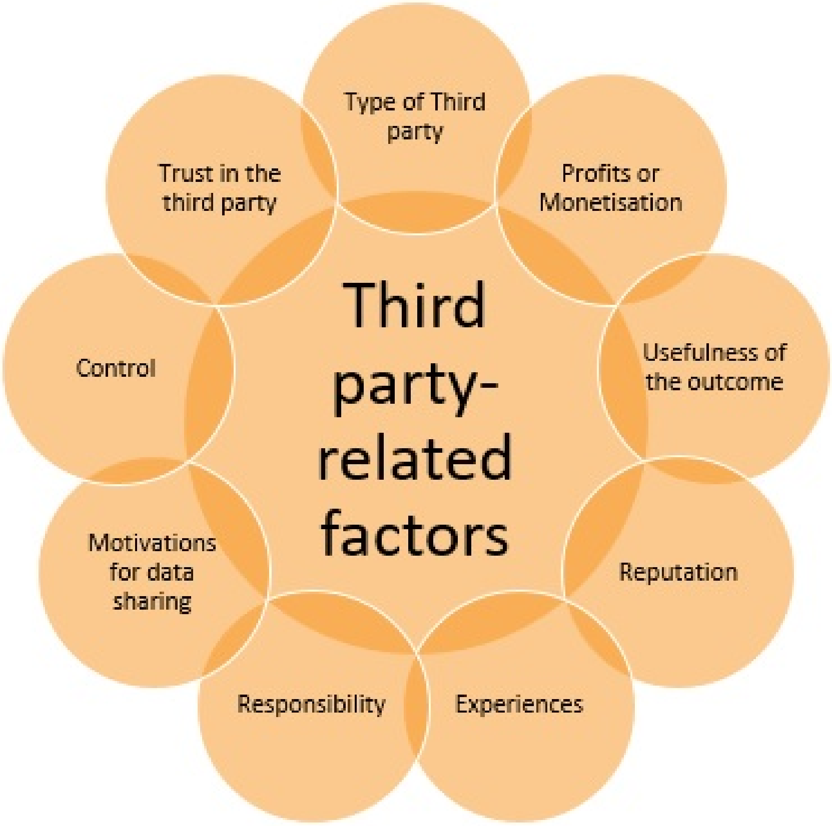


Figure 6.8: Conceptual map of themes identified in the data and related to the main theme: Third party-related factors. Source: author.

Type of Third party

This sub-theme relates to participants comments that revealed their reactions to specific third parties having access to the data or their willingness or not for a particular third party to have access. Third party types emergent from this study were (1) Companies or retail businesses, (2) Healthcare Providers, (3) Family Members and (4) Research Institutes, the observed particularities about which are discussed in the next sub-sections. This sub-theme explores access to data in detail and is closely related to Data sharing, which explores participants' perceptions of data sharing in more general terms.

Companies (retail businesses) It was observed that the participants expressed resistance to sharing data with companies primarily concerned with profits for the organisation which impacts on trust in the outcome use for the user. This is seen in one example below from P6:

> *... that would concern me, not about sharing with health and pharmacy or research institutes or people, my family, I would strongly be very worried if I saw the third one about companies. And I – I – I've said that, and it always worries me about privatisation of the NHS. So if that's something that's been put in, it's obviously something that's been in someone's mind... why would companies want it? (P6)*

However, participant P8 expressed that there are advantages to sharing data with companies considering that this kind of organisation may develop a new product or service that could benefit people's health:

> *But at the end of the day, I mean let's be honest, companies are the people that develop new drugs. It's not done on the NHS. So if we want to improve our health conditions, surely let the companies get on with it. They may come up with a new medicine. I mean we've got this problem around ageing with this dementia situation. There's no cure for it. The more data companies can get, they – they might come up with a medicine. (P8)*

This sub-theme is further explored in the sub-theme Profit and Monetisation.

Table 6.3 highlights the observed factors in terms of facilitators, barriers and moderators, that would affect the willingness to allow access to the data by companies:

Table 6.3: Access to data by companies.

Main domain	Factor	Example quote
Facilitators	Warranties and Responsibility	P2: But I would – yeah, I would want something there that says, you know, if you make this selections, we can guarantee your information will not be shared with anybody else other than those that you are selecting.
	Choices	P12: I don't think it really matters what they offer, provided you have a guarantee of opt out.
	Improved recommendation/services	P2: Then I'd say like same as the advert, the cereal information, that's what you would expect, is something useful to you. P7: I've paid for it upfront, but I'll expect service thereafter, better service.
	Development of new products	P8: I mean we've got this problem around ageing with this dementia situation. There's no cure for it. The more data companies can get, they – they might come up with a medicine.
Barriers	Amount of ads	P10: It says in the for thing, it says it offers personalised content and ads. I do not want to be bombarded with ads.

Table 6.3: Access to data by companies.

Main domain	Factor	Example quote
		P2: You're just going to – your inbox is going to be full of emails from these people.
	Trust	P12: Well, just a guarantee, a simple statement that says, we will not under any circumstances share the information without your agreement. P6: I really worry if I'm going for an ear test or an eye test, do I really need the thing that they're trying to sell me for a health reason or do I – they need me to pay for something that's aesthetically expensive.
	Profit or Monetisation	P6: I trust the NHS to tell me something I need for a health reason. I don't trust companies that tell me I need something 'cause they're making a big profit out of it.
Moderator	Loyalty programs	P1: You might get a few more points on your Clubcard or something. P12: They're not worth a lot, are they?

Some of the above factors such as Trust, Profits or Monetisation are discussed further in the next sub-themes. The next type of third party to be explored is healthcare providers.

Healthcare Provider A greater willingness for healthcare providers to have access to the data was observed among participants, given the greater use of the outcome for this party and as a consequence, increased purpose for sharing. This type of party comprises (1) Doctor, (2) NHS in general, (3) Health insurance, and (4) Pharmacy.

Doctor's access to data was seen as beneficial considering potential usefulness of outcome. Therefore, a willingness among participants for sharing data with this health care professional was observed, as can be seen in the example quotations below, relating to improved health services:

> *I think I'd – personally I'd be happier to share that with my GP rather than the NHS as a big, wide organisation. I think they're most likely to actually look at it and – it would more benefit to you. (P10)*
>
> *I think it might help in terms of doctor/patient, because doctors are after hard information, and often let's say in consultations, the patient doesn't – reveals very little and reveals very late. So sometimes, you know, the data provision to a doctor may actually help things, as long as it's being looked at with other things. (P7)*

Regarding the National Health Service (NHS), having access to the user's data, it was observed that participants had a willingness to share data for various reasons: (1) trust in their services, (2) being a non-profit making organisation, and (3) it could bring benefits for the user or wider community. Trust and its status as a non-profit organisation is reflected in the comment from P6:

> *Yeah, yeah, but that – that's the only – that's the only reason I – I worry about it. I trust the NHS to tell me something I need for a health reason. I don't trust companies that tell me I need something 'cause they're making a big profit out of it.(P6)*

Further, participants P2 and P17 point out the benefits that sharing data with the NHS could have both for the individual user and for the community in general.

> *I'm happy to share it, my view is, with the NHS, yeah, have it, please have it. If it's beneficial to you, fine. As long as you're not going to share it with people I don't want it shared with. But I'm not bothered about the wider community or anything else really (laughs) I'm just think – my view would be, as long as I know it's being kept private and it's – if it's helping somebody or some – you know, me or anybody else for that matter, then that – I'm fine with that. I'm not bothered about feedback or anything else. (P2)*
>
> *Yeah. My immediate concern would be, I don't have any problem with data collection, it's who is collecting it and for what purpose. I could just split it into two, which is I would be more than willing for any data whatsoever to go to companies that are for the good of people's health, NHS. Okay? But commercial organisations is a different matter.*

Regarding health insurance companies having access to the data collected, it was observed that participants were concerned that information shared could be used against the user:

> *My thing would come in, on here you've got medical health insurance, Bupa, etc. My thing that I find annoying, I take a blood pressure tablet and a cholesterol tablet to stop me having a heart attack hopefully and reduce the risk. My insurance company have to tell them that. It puts up my holiday insurance. So if this information goes to an insurance company they're going to people who are vulnerable, perhaps, who may have a slight heart condition, etc., they're gonna say, "We won't insure you," or you've gonna have to pay an arm and a leg. So that gadget is lessening the likelihood of them being ill but increasing the cost of the*

> *medical insurance and that, because of the – the experience I've had, I find that the – as soon as any information gets to an insurance company ... It goes against you.(P30)*
>
> *They either won't give you a policy or your policy goes through the roof. (P28)*

Regarding sharing data with pharmacies, it was observed that willingness varies. Some participants see it as a barrier in terms of potential to make a profit, whereas others see these as trustful organisations or consider the usefulness of the outcome. Participant P22 expressed their lack of trust due to the aim of making a profit:

> *I'd be interested in GP surgery, but not the other two, not pharmacy or - I don't trust pharmacists, they're self-employed for profit. They're self-employed, when I went into my pharmacy, they encourage me to claim prescriptions just by squiggling it because they are very happy... They're motivated, without any doubt, by profit. GP surgeries are different, and NHS completely different. (P22)*

Similar feelings were observed in the comments of other participants:

> *I mean, people like – I didn't – I only realised recently that say pharmacy – Boots pharmacy for example, if you have repeat prescriptions, they want you to do it through them because they'll be paid for that, rather than do it through your GP. They want to give you a flu jab because they'll be paid for that, they want to take that service away from the GP practice into the commercial environment. So it's constantly all of these things have a commercial end point, don't they, even to a pharmacy. (P32)*

P26 raised concerns regarding the lack of control over who would have access to the data:

> *Yes, because I don't think they have the same level of integrity of information in the pharmacy. There are too many people who if you use a local pharmacy live down the road from you would know too much information about you. I'm very wary of the pharmacies. But the GP practice, that has to have integrity. So I have no problem with that... They get paid in the pharmacy, they get paid. (P26)*

Participant P34 outlined that limited access to a chemist could be granted but overall he would not be willing for his data to be shared:

> *I think the key phrase for me here, would you be willing to share your personal health data? No. Fundamentally I don't want to share it with Boots, I don't want it share it with anybody. I don't mind a chemist having limited information, but I even find them a bit intrusive to be perfectly honest. (P34)*

Participant P15 highlighted that they would like to share only certain specific data:

> *But in this particular scenario, my take on it was, okay, but not all of that data, because, you know, the big long list and if you go back to the scenario, there's only concerns around high blood pressure and a bit of arthritis. So I would say sharing blood pressure and I think it was step count, for me would be fine. But I have a concern here that if it's going to go the NHS, I don't see any reason why it shouldn't go to the GP and I take your concerns on board, definitely, but I think I probably would be happy to share to pharmacy. But what does the NHS as a block do with it? I can see what the doctor does with it, I can somehow see what the pharmacy does with it. The NHS is a huge monolith, why do they need it? (P15)*

For participant P11, sharing data with a pharmacy would be acceptable but raised the concern of lack of traceability:

> *Yeah, so with the data that you – they go to, okay, it might say that it's going to just your doctor and your pharmacy. But how do we know that it stops there, and I don't believe it does. (P11)*

Trust in the pharmacy was also highlighted by participant P18:

> *If it was going to my pharmacy, and I knew they were going to read it, I think that's fine, because they might help me with getting something... Well, I trust my pharmacy. (P18)*

Table 6.4 highlights the barriers and facilitators observed that would impact on willingness to allow access to data by pharmacies:

Table 6.4: Access to the data by pharmacies.

Main domain	Factor	Example quote
Barriers	Profit	I went into my pharmacy, they encourage me to claim prescriptions just by squiggling it because they are very happy... They're motivated, without any doubt, by profit. (P22)
	Lack of control	I don't think they have the same level of integrity of information in the pharmacy. There are too many people who if you use a local pharmacy live down the road from you would know too much information about you. (P26)

Table 6.4: Access to the data by pharmacies.

Main domain	Factor	Example quote
Facilitators	H limited access to the data	But in this particular scenario, my take on it was, okay, but not all of that data (P15)
	Intended Use	If it was going to my pharmacy, and I knew they were going to read it, I think that's fine, because they might help me with getting something. . . (P18)
	Trust	P18: Well, I trust my pharmacy.

As regards the factors in Table 6.4 influencing acceptability of data sharing with pharmacies, some, as in Trust and Profit, are further discussed in the next sub-themes.

The next type of third party to be explored is family members having access to the user's data.

Family members Some participants' perceptions of sharing data with family members were positive in that the family views could be helpful as participant P19 outlined. Participants P25 and P18 further note benefits that such access would bring. For participant P23 willingness to share data would depend on the user's health. For participants P28, P29 and P34 the possibility of sharing data with family members would promote independent living for older adults, those that live on their own or suffer some health condition. Table 6.5 shows various factors that the analysis has shown to play a role in the acceptability of data sharing with family members.

Table 6.5: Overview of facilitators, barriers, and moderators observed that would affect willingness to allow access to the data by family members.

Main domain	Factor	Example quote
Facilitator	Supports need for care	P10: Well, I just thought that might be useful because his lack of sleep might indicate sleep apnea, that's what I put down. So it could be that, and he may not be aware of it, you see. So if his daughter's got that information, she could perhaps alert him to go and see the doctor. P25: They can actually do something about it, because we've kept it to ourselves because we don't want to worry them.
	Promotes proximity	P2: I think it could be useful in exactly the situation that [participant's name] has just described, where your children are far away. And if you're not – and they're concerned about your health, and it may not just be sleep, but it may be on other measures. [...]
	Supports independent living	P28: I would certainly think with somebody who was quite elderly, sharing data with a family member could be a big plus ... P29: Especially if they're on their own.

Table 6.5: Overview of facilitators, barriers, and moderators observed that would affect willingness to allow access to the data by family members.

Main domain	Factor	Example quote
		P28: ...for both the person and the family member because you might be worried about an elderly parent or something and you've not had a phone from them that particular morning or what have you. But if you could see that they're up and about and their heart rate's, okay, etc… P29: Still breathing. P28: …that would be good.
	Supports people with health conditions	P33: I'm not saying while you're perfectly healthy and you can do things, but I mean, at the moment I've known – I know on at least two, maybe three occasions someone who's got dementia, and quite bad, and they now have – everybody will have to know everything about them.
	User decision-making power	P16: There are certain members that you might share it with, but there might be things that you wouldn't say to someone else.
	User decision-making power	P16: There are certain members that you might share it with, but there might be things that you wouldn't say to someone else.

Table 6.5: Overview of facilitators, barriers, and moderators observed that would affect willingness to allow access to the data by family members.

Main domain	Factor	Example quote
	Trust in family member	P26: As long as there's trust, and that people don't feel – like both parties have to be full of trust and respectful. And I think there is a danger it becomes automated. I mean, I've shared data, just step data with the family, and I come off worst. And they have occasionally sent me nudges and smiley pictures (laughs) to encourage me. But I think if it's something serious, I think the trust thing has to be—. F: Has to be there. P26: There. F: So as long as you can choose the family member and you have… P26: Yes.
Barriers	Feeling patronised	P6: …I like a glass of wine at night. If my daughter came back to tell me she was worried with my alcohol consumption, I'd tell her to bugger off. (laughter) You know, it depends on it, doesn't it? P5: …because I – I – I'm on my own and they take on me as a project, sort of thing. (laughs) I – I – I want a bit of freedom. I want – I know I'm a mother but I'm also me. I don't want the – the burden of children being worried about me. P9: You can worry about me when I tell you to.

Table 6.5: Overview of facilitators, barriers, and moderators observed that would affect willingness to allow access to the data by family members.

Main domain	Factor	Example quote
		P18: No way at all, everybody would worry about how much I'm drinking, how much I'm sleeping, how much I'm doing. So I don't want them to know (laughs).
	Causing family concern	P2: But if you go to the doctors with whatever heart rate or whatever, and then you talk to your family member on the telephone and they say, you know, "What did the doctor say?" And you say, "Well, the doctor said my heart rate was very high." Then isn't that just passing on the same worry as the Fitbit would? P10: Yeah, but they're receiving it from you. P3: They receive it from you rather than your device.
Moderator	The user's health	P23: I think again it would very much depend on the actual person's health. Because there are things like with children that have breathing difficulties and things, that may be a life and death situation, where an alarm may go off, and say someone's oxygen's gone off or something. So it would be a very, very personal thing that was made just for that one person.

Research institutes Participants' perceptions of sharing data with research institutes was seen as positive, the main reason being that they see a purpose for the research institute having access to the data.

Participant P33 related the scenario with a project that he is already part of, stating the benefit for future use of this information:

> *Well, I'm already doing this, so – I belong to Biohealth, and I don't know if you know what it is, but this is what's – they've got all my – every single bit of information about me, they even gave me a brain scan, you know, what do you call that machine you have to go into? (P33)*
>
> *Oh, the MRI scanner, yeah. (P27)*
>
> *Yeah, I've had everything done, and they've got all my – every single bit of my information that will be kept for further generations. And the idea is, if they'd have done this say in the 1940s, we probably wouldn't have had Aids or lots of other things, but they didn't have the technology. But what has happened is now, is if somebody gets something in some future time, they'll be able to go to Biohealth and they can then check it up and they can see that a certain person had that say in 2010 or something. (P33)*

Further, participant P19 presented a willingness for research institutes to access data to benefit research into treatment of diseases:

> *Well, there's bio bank isn't there, for a start, where you go along and they take a lot of measurements and they use that for research. And there have been various cancer research programmes going, haven't there? (P19)*

Although some positive rationale were presented, participant P28 stated that he would like the information to be anonymised to avoid private companies associated with the research institute making unwanted contact:

> *I wouldn't – I wouldn't mind my information going anonymously for research, etc. I'd have no problem with that at all. What I wouldn't want, because we've had it in lots of other ways, is to be bombarded by, "You should be taking this vitamin. You should be taking this sleeping tablet to help you with your sleep 'cause you're not sleeping," constantly. (P28)*

A similar barrier regarding organisations with which institutes could be associated, was mentioned by participant P25:

> *No [not selected research institutes on the App], same applies, you don't know who they're connected to. (P25)*
>
> *And that could just be a cover. (P25)*
>
> *Pharmaceutical companies. (P24)*
>
> *Exactly. (P25)*

To sum up, this sub-theme showed the role that different types of third parties play in the participant's views on willingness to share health-related data with them. The factors that act as facilitators, barriers and moderators have been presented.

Aside from the type of third party-related factors presented in this section, further factors that play a role in the acceptability of data sharing are associated with both direct and indirect benefits will be described in more detail in the Usefulness of the Outcome section 6.3.3. In contrast, profit or monetisation was a barrier considering the potential risks that the benefit to participants would not be genuine and related to profits. This sub-theme is described in the following sub-section.

Profits or Monetisation

This sub-theme emerged in comments that participants raised regarding the profits that organisations could make by using the data, which was seen as a barrier by a number of participants, for instance:

> *That's – you've got an excellent point. I would question the reason that they're selling you this gear. And if it was for purely the sake of my health and everything, that would be wonderful, but I just don't believe that. These are commercial companies who are there to make a profit, and to sell. (P17)*
>
> *It's business, isn't it? (P20)*
>
> *It's for their benefit, isn't it? (P13)*

The fact that companies aim to make profits led to participants expressing concerns regarding use of Data Protection being transparent to the user, as can be seen in the quote below:

> *The new data protection laws would say that these companies cannot share that data and must keep it safe, so there's a lot of – in the data protection. But the minute you tick a box saying, you know, it's okay to share that data with somebody else or with a – particularly a company like Tesco's, etc., which, you know, are going to use it to sell you things, you've opened the floodgates from personal experience. (P28)*

Usefulness of outcome

To verify whether the usefulness of sharing data with a third party was associated with some factors that would facilitate and others that would be a barrier to data sharing. Participant P21 expressed that although he would like one specific service, he would be wary of data sharing and receiving a large amount of unwanted communication:

> *... and although I'm a sceptic about alternative medicine, I'm not actually a sceptic about chiro, because it worked for me once. (Laughter) So I am interested in this bit of paper, the big bit, and that question. But when it comes to this bit of paper, would you be willing to share your personal health data with companies such as – and why, no, I wouldn't, and the reason is the same as yours. I'd put not really, too much interaction would follow equals bombarded with stuff... (P21)*

For participant P2 the follow up of booking an appointment with the GP, for example, would be necessary only if there were key concerns that could impact significantly on a person's health:

> *I think it's useful [the follow up from the NHS booking an appointment with the GP] if it's taking information related to something that might be a problem. But if it's just sort of saying, look, you're not walking enough, you know, or you're not eating the right – or what - you know, it's, come and talk to us, you know, so you ignore it, and then it comes back and says, you've still not contacted us so we've made an appointment for you, you know. Then it starts [to feel invasive]– yeah. (P2)*

Another observed factor in Usefulness of the Outcome that would impact on the decision to allow data sharing with third parties would be how the data will be used and the extent to which worry could negatively affect the user. This is evidenced by comments from participants P15 and P17 who expressed their worries regarding the safeguards and information that could be used against the user, for example by insurance companies:

> *I think that the information that is being asked for here is actually quite personal health information that I don't think any commercial organisation should necessarily need to know. And it does concern me a bit because, okay, if my stress level is a bit high, if my blood pressure is a bit high, you know, there isn't an insurance company named on here, but neither is there any safeguards about it not reaching potentially insurance companies. (P15)*
>
> *P17: That's exactly what I've written down actually.*

In the case of sharing data with family members, some participants raised concerns that the data could alarm and inconvenience family members:

> *I think I'd be concerned about sharing my data with my children. Because I wouldn't want them to worry, because for me personally, none of them live close to me. So I wouldn't want them tanking up from the other end of the country because you'd been missing a bit of sleep over a couple of nights. (P10)*

Table 6.6 below summarises the factors observed that would act as a barrier to the use of content shared:

Table 6.6: Barriers perceived by participants regarding lack of usefulness of outcome.

Factor	Example quote
Amount of advertisement	P21: too much interaction would follow equals bombarded with stuff...
Information that could be used against the user	but neither is there any safeguards about it not reaching potentially insurance companies.

Table 6.6: Barriers perceived by participants regarding lack of usefulness of outcome.

Factor	Example quote
Worry about family members' reaction	P10: I think I'd be concerned about sharing my data with my children. Because I wouldn't want them to worry, because for me personally, none of them live close to me.
Amount of low priority follow ups by the healthcare provider	P2: I think it's useful if it's taking information related to something that might be a problem. But if it's just sort of saying, look, you're not walking enough, you know, or you're not eating the right – or what - you know, it's, come and talk to us, you know, so you ignore it, and then it comes back and says, you've still not contacted us so we've made an appointment for you, you know. Then it starts [be inconvenient] – yeah.

Reputation

Participants expressed their beliefs and opinions about some specific companies as factors that would affect the willingness to share the data with that company as can be seen in quote below:

> *Something that perhaps had got a well established name that you knew over a number of years, you know, like Boots and the research that's*

> *gone into their products and things like that. (P23)*

A further factor that would influence third party access would be previous experiences, discussed in the next sub-section.

Experiences

Participants pointed out that previous experiences with organisations would impact on their willingness for data sharing as seen in the quotes below:

> *Yeah, I'm happy to share it with John Lewis. [. . .] I like the company and then I'm very happy to get their health insurance which. . . (P8)*
>
> *[. . .] I had a good thing once with sciatica actually from a chiropractic thing, and I didn't expect it to work and it jolly well did. So because of that one specific thing, it's not the size of the company, it's that particular issue. (P21)*

These quotations reflect situations raised by participants where previous experiences would influence their willingness for data sharing with a specific third party.

Responsibility

This sub-theme emerged from participants' comments regarding the duty that organisations should observe. Three main factors were found as listed below in Table 6.7, comprising views that organisations have (1) the duty to deal with recommendations that could be detrimental to the user, (2) ethical responsibilities that they should consider, and (3) the responsibility for having the control over the data shared:

Table 6.7: Facilitators observed regarding responsibility of organisations that would promote access to the data.

Factor	Example quote
Responsibility over recommendations	P26: Well, they would say you've made that choice. For example, I'm violently allergic to aspirin, but if there was something which was slightly based with aspirin in it, I would end up collapsing. But they're – I'm not sure that they would necessarily check those things with me. I mean, I have the personal integrity to say, is there any aspirin in this but whether the assistant on the counter would know.
Ethical responsibilities	P35: Well, that's a – I mean it – it – I – I have been told, and I don't – I – I haven't got the capability to know whether it's truthful or not, I understand that if in fact these companies, like Tesco, John Lewis and Amazon and etc., who are now making a contribution, would pay their taxes that was expected of them, nothing less or nothing more, but just as should be expected of them, then the NHS wouldn't have any problems on funding.
Responsibility of having control over data shared	P2: I would want something there that says, you know, if you make this selections, we can guarantee your information will not be shared with anybody else other than those that you are selecting.

Motivations for data sharing

Regarding factors that would motivate the decision to share data, it was observed that two facilitators were (1) better services, and; (2) useful information.

The possibility of receiving better services from third parties such as improved quality of content, services or products was seen in some comments as a factor that would motivate the decision to allow access by a third party to users' data as reflected in the quotes below:

> *If it was going to my pharmacy, and I knew they were going to read it, I think that's fine, because they might help me with getting something. (P18)*
>
> *Could be, or any research – not necessarily discounts, no, but any research that's going on currently into that area, that would be useful. (P19)*

Further, use of information from the user was seen as a facilitator to motivate data sharing as evidenced in the quotes below:

> *And the more specific information they've got about you, the more they can personalise what they're trying to sell. (P16)*
>
> *That's what I was thinking. I wouldn't mind sharing, but it depends, with reservations, because it can be quite time saving. And as you say, if a new product comes around, you know, you might become aware of it quite early on. (P19)*

Control

This sub-theme refers to situations observed in participants' comments regarding control and autonomy they would expect when sharing data with third parties.

> *Participant P12 highlighted that control over whether or not to participate would be a key factor impacting his willingness to share data:*
>
> *I don't think it really matters what they offer, provided you have a guarantee of opt out. (P12)*

Participants P12 and P23 highlighted the need for control they would like to have over with whom the data would be shared:

> *But perception would have a lot to do with this as well, if you saw it's being shared with John Lewis, you'd think, oh, that's probably all right. Shared with Wilco, no, I'm not sharing (laughs). (P12)*
>
> *I put only with the companies that would need to know, that actually relate to my health. I wouldn't want it to be (P23)*

Participant P19 further raised the comment that she would like to have control over sharing data only with companies that would be relevant to her health such as pharmacies:

> *Well, I just think if it's to do with health the only one I would go for would be the pharmacy. You know, I don't see the relevance of... Wilko or... (P19)*

Participant P33's comments highlight the connection between an individual's control to decide who to share the data and the outcome use:

> *Well, if they're doing something that's good for it, I don't know. I mean, what actually harm could they do me? It's up to me whether I buy their products. Now, I went to Boots for a hearing test, right, now I could go in there, the guy wanted to sell me hearing aids, and I wasn't too sure about it. And then he kind of come out and I eventually ended up going to the national health one. And I did need it. Where if I'd have gone there, I'd have had to pay for it. Going to national health I didn't. But there again, he still took my name and all my details and everything like that. I mean, I haven't had actually any paperwork or anything come through since that, so I don't know why, but I mean, they could send me things, yeah. (P33)*

Giving the user the control over with whom they would like to share the data and allowing the user to opt in or out were factors observed that would facilitate willingness to allow access by third parties.

To sum up, it was observed that if the user perceived that sharing data promotes a better quality or improved services and/or information this would be a factor impacting positively on their decision to share data.

Trust in the third party

Trust in the third party was seen as a key factor that affects the willingness for data sharing and this permeates factors observed in this research and could be seen when discussing the sub-themes of Type of Third party, the trust factor was present in access to data by family members, companies, and healthcare providers.

In general, it was observed that trust relates to the profits and therefore level of trust is higher towards not-for-profit organisations, such as the NHS. The NHS was seen as a trustworthy organisation in that it does not have the aim of making a profit and consequently those who do have the primary aim of making profits were seen as untrustworthy, which reduces the willingness for data sharing for the same reason, as can be seen illustrated in the quote below:

> *I trust the NHS to tell me something I need for a health reason. I don't trust companies that tell me I need something 'cause they're making a big profit out of it. (P6)*

Similarly, this aspect was raised by participant P25 and P18 regarding allowing access to his data by a chiropractic clinic and an organic store:

> *P25: You don't trust these (chiropractic clinic and the organic store) you know, well, you don't because you don't know what – I mean, are they on with medical things or are they on with financial things? I suspect they're on with financial things...*
>
> *P18: They are, it's all about flogging you something.*
>
> *P25: ...and therefore I don't trust them.*
>
> *P18: Yeah, you're right, I mean, you're giving them something to help them sell.*
>
> *P25: Yeah, it's all big business, isn't it, at the end of the day?*
>
> *P18: It is – yeah.*

One factor seen as impacting on the trust is perceived risk. It was observed in one participant's comment that trust is higher when risk is perceived as lower, and therefore the willingness to allow access to data by third party is positive:

> *Well, if they're doing something that's good for it, I don't know. I mean, what actually harm could they do me? It's up to me whether I buy their products. (P33)*

To sum up, this main theme of third-party related factors identifies that trust is a factor that permeates the willingness to allow third parties to have access to data. The higher the risk observed by allowing access to the data by third parties, the lower the willingness to share the data. Those findings are also part of the model of Privacy Calculus. Furthermore, seeing the potential usefulness of the outcome is a key factor in facilitating willingness to share data, if the end user sees a perceived benefit; such benefits might be improved care planning, better recommendations, or development of new treatments and medicines. The findings from this theme help in understating mainly RO2 regarding identifying the factors that affect the decision for sharing personal data as well responding to RO3 regarding the use of the data collected and the desirable outcome expected by the user. Moreover, others factors such as reputation and previous experiences influence trust in a third party and as a consequence, the willingness for data sharing. The next section presents the theme of User-related factors that influence participants' willingness to allow access to their data.

6.3.4 User-related factors

The main theme user-related factors encapsulates nine sub-themes that emerged from participant opinions. Figure 6.9 illustrates the codes relates to the main theme: user-related factors. The definition of each sub-themes are presented next:

- Actionability of Data: views on the ability to take action in response to the data.
- Agency: comments regarding both their ability to take control and make decisions or a lack thereof.
- Caution: comments expressing worries.
- Choice: referring to having choices available to them, a desire to have other

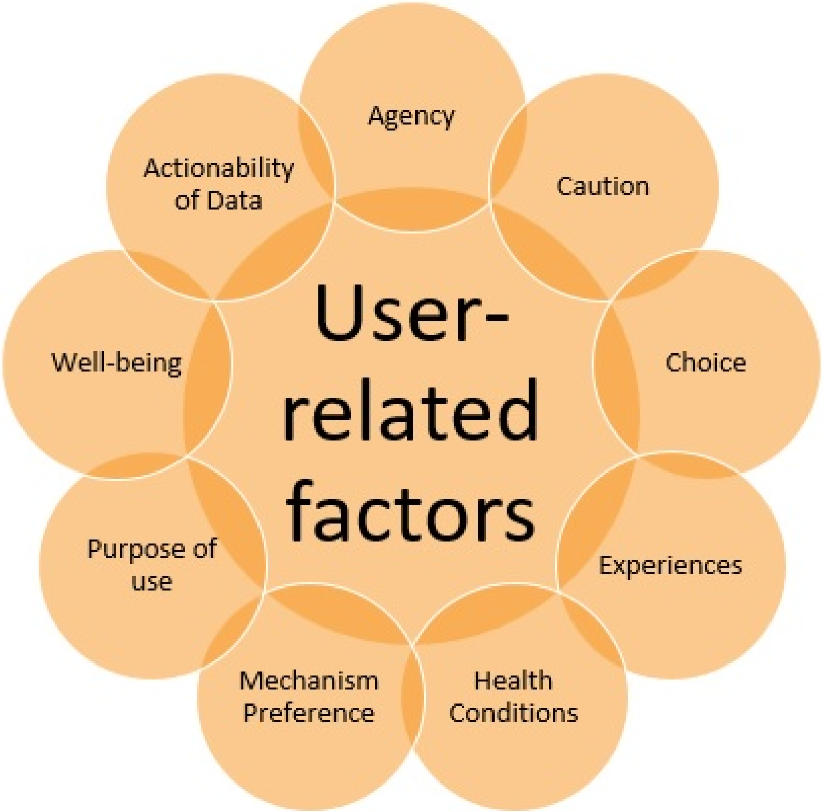


Figure 6.9: Conceptual map of themes identified in the data and related to the main theme: User-related factors. Source: author.

options, or a perception of lack of choice.

- Experiences: situations that have happened with the participant or that the participant has brought about.
- Health conditions / self-awareness: aspects related to health and attitudes towards preventing health problems.
- Purpose of use: seeing (or not) a reason(s) in the use of the device and therefore for allowing the data to be accessed by third parties.
- Well-being: Information relating to whether participants' experiences effect their wellbeing – that is, the state of being comfortable, healthy or happy. This may be something that effects their sense of wellbeing either positively or negatively.

Actionability of Data

This sub-theme relates to participants orienting to the potential to act on the data; the theme was particularly observed in the comments on Scenario 1 regarding sharing data with the healthcare system, where the persona received a letter that an appointment with a GP had been made. For this situation, it was observed that when the user sees that the action is taken based on the data, it is critical that they have a choice or say in this:

> *... I've got a GP friend, the fact that they can actually target individuals with problems and then schedule them into the appointment schedule is that they can offer, it's up to the individual whether they want to take that.(P7)*

Moreover, participant P32 highlighted the importance that all action needs to be optional:

> *You probably – in a way that's perhaps what you wanted, you know, okay, I should be increasing my... But the second one, and particularly the third one, you know, that an appointment is made for you, that's really moving into a different area. (P32)*

Further, P26 similarly mentioned that action taken in response to the data that impacts on the user needs to be offered as optional and not compulsory:

> *I think the appointment should have come earlier and should be offered not made. Because I think most people object to something being made for them when they haven't asked for it. But I think to discuss the benefits of following the guidance earlier on, if you're going to involve the time and cost of a health visitor, it might have been better before Adam's already working out how to burn his fitness tracker.(P26)*

In general, it was observed that action based on the data shared needed to be taken by the user rather than actions being made for them. As an example, the user needed to have the agency to accept or decline the option offered by the healthcare system.

Agency

This sub-theme emerges in participants' emphasis that their ability to be able to make their own decisions is important, and conversely, that a lack of this decision-making ability is not welcome.

Related to the above sub-theme, some comments speak to participants desire to discuss any actions potentially to be taken:

> *I think I have a share in that decision. Rather than just handing over all my data. (P7)*

> *That's what I'm saying, that's – it's – we're assuming that if you've got this data going through and it's constantly showing this person with high heart rate, you'd think – but we're not – are we here to discuss what he's going to do with it, or are we here to discuss whether we're happy to share it? (P2)*
>
> *Well, I mean I think they need to treat you like adults, so they need to have the discussion with you. I mean I – I've – have friends who live in France and – and their healthcare system is different in that every time you go to the doctor and you get tests and things like that, you actually have your medical records. You get a copy of your medical records as well as the doctor. (P6)*
>
> *And then you, when you're going to the doctor next, you take your last one and you have a discussion. I think we're treated like children sometimes with – by the NHS. Doctor knows best. But they have to have a discussion with you first. (P6)*

Overall, there was agreement among participants that their agency is important, that they want to be part of the decision-making process, and be able to have access to their health data more readily.

Caution

This sub-theme emerged in situations in which participants expressed some caution or concern regarding use of the data.

Participant P11 raised a concern regarding the lack of control when deciding about data sharing:

> *P11: Yeah, so with the data that you – they go to, okay, it might say that it's going to just your doctor and your pharmacy. But how do we*

> *know that it stops there, and I don't believe it does. (P11)*

Further, the use of business partners was mentioned by P22 as an aspect that would increase the lack of control:

> *Second thing is like even if they say they're only going to use it themselves, they have a partner. That partner, it doesn't tell you what the partner will do with it. Now there are plenty of cases where a partner has sold all the data to a company that was a fraud company. (P22)*

Participant P15 outlined their concern regarding the information being accessible to unqualified persons such as family members that do not have a healthcare background:

> *Now one of my concerns here is what kind of skills or qualifications has Clare got to actually be concerned about her dad's sleep pattern? (P15)*

It would be a concern if a family member's concern was not corroborated by qualified professionals:

> *Provided that was something that the NHS said – it stops with the NHS (P2).*

Further, participant P11 expressed worry about feeling pressure regarding the outcome from commercial use of the data shared:

> *But would it worry you that with – would it keep being sent to you? In the end it keeps saying, "Well, you need this, that and the other," and you disagree but they keep – they will keep pushing that. (P11)*
>
> *Then you have to unsubscribe, or you have to have the— (P4)*

> *Pushing it until you actually turn around and say, "Okay, I'll have it." (P11)*

Participant P2 raised concerns regarding the accuracy of the data collected:

> *I'd be happy to share that with the NHS, but I wouldn't want to be sort of creating potential time and effort on behalf of the NHS to monitor something that came from a device that I'm not sure is accurate.*

Participant P21 outlined the danger that inaccurate data could bring:

> *P21: I was once a glaucoma suspect eight or nine or ten years ago and then they ruled it out. So it's wrong data.*
>
> *P17: It's invasive, yeah.*
>
> *P21: And it could really mess up—*

Participant P15 raised concerns about how sensitive information could reach companies that the user would not have control over:

> *I think that the information that is being asked for here is actually quite personal health information that I don't think any commercial organisation should necessarily need to know. And it does concern me a bit because, okay, if my stress level is a bit high, if my blood pressure is a bit high, you know, there isn't an insurance company named on here, but neither is there any safeguards about it not reaching potentially insurance companies. (P15)*

Some participants outlined that the healthcare system would be overloaded with information:

> *And all this information went into the NHS, how would they cope? (P1)*
>
> *That's assuming that it's being monitored. And I don't think that the GP service could possibly— (P1)*
>
> *No, it wouldn't cope with it. P3)*

A similar concern was voiced by participant P34:

> *I wonder that. The poor old NHS, they're already overburdened, how on earth are they going to sort all this lot out. (P34)*

Caution regarding invasive devices being used inside people's bodies were raised by participants P3 and P12, whereas participant P10 expressed her discomfort with this kind of invasive device:

> *P3: Do you think in time that we'll have a chip implanted in ourselves?*
>
> *P12: This is going to happen, it's not an if, it's when.*
>
> *P10: It all seems a bit Big Brother really, 1984.*

To sum up, participants pointed out several factors that would bring about caution regarding the use of data, specifically: (1) lack of control by the user; (2) information being accessible by an unqualified person; (3) pressure that it could bring to the user; (4) use of sensitive data by untrustworthy parties; (5) healthcare system being overloaded and, (6) use of invasive devices.

Choice

This sub-theme emerged from participants' comments regarding their desire to have other options or a perceived lack of choices. It was observed that having options would be a facilitator for their willingness to share data.

Choices of functions in the app were observed as allowing the user to opt in or out at anytime:

> *Doesn't number one do that for you, disconnect from the NHS app, and it stops data sharing that does, so you have a choice there to do that. (P3)*

Further, a desire for choices were observed around whether and what kind of information to receive from the App:

> *as suggestions for walking programmes nearby. Adam in my opinion should then have a choice of, well, do I want—*
>
> *F: To receive that or not?*
>
> *P7: Yes*
>
> *P7: Well, Adam receives a letter with tips to increase his activity level as well*

From the example quotes above, it can be seen that the user would like to have choices in the use of the App to opt in and out at anytime and to have control over the information received.

Experiences

This sub-theme emerged in participants' bringing up their own prior experiences. It was observed that participants, based on previous experience, saw some benefit to data being shared more widely than with their GP, particularly in an emergency situation as described by P12:

> *You know, on the point you're making about just sharing with your GP, I know it's only – it's not totally relevant, but my brother had a stroke*

> *and he's got a defib and what do you call it, the pacemaker. Recently went in holiday, got to Lancaster from Preston and his thing kicked in, contact the hospital straightaway, and the data is transmitted to the NHS without any intervention from your GP, surely that would be desirable? (P12)*

Participant P10 mentioned their experience sharing data with a research organisation can positively mitigate against not having an immediate benefit to the user:

> *P10: With bio bank you do sign up in the first place to say that you personally are not going to benefit from it.*
>
> *P12: Which is correct. What happens to all the information?*
>
> *P10: Well, researchers do use it.*

Participant P18 commented that from his experience even the monitoring of his own health data may be detrimental, as he has experienced with his overzealous relative:

> *I wouldn't give my information to those companies anyway. And I wouldn't even want the information myself. (Laughter) I wouldn't look at it. Because my brother-in-law uses something to check his blood pressure and his breathing, and sometimes he'll say, "Oh, me blood's bad today, I'm going to stay in bed." And I think it's making him ill. (P18)*

In contrast, another participant mentioned a situation that happened with his wife where the use of medical devices was beneficial:

> *Well, I can give you an example. We mentioned it earlier. Four years ago now, [name], my wife, got up one morning and didn't feel very well. She'd got a little bit of a pain in her back, nothing bothered her that*

> *much, felt a little bit breathless. After an hour or two, you still didn't feel very good, did you, but we've also got a blood oxygen meter. So she stuck that on her finger and her blood oxygen level was extremely low, well below what it should have been. So we rang triple one and gave them the reading and they said, "Get her to hospital straight away." And it turned out she'd had a pulmonary embolism, a blood clot on her lung. And if we hadn't have had that blood oxygen meter, she wouldn't have gone to hospital because she didn't feel that ill; she just didn't feel very well so we just checked what we thought was going on. (P28)*

To sum up, it is possible to see from the above quotes that participants brought some experiences into the discussion that were seen as positive and that would facilitate the acceptance of use and data sharing, when the participant sees the benefit themselves or for others, as in the case of research. However, negative experiences were also observed regarding the data causing behaviours that could lead to anxiety and paranoia in the user.

Health conditions / self-awareness

This sub-theme addresses aspects observed during the discussion that related to participants' attitudes towards what they do or would do regarding a health condition. Regarding the App option to select or not different types of data to be shared, participant P19 mentioned that this type of data selected would depend on the health condition:

> *It depends what your problem is, isn't it? If you know you've got a problem with your heart you might want somebody to be checking that. (P19)*

Participants P32 and P26 also raised the point that this kind of data access could be useful to detect conditions before symptoms started:

> *P32: I actually had a blood test to do with something else and they said whatever it was you're fine, but you've got diabetes. And I got that before I had any symptoms. So that for me was much better than the other way round.*
>
> *P26: Likewise. Because I had no idea what the symptoms are of diabetes, but I am diabetic. Because it was picked up early in the screening.*

Another situation related to the user monitoring his own health condition, healthcare professionals would have more time to spend with patients in greater need:

> *P28: Well I was – I was surprised. I'm on a blood pressure tablet and once a year they get me in and just check my blood pressure. This year they rang me up and said, "Well, you need an appointment." I said, "Well, I keep an eye on my own blood pressure. I've got a – we've got a monitor." And they said, "Oh, just take your blood pressure and ring – ring it into us."*
>
> *P31: Oh.*
>
> *P28: So presumably that saves the time of a nurse or a doctor...*
>
> *P31: Ooh, yeah. Mmm.*
>
> *P28: ... that could be dealing with somebody with something more serious, as long as my blood pressure's okay.*

To sum up, it is evident that participants' own experiences relating to their health condition or that of a loved one act as a moderator of the willingness to monitor or share specific health data. Monitoring and data sharing in the case of a health condition facilitates seeing benefits for the actual user (early detection of diseases) or for the health care system (better use of time of healthcare professionals).

Purpose of use

This sub-theme emerges in participants' comments on whether and how they see a purpose in using the App or wearable device. In this section, the factors that facilitate seeing a purpose in using the App or the wearable device are presented. This sub-theme relates strongly with the sub-theme Health Condition and was observed in all six discussion groups that took part.

One of the factors that would influence seeing the purpose of use was related to the benefit for the actual user:

> *Well, I don't really mind. If somebody comes up with something that might help me then that's a good thing and I don't look at it negatively. (P8)*

Self-awareness Another factor that facilitated seeing a purpose of use was a potential benefit to self-awareness.

> *If the device was showing your heart rate for instance was high or whatever, then that would be a prompt to yourself. (P2)*
>
> *That gives you an – assessment of your condition of your heart. (P28)*

Participant P28, further observed that from his own experience the use of a wearable device can help with self-awareness:

> *I – I – I do think from personal experience, these gadgets actually do help you to be aware of if you're not moving about enough, etc., because the information is there and they compare like last week, week before how much you've moved, etc. It does make you aware, particularly if you look over a period of time, well, I'm slowing down. I'm not... ...as active as I used to be. (P28)*

Information use in the case of healthcare needs A further facilitating factor was if monitored data could be used to prevent existing conditions from getting worse.

> *But if you went to the hospital, if you were – was ill, I suppose they could have a look at that. I don't know how - (P29)*

Consequently, as the device would provide useful information for health care it was also seen as potentially optimising health care resources:

> *P28: Well I was – I was surprised. I'm on a blood pressure tablet and once a year they get me in and just check my blood pressure. This year they rang me up and said, "Well, you need an appointment." I said, "Well, I keep an eye on my own blood pressure. I've got a – we've got a monitor." And they said, "Oh, just take your blood pressure and ring – ring it into us."*
>
> *P31: Oh.*
>
> *P28: So presumably that saves the time of a nurse or a doctor...*
>
> *P31: Ooh, yeah. Mmm.*
>
> *P28: ... that could be dealing with somebody with something more serious, as long as my blood pressure's okay.*

Participant P6 sees that use of this information would be useful for both the NHS and the user:

> *I think there's – yeah, I think they'll save huge amounts of information – huge amounts of money by doing this, keeping you healthy, stopping you going into long-term hospital. The way that the NHS have been overspent at the moment is because there are too many people who were*

> *stuck in beds 'cause they can't get home and they can't support them in the community. I think this is the way forward, it just needs to be done carefully. (P6)*

To sum up, factors that facilitate participants seeing a purpose in using the device are (1) benefit for the actual user, (2) improved self-awareness, (3) use of information to monitor existing conditions.

Wellbeing

This sub-theme emerged in comments orienting to participants' wellbeing with regards to the acceptability of wearable devices or data sharing.

Participant P9 brought in to the discussion that to be aware of some data would bring a feeling of anxiety:

> *P9: Well, I've always thought a wearable device would make me anxious.*
>
> *P9: Just the having of it...*
>
> *F: Ah, okay, okay.*
>
> *P9: ... and – and just looking at my sleep pattern.*
>
> *P4: You can become obsessed.*
>
> *P9: What can I do about my sleep pattern? Just getting worse because I've been so anxious about it, so I really don't think I need to have -*
>
> *P9: And I don't need to know how many steps I take in a day. I know I don't do enough. I don't need something to tell me to make me more anxious.*

A similar perception was raised by P5 that the type of data collected and shared could act as a fuel for people to obsess over:

> *Sorry, no, I was going to say, I – a – another thing that's just sort of struck me is that I've known people that have been interested in health to an unhealthy degree. Is this just fuelling that? (P5)*

Further, participant P34 raised the comment regarding the importance of wellbeing and that the data collected could support the NHS to target the general wellbeing of specific people:

> *You know, like high blood pressure for example, on a consistent level. Or glucose level, where you've got diabetes looking, when that became – something that could be flagged up, then that could be picked up. Especially for the NHS. I know on Living Well in Rushcliffe, I know there's a programme to try and improve people's overall general wellbeing, there's people feel alienated or have long-term conditions. So I do know that wellbeing is important. (P34)*

To sum up, it was observed that the comments raised regarding wellbeing reflected some caution from participants in that monitoring of health data and sharing it could bring anxiety to the user.

6.3.5 Technology-related factors

The main theme of technology-related factors encapsulates six sub-themes emerging in participants' statements on the App and related data sensor, or on general digital technology. Figure 6.10 illustrates the sub-themes comprising the technology-related factors. In the following the six sub-themes are described before they are presented with participant quotes in more detail.

- Output Quality: sub-theme relating to whether participants can or cannot see

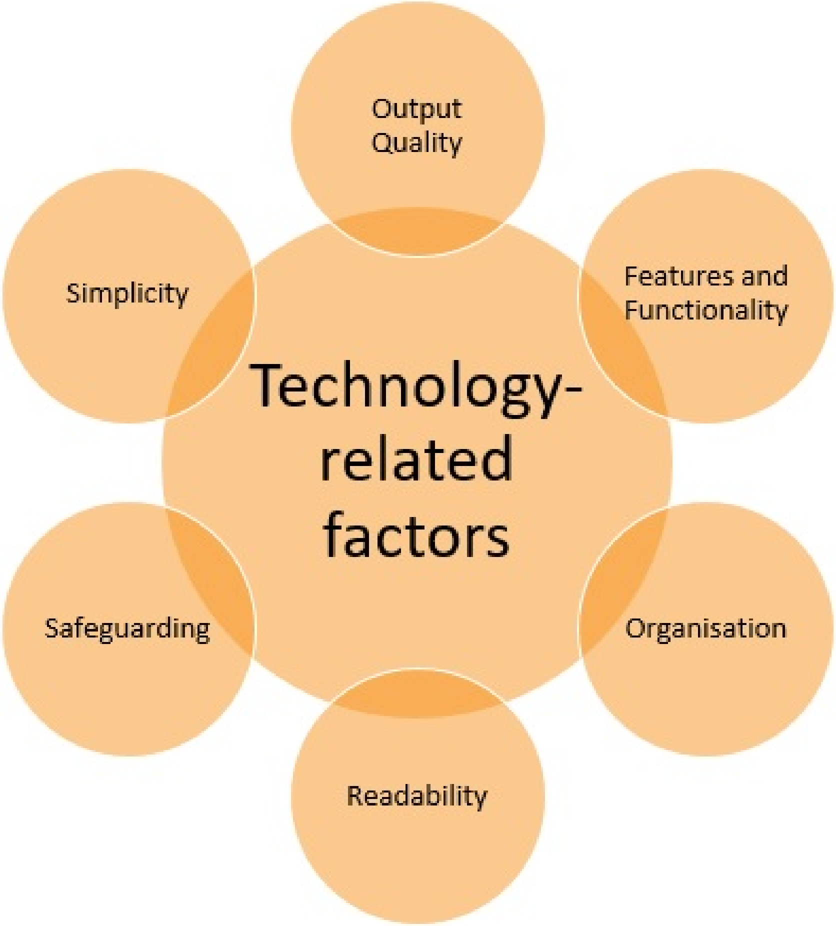


Figure 6.10: Conceptual map of themes identified in the data and comprising Technology-related factors. Source: author.

the value in the content displayed in the App, and comments on what would be desirable content.

- Features and Functionality: sub-theme comprising participants statements on operation, aspects and functions that the App has or should have.
- Organisation: participants' comments regarding systematisation of the content displayed on the App.
- Readability: participants' comments regarding either legibility or understandability. Legibility refers to factors such as font size, colour combinations, background, word style. Understandability involves factors such as word choice and sentence length.
- Safeguarding: comments regarding protection responsibilities that they desire or for which they see the need.
- Simplicity: comments regarding the need for the simplest way to achieve their goals via App use or a simple and minimal design.

Output Quality

This sub-theme explores participants' comments regarding seeing (or not) value in the content displayed in the App or what would be desirable content. One participant stated that to see on screen a list of independent businesses in his area (Scenario 2, Figure 3, Appendix L) would be interesting content to see and therefore would encourage use:

> *P6: But I might go as far as figure three [Appendix L – Figure 3 - Options available on the menu Independent Businesses] just see what – where the independent businesses in my area because you – you sometimes don't know. I mean I think I would be quite interested to find out there's a chiropractor nearby and there's an organic food store.*

> *P4: You've only got – you've only got to put into your search engine ... chiropractors in Nottingham or Beeston or wherever you live.*
>
> *P6: Yeah, but sometimes you don't know what you don't know. I mean I think I might go as far as that and then think, "Oh, that's interesting."*

In contrast, participant P34 raised a concern about the safety of the product being offered:

> *Indicated some products which they consider might be helpful but have not been through any formal testing as far as the scenario says. Not been approved by the NHS or by NICE, so thanks but no thanks, I'm not interested. (P34)*

Table 6.8 presents a list of items observed during the focus group where participants expressed points relating to content they would or would not like to have displayed:

Table 6.8: List of factors relating to output quality of the App.

Factor	Example quote
Being able to view organisations in their areas without the need to share data	P21: On figure one, the one thing I can read is a new feature is available, do you want to check the options available in your area? The answer is yes, I'm actually quite interested in it.

Table 6.8: List of factors relating to output quality of the App.

Factor	Example quote
	P21: And I can see that on this bit of paper because it mentions chiropractic…and although I'm a sceptic about alternative medicine, I'm not actually a sceptic about chiro, because it worked for me once. (Laughter) So I am interested in this bit of paper, the big bit, and that question. But when it comes to this bit of paper, would you be willing to share your personal health data with companies such as – and why, no, I wouldn't, and the reason is the same as yours. I'd put not really, too much interaction would follow equals bombarded with stuff ...
Reassurance that data will not be shared with business partners	P11: Does it – there is a little comment on most – I – with the data that we will not share this data with anybody else or anything. P6: Yeah, partners, yeah, yeah, yeah. P11: That is not on here at all, is it? P2: Well, I would like to see something on there that says, this data will not be shared with any other source.

Table 6.8: List of factors relating to output quality of the App.

Factor	Example quote
Being aware of a potential outcome before taking decision to allow data sharing	I'm still – the following data will be shared with the NHS, I'd just like to know at the outset, what – how that sharing is going to benefit me, you know, that the – the wider community, and the NHS. And to be remind – you know, reminded of that, rather than just giving it over.
Reassurance that consent will always be requested before data sharing started	P12: Just saying under no circumstances will this data be shared without your permission.
Having content displayed in summarized format	P7: You could make it down to one page, rather than ten pages. P1: You could have it in main points. P20: Probably too much, but – tried to put too much in that paragraph. You could probably knock a couple of words out and it would make more sense.

To sum up, Table 6.8 summarises five aspects regarding the content displayed in the App: (1) being able to view organisations in their areas without the need to share data; (2) reassurance that the data will not be shared with business partners; (3) being aware of the potential outcome before taking the decision to allow data sharing; (4) reassurance that consent will always be requested before data sharing; (5) having content displayed in summarised format.

Only this last item relates to content presentation, with the four other items concerning information that would provide reassurance about how the data will be used. Therefore, this sub-theme highlights the concerns of the participants regarding data sharing and data privacy that could be addressed through adjustments to the App's content and design.

Features and Functionality

This sub-theme explores participants' comments regarding features and functions of the App. Table 6.9 below presents a list of eight factors expressed by participants during the focus group regarding what they would like or dislike regarding features and functionalities of the App:

Table 6.9: Factors relating to features and functions of the App.

Factor	Example quote
Receiving notifications	P6: . . . there needs to be an alert there for Adam. . . that if the data shows a concern that he may be contacted. P25: I mean, it's alerting you to things you didn't know about, isn't it? P25: Yeah, I wouldn't know flaxseed is good for my bowels (laughs). P19: Yeah, if it's relevant, hmm.
Having the option to opt in or out at any time	P7: Yeah, but I think it's so I can constantly evaluate that decision, rather than just making it once, and that's it.
Options to receive alerts in different formats (SMS, e-mail) and less frequently	P20: I would say text because NHS use text such a lot about appointments and stuff, reminders. (General agreement)

Table 6.9: Factors relating to features and functions of the App.

Factor	Example quote
	P15: And I think certainly if I was using this kind of app, I probably wouldn't open it that often. F: Ah, I see. P15: So maybe I wouldn't see that notification, whereas I would pick it up, if it appeared as an email. And I'd just prefer email to text. P28: Perhaps a reminder at – at reasonable intervals.
Ability to see brief content of the option before selecting	P21: Sometimes with some screens for some things, if you just reset your cursor on something without clicking it, you get a little - P17: Cross on. P13: Yeah. P21: And if that were truncated and brief and clear, one could do that without committing if you see what I mean, it would just tell me what you meant by purpose. I find that quite useful. Clicking is a bit of a big step. Resting your cursor is a little step.

Table 6.9: Factors relating to features and functions of the App.

Factor	Example quote
Option to change settings	P20: Sorry, did you want to finish, there's something I wanted to point out. You've got option one, disconnect from the NHS app will stop any data sharing. I think that should become option two. Option one could be change data and update. P20: Because things change, your body changes, you get older, dah di dah. P20: Yeah, to be able to change anything that you want to or need to. P15: Oh yeah, good point. P20: Or if you move of course, you've got your – even if they've just got your postcode and you move.
System that can work offline	P20: I'm not on the internet, I pinch internet, so that wouldn't work for me, because you've got to be on the internet. I mean, one thing hopefully they'd be able to do something that it will store the data, then when you hook into the internet it'll go, whoosh, do you know what I mean? Because like my emails at the moment, I can prepare an email at my leisure, as soon as I hit the internet that email will go through.

Table 6.9: Factors relating to features and functions of the App.

Factor	Example quote
App should be secure and provide notifications about what is going to happen	P15: I'm going to disagree actually. Because I think that the information that is being asked for here is actually quite personal health information that I don't think any commercial organisation should necessarily need to know. And it does concern me a bit because, okay, if my stress level is a bit high, if my blood pressure is a bit high, you know, there isn't an insurance company named on here, but neither is there any safeguards about it not reaching potentially insurance companies. P17: That's exactly what I've written down actually. P15: And the safeguard on that first screen, I don't think is a safeguard at all, because it doesn't tell us – all that is is an advertising blurb for new services. It's not until screen four you get any information about what information is going out.
Readability	P21: . . . if a graph is perceived to be unreadable, it's really irritating. (Laughter) I cannot see the axis on there. At first look it looks like P15: Yeah.

Table 6.9: Factors relating to features and functions of the App.

Factor	Example quote
	P21: ... two sets of times, so maybe I'm being a bit dim, but I can't actually read that very – it's presumably telling me -
	P15: That looks fine to me, but I think rather than having the list of things, I might have preferred each to be bulleted on a separate line or something like that. That might be easier to understand which one, but that's all.

To sum up, the factors in table 6.9 relate to the features or functionalities of the App that facilitate acceptance: (1) Receiving notifications; (2) Having the option to opt in or out at any time; (3) Options to receive alerts in different formats (SMS, e-mail) and not too frequently; (4) Being able to see a brief content of the option before selecting; (5) Option to change the settings; (6) System that can work offline; (7) App should be secure and provide notifications about what is going to happen and (8) Readability. Looking at these items and comments, it is possible to see that the majority of items (with the exception of items 6 and 8) relate to provision of features that facilitate control of the App or the data. This suggests that features that empower the user to take control at different levels are critical when designing a system that collects and shares personal data such as the device presented in these focus groups.

Organisation

This sub-theme explores participants' comments regarding organisation of the App screens.

Participant P15 (Scenario 2, figure 4) stated the potential negative impact on the user of combining two options on a screen which may be of no interest to the user:

> *I think there's a point about the acceptability to the respondent, the acceptability of a screen when you get two different things on it. For example, I mean, I could illustrate it if you put two political names that were opposed on the same screen, you might go, I love that one, I hate that one, yuck, I don't want anything to do with the whole screen. Here we've got a chiropractic clinic and organic store. Now I'm not inviting people to agree with me on this, but because of what I'm already said, I feel benign to chiropractic. I think a lot of organic things are rubbish. Therefore the very existence of that would make me hostile. (P15)*

Participant P26 emphasized the preference for a screen to be organised in such a way that it does not present too much information at the same time, even if this would mean the need to visit more screens (see Scenario 2, comparison of Figures 4, 8 and 9, Appendix L).

> *Because not so much is lumped together and not so much is concealed, so you feel you're going through in a logical order, checking from the outset what you're prepared to be open to, not discovering afterwards that you've actually agreed to something you didn't really think you were agreeing to...*
>
> *It's clearer, and it's more structured. And I think it needs to be when you first use it. Even if you think, oh for goodness sake, when can I just*

> *start using this app. I think when you first start you've got to go through this sort of level of acceptance or denial of what they're offering. (P26)*

To sum up, it is possible to see that the way in which information is organised on screen could influence negatively or positively the willingness to share the data depending of the options being presented together. Furthermore, it was observed that too much information displayed on the same screen, even if this meant consulting other screens to get the information needed, could bring a feeling of lack of clarity and therefore impact negatively on participants' perceptions of the App's safety.

Readability

This sub-theme explores participants' comments regarding either legibility or understandability. Legibility refers to factors such as font size, colour combinations, background, word style. Understandability involves factors such as word choice and sentence length. It was further observed that some word choices raised questions about the lack of clarity of meaning as can be seen in the quotes below.

Participant P4 questioned the word connection used in Figure 9 Scenario 2 (Appendix L) regarding the data being kept for 2 years after your last connection:

> *Now what – what represents a connection? It's what they tell you represents— (P4)*

Further, participant P25 questioned the use of the term 'partner' and what exactly these settings would represent:

> *My immediate question was, what does the word associating [meaning partners] mean. And also what does click in settings mean. (P25)*

Presentation of information in tabulated form, using bullet points in a list was seen as a factor that could increase the readability of the information presented, as reflected in the following quotes:

> *It's much clearer, and actually rather than just a listing there, the very fact that it's tabulated, kind of encourages you to go through the choices. (P7)*
>
> *It's easier to see the content in this bullet point list here than it was in the other block. (P34)*

Regarding the ten pages of privacy policy presented in Scenario 1, participant P28 mentioned that the alternative version in Scenario 2 would be an easier read:

> *Well, it raises the relevant points so you're much more likely to read it and then go further into a section that you're not happy with, where if it's just ten pages of text, you'll never read it. (P28)*

To sum up, it was observed that designers need to consider appropriate word choice for the system, aiming for maximum clarity for the user, and that additional information may need to be added, as seen in the Features and Functionality subsection in relation to item (4) Being able to see brief content of the option before selecting could be an alternative to reducing uncertainty about a word that may not sound clear to the user.

To increase readability, participants suggested the use of indentation and bullet points to facilitate system legibility.

Safeguarding

This sub-theme refers to participants' comments regarding responsibilities of protection that they desire to see in the system.

Participant P15 suggested the need to receive notifications about what will happen to the user's data:

> *And the safeguard on that first screen, I don't think is a safeguard at all, because it doesn't tell us – all that is an advertising blurb for new services. It's not until screen four you get any information about what information is going out. (P15)*

Therefore, he would reject the system if it appeared untrustworthy:

> *P15: I've got to say I would actually click no on that very first screen.*

One participant in another group stated that they would simply move further on from that first screen, if they wanted to share data with the company:

> *I mean, if I'd got to figure four I would have already decided that I was happy to go ahead with it and I would click connect. (P25)*

This participant further points out that the confirmation screen is seen as safeguarding that improves trust in the service:

> *It confirms, it would confirm that my judgement is that this is the NHS, it's trustworthy, it's okay. (P25)*

To sum up, it was found that safeguarding would promote willingness to share data, and that information providing transparency on what would happen with the data such as notifications and confirmation screens would increase the perception of safeguarding.

Simplicity

This sub-theme emerged in participants' comments articulating the need for the simplest way to achieve their goals using the App or the need for a simple and minimal design.

Participant P11 stated that they would like a straightforward way to disconnect without the need to go through three screens as presented in Scenario 1 (Figures 6 to 8, Appendix K)

> *It is, it's too long.*
>
> *You – you – you're going from screen to screen and then you – you think you've wasted time. (P11)*

Further, presenting the Privacy Policy option in full was seen as a bombardment of information for the user as reflected in the comments of participant P15:

> *P15: I think life could well be too short for ten pages of turgid text on a phone screen (laughs).*
>
> *F: Yeah, so although you have the full information—*
>
> *P15: I love the tick list on figure ten, that's great, but frankly, the pages of privacy policy*

Provision of information in the right quantity that is clear and complete but also does not overload the user with information is a challenging balance to achieve when designing an App, as participant P6 commented:

> *It's a very, very difficult balance and that's exactly what I think. This is a better way. I think it's more open but perhaps it's too long. . . and I'm not sure if people would read it in full and understand. . . (P6)*

To sum up, it can be seen that participants require less screens and less information on each screen, therefore, a simple design would be better. Thus, they will be presented with a more enjoyable and easier experience; however, equally, participants would like to be made aware of everything that will happen with the data as seen in the Features and Functionality sub-section. Therefore, it is important to make the effort to try to find a good balance between meeting the needs for presenting information, whilst not overloading the user with text.

6.4 Summary

This chapter has presented the four main themes and their related sub-themes, that represent facilitators, barriers or moderators, particularly regarding people's willingness to share data as prompted by the App prototype and scenarios presented to focus groups in this study two. It is evident that the type of third party is a key influence in the participant's view of the potential usefulness of the outcome and their willingness to share data. Especially organisations whose main aim is to make profit represented a major barrier for data sharing. Further, participants' perceptions of this profit-making aim of companies has been seen to be associated with a lack of trust and a lack of seeing a beneficial purpose in using the technology.

This study has shown that the preferred outcome of participants relates to improving their own health or the health of others. Some of the key facilitators were needing to have control over the data, over the outcome and being able to opt in and out at any level.

The next chapter draws together the achieved understanding of the facilitators, barriers and moderators of the acceptability of health monitoring technology and concomitant data use and data sharing (from both studies), and on that basis moves on to present design guidelines (primarily based on the findings of this second study).

Chapter 7

Discussion

The introduction of this thesis presented the following key objectives to achieve:

- A - To identify factors that affect acceptability in the use of sensor-based technologies to monitor health and well-being in different contexts
- B - To investigate factors that affect the willingness to share personal data collected by sensor-based technologies with other individuals, groups or organisations

In the context of this research objectives, a set of factors have been presented in the two previous chapters, intended to support and provide an understanding of the elements that motivate and discourage older adults from using sensor-based technologies potentially and explicitly related to technology design and relevance to the needs of older adults.

Tables 7.1 to 7.5 present the relationship between the emergent factors identified in both studies (study one (1) and study two (2)) and the technology acceptance models considered in this thesis. The last column of the table applies only to study two, considering that it compares both studies related to the sub-theme used in Study 2. The sub-theme in Study 2 could be: Renamed from the first study: renaming involved modifying the name of the sub-theme to ensure it accurately represents the content of the data; Refined: refinement of the sub-themes it was used to entail a deeper analysis to enhance the specificity and granularity of the theme or ultimately, could be Discovered: a new theme that emerged just in study two.

Tables 7.1, 7.2, 7.3, 7.4, and 7.5 illustrate the relationship between the factors that emerged from the studies and associated technology acceptance models. The technology acceptance models were not used to test those models rather as a baseline for understanding the findings.

During the process of analysis it was identified that the use of more than one model would need to be adopted in this study. This was due to the absence of one single model that could address all the domains identified in these studies. It was identified that the models analysed have their limitations but that a combination of these models supported the data analysis and provided insights to develop the guidelines that are presented in this chapter.

Although this study is not designed to directly test models of technology acceptance, the results here can contribute to their specification by providing information about the reasons that drive the factors of these models and promote a model that can truly unify technology acceptance models of health-related technologies that are designed for older adults.

Regarding the guidelines, these were generated empirically by analysing the factors found, the models that are related and critically reflect the key findings to summarise and make them clear and straightforward as suggested by Abascal and Nicolle (2005).

This chapter has two aims. First, to show the extent to which the first and second research objectives have been met by summarising factors that affect the acceptability of sensor-based technology. Secondly, it seeks to contribute a set of abstractions intended to support the work of designing better sensor-based technologies in the

Table 7.1: Relationship between the emergent factors and technologies acceptance models (1/5). * TRF: Technology related factors, URF: User related factors, DRF: Data related factors, TPRF: Third-party related factors. ** Only applies for sub-themes of study two. Source: author.

Study	Theme*	Sub-theme	Description	Objective	Model	Model-related Factors	Comparison with study one**
1	TRF	Features and functionalities	Range of operations and functions of the device as highlighted by participants during the interview.	A	TAM	Perceived usefulness Perceived ease of use	
1	TRF	Warranting alerts	Situation and perception of participants about how an alert would be helpful.	A	TAM	Perceived usefulness Perceived ease of use	
1	TRF	Metrics	Kind of measurement participants were interested in being collected by devices.	A	TAM	Perceived usefulness	
					HITAM	Health Status Health Beliefs and Concerns	
1	TRF	Wearability	Characteristics related to the wearability of the device, predisposition related to wearing or using the device.	A	HITAM	Objective Usability	
1	TRF	Contextual metric data	Data collected using self-report diary to measure mental well-being and preferred way of filling out this diary (mechanism preference).	A	HITAM	Objective Usability	
1	TRF	Data representation and report	Preference for kind of report to visualise information collected. Opinions related to a self-report combined with fitness tracker data.	A	HITAM	Output Quality	
1	TRF	Technology preference	Preferred kind of wearable device.	A	HITAM	Objective Usability	
2	TRF	Output Quality	Extent to which participants can (or cannot) see value in the content displayed in the App, and what would represent desirable content.	A	TAM	Perceived Usefulness	Discovered
	TRF				HITAM	HIT Reliability	
2	TRF	Features and Functionality	Statements on operation, aspects and functions that App has or should have.	A	TAM	Perceived Usefulness Perceived Ease of Use	Refined
2	TRF	Organisation	Comments regarding the systematisation of content displayed on the App.	A	TAM	Perceived Ease of Use	Discovered

future. The discussion is grounded in the material presented in Chapters 5 and 6, with an emphasis on the second study reported in Chapter 6, considering that this further explored aspects observed in the first study and the literature review

Table 7.2: Relationship between the emergent factors emerged and technologies acceptance models (2/5). * TRF: Technology related factors, URF: User related factors, DRF: Data related factors, TPRF: Third-party related factors. ** Only applies for sub-themes of study two. Source: author.

Study	Theme*	Sub-theme	Description	Objective	Model	Model-related Factors	Comparison with study one**
2	TRF	Readability	Comments regarding legibility or understandability. Legibility includes font size, colour combinations, background, and word style. Understandability includesword choice and sentence length.	A	TAM	Perceived Ease of Use	Refined (based on Data Representation in the study one)
2	TRF	Safeguarding	Protection responsibilities that participants desire or for which they see the need.	A	Privacy Calculus Study	Perceived Privacy Risk Perceived Benefit	Refined (based on Security in the study one)
2	TRF	Simplicity	Need for the simplest way to achieve participants' goals via App use or simple, minimal design.	A	TAM	Perceived Ease of Use	Refined (based on the technology Preference)
1	URF	Experience	Participants' situations experienced in the past.	A	UTAUT	Experience	
1	URF	Health condition and self-awareness	Health-related aspects raised and attitudes towards prevention.	A	HITAM	Health Status Health Beliefs and Concerns	
1	URF	Purpose of use	Identifying or not reason for technology use.	A	TAM	Perceived Usefulness	
1	URF	Mechanism preference	Identifying participants' preferred way of completing self-report on wellbeing.	A	TAM	Perceived Ease of Use	
1	URF	Routines	Habits and routines in daily life.	A	STAM	User Context	
1	URF	Technology attitudes	Views and reactions towards technological devices.	A	TAM	Attitude Towards Use	
2	URF	Actionability of Data	Refers to the views about the ability to take action in response to data.	A	TAM	Attitude towards Use	Refined
2	URF	Agency	Refers to the participant's ability to take control and make decisions or lack thereof.	A	Privacy Calculus Study	Perceived Privacy Risk Perceived Benefit	Refined
2	URF	Caution	Expressed worries.	A	Privacy Calculus Study	Perceived Privacy Risk Perceived Benefit	Refined (based on Boundaries for sharing)

presented in Chapter 2.

The discussion focuses on the qualitative results of the thematic analyses presented

Table 7.3: Relationship between the emergent factors and technologies acceptance models (3/5). * TRF: Technology related factors, URF: User related factors, DRF: Data related factors, TPRF: Third-party related factors. ** Only applies for sub-themes of study two. Source: author.

Study	Theme*	Sub-theme	Description	Objective	Model	Model-related Factors	Comparison with study one**
2	URF	Choice	Refers to comments about having available choices, desire for other options, or perception of lack of alternatives.	A	Privacy Calculus Study	Perceived Privacy Risk Perceived Benefit	Discovered
2	URF	Experiences	Situations experienced or brought about by participants.	A	UTAUT	Experience	Refined
2	URF	Health conditions/self-awareness	Aspects related to health and attitudes towards preventing health problems .	A	HITAM	Health Status Health Beliefs and Concerns	Refined
2	URF	Purpose of use	Seeing the (or not) reason(s) for the use of the device, then allowing third party data access.	A and B	TAM	Perceived Usefulness	Refined
2	URF	Well-being	Information relating to whether participants' experiences affect their wellbeing – that is, the state of being comfortable, healthy or happy. This may be something that affects their sense of wellbeing either	A	HITAM	Health Status Health Beliefs and Concerns	Discovered
1	DRF	Intimacy	Comments related to feeling exposed or invaded upon.	A	Privacy Calculus Study	Perceived Privacy Risk	
1	DRF	Technology not warranted	Expressions of caution regarding use or usefulness of technology to monitor or assess user.	A	Privacy Calculus Study	Perceived Privacy Risk	
1	DRF	Warranting invasive tracking	Refers to circumstances that warrant specific monitoring despite potentially invasive nature.	A	Privacy Calculus Study	Perceived Privacy Risk	
1	DRF	Consent	Refers to expressions of need for consent of the primary user of the device, e.g. to collect or share data.	B	Privacy Calculus Study	Perceived Privacy Risk	
1	DRF	Responsibility	Responsibility of physicians regarding sensor-collected data shared with them.	B	Privacy Calculus Study	Perceived Informativeness	
1	DRF	Data sharing	Statements regarding facilitators and barriers to allow third party access (family members, physician, health care system, places visited) to sensor-collected data in different contexts.	B	Privacy Calculus Study	Perceived Privacy Risk Perceived Benefit	
2	DRF	Data collection	Comments regarding data collected by wearable devices presented in the study or other technologies.	A	TAM	Perceived Usefulness	Renamed - Features and Functionalities and Metrics

in Chapters 5 and 6. Although the two previous chapters provided numbers of participants who fall into a given category, these were included to provide context. The same is true for the quantitative data collected via questionnaires during the

Table 7.4: Relationship between the emergent factors and technologies acceptance models (4/5). * TRF: Technology related factors, URF: User related factors, DRF: Data related factors, TPRF: Third-party related factors. ** Only applies for sub-themes of study two. Source: author.

Study	Theme*	Sub-theme	Description	Objective	Model	Model-related Factors	Comparison with study one**
2	DRF	Data protection	Comments regarding process applied or that should be applied to safeguard data and comments regarding the UK adopted General Data Protection Regulation (GDPR).	A	Privacy Calculus Study	Legislative Protection	Renamend - Security
2	DRF	Data sharing	Comments regarding data access by third parties or act of sharing data with third parties (family members, healthcare system, retail businesses and others).	B	Privacy Calculus Study	Perceived Privacy Risk Perceived Benefit	Refined (based on Data Sharing)
2	DRF	Data use	Comments regarding how data will be used.	A	Privacy Calculus Study	Perceived Privacy Risk Perceived Benefit Information Sensitivity	Refined (based on Technology attitudes)
2	DRF	Invasive Tracking	Feelings around intrusive nature of data collected by device or device itself.	A	Privacy Calculus Study	Perceived Privacy Risk Perceived Benefit	Refined (based on Warranting invasive tracking)
2	DRF	Data Privacy/Privacy	Desire to keep away from others or to maintain seclusion as noted in the study one, including data privacy, right to control how personal data is collected and boundaries to protect from unwarranted	A and B	Privacy Calculus Study	Perceived Privacy Risk Perceived Benefit	Refined (based on Privacy)
2	DRF	Privacy Policy	Comments regarding privacy policy - a concept used in wireframes to promote discussion and explore how data could be presented to facilitate greater user confidence. Alternatives ways to present privacy policy	A and B	Privacy Calculus Study	Legislative Protection	Discovered
2	DRF	Data Security	Concerns regarding data being protected from unauthorised access.	B	Privacy Calculus Study	Perceived Privacy Risk Perceived Benefit	Refined (based on Security)
2	DRF	Unwarranted technology	Caution over the use or usefulness of technology.	A	TAM	Perceived Usefulness	Renamend - Technology not warranted
2	DRF	Transparency and Traceability	Comments on the data flow process, clarity of process, and perceptions around lack of transparency.	A	Privacy Calculus Study	Perceived Privacy Risk	Discovered
2	DRF	Trust	Feelings of trust or confidence in the reliability of data collected.	A	PTAM	Trust	Renamed - Trust/Confidence
2	TPRF	Third party type	Partipants' reactions to specific third parties having data access or willingness for the particular third party to have access.	B	Privacy Calculus Study	Perceived Privacy Risk Perceived Benefit	Discovered
2	TPRF	Profits and monetisation	Comments regarding potential profits for organisations using the data.	B	Privacy Calculus Study	Perceived Privacy Risk Perceived Benefit	Discovered

first and the second study; these data were collected to capture some background of the participants, not to test for statistical or quantitative significance. Through thematic analysis, the most interesting or salient quotes to embody each sub-theme

Table 7.5: Relationship between the emergent factors and technologies acceptance models (5/5). * TRF: Technology related factors, URF: User related factors, DRF: Data related factors, TPRF: Third-party related factors. ** Only applies for sub-themes of study two. Source: author.

Study	Theme*	Sub-theme	Description	Objective	Model	Model-related Factors	Comparison with study one**
2	TPRF	Usefulness of outcomes	Comments related to desirable or undesirable outcomes.	B	TAM	Perceived Usefulness	Discovered
	TPRF				Privacy Calculus Study	Perceived Benefit	
2	TPRF	Reputation	Participants' beliefs and opinions about certain companies affect their willingness to share data.	B	PTAM	Trust	Discovered
					Privacy Calculus Study	Perceived Privacy Risk	
2	TPRF	Experiences	Participants' previous experiences with organisations and impact on willingness to share data.	B	UTAUT	Experience	Refined
2	TPRF	Responsibility	Comments regarding duty that organisations should observe.	B	Privacy Calculus Study	Perceived Privacy Risk	Refined
2	TPRF	Motivations for data sharing	Motivations for the decision to either share or not share personal health data.	B	TAM	Perceived Usefulness	Refined (based on Data Sharing)
					Privacy Calculus Study	Perceived Privacy Risk Perceived Benefit	
2	TPRF	Control	Refers to participants' expected control and autonomy when sharing data with third parties.	B	Privacy Calculus Study	Perceived Privacy Risk Perceived Benefit	Refined (based on Agency)
2	TPRF	Third party trust	Refers to expressions of trust or distrust in third party.	B	PTAM	Trust	Discovered

were selected and included as illustrative examples. The factors and guidelines presented in this chapter have been developed in the previous chapters on the basis of data from interviews conducted in the first study and focus groups conducted in the second study.

A list of, in total, 13 main facilitators, and 11 main barriers is presented to address the first and second research objectives regarding factors that affect the acceptability of sensor-based technology and willingness to share data. The guidelines presented in the next section have therefore been developed on the basis of these factors presented in the research. The list of factors and the guidelines are intended to complement one another. Specifically, the list provides general factors that do not relate to a particular system scenario, but rather are relevant to sensor-based technologies more broadly; these guidelines have been developed more specifically on the basis of comments received regarding the prototype presented in the second study.

7.1 Main facilitators of technology acceptability and data sharing

The list highlights the main facilitators of acceptability, including participants' perceived potential benefits in using this technology, confidence in the third parties, and additional factors observed that are generic and not particular to the system presented in the scenarios in the two studies.

To identify the main factors presented in this thesis, a review and reflection were undertaken on the sub-themes that emerged from the thematic analysis of both studies. By critically examining these sub-themes, the participants' comments regarding their perceptions of the presented scenario were analysed, considering whether they expressed positive, negative, or neutral thoughts.

The identification of the main facilitators involved a thorough review and reflection on the sub-themes of aspects that enable and/or support a positive perception of the participant, aligning them with the key objectives outlined at the beginning of this chapter. This analysis considered the potential of the sub-themes to offer insights and implications relevant to the research.

Furthermore, the findings from the thematic analysis were translated into practical and applicable recommendations for the design and development of interactive systems, thereby establishing these recommendations as key facilitators within this project. In this process, the recommendation put forth by Abascal and Nicolle (2005) regarding the importance of clear and straightforward guidelines for designers in implementing and validating their systems were taken into account.

Table 7.6 illustrates the main factors facilitating data sharing and technology acceptability.

Table 7.6: Main facilitators affecting acceptability in the use of sensor-based technologies.

Item	Description	Data-related factors	Third party-related factors	User-related factors	Technology-related factors
1	Identification of purpose of use of device			X	X
2	Improved recommendation/services to user		X	X	X
3	Development of new products/medicines		X		
4	Improved health care delivered		X		
5	Foster linkages to people		X	X	
6	Promote independent living to user		X	X	
7	Support user with health conditions		X	X	

The factors listed below are separated between research objectives A and B, however, it can be seen that these are intrinsically related and may impact both acceptability of sensor-based technology and willingness to share personal data.

A.1) Main facilitators affecting the acceptability of the use of pervasive technologies to monitor health and well-being:

1. **Identification of a purpose of use in the device:** If the user identifies that the use of the technology brings an advantage, a useful outcome, this is positively associated with acceptability. It was observed that most highlighted reasons for seeing a purpose of use related to having a health condition that justifies use, which would increase the perceived usefulness of the device, as one of the variables of the Technology Acceptance Model (TAM) (Davis, Bagozzi, and Warshaw 1989).
2. **Improved recommendation/services to user:** Based on data collected, improved recommendations of products and services could be delivered to the user. This was one potentially useful outcome pointed out by some participants.
3. **Development of new products/medicines:** With data shared, new products and medicines could be developed to help health conditions.
4. **Improving the health care delivered:** Based on the data collected, the health care system could be better informed regarding the health status, which could improve care planning and anticipate future demand.
5. **Foster linkages to people:** Sharing data with family members and friends could promote improved proximity between people as they can be made aware

of loved ones' health data.

6. **Promoting independence in the life of the user:** Use of wearable technologies was seen as a tool that could promote people's ability to live independently for longer.
7. **Support user with health conditions:** Users with health conditions could take advantage of the continuous monitoring of data and the possibility of sharing this data with the health care system and health care professionals, which could subsequently enhance the health care delivered.

B.1) Main facilitators that affect willingness to share personal data collected by sensor-based technologies with other individuals, groups or organisations. Table 7.7 presents the facilitators and related themes upon which they are based.

Table 7.7: Main facilitators that affect willingness to share personal data.

Item	Description	Data-related factors	Third party-related factors	User-related factors	Technology-related factors
1	Identification of a motivation for allowing data sharing	X	X	X	X
2	Adoption of Data Protection Measurements	X	X		
3	Warranties / Responsibility provided by Third Parties regarding use of data	X	X		
4	Trust in a third party		X	X	
5	Positive Reputation of the third party which will have access		X		

Table 7.7: Main facilitators that affect willingness to share personal data.

Item	Description	Data-related factors	Third party-related factors	User-related factors	Technology-related factors
6	Positive previous experiences with the third party		X		

1. **Identification of motivation in allowing data sharing:** It was observed that when participants perceived usefulness in allowing data sharing affected by the context, their willingness for data sharing was higher

2. **Adoption of Data Protection Measurements:** Participants expressed a need for reassurance that the third party is following Data Protection regulations

3. **Warranties / Responsibility provided by Third Parties:** Users need reassurance that data will not be shared with (business) partners. Participants expressed the need to receive information about what will happen to their data

4. **Trust in the third party:** The user needs to be able to trust in the reliability of the third party to facilitate willingness to share data with the third party

   It was observed in the first and second studies that trust in Health Care Systems such as the NHS and subsequently willingness to share data was higher compared with companies; this is due to a lack of trust that companies will deliver services that are free of interest in making a profit rather than the health of the users

5. **Positive Reputation of the third party which will have access:** Opinions held by the user regarding a third party's reputation impact on the decision whether to allow that party access to the data.

6. **Positive previous experiences with the third party:** previous experiences with the third party influence the user's willingness for data sharing.

In the work of Mitzner et al. (2010) that explores the use and attitudes of older adults towards technology, positive and negative attitudes were identified in this study which considered a broad range of technologies in the context of the home, work, and healthcare, from which the attitude coding scheme presented some of the factors that are identified here which were the support for activities, convenience, and features as the top three reasons why they like technology. In the work of Vaportzis, Giatsi Clausen, and Gow (2017), barriers, concerns, advantages and disadvantages were identified related to three core highlighted themes: positive features of tablets, accessing information and the Willingness to adopt the technology. The study of Simblett, Matcham, Siddi, Bulgari, San Pietro, et al. (2019) aimed to identify barriers to and facilitators of engagement with mHealth technology; the findings were categorised into health-related factors, user-related factors, and technology-related factors. This study identified some similarities regarding user-related facilitators and barriers related to the perceived utility, concerns about privacy and security, reliability, convenience, and intrusiveness; however, factors that were not addressed in this research specifically related to data sharing and trust. In this context, it is possible to identify similarities as some features of technology relate to the identification by the user of Perceived Usefulness, which is highly associated with the justification of the main facilitators to accepting technology and data sharing. However, this study brings novelty and innovation to this area, considering it addresses topics not identified in other research.

7.2 Main barriers to technology acceptability and data sharing

To identify the main factors addressed in this thesis, a comprehensive review and reflection were conducted on the sub-themes that emerged from the thematic analysis of both studies. Through carefully examining these sub-themes, the participants' comments regarding their perceptions of the presented scenario were analysed, taking into account whether they expressed positive, negative, or neutral viewpoints.

Identifying the main barriers presented in this section also involved an extensive review and reflection on the sub-themes that represented aspects associated with negative perceptions as observed in the participants' statements. These sub-themes were then aligned with the key objectives outlined at the beginning of this chapter. The analysis considered the potential of these sub-themes to provide insights and implications pertinent to the research.

Table 7.8 presents the three main barriers to technology acceptability and data sharing.

Table 7.8: Main barriers that affect the acceptability of the use of sensor based-devices.

Item	Description	Third party-related factors	User-related factors	Technology-related factors	
1	Inaccurate data being presented			X	X
2	Feeling anxious about using the technology			X	
3	How invasive the device itself is for the user to wear			X	X

A.2) Main barriers that affects acceptability of sensor-based technologies to monitor health and well-being:

1. **Inaccurate data being presented:** some participants stated concerns regarding accuracy of the technology and that wrong decisions could be made on the basis of inaccurate data by the user or the healthcare system
2. **Feeling anxious about using technology:** some participants stated that continuous monitoring could increase their anxiety level caused by using this technology.

   This barrier relates to the findings of Czaja et al. (2006) that indicate that higher computer anxiety predicted lower use of technology. In contrast, this study shows that higher cognitive ability and computer self-efficacy were associated with higher technology adoption.
3. **How invasive the device itself is for the user to wear:** some participants raised concerns regarding devices that were uncomfortable, visible to others, or could even be located subcutaneously and implications this could have on comfort, privacy and security

B.2) Main barriers affecting willingness to share personal data collected by sensor-based technologies with other individuals, groups or organisations.

Table 7.9 represents the main barriers to data sharing and technology acceptability.

Table 7.9: Main barriers that affect the willingness to share personal data.

Item	Description	Third party-related factors	Third party-related factors	User-related factors	Technology-related factors
1	Advertisement that the user could be exposed to	X	X	X	X
2	Profits or monetisation of the data shared		X		
3	Data could be used against user's interests	X	X		
4	Lack of control over access	X	X	X	
5	Feeling patronised		X	X	
6	Brings concern to family members		X		
7	Information being accessible to unqualified persons			X	X
8	Healthcare system could be overloaded		X		

1. **Advertisements that the user could be exposed to:** Users were concerned that as a result of sharing the data with untrustworthy organisations, they could receive excessive advertisements

2. **Profits or monetisation from data shared:** participants were wary of sharing their data with for-profit organisations for fear that their data could be monetised and that products or services recommended by the organisation

would be influenced by their aim to generate profits

3. **Data could be used against user's interests:** concerns were raised that the data shared could be used to deny or increase the cost of health services such as health insurance

4. **Lack of control over access** a lack of control regarding who has or is given access to shared data was voiced as a key concern affecting willingness to share data

5. **Feeling patronised:** some participants felt worried about sharing data with family members due to being afraid of being monitored constantly and the resultant potential to have their actions questioned by family members

6. **Brings concern to family members:** that data could bring concern for family members was also seen as a barrier to data sharing

7. **Information accessible to unqualified persons:** Information could be detrimental or even hazardous to the user's health if people without proper qualifications were allowed to recommend treatments based on this data

8. **Healthcare system could be overloaded:** with the use of the data by the National Health Services, some participants stated that the healthcare system might be put under more pressure to analyse and respond to such significant amounts of data

7.3 Design guidelines for sensor-based technology addressing requirements of older adults

The guidelines presented in this section were developed based on the findings and objectives of this research presented in earlier chapters. Considering the secondary project aim of supporting the design of sensor-based technologies, a list of requirements based on the findings of facilitators of and barriers to acceptance found in this research is presented in this section.

Regarding the guidelines, a reflection based on the material presented throughout this thesis has been undertaken to develop a set of guidelines to the themes that link this material together. Thereafter, a series of judgements have been made about the relevance of these themes to the design of sensor-based technologies and the novelty thereof. These judgements have drawn on the review of literature relating to older adults and ubiquitous technologies in Chapter 2, and on the author's knowledge of literature relating to domains in HCI, which is referenced throughout.

According to Häkkilä and Mäntyjärvi (2006) design guidelines have the power to improve the usability of a product by helping designers to achieve the optimal outcome when designing a product. The authors explain that guidelines should be considered a summary or abstract of current knowledge and a stimulus to further knowledge growth and that these can include restrictions. Furthermore, Mosier and Smith (1985) suggest that guidelines can be generated based on empirical data or from a literature review in the area of interest. The guidelines presented in this chapter are derived from the results of the studies carried out in this research.

Design guidelines are an essential part of human-computer interaction field, considering that they provide an outline of the requirements and needs of a user on how best to interact with technology devices. In the work of Nurgalieva et al. (2017), the abilities of older adults to interact with computers has motivated a wide range of contributions in the form of design guidelines for making technologies usable and accessible for the elderly population. However, despite the growing effort by the research community, the adoption of guidelines by developers and designers has been scant or not adequately translated into more accessible interaction systems, one of the reasons that are presented in this work is due to the lack of clarity of the guidelines, considering that the majority of the guidelines are presented in the form of discussion and using unclear formulation. In this work, the guidelines generated here are shown in topics and with a brief in order to make it clear and straightforward. Furthermore, this research address not only the aspects related to technologies but as well the aspects related to privacy issues that concern older adults, and there is a gap in the literature about research that approach both elements in one study. By integrating aspects related to the technology and privacy concerns in the same study, we found that this study is comprehensive and therefore offers important insights regarding the model to understand the acceptance that can unify that. Considering its multifaceted and complex factors, an expansion of the model would bring an essential contribution to the field.

Although this study is not designed to directly test models of technology acceptance (e.g., TAM), the results can contribute to their specification by providing information about the reasons that drive the factors of these models.

The research presented in this thesis has developed an understanding of the acceptance of sensor-based technologies. As part of this investigation, it is possible to generate a list of design recommendations based on the study results. Table 7.10 depicts the connection between the guidelines and themes. Each guideline is then elaborated upon in detail in the next section.

Table 7.10: Connection between themes and guidelines.

No.	Guideline Title	Tech-related factors	User-related factors	Data-related factors	Third parties-related factors
1	System should inform the user of the effects in case of data sharing	X	X		

Table 7.10: Connection between themes and guidelines.

No.	Guideline Title	Tech-related factors	User-related factors	Data-related factors	Third parties-related factors
2	System should allow the user to receive information from places without the need for the user to share the data	X	X		
3	System should allow the user to unsubscribe or cancel easily	X			
4	System should allow the user to opt-in or out at whatever level when Privacy Policy is been displayed	X			
5	System should inform the user how the data is going to be stored and for how long	X	X	X	
6	System should inform the user of possible partners and other companies that will have access to the data		X	X	

Table 7.10: Connection between themes and guidelines.

No.	Guideline Title	Tech-related factors	User-related factors	Data-related factors	Third parties-related factors
7	System should allow the user to change their choices	X	X		
8	Users should have control over content received		X	X	
9	Users should be in charge of decisions, having the system as a tool to present advice and/or options	X	X		
10	Users should have control regarding which kind of data they want to share		X	X	
11	Third parties should be cautious regarding the output quality and frequency that information is sent to the user		X	X	

Table 7.10: Connection between themes and guidelines.

No.	Guideline Title	Tech-related factors	User-related factors	Data-related factors	Third parties-related factors
12	Extended textual information should be displayed using key concepts in bullet points and offer option for further reading	X	X		
13	System should starting sharing data only after the consent of the main user is requested and given		X	X	

7.3.1 System should inform the user of the effects in case of data sharing

This guideline states that the system interface for sensor-based technologies should have the functionality to alert the user of the possible outcomes if the data collected is shared. Regarding the first study, participants emphasised that in the case of opting for sharing with places visited, they wanted to be aware of the outcomes. Regarding the second study, participants stressed the need to receive an alert to make the user aware that the data show a concern and that they may be contacted. Participants further stressed that this follow-up needs to be made clear on the App instead of providing implicitly understood information. As observed in the first and

Table 7.11: Relationship between the emergent factors and technologies acceptance models in Study Two (1/3). Source: author.

#	Guideline title	Tech-related factors	User-related factors	Data-related factors	Third-party related factors
1	System should inform the user of the effects in case of data sharing	▨	▨		
2	System should allow the user to receive information from places without the need for the user to share the data	▨	▨		
3	System should allow the user to unsubscribe or cancel easily	▨			
4	System should allow the user to opt-in or out at whatever level when Privacy Policy is been displayed	▨			
5	System should inform the user how the data is going to be stored and for how long	▨	▨	▨	
6	System should inform the user of possible partners and other companies that will have access to the data		▨	▨	
7	System should allow the user to change their choices	▨	▨		
8	Users should have control over content received		▨	▨	
9	Users should be in charge of decisions, having the system as a tool to present advice and/or options	▨	▨		
10	Users should have control regarding which kind of data they want to share		▨	▨	
11	Third parties should be cautious regarding the output quality and frequency that information is sent to the user		▨	▨	
12	Extended textual information should be displayed using key concepts in bullet points and offer option for further reading	▨	▨		
13	System should starting sharing data only after the consent of the main user is requested and given		▨	▨	

second studies in the case of the user deciding to share data with third parties, they need to be aware of possible outcomes. Users may not wish to be contacted as a result of the data without prior consent.

7.3.2 System should allow the user to receive information from places without the need for the user to share the data

Participants commented that they might be interested in receiving alerts and content from an organisation; however, this does mean that they would like to share their personal data collected through the wearable device. Therefore, it was suggested that there should be an option in the system for the user to enable notifications from selected places without sharing. In this case, potential benefits that sharing the data would have, such as receiving personalised content, were not seen. In the context of the App shown in Study Two however, receiving personalised content was seen as one of the benefits, as shown in the comments of some participants (P4, P6, P19, P21, P25) in the Output Quality sub-theme regarding Technology-related-factors theme.

7.3.3 System should allow the user to unsubscribe or cancel easily

One of the factors that affect acceptability of use is management by the user; one point suggested refers to the user having the option to unsubscribe or cancel easily, and that this function should be easily found on the App and simple to execute (P33). In addition, the user would like to have the option to see and make changes regarding which data is being shared rather than just given the option to stop data sharing completely (P15, P21).

7.3.4 System should allow the user to opt-in or out at whatever level when Privacy Policy is been displayed

Participants commented that as regards the extension of the Privacy Policy document they would like to opt-in or out on whatever page of this document is being displayed (P27, P34); this feature would increase options for the user and would impact the perceived ease of use of the system.

7.3.5 System should inform the user how the data will be stored and for how long

Participants would like to have transparency from parties with whom their data will be shared, in terms of informing the user for how long the data will be stored and how, such as using cloud services, via which provider, and for how long, as this information would impact on user confidence. (P26, P34)

7.3.6 System should inform the user of possible partners and other companies that will have access to the data

Some participants raised concerns regarding the use of partners or connected parties by some companies and the perceived risk of sharing data with such companies. Therefore, the user would like to be aware of partners and other potential parties that would have access to the data. (P22, P2, P25)

7.3.7 System should allow the user to change their choices

Participants stated that they would like the system to allow them to change their choices regarding which data they want to share and with whom they want to share it. The option to select specific data was highlighted as a positive factor by the participants.

7.3.8 Users should have control of content received

Participants highlighted the need for control regarding the outcome content that they are going to receive. This means that they would like to be given an example of what they are going to have displayed in the system and any other outcomes, such as the example used in the scenario of receiving a letter whereby a GP appointment is booked as a result.

7.3.9 Users should be in charge of decisions, having the system as a tool to present advice and/or options

The user wishes to be in control of the decisions and actions to be taken in response to the data. They would like to be part of the decision-making and to not have decisions being made without their knowledge. For example, if a GP appointment is booked, as presented in Scenario 1 of the second study, some participants stated that this appointment needs to be optional and the user would like to know beforehand that this is one of the possible outcomes before signing up and allowing the data to be shared with the healthcare system.

7.3.10 Users should have control regarding which data they want to share

Some participants expressed that they would like to be able to select which data they would like to share and with whom. The user would like to be able to select and deselect specific data to be shared, this decision would be based on the perceived usefulness of the outcome and confidence in the third party.

7.3.11 Third parties should be cautious regarding the output quality and frequency with which information is sent to the user

The user may like to receive notifications but in a balanced manner avoiding excessive notifications. Therefore, third parties need to use this feature carefully as regards amount of notifications sent to the user, as well as potential usefulness of the content sent.

Considering that output quality was one of the key points of perceived benefits that impact willingness of data sharing, third parties should concentrate efforts on the potential value of information and its relevance to the end user, considering that this will have a direct impact on perceived usefulness, one of the determinants of user acceptance by the Technology Acceptance Model by Davis, Bagozzi, and Warshaw (1989).

7.3.12 Extended textual information should be displayed using key concepts in bullet point format and offering the option for further reading

It was observed that when the privacy policy was presented in full as a prompt to explore perception regarding ways to display regulatory information (normally these are long documents) participants expressed criticism of the lack of readability. In contrast, when presenting the privacy policy only as a link, participants expressed frustration with the lack of information and despite being able to simply click on the link, this rarely ever happens.

Another option outlined during the focus group was where the privacy policy was presented using only keywords on the main page with the option to select or deselect each link and to read more about that section; this option received more positive comments among participants in relation to readability and promotion of choice for the user. Several participants (P2, P5, P7, P11, P26, P27, P28, P31, P32, P33, P34) expressed that use of bullet points makes it more readable and encourages the user to go through the choices. Therefore, the use of bullet points and information displayed in this concise way with the option to read more was favoured by participants. The use of fewer screens and less information on each screen was also stated as a positive aspect by participants.

7.3.13 System should starting sharing data only after the consent of the main user is requested and given

It was observed that participants' would like reassurance by the system that consent will always be requested before data sharing occurs (P12). This sub-theme observed in the research is crucial especially given that the more intrusive the device seems to be, the more participant's highlighted this requirement. The example was the indoor sensor in the first study where this guideline was mostly cited due the perception of invasiveness and the decision made by someone other than the main user to install it in the house.

7.4 Summary

In this section, it was possible to identify the main facilitators to and barriers of the acceptability of sensor-based devices, relating in part to Objective A, achieved with the findings from the Thematic Analysis in the first study, Chapter 5. These findings were then further explored in the second study, the main factors of which are presented in Tables 7.6 and 7.8.

Objective B relating to identifying factors that affect the willingness or not for data sharing was achieved with the second study. While investigation of the Data Sharing theme began in the first study, this was narrowed down with further exploration of the additional theme of type of third parties, and presented in the second study in Chapter 6 as a key aspect for data sharing. Key aspects of factors affecting willingness or not of data sharing are presented in Tables 7.7 and 7.9.

To achieve the main aims of this research of identifying factors that affect the acceptability of sensor-based devices and to address the individual needs of older adults, guidelines comprising 13 items were identified and presented as recommendations to designers and developers, are presented in Table 7.3.

The comprehensive examination conducted in this thesis, which generates the list of main facilitators, barriers, and guidelines presented in this chapter, contributes to advancing knowledge in the field of human-centred design regarding the factors influencing the acceptance of sensor-based devices. The key aspects discussed in this chapter make contributions to the field by identifying:

Worries and cautions: This work sheds light on the concerns of older adults regarding the use of personal health data. These concerns encompass the perceived lack of control over data access, potential access by unqualified individuals, fears of data misuse against user interests, and the commercialisation or monetisation of shared data. Previous research by (Nadal, Sas, and Doherty 2020) has highlighted concerns about information security, while the (AARP 2019) report has expressed worries about privacy and security when sharing personal health data. It is noteworthy that despite these concerns, AARP reports indicate an increase in technology usage among Americans aged 50 and above. This work provides reflections and considerations to address user needs and address the observed concerns in this context.

Elements influencing user acceptance: The research identifies crucial factors that influence users to accept the technology adoption, including clearly defining the purpose of use, improving recommendation services, and developing new products or medications to address health conditions. This addresses the concern raised by Kao, Nawata, and Huang (2019) that IoT-based wearable trackers often fail to meet consumer needs.

Overall, the results of this research provide a comprehensive understanding of older adults' perceptions and concerns related to the use of sensor-based technology. Building upon and expanding the findings reported by Czaja et al. (2006), this thesis suggests that the relationship between older adults and technology is more complex than stereotypical perceptions may suggest, challenging the notion that they are simply afraid of and unwilling to use new technology. The findings highlight the intricacies and various factors influencing their willingness to adopt sensor technology and engage in data collection and sharing, as voiced by older adults in this study.

By presenting these reflections and concerns, this work contributes to the understanding of user needs and offers potential strategies to enhance the acceptance and adoption of sensor-based devices. These insights have significant implications for the design of human-centred systems and can inform the development of guidelines in the field of HCI.

The next Chapter 8 Conclusion provides a comprehensive overview of the thesis, in terms of detailed reflection on contributions, limitations and future research direction.

Chapter 8

Conclusions

8.1 Thesis Overview and research findings

The purpose of this chapter is to provide a detailed reflection on materials and key findings presented in this thesis. This conclusion begins with an overview of the research structure and considers significant contributions. Then, a discussion presents a summary of the concept of acceptability from the perspective of perception before first use, as outlined in Chapter 1. This discussion considers knowledge gained and developed through the work presented in this research, and incorporates an evaluation of how to design a technology that addresses the individual needs of older adults as regards the use of their data to monitor physical and mental health, which forms part of the main objective of this thesis. To address these questions, this research focused on two specific objectives.

The first objective aimed to identify factors that affect the acceptability of sensor-based technologies to monitor health and well-being in different contexts. Study One mainly focused on this objective in chapters 4 and 5. The scenarios developed in Study One then explored different sensors used by the main persona, in different places and contexts. The findings comprised the identification of 28 factors grouped into three main themes: user-related, data-related and technology-related factors, with each theme impacting the wearable device's acceptability and willingness to share the associated data.

The study's results led to a desire to understand further the factors that affect the acceptability of sensor-based technology. Furthermore, the concept of data sharing, in particular, was explored in more depth in the second study, as presented in chapter 6, and focused on exploring different types of third parties. The results also highlighted the importance of the kind of third party that would access the data; therefore, it was deemed worthwhile to study the impact on the willingness or lack thereof of data sharing in the second study. Among the study's participants, physicians, the NHS and family members ranked higher when discussing the desire to share data. The most common explanations were the perceived potential usefulness of the outcome and trust in the third party.

Considering that the wrist-worn device was the type of device found most frequently by participants in the first study to be of greater interest, this device was used in the second study's two explored scenarios, presented as a Mobile App on this device through the use of Wireframes. These were (1) Scenario One regarding data sharing with the healthcare system and the NHS, and (2) regarding sharing data with companies. The choice to present a Mobile App was made based on two factors (1) findings from the study of Umemuro (2004) that found the use of a touchscreen terminal reduced participants' anxiety level given it was perceived as less complex Vaportzis, Giatsi Clausen, and Gow (2017) and (2) smartphones were presented as one of the technologies more often used by participants in the first study 4.2.2.

This study two addressed the second objective: to identify factors that affect the willingness to share personal data collected by sensor-based technologies with other individuals, groups or organisations. In study two, the findings from thematic analysis and the post-survey showed that most participants were willing to accept the technology presented (28 of 35 participants answered in the post-survey that they see a benefit in using a wearable sensor in their daily life). Therefore, this analysis concluded that this perception is impacted primarily when the perceived potential usefulness and usability are the foundation of the Technology Acceptance Model (TAM) framework by Davis, Bagozzi, and Warshaw (1989), surpassed their concerns regarding Data Privacy and Data Security. Similar results were observed in the study by Vaportzis, Giatsi Clausen, and Gow (2017), which showed that participants expressed an apparent willingness to adopt new technologies when usability and usefulness surpassed the feeling of inadequacy. However, concerns regarding loss of social contact and the complexity of technological devices, alongside society's over-reliance on technology, also surfaced in that study. Similarly, while this research showed that participants noted the potential that wearable devices have to enhance health by providing a personalised health service to the user (29 of 35 participants) focus group discussion revealed participants' significant concern regarding data privacy and data security, specifically to the type of the third party that would have access to the data (see section 6.3.3).

The most acceptable third party to have access to the data was the healthcare system, in this specific scenario presented, the UK National Health Service (NHS). Two factors justified this acceptability: (1) the trust that participants have in this organisation and (2) the perceived potential benefits of allowing this access, such as the potential to improve care planning and anticipate future demand. The fact that this organisation is non-profit making is also a crucial factor that impacts this willingness for data sharing, considering that the exact opposite perception was identified when exploring perceptions of sharing data with companies. Companies were the third-party that raised more concerns around barriers to the willingness of data sharing due to the aims of monetisation and profit that those organisations are perceived to have. Although some participants highlighted possible positive outcomes, such as the development of new medicines and improved services, the predominant view highlighted by many participants in all six groups was that this type of organisation would not act in the user's best interest. Another concern regarding sharing data with organisations concerned the amount of advertising and unsolicited communication that would potentially be received, and that data could be used against users' interests, for example, by Health Insurance Companies to increase the cost of policies.

The key findings of the second study were clustered in four main themes: (1) data-related factors, (2) user-related factors, (3) third party-related factors and (4) technology-related factors; a list of main facilitators of and barriers to the acceptability of using sensor-based technologies, and facilitators and barriers affecting willingness for sharing personal data were identified and presented in Chapter 7. These factors address the aim of the second study by identifying the main facilitators and barriers that influence the willingness of data sharing alongside the objective of the first study to identify facilitators and barriers that influences the acceptability of wearable devices achieving, thus, achieving Objective B of this thesis.

Finally, the research elaborates 13 recommendations for designers and developers (see 7.3), which reflect the priorities, desires, limitations and voices of the participants of this research. Most of the recommendations refer to the user's control through the features and options available in the system, aimed at raising awareness of the consequences of system actions and possible outcomes.

8.2 Contributions and summary of thesis structure

Contributions to these topics have been drawn on data and analysis collected through two studies. These studies are structured as follows:

Chapter 4 presented findings from the quantitative data collected by WHOQoL-BREF questionnaires to understand the complexity of Quality of Life that impacts health and well-being. Further, the demographic data of participants presented here provides an understanding of participants' use of technology and their preferences for sensor adoption in this research.

Chapter 5 presented the findings from qualitative analysis in the first study that shows a series of factors that facilitate or are barriers to the acceptability of sensor-based devices.

Chapter 6 presented the findings from quantitative and qualitative analysis from the second study that shows a series of factors that facilitate or are barriers to the willingness for data sharing with third parties.

Chapter 7 presented the main factors that facilitate acceptability of and willingness for data sharing, the barriers, and a list of guidelines addressing older adult requirements.

As regards the contributions of this thesis:

1. This research has explored the acceptability of new technologies. It thereby may contribute to understanding future technology adoption, considering that understanding the acceptability of potential technology before use may facilitate valuable insights for possible adoption.

2. Acceptability and adoption of technology can critically maximise independence for older adults, considering the existing context of an ageing population. Increasing independence can promote a better perception of quality of life (Lee and Coughlin 2015). Government agencies could therefore use the results of this thesis to develop public policies and actions to increase and promote physical and mental health.

3. Detailed analyses of the material collected during these studies and the resultant set of facilitators and barriers contribute to supporting the improved design of sensor-based technologies with a focus on health and well-being.

4. The guidelines presented as a result of the findings from both studies conducted in this research offer recommendations regarding user requirements that designers and developers of sensor-based technologies could use.

5. The findings from this research might contribute to the specification of technology acceptance models by providing information about factors that drive these models. This research did not aim to test models of technology acceptance; rather, the TAM model proposed by Davis, Bagozzi, and Warshaw (1989), HITAM model proposed by Kim and Park (2012), Privacy Calculus Study proposed by Li et al. (2016), PTAM proposed by Connelly (2007) and STAM model proposed by Renaud and Biljon (2008) were used as a base to contextualise the findings. Thus, a potential gap in the HCD field was found, as no single model was evident that could address all factors identified by this research.

8.3 Limitations and suggestions for future work

Whilst the work described here addresses the project aim and objectives of the thesis, many areas could be expanded upon, as detailed below.

1. Investigate the correlation between the participants' quantitative and demographic data. One possible future direction to investigate the factors found could be to triangulate the demographic and quantitative data collected during the studies. As the focus of this study was the use of qualitative methods, the use of quantitative methods could be applied to triangulate the data in further work.

2. Investigate the application of the guidelines. Based on the recommendation, implement the recommendations in a prototype and test with other focus groups of older adult participants to elicit perceptions.

3. Explore the mobile app. Execute workshops with designers to verify the feasibility of the recommendation when designing a new app.

4. Investigate other age groups to test the existence of a generational gap.

5. Explore different types of sensor-based devices. The first study showed various interest levels regarding the sensor-based device used. Given the popularity among participants, this research focused on the wrist-worn device in the second study. However, it may be that the level of acceptability differentiates further depending on the details of the particular sensor-based device. Hence, further research could be carried out to investigate other sensor-based devices to identify associated similarities and differences in facilitators and barriers.

6. Develop a proposal for a specification of a technology acceptance model that unifies the findings from this study. The results from the first and second studies showed the need to adopt more than one model of acceptance to understand all the factors identified. Further work could propose a model to unify and cover the gaps in knowledge in a number of areas, including health, privacy risk and trust aspects of pervasive technologies related to mHealth.

8.4 Final words

This thesis has presented a body of work structured around understanding barriers to and facilitators of the acceptability of sensor-based health-related technologies with a focus on older adults. This research used questionnaires, interviews and focus groups to collect extensive data from more than fifty participants. Twelve recommendations were made for software developers and designers from more than forty themes and sub-themes identified in the users' dataset. What, when, and with whom the user's health data is shared were key and common topics across the recommendations.

The pandemic that started during this research project highlighted the importance of acceptability of new technology that can help users such as patients, health workers and government agencies face the multitude of challenges of COVID-19. Several scenarios used in this project could be easily read as a COVID-related scenarios. Sharing and monitoring patients' conditions remotely was a challenge that health services such as the NHS faced worldwide due to the lack of available health workforce. Given the potential to have COVID-19 as an endemic disease for many years, it is even more important to research and translate the findings into innovation that can help address similar health emergencies.

With an ageing global population, several organisations such as charities, NGOs, pharma and the insurance industry, among others, can benefit from the advances in widespread adoption of technology that can help monitor, share, and provide feedback about individuals' health conditions. The industry, in particular, cloud companies such as Amazon, Google, Microsoft, and others, have been investing in infrastructure that will allow the safe storage of individuals' health data and tools to enable users to decide with whom they want to share their data. In this context, the research conducted in this project has helped identify what aspects can facilitate an increase in the adoption of such technologies.

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Appendix A

WHOQoL-BREF

WHO/MSA/MNH/PSF/97.6
English only
Distr.: Limited

WHOQOL-BREF

PROGRAMME ON MENTAL HEALTH
WORLD HEALTH ORGANIZATION
GENEVA

For office use only

	Equations for computing domain scores	Raw score	Transformed scores*	
			4-20	**0-100**
Domain 1	(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18 ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐	=		
Domain 2	Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26) ☐ + ☐ + ☐ + ☐ + ☐ + ☐	=		
Domain 3	Q20 + Q21 + Q22 ☐ + ☐ + ☐	=		
Domain 4	Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25 ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐	=		

* Please see Table 4 on page 10 of the manual, for converting raw scores to transformed scores.

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I.D. number

ABOUT YOU

Before you begin we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

What is your **gender**?	Male	Female
What is you **date of birth**?	________	/ ________ / ________
	Day	/ Month / Year

What is the highest **education** you received?
None at all
Primary school
Secondary school
Tertiary

What is your **marital status**?
Single
Married
Living as married
Separated
Divorced
Widowed

Are you currently **ill**? Yes No

If something is wrong with your health what do you think it is?__________________________illness/ problem

Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks.** For example, thinking about the last two weeks, a question might ask:

		Not at all	Not much	Moderately	A great deal	Completely
	Do you get the kind of support from others that you need?	1	2	3	4	5

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

		Not at all	Not much	Moderately	A great deal	Completely
	Do you get the kind of support from others that you need?	1	2	3	4	5

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4(F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5(F4.1)	How much do you enjoy life?	1	2	3	4	5
6(F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7(F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither	Good	Very good

				poor nor good		
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18(F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20(F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21(F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22(F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23(F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24(F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25(F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did someone help you to fill out this form?..

How long did it take to fill this form out?..

Do you have any comments about the assessment?

....
....

THANK YOU FOR YOUR HELP

Appendix B

Study one - Advert

HELP SCIENCE TO UNDERSTAND: WHICH TECHNOLOGY DO YOU LIKE TO USE TO MONITOR YOUR WELL-BEING IN THE FUTURE?

We are looking for participants to help give an opinion about 3 devices that will be presented during the study. We want you to help us understand which features of new technologies you are comfortable with and your concerns in use these technologies.

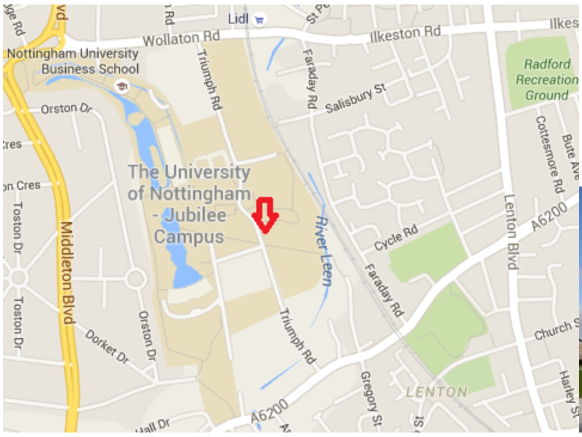
For a maximum of 90 minutes of your time, you will get the chance to give your opinion about technologies to monitor your health in the future. Your feedback will help shape the project's next phase and design. You will also receive a £10 Amazon voucher as compensation for your time on completion of the study!

For more information or book your time slot, please send an email to: elaine.venancio@nottingham.ac.uk

Or call: 07826595628 (Elaine)

Or on the webpage: http://wellbeingnottingham.simplybook.me

The study will take place at Nottingham Geospatial Building, Triumph Rd, The University of Nottingham, Nottingham NG7 2TU. For your convenience, another place could be agreed.



Requirements:

- You must be a British citizen;
- You must be 45 years or over.

Ethical approval: This study has been approved by the University of Nottingham's Computer Science ethics committee.

Appendix C

Study one - Parish newsletter

Collection for Easter Flowers

We will have a collection after mass towards the cost of Easter flowers.

Blessed Sacrament Procession with Bishop Patrick McKinney To pray for the Beatification of the Venerable Mary Potter

Sunday 10th April 2016

Starting at **2.30pm** at St Mary's Church, Goodliffe Street, Hyson Green, NG7 6FY

Finishing at **5pm** at St Barnabas Cathedral, Derby Road, Nottingham, NG1 5AE

For more information please email: office@stbarnabascathedral.org.uk or call 0115 953 9839

Year of Mercy Parish Pilgrimage to Rome

From 27th June-1st July. The price will be £622 per person. Price includes flights, transfers, tour of Rome, and half board (breakfast and evening meal) at the hotel "Domus Carmelitana", *which is actually situated ten minutes walk* from St Peter's! The itinery is still being finalized, but will include daily Mass (including hopefully at St Peter's Basilica) a Papal audience, a Chance to go through the Holy door at St Peter's. As well as many of the other sights. There will also be plenty of free time to explore the delights of Rome, enjoy the Cafes, and, if you want, go shopping.

Repository

Now available: Easter cards, Mass cards and Rosaries.

Vacancy

Our Lady of Perpetual Succour Catholic Primary Academy, Nottingham are seeking to appoint a KS1 or KS2 Phase Leader. Further details are available from the school, admin@ourladyops.nottingham.sch.uk Closing date: 20th April 2016

Silver Jubilee

Fr Michael Gilligan Is celebrating his silver jubilee of ordination this year with mass at St Barnabas Cathedral, 3pm Saturday 7th May. *If you know him and would like to* go, please let Fr David know so he can pass numbers onto Fr Michael by the 10th April.

The Briars Catholic Youth Retreat Centre

The Nottingham Diocesan Catholic Youth Service Trustees seek to appoint to our busy residential youth centre a high quality, suitably qualified **Programme Coordinator** to deliver residential retreat programmes to young people age 11-18.

The successful candidate will be a committed, practising Catholic, have experience in youth ministry, excellent creative and communication skills, be dedicated to young people; their spiritual and human development. Starting salary scale; JNC 6 dependent on qualifications and experience. On-site accommodation provided whilst leading programme. For further details and application pack, contact: Angela Gillespie 01773 852044 angela@ndcys.com

Closing date for applications; Friday 15th April 2016

Interviews; Thursday 28th April to start 20th August.

Clocks Change

Don't forget that the clocks change next weekend.

WHICH TECHNOLOGY WOULD YOU LIKE TO USE TO MONITOR YOUR WELL-BEING IN THE FUTURE?

The University of Nottingham is looking for participants to give an opinion about devices that collect health information. We want to understand which features of these devices could make the user experience more comfortable and enjoyable. You will also receive a £10 Amazon voucher as compensation for your time on completion of the study. Requirements: You must be a British citizen and be 45 years or over. For more information or book your time slot, please send an email to elaine.venancio@nottingham.ac.uk

Sing a New Song

A workshop for parish musicians and all lovers of music with Tony Wheat. Saturday 21st May 10.00am - 4.00pm (tea & coffee from 9.30am) Holy Trinity Community & Partnership Centre, Boundary Road, Newark, NG24 4AU

Cost: £10

International food festival! - Thank you!

We would just like to say a huge thank you to all who made the food festival last weekend such a success and such a fantastic night! Thank you to everyone who cooked food - we couldn't have done it without you! Thank you to all who came to eat the food - we would be up at least two dress sizes if you didn't come! Finally, thank you to the student group for organizing and running the event!

We finally have a name! Agápē - 18-40 Student group

Calling all new students to the Parish! Please do come and join us, whether you're starting a Bachelor's degree or finishing your PhD! We will now break for Easter, have a wonderful time off! Our next meeting will be Friday, 22nd April, at Luke and Ula's house! Do join us for an evening of laughter, games and prayer! As always bring something to nibble on! Contact me for more details, Luke Matthews 07786 012 071 Luke.j.k.matthews@gmail.com

Solidarity For CAFOD - Last few weeks!

Bags of rice of the equivalent size of one day's worth of food in some of the poorest parts of the world will be available throughout lent at the back of the church in both St. Mary's and St. Paul's. Take a bag, put a donation in the tin and all the proceeds will go to CAFOD. We Challenge you to live one day in solidarity with our poorer brothers and Sisters!

Appendix D

Study one - Consent form and scenarios

STUDY DESIGN

This study aims to investigate how cultural differences affect acceptance of the use of different pervasive technologies to monitor well-being and confidence of the users about sharing personal health information with other individuals or organisations. This study will take place in England and Brazil. The interviewer will ask the participants to give their opinions on situations described in scenarios involving attitudes related to the use of sensor-based technologies.

We plan to interview between 10 and 14 participants in each country. The participants must come originally from either England or Brazil. They must also be over 45 years old and be familiarised with the use of technologies, such as smartphones and computers. Before the beginning of the official interviews, we plan to run a pilot with 2 to 3 people to verify the clarity of the scenarios and the length necessary to conduct each interview.

The estimated time necessary to conduct the interview is one hour and thirty minutes maximum. The interviews will take place either in University offices or in an appropriate space in a more convenient location for the participant (e.g. at her/his home). The participants might receive compensation in the form of a shop voucher of no more than £10.00 as compensation for their time on the completion of the study, pending available funding.

The British participants will initially be recruited from members of staff at the University of Nottingham, community members through the website: www.CallForParticipants.com, churches and charity shops. They will be contacted personally, or through an advertisement or announcement at the church, or by email giving the address for a website containing information about the study and the time slots available for the interview. The Brazilian participants will be recruited from the researcher's family and friends. All the information presented to the British participants (i.e. information sheet, consent form, scenarios and personas) will be translated from English and presented in Portuguese to the Brazilian participants. The translation will be done by the researcher, who is a native speaker of Portuguese.

The participants will initially read the information sheet and sign the consent form. After that, they will be presented with one detailed sensor device scenario at a time on a separate sheet. After reading the scenario and seeing the pictures through the storyboard, the participants will be able to ask the researcher any questions to make sure they have fully understood.

The interview process will be semi-structured. The researcher will ask participants questions regarding the scenario they have just read. Depending on their previous answers, other questions may also be asked. After all the questions regarding this scenario have been answered, participants will then be presented with the next scenario and the same process will start again. The order of the scenarios will change for each interview conducted.

After the interview's questions from all the scenarios have been answered, the researcher will give the participant a questionnaire contains 26 questions; the participant will fill it and with this complete their participation in the study.

The questionnaire to be used at the end of the study is from World Health Organization(WHO), the WHOQOL-BREF it's a brief version of the WHOQOL-100. It is an instrument to assessment the Quality of Life. It was developed by the WHOQOL Group and already has the Portuguese version that is going to be used in Brazil and English version to be used in UK. This instrument is attached at the end of this document and the permission to be used is pending.

The results of this study and the transcript of the interviews will be used solely for the purpose of this research and for publications at academic journals and conferences. Paper records from this study will be stored in a locked filing cabinet. All digital data collected, such as, audio recordings will be stored only on a password-protected computer and on a secure server. In accordance with the Data Protection Act, the data will be kept securely for seven years following publication of results. After this time, electronic files will be deleted and any hard copies will be destroyed. At the end of her PhD, the researcher will ensure that all data from this study is passed on to her academic supervisors. The supervisors will then have responsibility for the storage of that data.

Personal information will not be associated with participants' responses, i.e. it will not be possible to identify their names from their responses. Participants will be allocated an ID number on arrival and this will be used with their responses.

The following sections include the documents that will be used in the proposed study.

PARTICIPANT INFORMATION SHEET

Thank you for taking part in this study. This document explains in more detail the steps involved in this experiment.

The goal of this study is to properly investigate how cultural differences affect acceptance of the use of sensor-based technologies to monitor health activities related to well-being. Further, to investigate the confidence of the users about sharing personal health information with other individuals or organization. This study explores aspects of the health, well-being and quality of life, for this reason, includes some sensitive topics such as: physical health, sexual health and psychological health.

The whole study will take no longer than 1 hour and 30 minutes.

Firstly, after reading this information sheet you will be asked to read and sign the enclosed consent form. Feel free to ask any questions you like before the interview begins. After that you will be presented with one detailed scenario at a time on a separate sheet. After reading the scenario you can also ask the researcher any questions to make sure you have clearly understood.

The interview then begins and the researcher will ask you some questions regarding the scenario you've just read. After all the questions regarding that scenario have been answered, you will then be presented with the next scenario and the same process starts again.

After answering the questions from all the scenarios, the researcher will then ask you a few more general questions. You can quit the study at any time without penalty if you simply do not wish to continue. You can also do not answer any question that you do not want to. You can withdraw during or after the study and the data will be deleted. However, if the withdrawal occurs after the end of the study, the data may already have been sent to an academic publication. In this situation, it is not possible to delete the data.

The results of this study and the transcript of the interview will be used solely for the purposes of this research and for academic publication at journal and conferences. Paper records from this study will be stored in a locked filing cabinet. All digital data collected, in this study, such as audio recordings will be stored only on a password-protected computer and on a secure server. In accordance with the Data Protection Act, the data will be kept securely for seven years following publication of results. After this time, electronic files will be deleted and any hard copies will be destroyed. At the end of her PhD, the researcher will ensure that all data from this study is passed on to her academic supervisors. The supervisors will then have responsibility for the storage of that data. Personal information will not be associated with your responses i.e. it will not be possible to identify your name from your responses. You will be allocated an ID number on arrival and this will be used with your responses.

At the end, you will then be asked to fill in a short questionnaire about Quality of Life, you can decide not to answer any question.

If you have any questions, please feel free to ask. The researcher can be contacted at elaine.venancio@nottingham.ac.uk or +44(0)7826595628. Alternatively, you can contact the main supervisor at: derek.mcauley@nottingham.ac.uk

CONSENT FORM

This research project aims to investigate how cultural differences affect acceptance of the use of sensor-based technologies to monitor health activities related to well-being. This study is being undertaken by Elaine Conceicao Venancio Santos at the University of Nottingham as part of her PhD research. Participation in this study is voluntary and you are free to stop the study at any time, without penalty.

The results of this study and the transcript of the interview will be used solely for the purposes of this research and for academic publication at journal and conferences.

The researcher may use some quotation of your interview for academic purpose, if you agree please tick the box below to indicate your consent.
(   ) Yes, I consent   (   ) No, I do not consent

Subject Consent Form

- I confirm that I am a British national and I am 45 years old or over.
- I confirm that I have read and understood the above description.
- I confirm that I agree to audio recording of my interview.
- I confirm that I have read the Participant Information Sheet and the nature and purpose of the research project has been explained to me.
- I confirm that I have received a copy of the Participant Information Sheet.
- I understand and agree to take part in this study.
- I understand that while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
- I understand that data will be stored in accordance with the Data Protection Act 1998.
- I understand that I may withdraw from the study. However, if I withdrawal after the end of the study, the data may already have been sent to an academic publication. I understand that in this situation, will not be possible to delete the data.
- I understand that I may contact the researcher or supervisor if I require further information about the research.

In case you would like to be contacted in the future please provide your e-mail address.

E-mail: ____

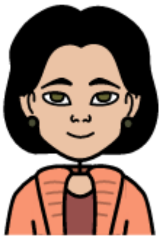
Print Name: ____

Signed: _____________________________   Date: __________________

Interview – Scenario 1

Person 1: Anna, primary teacher, 60 years old

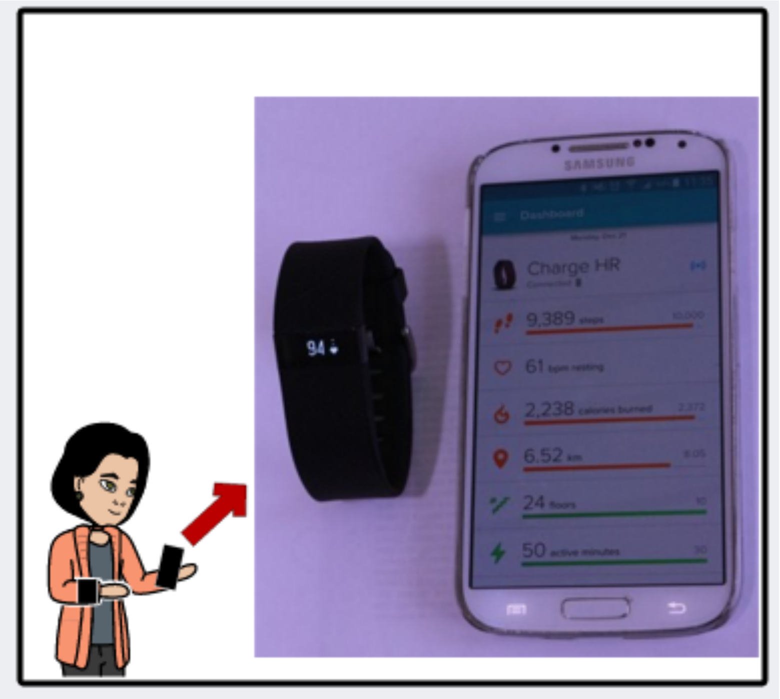
Illustration: Anna's picture



Anna is 60 years old. She married and lives with her husband near her work, which is in a primary school. She has three sons that are adults now and don't live anymore in the same house.
Anna has overall a good health. She doesn't have any condition such as diabetes, high blood pressure, she has healthy eating habits, but she doesn't practice any regular exercise apart from walking to her work, which is 10 minutes on foot from her house.

Scenario 1: Anna using Fitbit and self-report
It is Anna's birthday and she receives as a gift a "Fitbit". This Fitbit is a wristband. It has the time like a regular watch, but this device allows the user to check distance walked during the day, continuous heart rate, calories burned, floors climbed, active minutes, time sleeping and location. And the historical data can be check on a mobile phone or computer.

Illustration: Fitbit's picture

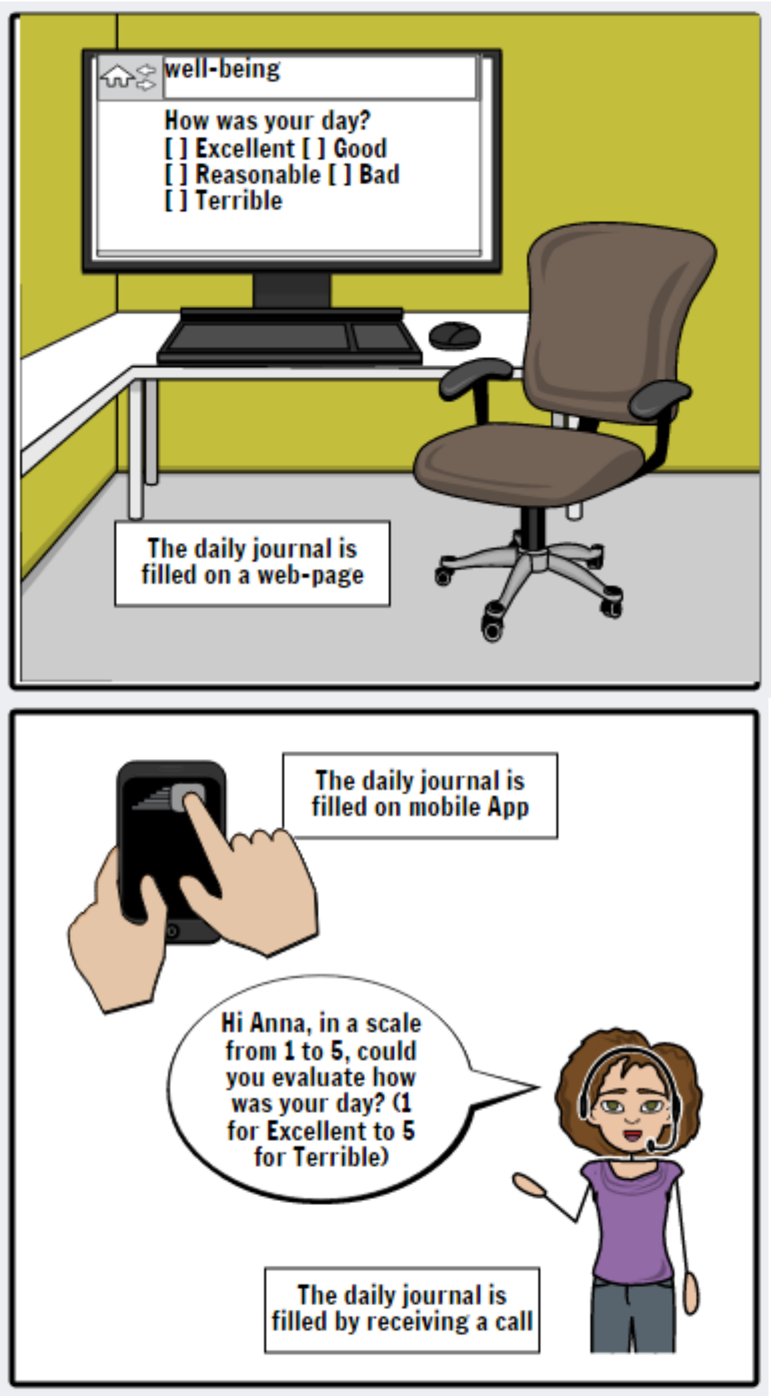


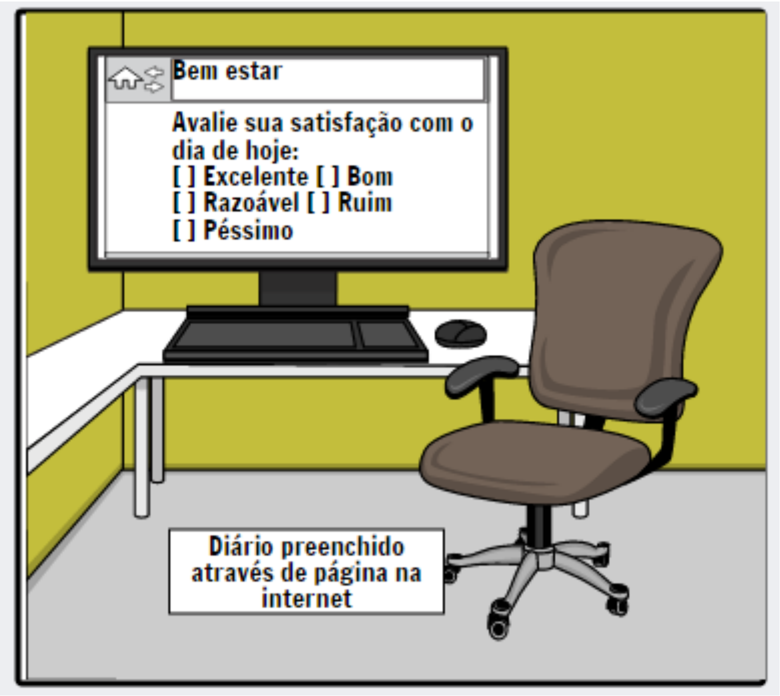
Anna is not sure if she wants to use the Fitbit: she doesn't know how the device works and doesn't think she will get used to wearing every day even to sleep if she wants to monitor her sleep pattern. But, she decides to try to test this device. Some days she forgets to wear it, but on the days that she is using the device, she checks her steps, heart rate and other measures from time to time.

Illustration: Anna wearing the Fitbit
One of her colleagues from work, Lisa, shows Anna a new feature available for Fitbit users, the "MyWellbeingdiary". The "MyWellbeingdiary" is a short daily questionnaire about her subjective well-being, that asks some questions about perceptions and feelings, and combines data from the Fitbit giving information about her overall well-being. She can complete the questionnaire in three

ways: on her mobile phone, using the website or by receiving a call. Anna decides to give to this new feature a go and answer the few questions about her daily perceptions. She chooses to answer the questionnaire by receiving a call, so every day at 7 pm someone call her and make the questions.

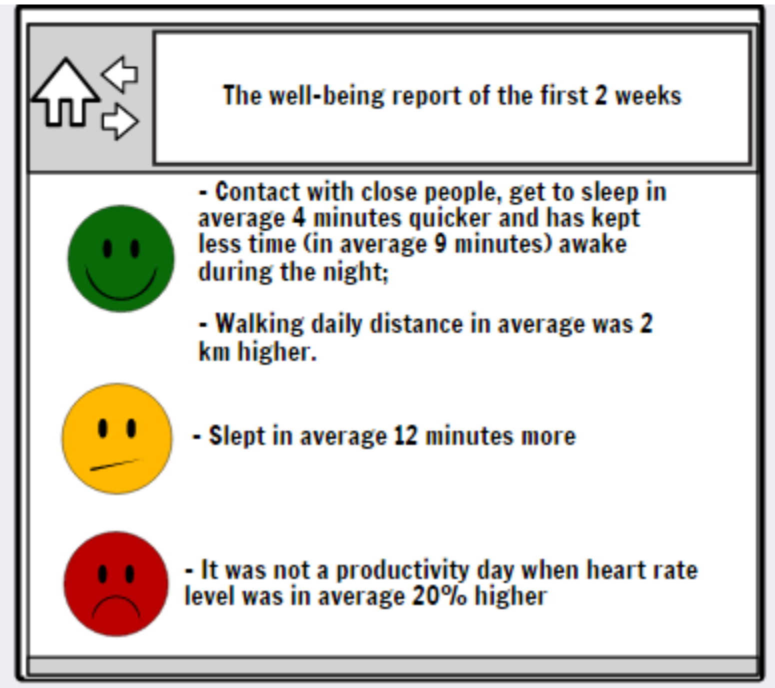
Illustration: Anna checking the options to fill the self-report

	One of her colleagues from work, Lisa, shows Anna a new feature available for Fitbit users, the "MyWellbeingdiary". The "MyWellbeingdiary" is a short daily questionnaire about her subjective well-being, that asks some questions about perceptions and feelings, and combines data from the Fitbit giving information about her overall well-being. She can complete the questionnaire in three ways: on her mobile phone, using the website or by receiving a call. Anna decides to give to this new feature a go and answer the few questions about her daily perceptions. She chooses to answer the questionnaire by receiving a call, so every day at 7 pm someone call her and make the questions.



After two weeks, she opens the program to check her data, and she discovers that when she has contact with people close to her she sleeps better. And, when she manages to walk extra 30 minutes in the day she fells more satisfy with her life. However, there doesn’t seems to be any other connection about her feelings and the physical measures collected on Fitbit.

Illustration: Anna checking the report

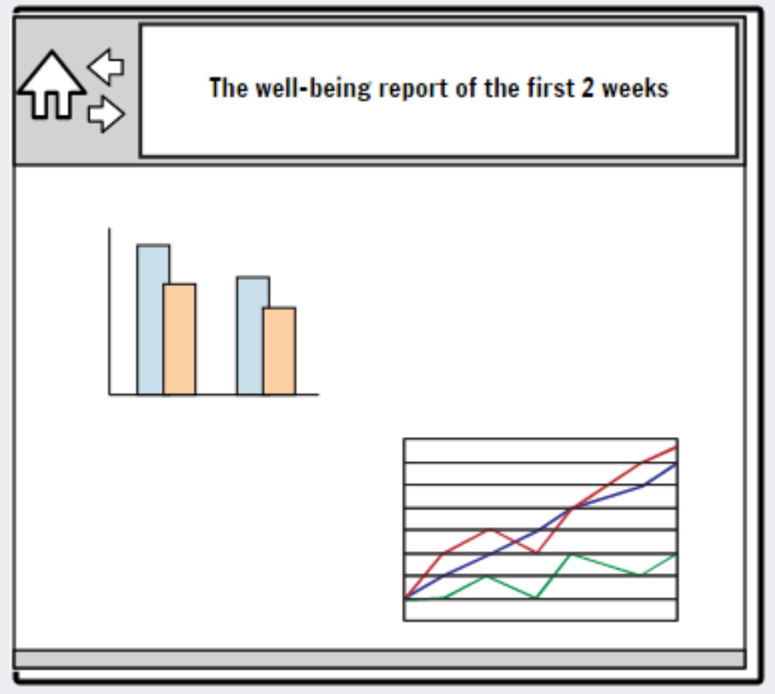


The well-being report of the first 2 weeks

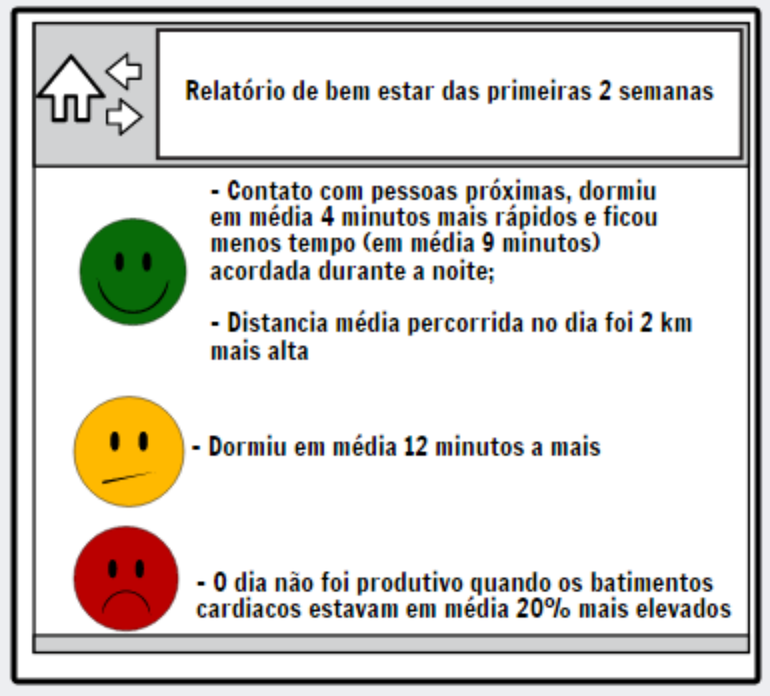
- Contact with close people, get to sleep in average 4 minutes quicker and has kept less time (in average 9 minutes) awake during the night;
- Walking daily distance in average was 2 km higher.

- Slept in average 12 minutes more

- It was not a productivity day when heart rate level was in average 20% higher



The well-being report of the first 2 weeks



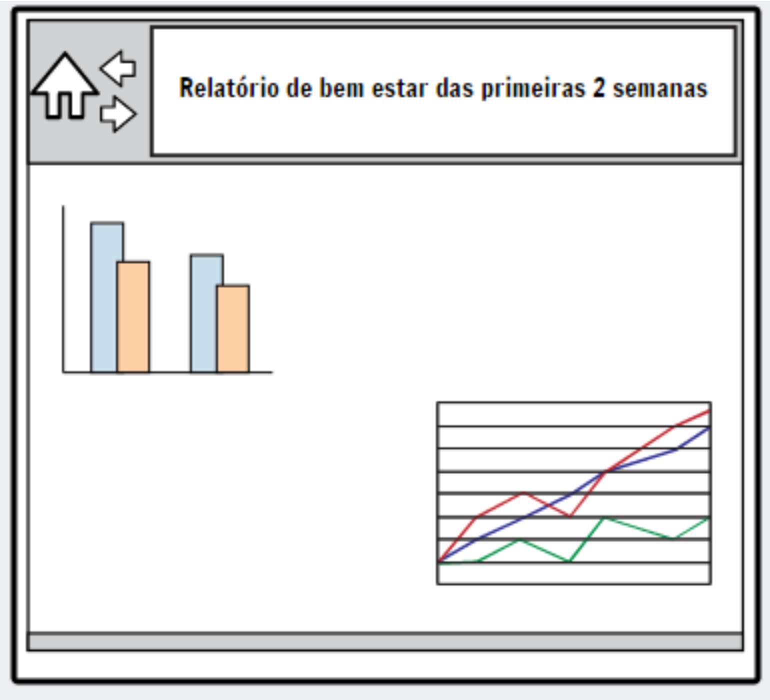
Relatório de bem estar das primeiras 2 semanas

- Contato com pessoas próximas, dormiu em média 4 minutos mais rápidos e ficou menos tempo (em média 9 minutos) acordada durante a noite;

- Distancia média percorrida no dia foi 2 km mais alta

- Dormiu em média 12 minutos a mais

- O dia não foi produtivo quando os batimentos cardiacos estavam em média 20% mais elevados



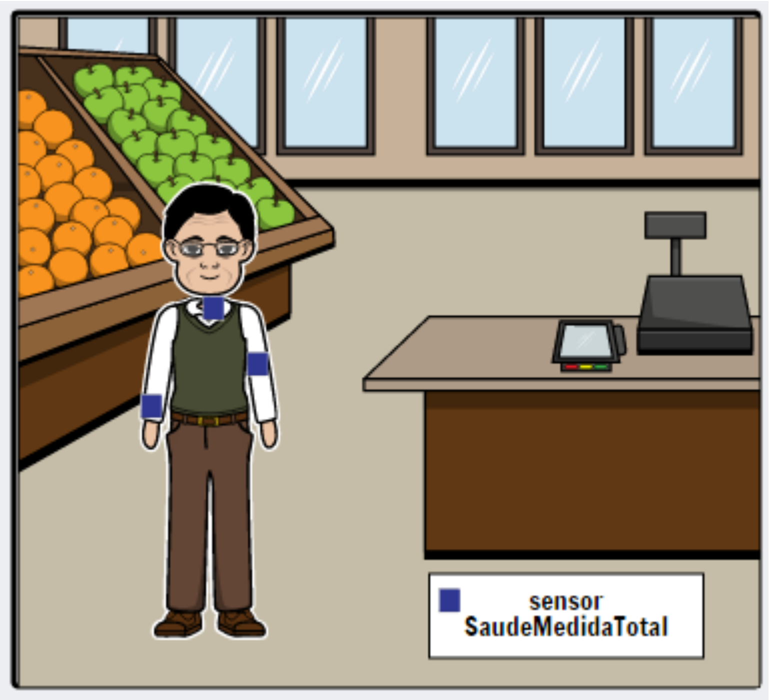
Relatório de bem estar das primeiras 2 semanas

Anna decides to keep her data private, and do not share with family or friends. She knows that she can share this information, but she prefers to keep it because she doesn't feel comfortable sharing it.

Interview – Scenario 2

<u>Person 2: Peter, owner of a grocery store, 50 years old.</u>
Peter is 50 years old and has a respiratory problem. It is a progressive disease that makes it hard to breathe.
Illustration: Peter's picture

Scenario 2: Peter is using an AllMeasureHealth which can communicate with places that he visits
Peter is using a technology called AllMeasureHealth. This is a combination of 3 wearable devices: adhesive in the neck, adhesive in the arm and a wristband. These sensors can monitor respiratory rate, heart rate, blood pressure, electrodermal response, sweat rate, sugar level, body temperature, distance walked during the day, continuous heart rate, calories burned, floors climbed, active minutes, time sleeping and location.
Illustration: Peter wearing the AllMeasureHealth



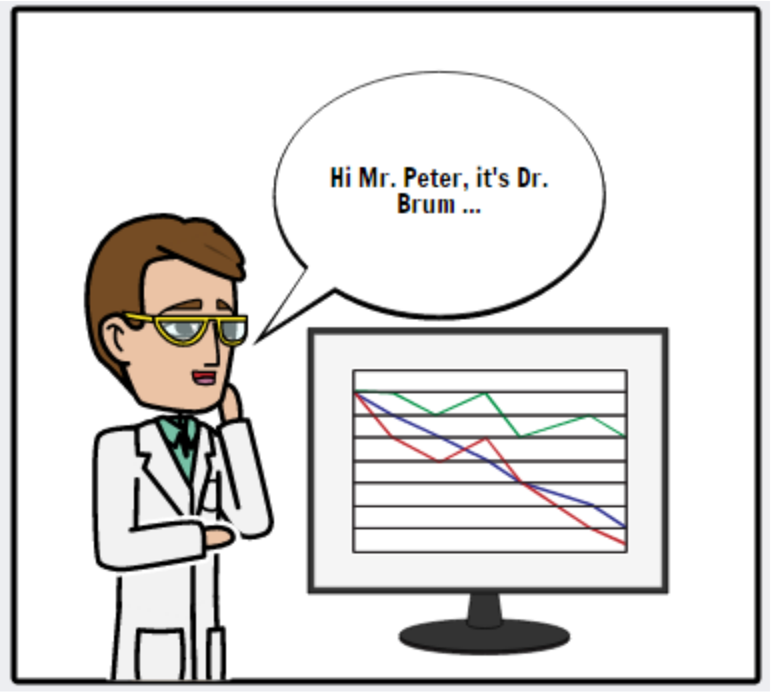
When Peter bought the AllMeasureHealth he started wearing it is composed of it every day and only took it off to take a shower. Even though it is comped of 3 devices, he doesn't find it difficult to remember to wear it. He decides to wear the AllMeasureHealth because he can monitor his health using this data collected.

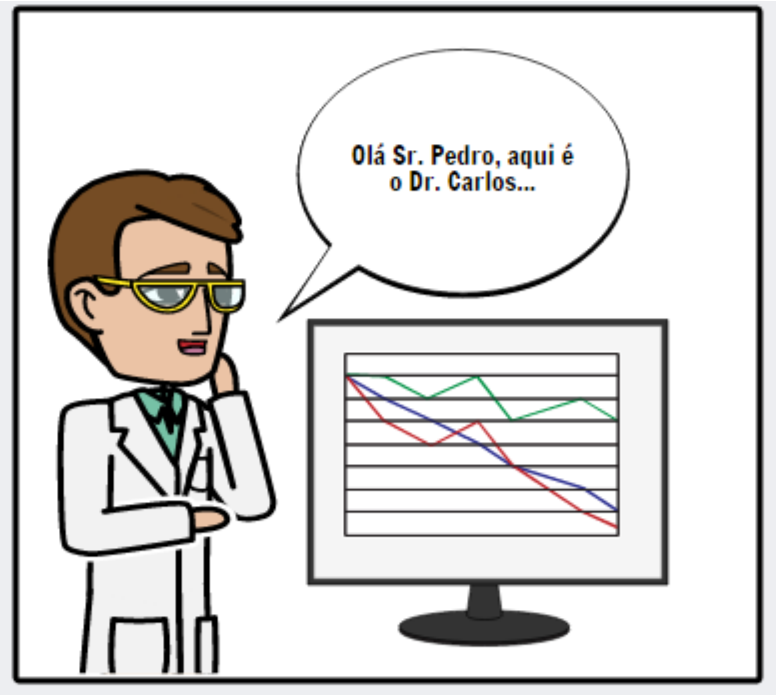
Peter notices some changes in his respiratory and heart rate so books an appointment with his doctor to ask about it. The doctor verifies the data and asks Peter how he has been feeling in the last month. He also asks to Peter if he has been having difficulty breathing, and what has been his level of physical activities, in order to check the accuracy of the data collected by the AllMeasureHealth device.

Illustration: Peter at the GP

After Peter confirmation on the data collected, the doctor decides to give to Peter a new prescription to assist with his breathing. He also asks Peter authorisation to access the data of his wearable device. So, the doctor can check how Peter is responding to the new medicine.
Peter has been using the new prescription for 10 days now and receives a call from his doctor saying that the breathing rate is more normal now but that Peter has decreased his activity level, and this is dangerous due his condition. So, the doctor asks Peter increase his activity level.

Illustration: Peter receiving a call from his doctor





Peter is heaving a really busy week at work and now he is feeling better, he is not managing time to do exercise anymore. He intends to return to his exercise routine: however he doesn't like this call from his doctor because he feels that his doctor is putting pressure on him.

After some tough weeks Peter is going to spend some days off and is going to visit his brother in another region. He is at the airport waiting for his flight, but he is not feeling very well so he goes to the toilet and remains there for some minutes to see whether he feels better.

Illustration: Peter is not feeling well at the airport

A few minutes later, two airport staff knocks his door asking if everything is fine. They received an alert from his device informing that something was wrong with him.
Peter is already feeling better and leaves the toilet. It was just a minor indisposition but he feels very annoyed by somebody bothering him in the toilet.

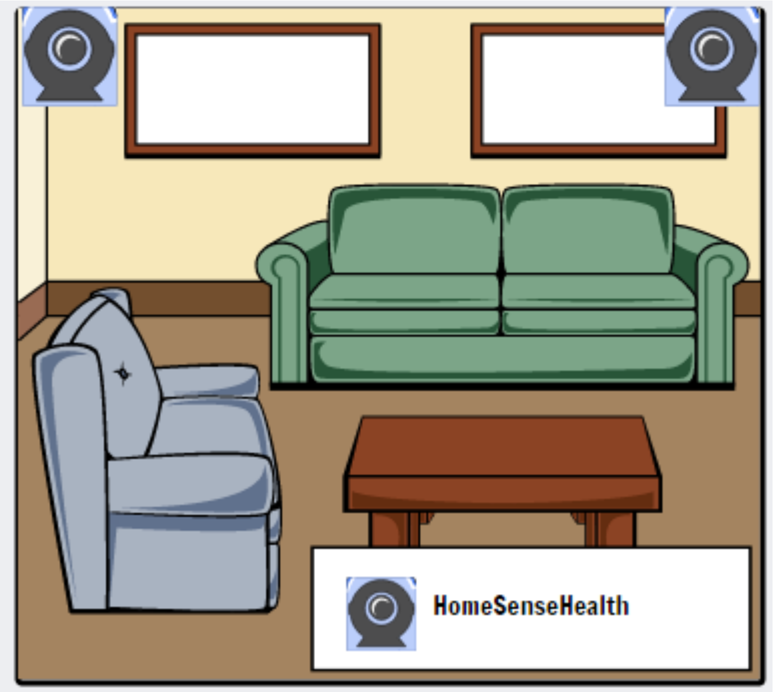
Interview – Scenario 3

Person 3: Helena, 67 years old, depression
Helena is 67 years old. She retired 2 years ago and she is struggling with some episodes of depression and adapting to the new routine. Currently, she spends most of her at home. Helena has some discomfort in her knee and some days her shoulder also bothers her. Because of that, she is not the active person that she used to be years ago. But even with a bit of pain, she likes to go outside and meet people.
Helena does not like to use technology. She only uses it to pay bills, read e-mails and news and check her bank account
Helena's daughter, Elisabeth, lives with her, and decided to install indoor sensors inside the house to monitor health related activities. She thinks that now that her mother is at home, it would be a good idea to follow her daily life activities, particularly because she cannot stay with her mother most of the time due to the busy routine.
Illustration: Helena's picture

Scenario 3: Helena has home HomeSenseHealth that her daughter installed

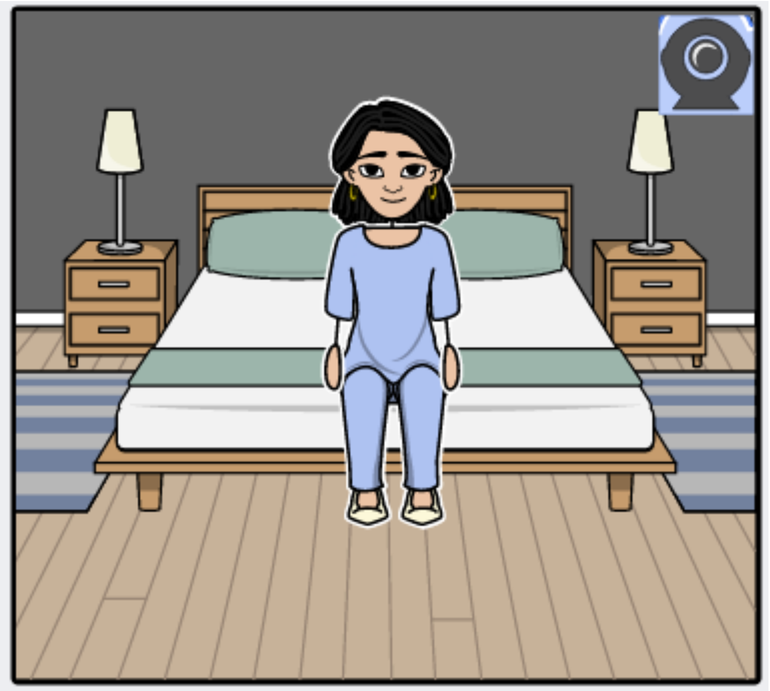
The indoor's sensors called HomeSenseHealth is able to detect: temperature inside the house, time spent in one of the rooms of the house, time spent on the same activity. In can also detect static activities such as: reading, working in a computer, watching TV and motion activities like cleaning the house, cooking or walking around the house. The system was installed by the decision of Elisabeth, Helena's daughter.

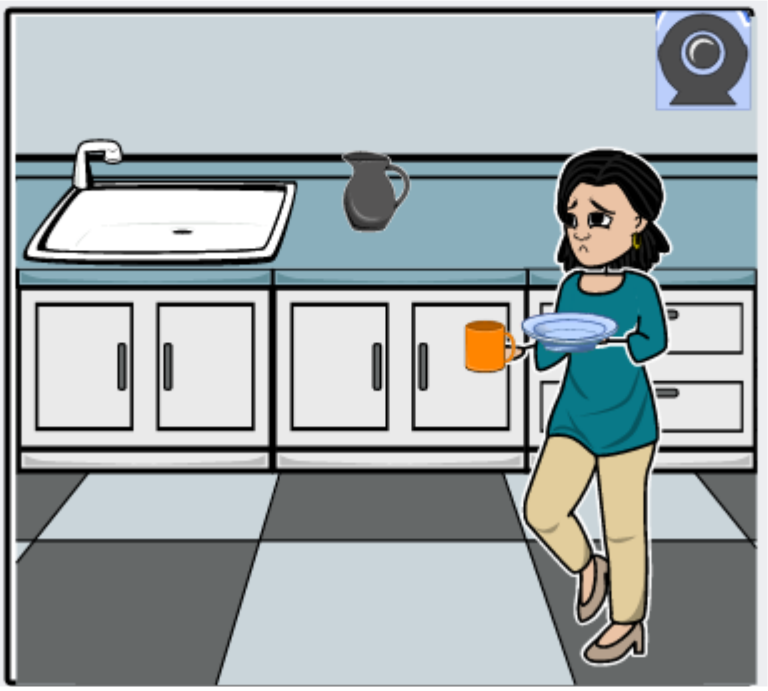
Illustration: indoor sensor



Helena spends most of the time inside the house and she is trying new activities that she may like to do. She is going out to talk with friends and helping the charity shop a few days as well. However, in the last days she has not been feeling in the mood to go out and she is spending all day inside the house. She is refusing invitations to go out with friends. In the evenings, she talks a bit with Elisabeth, her daughter, when she joins her for dinner.

Illustration: Helena doing housework inside the house with the indoor sensor





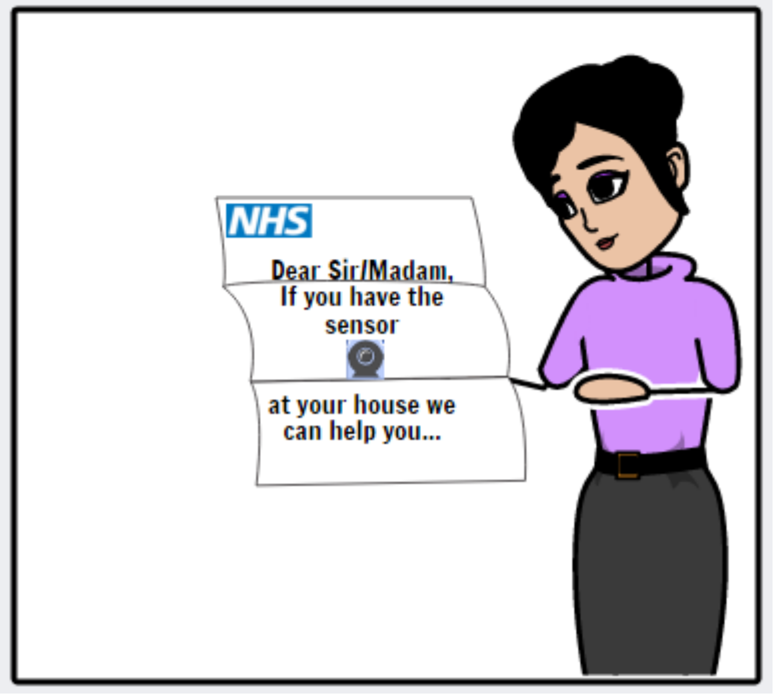
One night during the dinner, Elisabeth says to her mother that the HomeSenseHealth sensor, is reporting low activity level and she asks Helena the reason why she is not going out. Helena decides that she will go out more. But, in the following days she decides to stay at home to make the domestic activities and to watch TV programs and reading books that she likes.

Illustration: Helena reading a book

A few days later, Elisabeth asks Helena again to go outside and looks for mental support because she might suffer of depression. She has been seeing the reports from the HomeSenseHealth informing that Helena is staying most of her time watching TV and reading, Helena agrees to return to her outdoor activities but she doesn't agree with the mental support. She intends to go out but at the end just stays at home because she is not in the mood.

After a couple of weeks, they receive a mail from the public health care informing that they are asking people that have indoor sensor to authorise sharing the data collected with the health system. They want to provide advice customized and health program support to the person's situation based on the data collected. Elisabeth is considering that because it could help Helena's health.

Illustration: Letter from the Department of Health asking people to share data from the HomeSenseHealth




SAÚDE
Prezado Sr.(a),
Se você possui
o sensor
em sua casa nós
podemos
ajudar...

Interview Questions - Scenario 1:

a) How would you respond to a new technology device? Do you consider yourself excited to test new technologies?

b) What about wearing a device every day? Would it be a challenge for you? How about wearing one during sleep?

   OR

   How would you feel wearing a device every day?
   OR
   How would you react having to wear a device every day, even when sleeping?

c) What is your opinion about the daily short questionnaire? Which way would be easier to respond on daily basis? Mobile App, Website Questionnaire, Answering a call?

d) Would you consider subjective aspects such as life satisfaction and people's feelings important when evaluating well-being or objective measures collected through the Fitbit are enough?

e) In your opinion, Anna took a good decision keeping her data private? Why?

Interview Questions - Scenario 2:

a) Would you like having many measurements available, such as: monitor respiratory rate, heart rate, blood pressure, electrodermal response, sweat rate, sugar level, body temperature, distance walked during the day, continuous heart rate, calories burned, floors climbed, active minutes, time sleeping and location?
b) Is there any specific measurement that is interesting to you? Which measurement are not necessary?
c) Would you prefer a device with more capabilities (more measurement types) even if it means more sensors around your body or would you prefer having just one device with fewer measurement types?
d) If you notice something unusual in your wearable device's data, what would be your first thought? For example, your blood pressure looks high in the last days but you do not feel any discomfort.
e) Would you trust in the data collected through the device or would you consider the device's date incorrect?
f) Do you believe the data collected through the wearable device could provide the doctor a better information about how well Peter is responding to the new treatment?
g) Would you prefer give to your doctor access to the data as Peter did or keep the data private?
h) What is your opinion about the call? If were you, would you like the doctor accessing your data?
i) Do you think Peter has reason to feel under pressure due to the doctors call?
j) Do you like the idea of having a device that shares your information with the physician?
k) Would you like the device notifies you about the decrease of your activities level or is it irrelevant??
l) Do you think that a call from your physician would change your behaviour or routine?
m) In the last situation when Peter was at the airport, and the airport's systems received the vital signals and the location of the person. In your opinion, is it a good feature? Would you like to share your information with the places that you visit?

Interview Questions - Scenario 3:

a) Would you feel comfortable having an indoor sensor at your home?
b) Do you think the information Elisabeth received is important to help to monitor her mother's well-being?

c) Was the information that Elisabeth received useless? Could it be that the behaviour changes sometimes and it doesn't mean anything significant for well-being?
d) In your opinion, the change of Helena's behaviour from an outgoing person that likes to talk with people to someone who spend most of the time watching tv, a signal of wealthy issue?
e) In your opinion, has Elisabeth made the right decision monitoring her mother's activities inside the house?
f) In your opinion, is the data collected by these sensors import? Why?
g) In your opinion, should Elisabeth shares her mother's data the health care system? Could it be a good decision? Why?
h) From Helena's perspective, do you think her daughter has the right to share the data?

General question:

1) How many hours do you use technologies in your daily life?

2) What are the technologies that you are using in your daily life?

Appendix E

Study two - Project information

PROJECT INFORMATION

Date: 29/05/2019

Project: Exploring the potential benefits and the barriers of using personal data collected by wearable technology to promote health and well-being

School of Computer Science Ethics Reference: Ref no. CS-2018-R53

What is this research about?

This PhD project aims to explore the factors of acceptance on ubiquitous technologies in order to support the design with the focus on older adults. The contribution of this study is to explore potential aspects in accepting and using ubiquitous technologies and how these could have an impact on health and well-being.

Purpose of the workshop

The findings from the previous research have revealed factors that promote and factors that restrict the use of data collected through wearable devices regarding user protection, fairness, accuracy and traceability of the data that the user would be exposed. These factors result in concerns regarding data privacy and consequently, a breakdown of trust: user sometimes does not know when to trust, does not see reciprocity and/or benefits for the data being collected, used and/or shared.

The main topics we would like to explore with you in this workshop are:

- What are the user expectations and requirements regarding the balance between received personalised services and the use of the data collected by sensor-based devices?
- What is the impact of privacy in the acceptability of data collection and data sharing? How does it influence user wellbeing and agency?

- What would be useful to enhance trust in the use of the data and data sharing by the user? How should these issues be addressed?

Nature of participation in the workshop

Taking part is **entirely voluntary**. You will be thanked for your time with a £15 Amazon voucher for attending the session.

Participant engagement

We are inviting people aged **65 years old and plus** to take part.

The workshop is an interactive session, attended by a group of 10-12 participants and led by a trained facilitator who will provide a safe space for participants to express and share their views, and to work in groups. Sessions will be as interactive and fun as possible and will last around 2 hours and a half, including a break for refreshments (provided by us).

You will be asked to complete a survey both at the beginning and at the end of the session, a health monitoring form, and to complete and sign an informed consent form.

The workshop will be audio and video recorded and the audio will be transcribed, using an external company, and photos from the workshops may be collected.

There are no right or wrong answers. You should have previous experience of using digital technologies and internet search.

At the end of the workshops, we will ask you whether you would like to be contacted by us to take part in future Horizon related activities. You don't have to agree to this and it won't affect your participation in this workshop. If you do, we will ask you for your preferred way to be contacted (i.e. by email or by phone).

Workshops will take place on 26th of July at 10am, 30th of July at 2pm and 08th of August at 10.30am at Central Library – Cecil Roberts Room.

For more information, and to sign up, please contact **Elaine Venancio Santos – elaine.venancio@nottingham.ac.uk.**

Benefits and risks of taking part

It will help you to reflect and find out what you and other people think that makes the data collected through sensor-based devices online platforms and services acceptable and trustable. You will also have the opportunity to express your concerns, discuss, and learn about issues that might affect you when online. What else will you gain from taking part?

- Enhance critical thinking when making decisions about personal data and how this data could be used and shared in a fair way.
- A safe space to share your views and suggestions for change in relation to data privacy and trust when using online service.
- A £15 Amazon voucher thanking you for attending the session.

There are no risks associated with your participation.

Use of your data

Your ideas and other information generated from your participation (i.e. video, audio recordings, pictures, transcriptions, group work materials, surveys) will be only used for the team's research purposes, and any project results will not identify you. Dissemination of results of these research workshops will include publications in open access journals, conference presentations, public engagement, PhD Thesis and others research activities.

The materials produced during the workshops will be stored securely.

The University may store your data for up to 25 years and for a period of no less than 7 years after the research project finishes. The researchers who gathered or processed the data may also store the data indefinitely and reuse it in future research.

A University of Nottingham approved external transcription company will have access to the audio-recordings, and this will be conducted under strict best practice criteria that comply with General Data Protection Regulation (GDPR).

The video, audio recordings and photos and your contact details (if you consent to be contacted by us as explained above) will be stored securely on password-protected University-approved research storage in accordance with the Data Protection Act (1998). Only the research team will have authorised access to the full collected data. However, note that no computer system is completely secure, so it is always possible that a third party could obtain copies of your data.

Will pictures/videos be taken? What will they be used for?

Pictures will be taken from the paper material used during the workshop and of the participants, and will be used in research activities (publications on open access journals, conference presentations, public engagement, PhD Thesis and others research activities).

Videos will be recorded with the purpose to triangulate the surveys that are going to be completed at the beginning and the end of the session with the participant’s opinions and perceptions collected during the workshop.

Pictures from the video with your visual image might be taken to illustrate the use of the workshop in research activities. If this happens, we will contact you, and you will have the opportunity to opt out. Photographs and videos will not be anonymised. This means that we will not blur or pixelate faces. Personal names will never appear next to the corresponding image.

Future use of your data

The information gathered from your participation in this workshop may also contribute towards future research funding and/or public engagement applications. No contact details will be shared with any other parties. Anonymised transcriptions may be archived and reused in the future for developing further resources related to this research.

Anonymised transcribed material may be stored on external data repositories. This will be conducted under strict best practice criteria that comply with GDPR.

Mixed personal data

The research will gather ‘mixed’ personal data, i.e. data that simultaneously involves multiple participants and/or is irreducibly social in nature. In this case, mixed personal data includes multi-party conversation recorded on audio and materials that are produced from group activities. We can only delete mixed personal data if all parties to it withdraw their consent. However, we will redact any data that identifies you in public presentations and reports of this research insofar as this is practicable.

Procedure for withdrawal from the research

Participation is **voluntary**, and you have the right to **withdraw** at any time, without giving a reason. Once withdrawn, no further data will be collected and any data directly linked to you (e.g. surveys and health monitoring forms) will not be included in any further work and will be deleted if possible. However, much of the information collected is of group activity, so in many cases contributions will not be specifically linked to individual participants and so will not be identifiable for exclusion.

If you wish to withdraw during the workshop please speak to a member of the research team. Alternatively, after the workshop, please contact elaine.venancio@nottingham.ac.uk. To help us to withdraw your data, you will need to quote your ID number (given to you in the workshop). If you receive no response from the researcher please contact the School of Computer Science's Ethics Committee.

This PhD research is being supervised by Prof. Dr. Derek McAuley [derek.macauley@nottingham.ac.uk] and Dr. Joel Fischer [joel.fischer@nottingham.ac.uk] and the workshops are being supported by ReEntrust's project team.

Contact details of the ethics committee

If you wish to file a complaint or exercise your rights you can contact the Ethics Committee at the following address: cs-ethicsadmin@cs.nott.ac.uk

Appendix F

Study two - Consent form

CONSENT FORM

University of Nottingham
UK | CHINA | MALAYSIA

Date: 29/05/2019

Project: Exploring the potential benefits and the barriers of using personal data collected by wearable technology to promote health and well-being

School of Computer Science Ethics Reference: Ref no. CS-2018-R53

Please tick the appropriate boxes

1. Taking part in the study

	Yes	No
a) I have read and understood the project information sheet dated 29/05/2019 or it has been read to me. I have been able to ask questions about the workshops and my questions have been answered satisfactorily.	☐	☐
b) I consent voluntarily to be a participant in the workshop and understand that I can refuse to answer questions and I can withdraw from the workshop at any time, without having to give a reason.	☐	☐
c) I understand that taking part in the workshop requires me to provide data and that this will involve: filling in an anonymised health monitoring form and an anonymised pre-session and a post-session survey, having audio and video recordings taken that capture what I say and contributing to group activities during the session.	☐	☐
d) I consent voluntarily to photo images of group and the work written materials, that will be produced during the workshop, to be taken.	☐	☐
e) I consent voluntarily to photo images of group with my visual image to be taken	☐	☐
f) I understand that the audio/video recordings and photos of group work that will be produced consist of mixed personal data (i.e. data involving myself and others) and that this cannot be deleted without the other participants' consent if I choose to withdraw from the study.	☐	☐
g) I understand that if I withdraw from the study and the other participants do not withdraw their consent, any use of mixed personal data will not disclose my identity.	☐	☐

Please tick the appropriate boxes	**Yes**	**No**
2. Use of my data in the study		
a) I understand that for research purposes data which can identify me:		
– May be shared with researchers within the project team.	☐	☐
– Will be accessed by a University approved external transcription company.	☐	☐
b) I agree that the data provided by me may be used for the following purposes:		
– Presentation and discussion of the project and its results in research activities (i.e. project meetings, conferences, presentation as part of PhD Thesis).	☐	☐
– Publications and reports describing the project and its results.	☐	☐
– Dissemination of the project and its results including publication of data on web pages and databases.	☐	☐
– To be contacted by the research team to get involved in further Horizon related activities.	☐	☐
c) I give permission for my words to be quoted for the purposes described above.	☐	☐
d) I give permission for my survey responses (anonymised and combined with other participants’ responses) to be used for the purposes described above.	☐	☐
e) I give permission for my visual image contained in photos and video gathered during the research to be used for the purposes described above.	☐	☐
f) I give permission for photos of group work that will be produced in this workshop to be used for the purposes described above.	☐	☐
g) I give permission to the research team to contact me to take part in future Horizon related activities.	☐	☐
3. Reuse my data		
a) I give permission for the data that I provide to be reused for the sole purposes of future research and learning.	☐	☐
b) I understand and agree that this may involve depositing my data in a data repository, which may be accessed by other researchers.	☐	☐

Please tick the appropriate boxes	**Yes**	**No**
4. Security of my data		
a) I understand that safeguards will be put in place to protect my identity and my data during the research, and if my data is kept for future use.	☐	☐
b) I confirm that a written copy of these safeguards has been given to me in the University’s privacy notice, and that they have been described to me and are acceptable to me.	☐	☐
c) I understand that no computer system is completely secure and that there is a risk that a third party could obtain a copy of my data.	☐	☐
5. Copyright		
I give permission for data gathered during this project to be used, copied, excerpted, annotated, displayed and distributed for the purposes to which I have consented.	☐	☐

6. Signatures (sign as appropriate)

______________________________ ______________________________ __________

Name of participant (IN CAPITALS) Signature Date

If applicable: ☐

For participants unable to sign their name, mark the box instead of signing

I have witnessed the accurate reading of the consent form with the participant and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

______________________________ ______________________________ __________

Name of witness (IN CAPITALS) Signature Date

I have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.

______________________________ ______________________________ __________

Name of researcher (IN CAPITALS) Signature Date

7. Researcher’s contact details

Provide the participant with a copy of the completed form either by email or hard copy as they prefer.

Name: Elaine Venancio Santos

Phone: 07826595628

Email: elaine.venancio@nottingham.ac.uk

Appendix G

Study two - Privacy notice

PRIVACY NOTICE

The University of Nottingham is committed to protecting your personal data and informing you of your rights in relation to that data. The University will process your personal data in accordance with the General Data Protection Regulation (GDPR) and the Data Protection Act 2018 and this privacy notice is issued in accordance with GDPR Articles 13 and 14.

The University of Nottingham, University Park, Nottingham, NG7 2RD is registered as a Data Controller under the Data Protection Act 1998 (registration No. Z5654762, https://ico.org.uk/ESDWebPages/Entry/Z5654762).

The University has appointed a Data Protection Officer (DPO). The DPO's postal address is:

Data Protection Officer,
Legal Services
A5, Trent Building,
University of Nottingham,
University Park,
Nottingham
NG7 2RD

The DPO can be emailed at dpo@nottingham.ac.uk

Why we collect your personal data. We collect personal data under the terms of the University's Royal Charter in our capacity as a teaching and research body to advance education and learning. Specific purposes for data collection on this occasion are to understanding the factors of acceptance on ubiquitous technologies in order to support the design with the focus on older adults.

The legal basis for processing your personal data under GDPR. Under the General Data Protection Regulation, the University must establish a legal basis for processing your personal data and communicate this to you. The legal basis for processing your personal data on this occasion is Article 6(1e) processing is necessary for the performance of a task carried out in the public interest.

Special category personal data. In addition to the legal basis for processing your personal data, the University must meet a further basis when processing any special category data, including: personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation. The basis for processing your sensitive personal data on this occasion is Article 9(2j) when processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes. In this study we will be asking for your health status, only if you wish to share this information with us, this information will help us to understand if the health condition has an impact in your willingness to have health data collected and/or sharing the data.

How long we keep your data. The University may store your data for up to 25 years and for a period of no less than 7 years after the research project finishes. The researchers who gathered or processed the data may also store the data indefinitely and reuse it in future research.

Who we share your data with. Mixed data, data involving more than one participant, (e.g., transcribed materials) may be shared with researchers from Horizon Research Group. Extracts of these data may be disclosed in published works (e.g., academic and non-academic venues) and posted online for use by the scientific community.

A University of Nottingham approved external transcription company, GDPR compliant, will have access to audio-recorded files and it will not made public or shared with third parties. Anonymised transcriptions may be reused supporting further activities related to this research project and for applying to future research funding opportunities. Anonymised transcriptions will be safely archived, may be stored indefinitely on external data repositories (e.g., the UK Data Archive) and may be further processed.

How we keep your data safe. We keep your data securely and put measures in place to safeguard it. These safeguards include storing paper records in locked filing cabinets and keeping digital files encrypted and password protected.

The video, audio recordings and photos and your contact details (if you consent to be contacted by Horizon related activities) will be stored securely on password-protected University-approved research storage in accordance with the Data Protection Act (1998). Only the research team will have authorised access to the full collected data. However, note that no computer system is completely secure, so it is always possible that a third party could obtain copies of your data.

This will be conducted under strict best practice criteria that comply with GDPR.

Your rights as a data subject. GDPR provides you, as a data subject, with a number of rights in relation to your personal data. Subject to some exemptions, you have the right to:

- withdraw your consent at any time where that is the legal basis of our processing, and in such circumstances you are not obliged to provide personal data for our research.
- object to automated decision-making, to contest the decision, and to obtain human intervention from the controller.
- access (i.e., receive a copy of) your personal data that we are processing together with information about the purposes of processing, the categories of personal data concerned, recipients/categories of recipient, retention periods, safeguards for any overseas transfers, and information about your rights.
- have inaccuracies in the personal data that we hold about you rectified and, depending on the purposes for which your data is processed, to have personal incomplete data completed
- be forgotten, i.e., to have your personal data erased where it is no longer needed, you withdraw consent and there is no other legal basis for processing your personal data, or you object to the processing and there is no overriding legitimate ground for that processing.
- in certain circumstances, request that the processing of your personal data be restricted, e.g., pending verification where you are contesting its accuracy or you have objected to the processing.

- obtain a copy of your personal data which you have provided to the University in a structured, commonly used electronic form (portability), and to object to certain processing activities such as processing based on the University's or someone else's legitimate interests, processing in the public interest or for direct marketing purposes. In the case of objections based on the latter, the University is obliged to cease processing.
- complain to the Information Commissioner's Office about the way we process your personal data.

If you require advice on exercising any of the above rights, please contact the University's data protection team: data-protection@nottingham.ac.uk

Appendix H

Study two - Advert poster

Do you use digital technology in your daily life?
Eg. Smartphone and/ or Computer with Internet access

Are you aged 65 years old or more?

If **YES**, then **YOU** are invited to take part in one of this workshop exploring your views in relation to technologies to collected fitness data and the use of smart devices (e.g., smartphones, fitness Trackers: Fitbit, Apple Watch,…).

The session involves interactive activities and friendly discussion. Your contribution to this workshop will provide you, researchers and society in general, a better understanding of what makes the data and collected and shared through health and fitness trackers devices been engageable and trustable.

Friday 26th July at **10am**
or
Tuesday 30th July at **2pm**
or
Thursday 8th August at **10.30am**

Cecil Roberts Room
at **Nottingham Central Library**,
Angel Row, NG1 6HP.

No prior knowledge is required.

Workshop will last around **2 hours and 30 minutes** and you will be thanked for your time with £15 Amazon voucher.
Refreshments will be provided

For more information, and to sign up for one of the workshops, please email Elaine Venancio (Elaine.Venancio@nottingham.ac.uk).

Ethics Approval Number: CS-2018-R53

Appendix I

Study two - Advert page

Tweets by @HorizonDER

Horizon
@HorizonDER

New research will demonstrate benefit of culture and heritage to society
gov.uk/government/new…

New research will demonstrate benefit…
An ambitious new programme of researc…
gov.uk

20h

Horizon Retweeted

UKRI Research Node on TAS Governa
@tas_governance

We have a Postdoctoral opening to investigate issues around responsibility in ML-enabled

Embed View on Twitter

22
07 .19

Data privacy and potentials of data use in wearable technologies

Have you ever wondered what happens with the personal data that wearable devices such as fitness trackers collect? Where it is sent and what could be the potential for enhancing health services using this data? Have you ever scrolled through a privacy policy without understanding what the pages of text actually allow a company to do with information about you?

In this PhD project, Elaine is conducting workshops with the support from ReEntrust project team to explore people's views and perceptions regarding data sharing, and the potential data privacy issues that may arise in data collected through wearable devices.

Figure 1 – Participants and Elaine engaging in the discussion

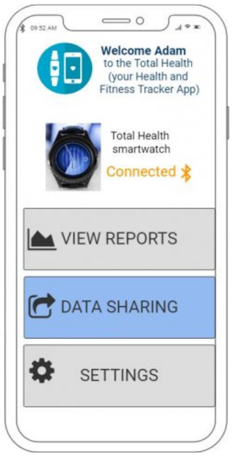
This project aims to explore the factors relating to the acceptance of ubiquitous technologies to support their design with the focus on older adults. The contribution of this study is to explore potential factors in accepting and using ubiquitous technologies, and how these could have an impact in enhancing the services on health and well-being.

Findings from Elaine's previous research have revealed factors that promote and factors that restrict the use of data collected through wearable devices regarding protection, fairness, accuracy and traceability. These factors result in concerns regarding data privacy and consequently, a breakdown of trust – for instance the user sometimes doesn't know when to trust, doesn't see reciprocity and/or benefits for the data being collected, used and/or shared.

In this context, the main topics we are exploring during the workshops are:

- What are the user expectations and requirements regarding the balance between received personalised services and the use of the data collected by sensor-based devices?
- What is the impact of privacy in the acceptability of data collection and data sharing? How does it influence user wellbeing and agency?
- What would be useful to enhance trust in the use of the data and data sharing by the user? How should these issues be addressed?

During the workshops, we will present a series of screenshots from our prototype (see Figure 2 and Figure 3 below) to encourage discussion relating to the topics above.



Welcome Adam to the Total Health (your Health and Fitness Tracker App)

Total Health smartwatch Connected

Figure 2 – Menu principal from the prototype

Figure 3 – Data sharing options from the prototype

The results from the workshops are going to help Elaine to design a user interface from low-fidelity to a high-fidelity prototype, helping to inform designers how to use and deliver the information collected by wearable devices in a trusted and engageable way to the user — taking into account the user's privacy, the transparency and fairness in the transaction.

This research is part of a PhD research project being supervised by Professor Derek McAuley and Dr Joel Fischer and the workshops are being supported by ReEntrust's project team.

For more information, please get in contact with **Elaine Venancio Santos**

School of Computer Science Ethics Reference: Ref. no. CS-2018-R53

Appendix J

Scenarios - Questions to participants

Part. ID ______________

Scenario 1 – Part 1

After reading the scenario please reflect on the following questions. Please feel free to take any notes

1) Would you like to have your health data collected as described in the scenario?
    a. If yes, would you like to share this data? With who?
    b. If no, any reason in particular?

2) In Figure 4, Adam saw some information about what is going to happen with his data if he chooses to go ahead and share it. What do you think about the information displayed on the screen?

Part. ID______

Scenario 1 – Part 2

After reading the scenario please reflect on the following questions. Please feel free to make any notes

3) What do you think about the follow up from the NHS that happened in the scenario? Do you think this is a good approach?

4) What would you expect in exchange for sharing your data with the NHS?

Part. ID_____

Scenario 2 – Part 1

After reading the scenario please reflect on the following questions. Please feel free to make any notes

1) Would you be willing to share your personal health data with companies such as: Tesco, Holland & Barrett, in exchange for a personalised service? Why?

2) In Figure 4, Adam saw some information about what is going to happen with his data if he chooses to go ahead and share it. What do you think about the information displayed on the screen?

Part. ID______

Scenario 2 – Part 2

After reading the scenario please reflect on the following questions. Please feel free to make any notes

3) Consider the notifications that Adam started to receive from other businesses such as the Organic Store after he decided to share this data. What do you think about these notifications?

4) What would you expect in exchange for sharing your data with companies?

5) What is your view about sharing data with family members?

Appendix K

Study two - Scenarios part 1

Scenario 1 – Part 1 A

Please read the hypothetical scenario presented below and feel free to take any notes or highlight anything that you find interesting.

Sharing data with the healthcare system

Adam is 70 years old and currently retired. Adam is healthy, and the only concerns that he has about his health are his high blood pressure and a little bit *of pain* in *the knees due to arthritis.*

He uses a wrist wearable device that is a smartwatch that collects fitness and health data, such as: stress level, heart rate, blood pressure, respiratory rate, glucose level, step count, sleep data, sedentary time and location.

The smart tracker has a mobile App with an option to share the data with the NHS App and others NHS service provider Apps, and Adam decides to try that feature. Adam also has the NHS App on his phone that he uses to book appointments with the GP and request repeat prescriptions.

When he clicks on the button for [Data sharing] (**Figure 1**), he sees a screen about data sharing that gives some options (**Figure 2**). Adam selects Health & Pharmacy and clicks on [View] and sees another screen with some new options. He chooses the NHS and clicks on [More Info] (**Figure 3**). He reads the message about the data that is going to be shared and the Privacy Policy and then clicks [Connect] (**Figure 4**) and receives a confirmation message about the connection.

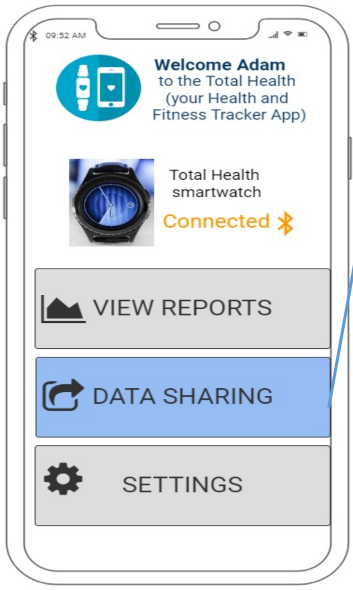


Figure 1 – Menu Principal

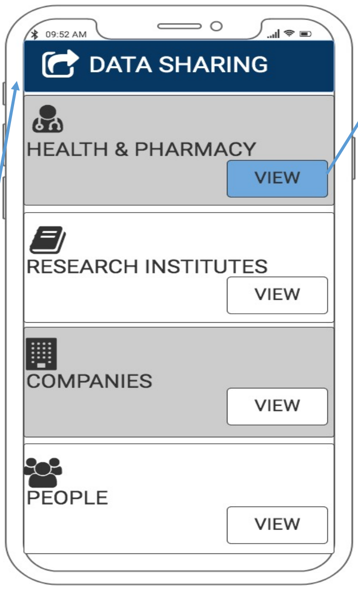


Figure 2 – Data Sharing options

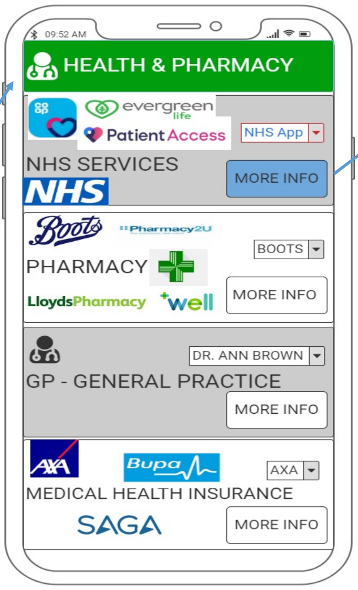
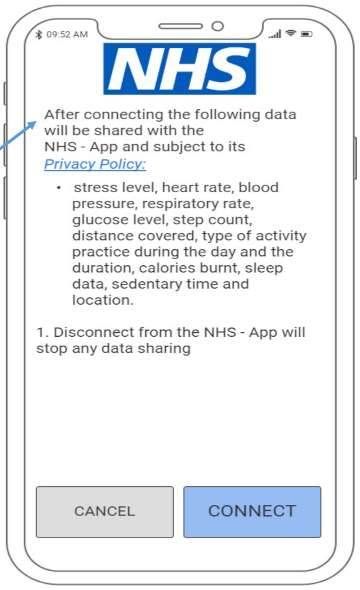


Figure 3 – Healthcare options available



After connecting the following data will be shared with the NHS - App and subject to its *Privacy Policy:*

- stress level, heart rate, blood pressure, respiratory rate, glucose level, step count, distance covered, type of activity practice during the day and the duration, calories burnt, sleep data, sedentary time and location.

1. Disconnect from the NHS - App will stop any data sharing

Figure 4 – Connecting the wearable App with the NHS - App

Scenario 1 – Part 2

A few days after connecting his wearable App with the NHS App, Adam receives a letter with tips to increase his activity level, as well suggestions for walking programmes nearby. In this letter, he also receives a flyer regarding dealing with stress and wellbeing issues, he has a look at the letter and keeps it.

After a couple of weeks, Adam receives a new letter asking him to contact the Rushcliffe Leisure Centre in his area, as they can offer a personalised activity programme that has been tailored for people with similar needs. Adam doesn't see the point of making this call.

Adam is aware that his activity level is low and that his stress level is on average high.

A month after receiving this letter, Adam receives another letter informing him that an appointment has been scheduled for him with the Health Visitor Team.

Adam decides to go back to his wearable App to check how to stop sharing his data with the NHS. He didn't expect that sharing his data would raise this kind of follow up by the healthcare system.

Going back to the wearable App, Adam selects the option for Data Sharing again as he did before and this time he identifies a notice "Data being shared" in the NHS option (**Figure 5**).

He clicks on [More info] and on the next screen, there is a message about the data that is being shared. Adam them clicks on [Disconnect] (**Figure 6)** and goes through two more screens before being able to disconnect (**Figures 7 and 8**).

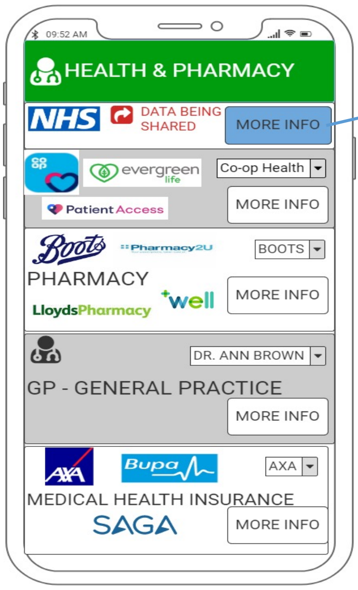
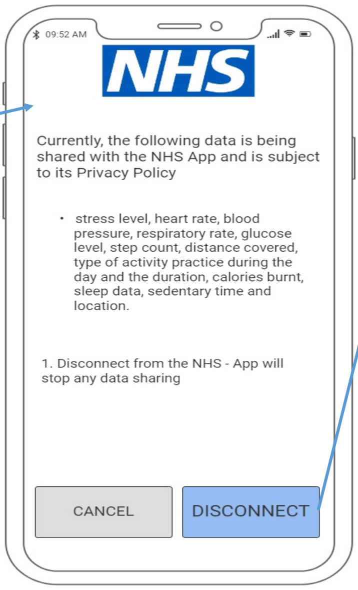


Figure 5 – Healthcare options with the note that Data is being shared with the NHS App

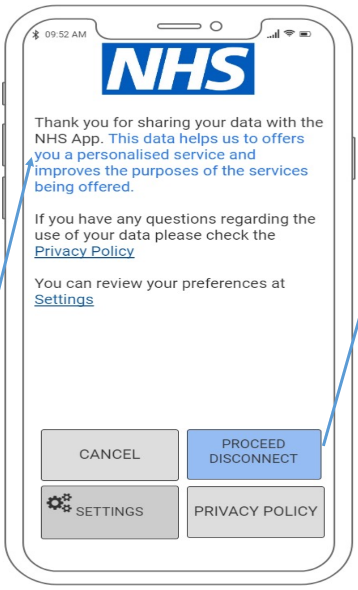


Currently, the following data is being shared with the NHS App and is subject to its Privacy Policy

- stress level, heart rate, blood pressure, respiratory rate, glucose level, step count, distance covered, type of activity practice during the day and the duration, calories burnt, sleep data, sedentary time and location.

1. Disconnect from the NHS - App will stop any data sharing

Figure 6 – Information about the Data Sharing

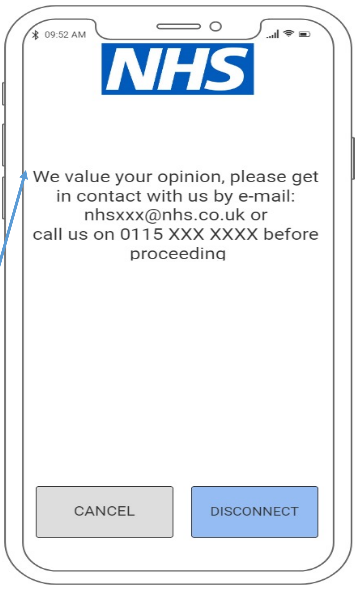


Thank you for sharing your data with the NHS App. This data helps us to offers you a personalised service and improves the purposes of the services being offered.

If you have any questions regarding the use of your data please check the Privacy Policy

You can review your preferences at Settings

Figure 7 – Information before disconnection



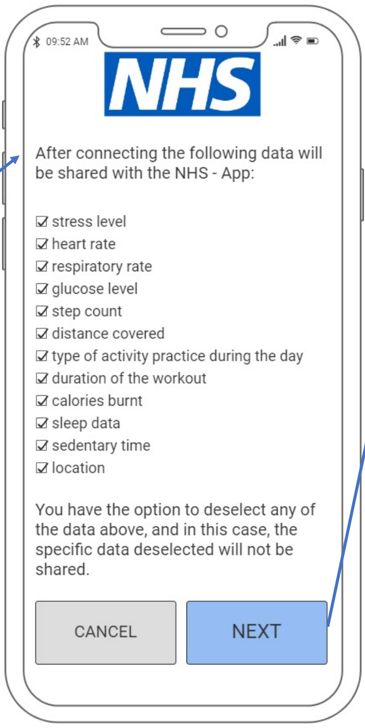
We value your opinion, please get in contact with us by e-mail: nhsxxx@nhs.co.uk or call us on 0115 XXX XXXX before proceeding

Figure 8 – Ways to get in contact before disconnection

Scenario 1 – Part 1 B

What is your perception about this alternative way for the information to be delivered to the user? (Figures 9 to 12)

Figure 9 – Health & Pharmacy options available

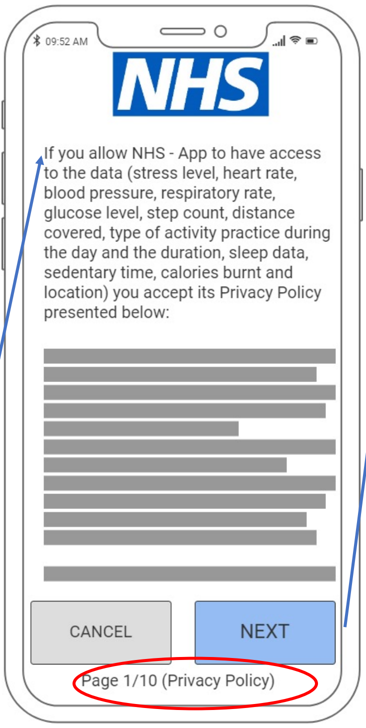


After connecting the following data will be shared with the NHS - App:

☑ stress level
☑ heart rate
☑ respiratory rate
☑ glucose level
☑ step count
☑ distance covered
☑ type of activity practice during the day
☑ duration of the workout
☑ calories burnt
☑ sleep data
☑ sedentary time
☑ location

You have the option to deselect any of the data above, and in this case, the specific data deselected will not be shared.

Figure 10 – Selecting the data to share with the NHS - App



If you allow NHS - App to have access to the data (stress level, heart rate, blood pressure, respiratory rate, glucose level, step count, distance covered, type of activity practice during the day and the duration, sleep data, sedentary time, calories burnt and location) you accept its Privacy Policy presented below:

Figure 11 – Going through the 1st of 10 pages about Privacy Policy that describes how the data is going to be used by NHS

[ ] I accept the Privacy Policy

Figure 12 – Going through the last page about the Privacy Policy.
The button [Connect] is disabled until the box "I accept the Privacy Policy" be checked.

Appendix L

Study two - Scenarios part 2

Scenario 2 – Part 1 A

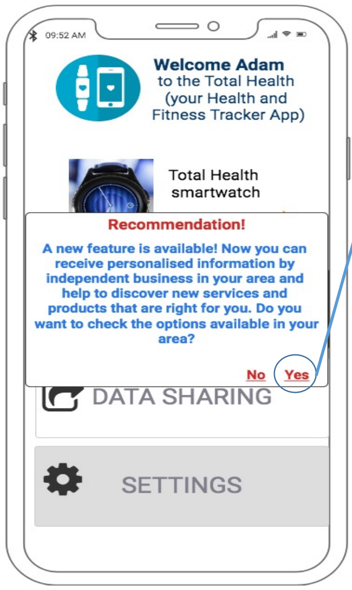
Please read the hypothetical scenario presented below and feel free to take any notes or highlight anything that you find interesting.

Sharing data with organisations and family

Adam is 70 years old and currently retired. Adam is healthy, and the only concerns that he has about his health are his high blood pressure and a little bit of pain in the knees due to arthritis. He uses a wrist wearable device that is a smartwatch that collects fitness and health data such as: stress level, heart rate, blood pressure, respiratory rate, glucose level, step count, sleep data, sedentary time and location.

After using the smartwatch for a few weeks, Adam received a recommendation from the App about a new feature (**Figure 1**). Independent businesses in his area are offering the service of providing personalised information to their customers based on their health and fitness data. To allow this, Adam would have to go to the option Data Sharing (**Figure 2**).

Adam sees the list of independent businesses in his area (this area is defined based on his location and his frequently visited places), and he selects two places that he knows well: an organic store and a chiropractic clinic, he checks the box [Allow] for both places and clicks on [Proceed] (**Figure 3**). Adam reads the screen presented and notices that there are options to check the Purpose, Partners and set up Settings and he selects [I Accept] (**Figure 4**).



Welcome Adam to the Total Health (your Health and Fitness Tracker App)

A new feature is available! Now you can receive personalised information by independent business in your area and help to discover new services and products that are right for you. Do you want to check the options available in your area?

Figure 1 – Menu Principal

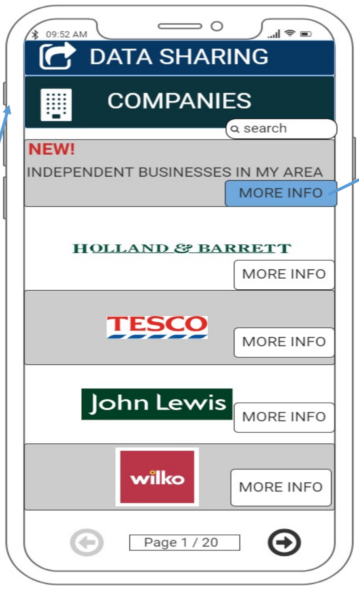


Figure 2 – Companies available in the Data Sharing options

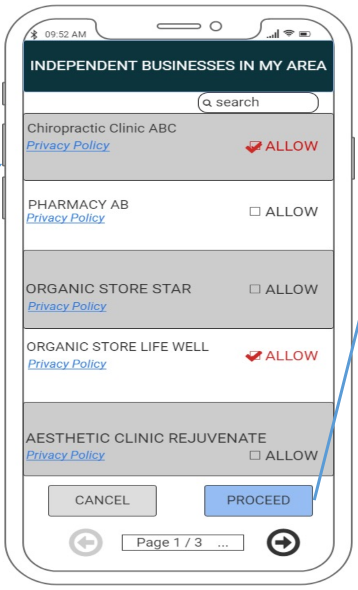
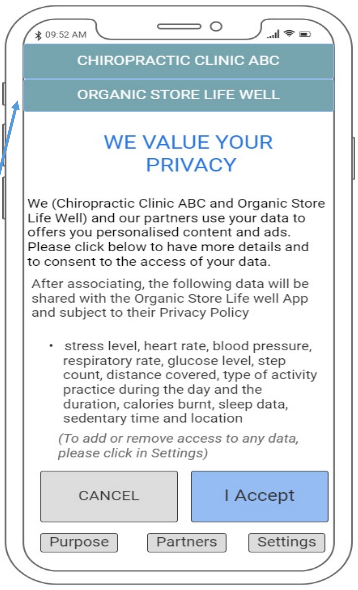


Figure 3 – Options available on the menu Independent Businesses



WE VALUE YOUR PRIVACY

We (Chiropractic Clinic ABC and Organic Store Life Well) and our partners use your data to offers you personalised content and ads. Please click below to have more details and to consent to the access of your data.

After associating, the following data will be shared with the Organic Store Life well App and subject to their Privacy Policy

- stress level, heart rate, blood pressure, respiratory rate, glucose level, step count, distance covered, type of activity practice during the day and the duration, calories burnt, sleep data, sedentary time and location

(To add or remove access to any data, please click in Settings)

Figure 4 – Accepting data sharing with some local businesses

Scenario 2 – Part 2

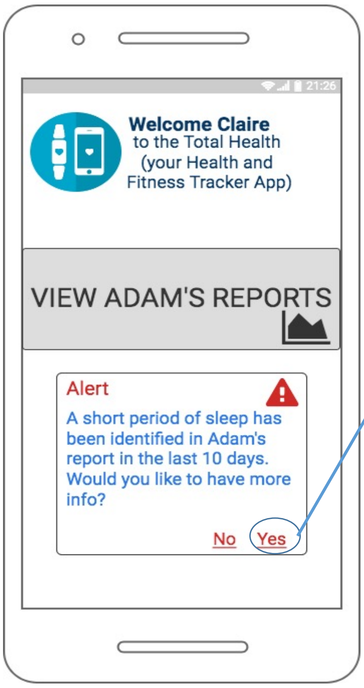
A few days after allowing the connection with the two businesses, Adam starts to receive notifications about products and services from the places that he had selected based on his data.

One notification, in particular, is an ad from the organic store that he is sharing data with, advertising a type of cereal grain. This cereal might help decrease blood pressure levels. He had never heard about that grain before so he is intrigued about it, and after doing some research online, he decides to try it.

The next day, Adam goes to the shop to buy the cereal grain, and he feels glad to have received the information about this product.

Later on, Adam receives a visit from his daughter, Claire. Adam had decided to share the data from his wearable device with Claire when he bought the device.

Claire mentioned that she is a little bit concerned about her dad's lack of sleep because she has seen from the App that Adam is having just a couple of hours of sleep lately. Last night, when Claire checked the App's device on her phone, she noticed an alert about the sleep pattern (**Figure 5**). Checking the chart, Claire observes that the maximum amount of sleep was less than 5 hours in the last 10 days, with some days where Adam has just over 2 hours of sleep (**Figure 6).**



Welcome Claire
to the Total Health
(your Health and
Fitness Tracker App)

Alert

A short period of sleep has been identified in Adam's report in the last 10 days. Would you like to have more info?

Figure 5 – Adam's daughter sees a notification when she opens the App

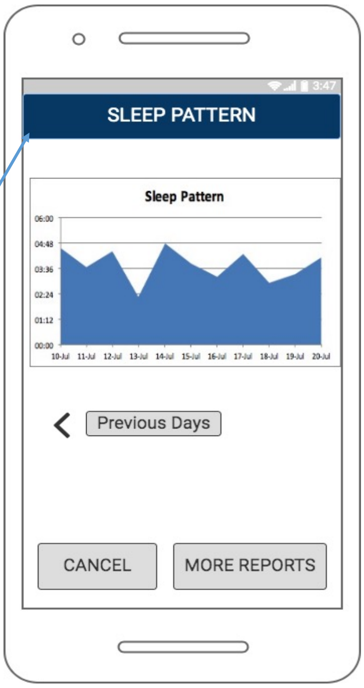
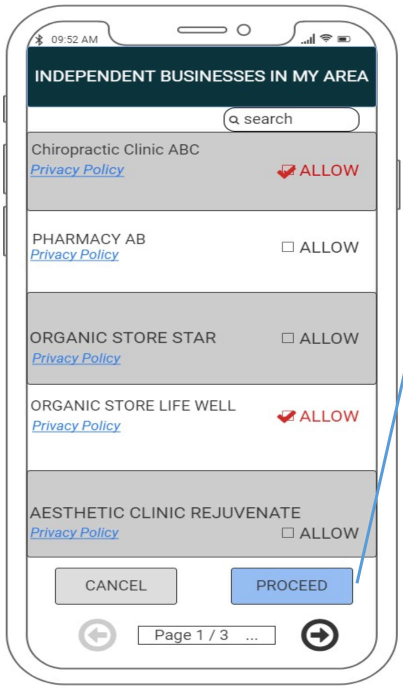


Figure 6 – Chart about the sleep pattern in the last 10 days that Adam's daughter sees

Scenario 2 – Part 1 B

What is your perception about this alternative way for the information to be delivered to the user? (Figures 9 to 11)



INDEPENDENT BUSINESSES IN MY AREA

search

Chiropractic Clinic ABC
Privacy Policy
☑ ALLOW

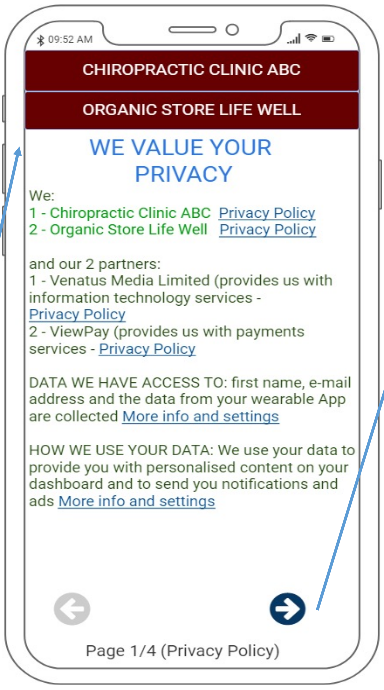
PHARMACY AB
Privacy Policy
☐ ALLOW

ORGANIC STORE STAR
Privacy Policy
☐ ALLOW

ORGANIC STORE LIFE WELL
Privacy Policy
☑ ALLOW

AESTHETIC CLINIC REJUVENATE
Privacy Policy
☐ ALLOW

Figure 9 – Options available on the menu Independent Business



CHIROPRACTIC CLINIC ABC

ORGANIC STORE LIFE WELL

WE VALUE YOUR PRIVACY

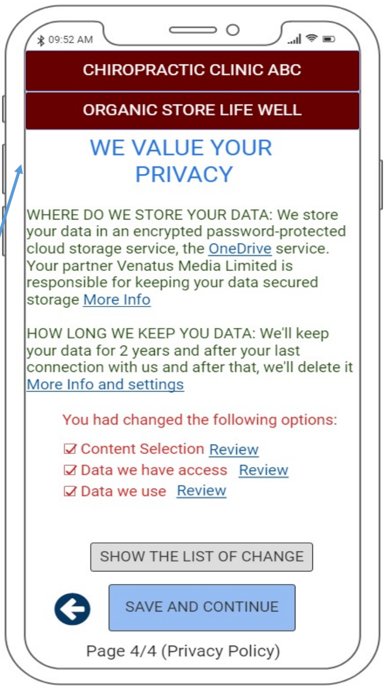
We:
1 - Chiropractic Clinic ABC Privacy Policy
2 - Organic Store Life Well Privacy Policy

and our 2 partners:
1 - Venatus Media Limited (provides us with information technology services - Privacy Policy
2 - ViewPay (provides us with payments services - Privacy Policy

DATA WE HAVE ACCESS TO: first name, e-mail address and the data from your wearable App are collected More info and settings

HOW WE USE YOUR DATA: We use your data to provide you with personalised content on your dashboard and to send you notifications and ads More info and settings

Figure 10 – Privacy policy description first page of four



CHIROPRACTIC CLINIC ABC

ORGANIC STORE LIFE WELL

WE VALUE YOUR PRIVACY

WHERE DO WE STORE YOUR DATA: We store your data in an encrypted password-protected cloud storage service, the OneDrive service. Your partner Venatus Media Limited is responsible for keeping your data secured storage More Info

HOW LONG WE KEEP YOU DATA: We'll keep your data for 2 years and after your last connection with us and after that, we'll delete it More Info and settings

You had changed the following options:

☑ Content Selection Review
☑ Data we have access Review
☑ Data we use Review

Figure 11 – Privacy Policy last page and overview of changes that has been made

Appendix M

Study two - Pre-survey form

Please remember this number: ID ____

Pre-session Survey

Age ______ **Gender** _______________

Education Level: ________________________________

1. What are the digital technologies that you use in your everyday life?

( ) Computer	( ) Laptop	( ) Mobile phone with internet access (smartphone)
( ) Tablet	( ) Sat-nav in the car or GPS in the car	( ) E-readers books (for example: Kindle)
( ) Technologies that enhance independent living (e.g. fall detectors, personal alarms, others) Please specify? ________________________________		
( ) Smartwatch or any kind of health/fitness tracker If Yes, please specify for how have you been using this technology ________________________________ If you had used health/fitness tracker before and stopped it, please specify why you stopped using it:________________________________		
( ) Other digital technology, please specify: ________________________________		

2. How many hours per day do you use digital technology in your daily life?

( ) Up to 1 hour	( ) Between 1 to 3 hours	( ) Between 3 to 5 hours
( ) Between 5 to 7 hours	( ) Between 7 to 9 hours	( ) Between 9 to 11 hours
( ) Between 11 to 13 hours	( ) Over to 13 hours	

Please Turn Over

Please remember this number: ID ____

3. **How long have you been using digital technology in your daily life?**

( ) Less than 5 years	( ) Between 5 to 10 years	( ) Between 10 to 15 years
( ) Between 15 to 20 years	( ) Between 20 to 30 years	( ) More than 30 years

4. **How often do you use the Internet?**

Several times a day	Once a day	Once every few days	Once every few weeks	Never

5. **What are your main reasons for using the Internet in the past four (4) weeks? Please indicate your primary reason with a number one (1), followed by any others that are appropriate in ascending order (1 to 5 -** 1 = primary reason,…, 5 = fifth reason**).**

Socialising (eg social media, whatsapp)	Health related reasons (eg book an appointment with GP / calories counter / Mental Health)	Paying, buying or booking things (including taxi/ travel/food)	Storing data in the cloud (e.g. photos, videos, documents)	Watching videos, listening to music or playing games (including TV/films)	Sharing content (eg photos, videos, documents)

Other ____

____

____

6. **If you have a smartphone/tablet, approximately how many Apps do you currently have installed on your phone/tablet?**

Several (20 or more Apps)	Various (between 10 to 19 Apps)	A few (between 4 to 9 Apps)	A little (between 1 to 4 Apps)	None (zero Apps)

Please remember this number: ID ____

7. What are your main reasons for using an App in the past four (4) weeks? Please indicate your primary reason with a number one (1), followed by any others that are appropriate in ascending order (1 to 5 - 1 = primary reason,…,5 = fifth reason**).**

Socialising (eg social media, whatsapp)	Health related reasons (eg book an appointment with GP / Personal Health App / Mental Health App	Paying, buying or booking things (including taxi/ travel/food)	Storing data in the cloud (e.g. photos, videos, documents)	Watching videos, listening music or playing games (including TV/films)	Sharing content (eg photos, videos, documents)

Other ____

____

____

8. How important is TRUST in how the data collected is going to be used, in your decision to use new technologies devices?

Very important	Quite important	Not very important	Not at all important	I don't know

9. How important is the TRUST in your decision to download a new App or to use a new service online?

Very important	Quite important	Not very important	Not at all important	I don't know

10. Have you ever stopped using a device, App or online service because you didn't trust how the data was used it?

a) Yes

b) No

If yes, please provide further details ____

____

____

____

____

Thank you!

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Appendix N

Study two - Post-survey form

Please remember this number: ID ____

Post-session Survey

1. **Which type of data collected through the sensor device would be more important to you?**

1 = not at all important → 7 = extremely important

	1	2	3	4	5	6	7
Heart rate							
Blood pressure							
Respiratory rate							
Glucose level							
Step count							
Distance walked							
Type of activity practice that day							
Sedentary time							
Calories burnt							
Sleep data							
Stress level							
Location (places visited)							

2. Do you see a benefit in the use of a wearable sensor in your daily life?

Yes, a lot	Yes, a little	No	I don’t know

3. From the topics discussed today do you think wearable devices have potentials to enhance the health by providing a personalised health service to the users?

Yes, a lot	Yes, a little	No	I don’t know

Please remember this number: ID ____

4. How much do you agree with the following statements:

1 = very little → 7 = very much

	1	2	3	4	5	6	7
I can control what happens to me and my personal data online							
I am free to decide for myself whether to use a particular platform							
I am concerned about my well-being when online							
The trust of how my data is being used would impact my decision of using a device							
Being able to keep my data stored locally, just on my computer/phone/external hard drive, is important to me							
I would be tempted to use a sensor-based technology							
I would stop using a device if I didn't trust how the data is stored							
The convenience of being able to access my data in different devices that cloud services (such as Google Drive, Dropbox) provide overcomes the potential security risks							
I like to have personalised services online, but the amount of personal data collected concerns me							
I feel that the owner of my personal data is the service/ platform that I've chosen to use and this concerns me							

5. How would you rate:

1 = very low → 7 = very high

	1	2	3	4	5	6	7
Your overall digital literacy							
Your knowledge of how to keep safe online							
Your knowledge of how to control your personal data online							
Your ability to find reliable information online							

6. What is the most important factor in whether or not you trust a digital technology?

____

____

Please Turn Over

7. Did you come up with any new ideas today about ways that data sharing could help to increase trust from their users?

Yes, lots of them	Yes, a few	No	I don't know

If yes, please provide further details

____

____

____

____

____

8. Please read ALL of the following statements before you answer the question.

How important is each factor in whether or not you trust a technology/platform?

1 = not at all important → 7 = extremely important

If there is anything else that might affect your trust in online platforms/services, please feel free to add it in the final empty box.

	1	2	3	4	5	6	7
Whether my friends and family use the device							
The number of options on the privacy settings							
How easy it is to get something corrected if there is a mistake							
How easy the terms and conditions are to understand							
How easy the terms and conditions are to find							
Being able to ask a person to explain the content you were given							
How much I can personalise the platform or device							
Knowing how the content is produced							
How easy privacy settings are to change							
How the platform or device uses my personal data							
How easy the platform or device is to use							
The reputation of the technology							
The precision of the sensor device							
Have information where my data is being stored							

Please remember this number: ID ____

9. Please think about *your general experience of using digital technologies* during the past 4 weeks. Then report how much you experienced each of the following feelings, using the scale below.

1 = Never
2 = Very rarely
3 = Rarely
4 = Sometimes
5 = Often
6 = Very Often
7 = Always

	1	2	3	4	5	6	7
High mood							
Anxious							
Pleased							
Powerless							
Safe							
Apathetic							
Paranoid							
Tracked							
Disempowered							
Creative							
Calm							
In control							
Empowered							
Low mood							
Annoyed							
Powerful							

10. Do you think the use of digital technologies affects your well-being? How?

____

____

____

____

Thank you!

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Appendix O

Study two - Health monitoring form

Please remember this number: ID ____

Health monitoring

We ask you to complete this form so that we can monitor and analyse information about the health of the people who take part in this activity. Any information you provide will be treated as confidential. You are not obliged to answer the questions on this form. If you do not wish to answer a question simply answer 'Prefer not to say'.

1. Are you concerned with any of those conditions?

☐ High blood pressure
☐ High cholesterol levels
☐ Arthritis or other similar condition that affect the joints
☐ Diabetes
☐ Atrial fibrillation (an irregular heart rhythm)
☐ Mental health
☐ Other ____
☐ Prefer not to say

2. How healthy do you consider yourself?

☐Unhealthy	☐ A little unhealthy	☐ Neither healthy or unhealthy	☐Healthy	☐ Very Healthy

☐ Prefer not to say

3. How would you rate your interest in health-related information:

☐ Uninterested	☐ A little interested	☐ Neither interested or uninterested	☐ Interested	☐ High Interested

☐ Prefer not to say

Appendix P

Study one - codebook

Study One - Preliminary Codebook Description

Code Name	Code Description
Accountability	doctor's advice based on data needs to be visibly rational / data treatment needs to be fully transparent)
Actionability of data	doing something in response to the data
Agency	ability to act
Behaviour change	
Boundaries to sharing	
Consent	person that had the data collect need to agreed with
Contextual metric data	self-reports
Cultural knowledge	Commom cultural knowledge
Data representation	reports and preference between charts or schematic faces
Experience	previous knowledge related to health or the use of similar devices
Features	Attribute or aspect
Functionality	the range of operations/ functions of the device, Eg.: having a reminder
Health conditions	
Intimacy	Intimate situation/place / Private eg. Toilet
Mechanism preference	Ways to fill a form
Metrics	Data collected
Physical property	Eg.: small
Privacy	not being observed or disturbed by others, data privacy (how the data is collected and used, for data sharing there's another code)
Purpose of use	
Reading data	Ease of legibility through contextualisation in self reports
Routines	Fits into routines, being 'a person of habit' / Get use to
Security / safeguarding	Reliability / measures taken to protect or to prevent something undesirable
Sharing data	
Technology not warranted	Pointless
Technology preference	Option of device, impressions about the device
Trust	Confidence on the device / Confidence on the data collected / Confidence on the report
Usability	Eg.: simple to use
Warranting alerts / Functionality	
Warranting invasive tracking	Justify or necessitate
Warranting tracking	Situations that the tracking it's justify or not Eg.: being worried, health conditions
Wearability	Related to wearing
Behaviour&Reaction/Boundaries with technology	Opinion and behaviour as a potential user of the device
Acceptance of the technology	

Appendix Q

Study two - codebook

Study Two – Preliminary Codebook Description

<table>
<tr><th>1st Tier Code Name</th><th colspan="2">Code Description</th></tr>
<tr><td>Awareness, Understanding, Knowledge</td><td colspan="2">Participants express facts or information about their experience of using digital technologies.
For example, how the platform operates or why they may need particular information about the user.</td></tr>
<tr><td>Companies</td><td colspan="2">Where participants discuss their issues/ concerns / or the benefits that they see of using or sharing data with a company</td></tr>
<tr><td></td><td colspan="2">2nd Tier (Sub-Code)</td></tr>
<tr><td></td><td>NHS</td><td>When the participant bring the topic of the NHS by themselves (used this code when the 2nd scenario was presented first)</td></tr>
<tr><td>Concern or Caution</td><td colspan="2">Where participants express worry in relation to their experiences</td></tr>
<tr><td>Traceability</td><td colspan="2">Where participants discuss the need or the desire to trace the data / information</td></tr>
<tr><td>Tracking, Surveillance</td><td colspan="2">Where the participants discuss the close observation or following of their behaviour or movements when they are using digital technologies</td></tr>
<tr><td>Trust-related</td><td colspan="2">Pertaining to any expression by a participant that refers directly to their experience or behaviour in the use of technology related to trust or distrust</td></tr>
<tr><td>Lack of transparency</td><td colspan="2">Where participants express an opaqueness of information available to the user</td></tr>
<tr><td>App Design</td><td colspan="2">Where the participants comment about the design of the App</td></tr>
<tr><td rowspan="4"></td><td colspan="2">2nd Tier (Sub-Code)</td></tr>
<tr><td colspan="2">Positive attitudes</td></tr>
<tr><td colspan="2">Negative attitudes</td></tr>
<tr><td colspan="2">Preferences</td></tr>
</table>