A design-driven conversational AI interface to enhance the self-management of patients living with IBS

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Trabalho efetuado sob a orientação da Professora Doutora Sandra Neves
e coorientação dos Designers Filipe Plácido e Nick Mueller.

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Declaration

I now declare that this thesis, entitled ‘Design-Driven Conversational AI as an Interface to promote IBS self-management,' is an original work and an integral component of my final project for the Master's Degree in Design for Health and Well-being.

All sources of information, including published and unpublished works, have been acknowledged and duly cited per academic conventions.

I declare that this work adheres to the principles of academic integrity and complies with all relevant institutional guidelines and ethical standards.

Dedication

"To leave the world a little better than you found it.
That's the best a man can ever do." - (Paul Auster, 2008)

I would like to express my sincere gratitude to my wife, Joana, and to my dearest friends: Ana do Mar, Luís Favas, Maria Inês de Almeida, and Filipe Plácido.

Special thanks are due to Marco Heleno for the many late-night discussions on topics related to artificial intelligence and academia, as well as for his unwavering support throughout the writing phase of this study.

Acknowledgements

I want to thank my supervisors for their support, guidance, and expertise, greatly enriching my master's thesis experience.

I want to give a special thanks to Professor Doc. Sandra Neves for all the support and for believing in my best work.

Motivation

My motivation to explore and develop this project brings a combination of personal experiences and professional aspirations. Over the last 14 years, I have experienced living with IBS, and I found a need to understand better the challenges this condition presents.

This personal experience opened my eyes to healthcare from a different perspective. As a designer, I wondered how to contribute meaningfully to this context.

Healthcare has been a constant presence in my life. My mother's 30-year career in a cancer hospital meant I grew up in and around medical environments. These experiences fostered an early understanding of the healthcare system and its impact on people's lives, contributing to my current path.

Due to my keen interest in health, design, and technology and my experience as a product designer, I began considering developing a product within this context.

With these new technologies, there is still much to discover and an opportunity to develop further products to help IBS patients live better lives.

Summary

In the past two decades, there has been an increase in gastrointestinal diseases worldwide, including irritable bowel syndrome (IBS), associated with a significant decrease in the population's quality of life (Rose et al., 2022), with a relatively high prevalence of 10-20% of the global population (Longstreth et al., 2006).

This study aimed to better understand the patient experience of individuals living with IBS and discover opportunities for a conversational AI interface to help patients better cope with their health condition and improve overall symptom management.

This study combines a human-centred design methodology with the iterative and non-linear approach of design thinking. A group of patients were involved in this study: five patients in semi-structured interviews, three in a co-design workshop and five in a pilot test to evaluate the new interface prototype.

This study found that patients face significant challenges in managing IBS. These findings highlight patients' experiences of isolation and lack of support, particularly during crises or when dealing with unfamiliar symptoms. Feelings of loneliness are particularly emphasised when immediate access to medical advice is not available. Participants also expressed concerns about the negative impact of IBS on their quality of life. This chronic condition requires constant daily adjustments to manage symptoms, which can be both physically and emotionally challenging. The study identified a need for effective strategies to promote patients well-being in the future. Fundamentally, these findings highlight the need to develop multi-faceted solutions that address the physical symptoms of IBS and offer emotional support, practical guidance for daily management of the condition, and strategies for maintaining a healthy social life.

In this study, exploring a conversational AI interface was considered relevant to address the issues highlighted by the participants. A conversational AI interface, in

the context of IBS, could offer a more personalised strategy tailored to better respond to each patient's individual needs. Co-design dialogues allowed patients to envision a conversational AI interface as a companion in managing IBS. These findings highlight patients' desires to manage their symptoms in a more socially supportive care.

The approach, tools and techniques used here contributed to development of a conversational AI interface prototype that was tested. This study may provide valuable insights into the guidelines and user interface patterns of designing for conversational AI, while adhering to the 10 Nielsen Heuristics for user interface design (Jacob Nielsen, 1994).

Abstract

In the past two decades, there has been an increase in gastrointestinal diseases worldwide, including irritable syndrome, associated with a significant decrease in the population's quality of life (Rose et al., 2022).

It is believed that IBS can affect over 800 million individuals worldwide (Longstreth et al., 2006), impacting patients' lives with gastrointestinal symptoms, fatigue, anxiety and depression, reducing the quality of life, and generating significant health costs that can go up to £2 billion a year in the United Kingdom (Goodoory et al., 2022; Gracie et al., 2019; Kearney et al., 2011; Saha, 2014; Talley & Spiller, 2002).

Irritable bowel syndrome patients were actively involved and participated in several phases and activities throughout this project.

This project documents the work and process to understand the IBS patient experience better and explore how patients could benefit from a conversational AI interface and find some relief, especially during flare-ups or symptom management situations.

The results highlight understanding the current patient’s needs in living with IBS. It also created the opportunity to co-develop ideas with patients that informed the prototype phase.

In this project, a design thinking framework was tested and proved adaptable to healthcare contexts, combined with the best guidelines and heuristics (Jacob Nielsen, 1994), to ensure usable user interfaces.

Keywords: Design, Conversational AI, AI, Irritable bowel syndrome, IBS.

Table of contents

List of Figures

List of Tables

List of Acronyms and Abbreviations

AI – Artificial intelligence

A&E – accident and emergency

IBS – irritable bowel syndrome

IBS-C – irritable bowel syndrome constipation type

IBS-D – irritable bowel syndrome diarrhoea type

IBS-M – irritable bowel syndrome mixed type (constipation and diarrhoea)

ML – Machine learning

LLM – Large language model

NPL – Natural language processing

HCD – Human-centred Design

GP – General practitioner

NHS – National Health Service (Also known as SNS in Portuguese)

UX – User Experience

UI – User Interface

1. Introduction

1.1 Research Questions, Aims and Objectives

Questions:

- How can design methods support the involvement of patients living with IBS to co-develop a conversational AI interface to facilitate effective self-management of flare-up symptoms for patients with irritable bowel syndrome (IBS)?
- What can Human-Centred Design methodology teach us about designing conversational AI interfaces to promote better health outcomes for IBS patients?

Aims:

- Gain a better understanding of the experiences of people living with IBS.
- Prototype a conversational AI product interface to support people living with IBS in self-managing their daily health and consequently promoting their quality of life.

Objectives:

- Mapping key interaction points between people and healthcare facilities to assess the suitability of conversational AI in improving IBS self-management.
- Explore the coping strategies patients employ during IBS flare-ups and identify opportunities for conversational AI to effectively support these strategies.
- Understand how patients currently manage their health and evaluate how these coping strategies could be integrated into a conversational AI agent.
- Uncover what are the best design patterns for this new type of interaction between human and AI.

1.2 Thesis Structure

The current document has been structured into 11 chapters:

- Chapter 1 introduced the study's project, objectives, and aims.
- Chapter 2 provides a contextual review of Irritable Bowel Syndrome (IBS), its definition, impact, prevalence, and overall patient experience.
- Chapter 3 presents a literature review with the intention of gaining an understanding of Design, Technology, and AI in Healthcare.
- Chapter 4 describes the Methodology, which will employ an integration of Human-centred design and design thinking approach to support the participation of people living with IBS and collect and analyse a diversity of information.
- In Chapter 5, "Empatise: exploring patients experiences in living with IBS", will present findings from Phase 1, illustrates what the five peoples' voices revealed by conducting interviews.
- Chapter 6, "Define: materialising initial research" demonstrates the design tools such as empathy maps, user personas, personas, and journey maps generated from Phase 1.

- Chapter 7, “Ideate: co-design workshop with IBS patients” provides the outcomes of conducting a co-design workshop.
- Chapter 8, “Prototype: Turning Ideas into Tangible Interfaces”, presents the first version of the prototype of the envisioned conversational AI product interface.
- Chapter 9, “Testing”, demonstrates the initial feedback from the people living with IBS about the prototype.
- Chapter 10, the Discussion, demonstrates the value of using a Human-Centred design approach in the context of IBS.
- Lastly, chapter 11, the Conclusion, reflects on this study's main contribution to knowledge and provides future research directions.

2. Irritable Bowel Syndrome

2.1 Introduction

This chapter aims to present a contextual review of Irritable Bowel Syndrome (IBS). This chapter begins by exploring what we know about its physiology, patients' and hospital administration's impact, and coping strategies.

This literature review explored the topic of IBS in greater depth to better understand its underlying physiology, prevalence, and multifaceted impact on individuals' lives. It also allowed us to identify key insights that could inform the subsequent design phase, ensuring that the approach taken is both evidence-based and responsive to the nuanced challenges faced by those living with IBS.

2.2 What is IBS?

Irritable bowel syndrome (IBS) is a condition that affects the digestive system (Saha, 2014). Although IBS is a complex health condition with a challenging aetiology, research suggests that it may involve a relationship between abnormalities in the digestive system movement, visceral hypersensitivity, inflammation, psychological state and microbiota changes (Gracie et al., 2019; Kearney et al., 2011; Lee & Bak, 2011; Talley & Spiller, 2002).

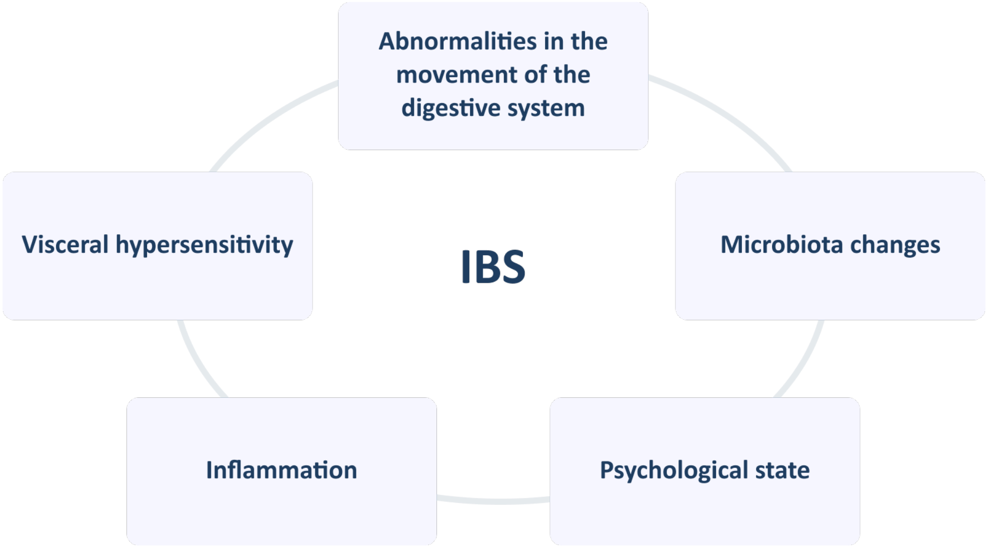


Figure 1 - IBS relationship (Gracie et al., 2019; Kearney et al., 2011; Lee & Bak, 2011; Talley & Spiller, 2002).

Main symptoms (Saha, 2014)**:**

- Abdominal pain
- Cramping
- Diarrhoea
- Constipation
- Changes in bowel habits
- Mucus in stool
- Incomplete evacuation

IBS is primarily a diagnosis of exclusion, meaning that physicians must rule out other conditions that could cause similar symptoms before confirming an IBS diagnosis. This typically involves a variety of exams, including blood tests, stool tests, and sometimes more invasive procedures like colonoscopy (Jeong et al., 1993; Lacy & Patel, 2017).

Rome IV diagnosis criteria (Lacy & Patel, 2017; Saha, 2014)**:**

- Recurrent abdominal pain or discomfort.
    - At least once a week
    - For the last three months
    - Associated with improvement of symptoms after defecation
- Variation in the frequency or form of bowel movement.

There is also comorbidity between IBS, oesophageal reflux, and high levels of stress, where gastric acid returns to the oesophagus, causing heartburn and significant discomfort. In more severe cases, it can cause aspiration pneumonia when the reflux passes through the trachea and manages to penetrate the interior of the bronchi (Konturek et al., 2011).

2.2.1 Physiology

To better understand the impact of IBS, we need to examine the normal functioning of the digestive system. This system is responsible for transforming and breaking down food for later absorption. The process begins in the mouth, where food is chewed and mixed with saliva to form a bolus. Saliva contains the enzyme amylase, which initiates the breakdown of starch. The bolus then travels through the oesophagus to the stomach (Deutsch, 1998).

In the stomach, digestion continues with the help of gastric juice, which contains hydrochloric acid and the enzyme pepsin, both essential for protein degradation (*Digestive Enzymes — Science Learning Hub*, n.d.). Trypsin, lipase, and amylase enzymes digest proteins, fats, and starch in the pancreas. Continuing the digestion process, we move on to the duodenum and small intestine, where most food absorption occurs.

The colon is responsible for water absorption, where significant problems due to IBS can arise. Finally, the rectum is where the expulsion occurs. Still in the intestine, we also have the enzymes maltase, sucrase, lactase, and protease (*Digestive Enzymes — Science Learning Hub*, n.d.).

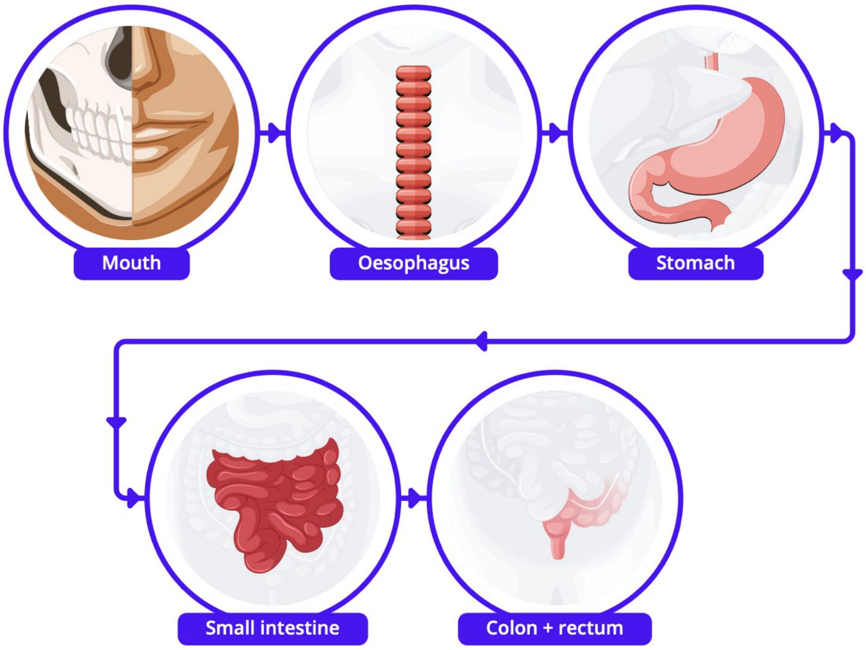


Figure 2 – Digestive system flow

Sub-types of IBS (Saha, 2014):

- **IBS with diarrhoea (IBS-D)**
    - In this subtype, there is a disruption of the balance between secretion and absorption in the intestine, increasing the number of daily stools, intestinal velocity and inflammation of the intestine, leading to the colon not having enough time to absorb all the water, causing the stool to come out liquid.
- **IBS with constipation (IBS-C)**
    - In the case of constipation, the problem is reversed, with a reduction in bowel velocity, causing the colon to absorb excess water
- **Mixed IBS (IBS-M)**

2.2.2 Treatment and Prognosis

Depending on the case and severity, various treatments can be prescribed (Gracie et al., 2019; Saha, 2014). The effects of other treatments with less scientific evidence are being studied, such as cognitive therapy, reflexology, and hypnotherapy. In addition, it is known that lifestyle changes can affect the quality of life, such as diet, physical activity, and the reduction of activities that can generate stress (Camilleri, 2018; Gracie et al., 2019; Talley & Spiller, 2002).

Available treatments for IBS (Saha, 2014; Talley & Spiller, 2002):

- Antispasmodics involuntary smooth muscle contractions.
- Antidepressants due to their relationship with the psychological.
- Probiotics
- Laxatives (IBS-C)
- Antidiarrheals (IBS-D)

Not having an apparent cure, this is a disease that should not be ignored due to its high morbidity and disabling symptoms that affect the quality of life of the population (Talley & Spiller, 2002), therefore creating a new opportunity to understand how we can help patients with this condition.

2.3 The Impacts of IBS

Irritable Bowel Syndrome (IBS) impacts on patients' lives with gastrointestinal symptoms, fatigue, anxiety and depression, reducing the quality of life (Saha, 2014).

The unpredictability of IBS symptoms is perhaps one of the most challenging aspects of the condition. The sudden and urgent need to go to the toilet can arise at inopportune moments, causing anxiety in social and professional contexts (Stanculete et al., 2015).

This urgency, combined with the frequent sensation of incomplete evacuation, creates a constant state of alertness that can be mentally exhausting and may find some people hypervigilant about bodily sensations, constantly monitoring signs of a possible worsening of symptoms (Hungin et al., 2003; Kutschke et al., 2022).

IBS also affects individuals' relationship with food, as it becomes particularly complex for those living with the condition, often leading to the development of anxiety around meals, with many fearing that certain foods may trigger symptoms (Saha, 2014). This preoccupation can lead to restrictive eating patterns and, in more severe cases, to the avoidance of social situations involving food, thereby creating the need to follow specific diets (Lee & Bak, 2011).

There is also a concern about the socioeconomic impact of IBS, absenteeism and health costs (Kearney et al., 2011; Kutschke et al., 2022; Quigley et al., 2006; Saha, 2014). The annual direct costs of IBS are estimated at between £1.2 and £2 billion in the United Kingdom, depending on the diagnostic criteria used (Goodoory et al., 2022).

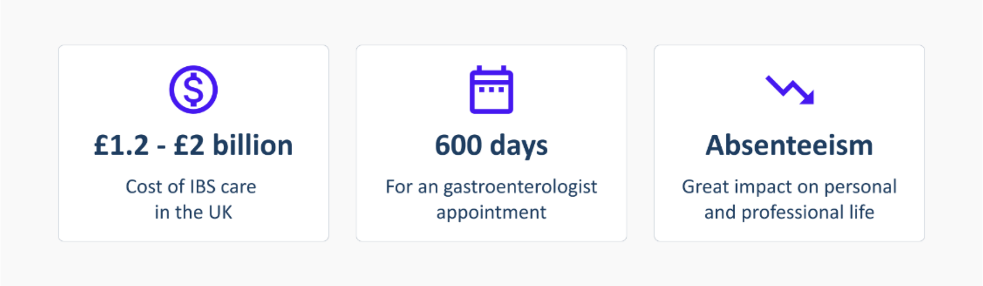


Figure 3 – Overview of IBS impact (Goodoory et al., 2022; Longstreth et al., 2006; Quigley et al., 2006; Saha, 2014).

Factors for the high costs of IBS care (Lovell & Ford, 2012; Quigley et al., 2006):

- The chronic and non-fatal nature of IBS.
- Incapacity to work and absenteeism.
- Excessive use of diagnostic texts.
- Lack of diagnostics tests.
- Lack of definitive cure.
- High prevalence (10-20% worldwide).

This rise in gastrointestinal diseases becomes concerning when waiting times for a gastroenterology appointment can exceed 600 days in some cities (Tempos de Espera Entre Os 1043 e Os 23 Dias, n.d.), This makes it clear that new technologies can be used to support the current IBS context.

2.4 Epidemiology of IBS

According to Quigley et al., (2006) estimating the incidence of Irritable Bowel Syndrome (IBS) presents significant challenges, largely due to the variability in diagnostic criteria used across different studies and regions. As a result, only prevalence data is readily available. It is estimated that IBS affects between 10% and 20% of the global population, with approximately 10% to 15% of individuals in Europe experiencing this condition (Longstreth et al., 2006; Quigley et al., 2006).

A gap was identified in understanding IBS prevalence in Portugal, as no articles providing this specific information were found. However, a general study conducted by Viegas at the University of Coimbra (2010) examined the prevalence of IBS among medical students at the university. Despite the study's small sample size and limited diversity, it is the most focused source of data specific to Portugal, revealing that 16.7% of the surveyed students exhibited symptoms consistent with an IBS diagnosis.

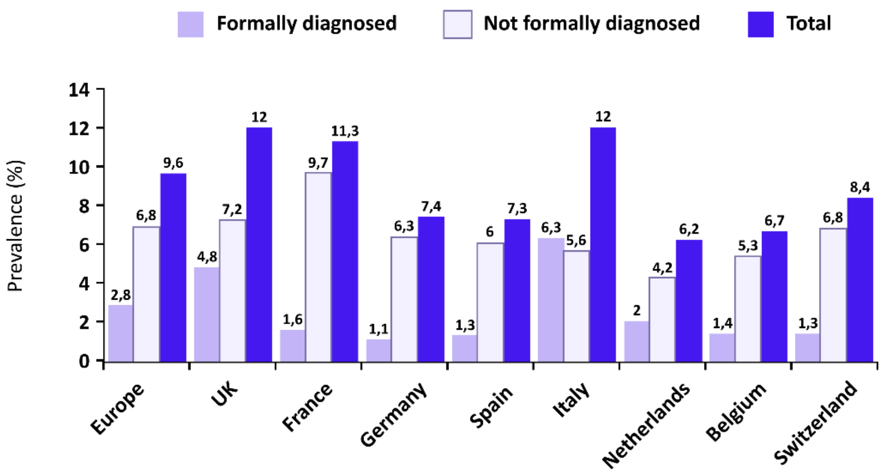


Figure 4 – Europe IBS prevalence (Hungin et al., 2003)

2.5 The Patient Experience in living with IBS

2.5.1 Patient care journey

As Saha (2014) notes, the patient care journey typically begins when a person identifies an intolerance to certain foods or notices changes in eating habits that seem to trigger gastrointestinal symptoms. This is usually followed by a visit to a general practitioner (GP), where patients often encounter significant challenges. Physicians may struggle to identify the appropriate treatment, frequently overlooking the diagnosis or downplaying the significance of IBS and the substantial impact it can have on individuals' lives (Sibelli et al., 2018). In fact, individuals with IBS can experience symptoms five years before having an official diagnosis (Burbige, 2010).

Throughout their journey within a GP or hospital environment, individuals undergo a variety of examinations and treatments across different settings and over extended periods (Talley & Spiller, 2002). These may include blood tests, stool tests, lactose and gluten intolerance tests, and imaging procedures such as ultrasound, X-ray, endoscopy, and colonoscopy (Black, 2021).

As Jarret et al. (2001) state, from here, it becomes a trial-and-error process to identify which foods might be causing these symptoms until the person eventually seeks help or finds a balance in their diet.

However, once individuals with IBS are discharged, they often struggle to understand the best practices and coping strategies on their own (Stanculete et al., 2015). This highlights a lack of effective communication between physicians and patients, which can lead to the adoption of ineffective or harmful strategies that may exacerbate their overall health (Skrastins & Fletcher, 2016).

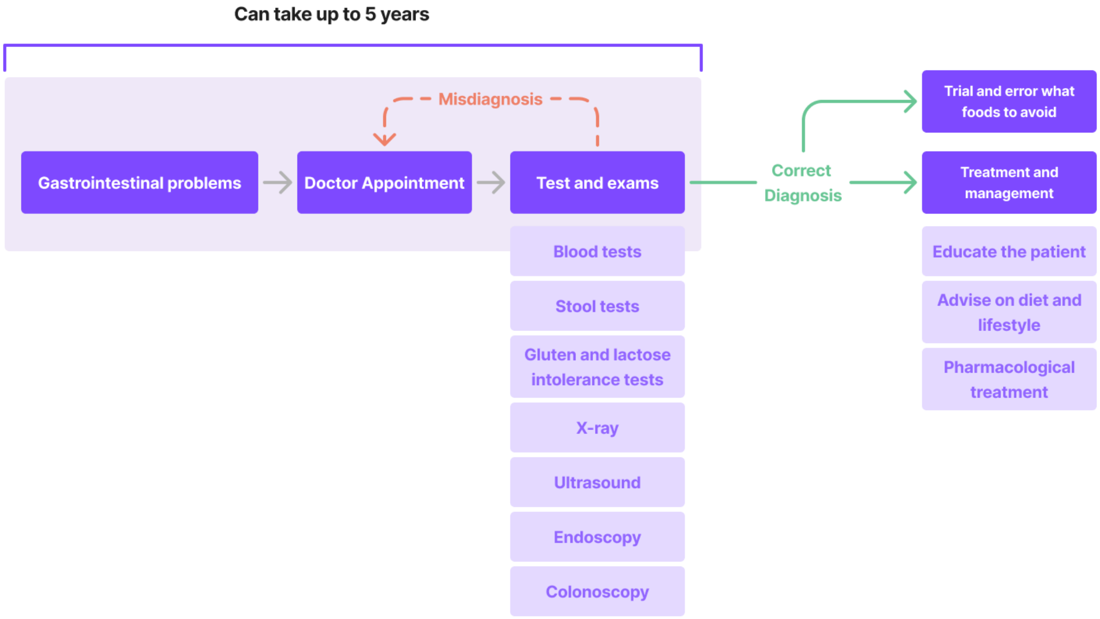


Figure 5 – Patient care journey (Jarrett et al., 2001; Sibelli et al., 2018; Simrén et al., 2017)

2.5.2 The patient's difficulties in managing IBS

Research exploring people's experiences of living with IBS shows that they can face significant challenges that go beyond the physical symptoms (Gracie et al., 2019).

Figure 6 – Overall challenges of living with IBS (Kutschke et al., 2022; Saha, 2014; Stanculete et al., 2015)

Managing IBS involves making informed choices when dining out at restaurants, socialising with friends and family, or during other social events (Banerjee et al., 2017).

Although there is a lack of research specifically addressing the daily challenges faced by individuals with IBS, evidence from studies on a similar condition - Inflammatory Bowel Disease (Quigley, 2016) - provide insights into common symptoms and management strategies. Martínez-Riera et al. (2022) discuss the findings of a qualitative study on the feeding difficulties encountered during the workday, highlighting the challenges of finding suitable and healthy food options in the workplace. The study also notes concerns about the lack of understanding of these intestinal conditions from the employer's perspective and emphasizes the importance of providing specific food options, as this can lead to feelings of isolation (Matinez-Riera et al., 2022).

2.5.3 Managing IBS Flare-ups

Each patient has a unique experience in managing IBS (Saha, 2014). What works for one individual may not effectively work for another, yet there is a wide variety of tools that individuals with IBS can use to overcome such scenarios (Stanculete et al., 2015).

Cognitive-behavioural therapy (CBT) based on self-management has been shown to be effective in reducing IBS symptoms and improving patients 'quality of life, making it a key strategy in controlling flare-ups (Moss-Morris et al., 2010).

Another example, from a pharmacological perspective, is the use of antispasmodic medications and certain specific antidepressants that help treat symptoms associated with IBS (Vasant et al., 2021). Other alternative therapies may also be used to help during an IBS flare-up, notably the use of peppermint tea (Moayyedi et al., 2019).

Although we have all these available options for managing a flare-up, Olivia Skrastins and Fletcher (2016), in their study "One Flare at a Time", expressed concerns about the coping strategies employed by patients in managing IBS flare-ups. They highlight that some of these strategies can be considered negative behaviours, which may negatively impact the management of symptoms. This is because most individuals with IBS tend to avoid eating or misuse the medication as a strategy to deal with the IBS flare-ups, leading to other health conditions such as food disorders and nutrition deficits (Skrastins & Fletcher, 2016).

IBS coping strategies (Kutschke et al., 2022; Skrastins & Fletcher, 2016; Stanculete et al., 2015):

Positive coping strategies:

- Seeking professional health advice
- Establishing a routine
- Diet management
- Seeking support
- Experimentation
- Maintaining a positive attitude
- Adequate rest/sleep
- Physical exercise
- Prescribed medication

Negative coping strategies:

- Misuse or avoidance of medication
- Avoidance behaviours, such as avoiding going into a public bathroom or refusing to eat
- Passive coping, as in choosing to suffer and endure the pain
- Consumption of trigger foods

2.6 Why Design?

Over the last two decades, the importance of innovating healthcare has been acknowledged, particularly regarding the design of better user interfaces (Patel & Kushniruk, 1998). This need emerges from the complexity of healthcare services and environments, which require engaging a diverse range of individuals, including patients with various health conditions, healthcare professionals, and others (S. Zhang & Song, 2023).

Design has also been recognized as a valuable approach for developing new digital products in healthcare, as it facilitates the rapid exploration of desirable ideas and enhances understanding of their feasibility and viability (Lyon et al., 2019).

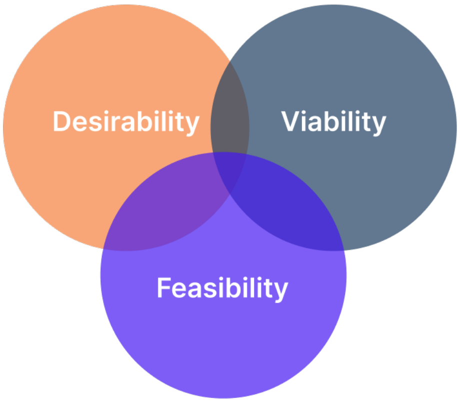


*Figure 7 – Intersection of design, an adaptation from IDEO (*IDEO Design Thinking | IDEO | Design Thinking*, n.d.)*

Design also places a focus on applying human-centred methods to promote active participation. Think, for example, involving both patients and healthcare professionals in the development of new solutions process (Lyon et al., 2019).

Research has shown that including patients in the design process of digital tools can also increase engagement and adherence to treatment, ultimately improving health outcomes (Birnbaum et al., 2015). Furthermore, design can enhance healthcare accessibility through digital interfaces that reduce geographical barriers, making services available to a broader population while potentially being more cost-effective (Aapro et al., 2020; Bhavnani et al., 2016) This is particularly important in remote areas or regions with limited access to specialized care (Stoumpos et al., 2023).

In 2015, IDEO, a global design and innovation company, also reported that design as an approach to healthcare improvements can contribute to rethinking healthcare environments, enhancing patient experiences and fostering a culture of continuous innovation and collaboration (IDEO.org, 2015; Lyon et al., 2019; *What Is Human-Centered Design (HCD)? — Updated 2024 | IxDF*, n.d.).

In summary, design can provide a better understanding of the patient's needs in this context of IBS. This knowledge can be useful to improve the patients' experience and contributes to more efficient and accessible healthcare systems and products (Aapro et al., 2020; Jones, 2013; Stoumpos et al., 2023).

3. Design, Technology and AI in Healthcare

3.1 Introduction

This chapter begins by introducing digital healthcare and defining artificial intelligence (AI), while also exploring how these emerging technologies are already shaping the healthcare industry. In this context, conversational AI will be explored in relation to the overall AI technology.

This chapter concludes by exploring the application of AI in healthcare and identifying its unique design challenges and opportunities. This sets the stage for deeper discussions of its design principles and implementation strategies.

3.2 Design for Digital Health Care

Over the last few years, digital healthcare products have been increased to support different conditions (Stoumpos et al., 2023). Amann (2017) notes that developing digital products is changing healthcare practices and patients' experiences.

Jones (2013) notes that designing for digital healthcare requires using human-centred design methods. It is not simply about making healthcare interfaces visually pleasing. Instead, it's about understanding the power of design to create human-centred solutions that fundamentally improve healthcare by acting as a bridge between what technology can offer and how it is used practically and beneficially in the daily lives of patients, physicians and hospital workers (Patel & Kushniruk, 1998).

Research shows that digital healthcare interventions are increasingly being applied in the context of remote patient monitoring and care. Remote monitoring solutions have emerged with the aim of improving patient experiences while potentially reducing the need for hospital admissions (Aapro et al., 2020).

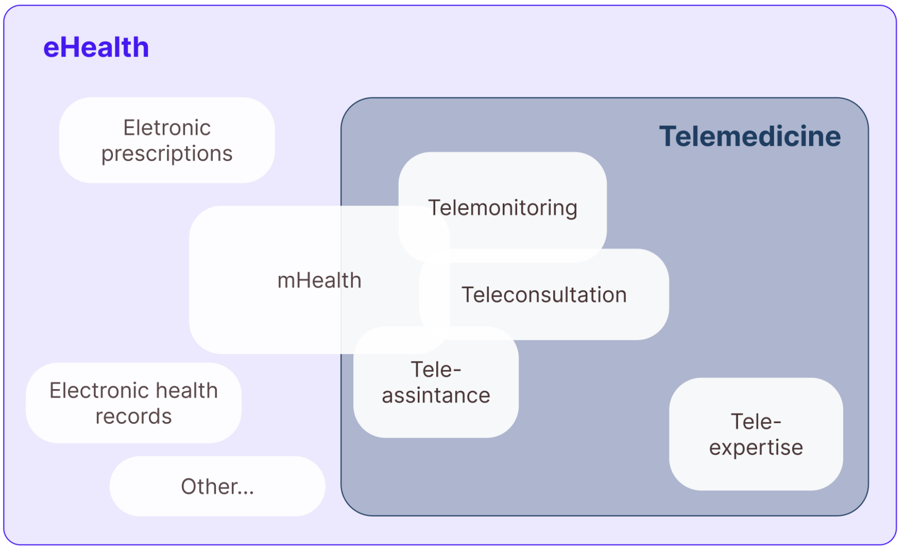


Figure 8 – Adaptation of the various forms of telemedicine within eHealth (Bensemmane & Baeten, 2019)

Differences between eHealth and Telemedicine (*The Various Forms of Telemedicine within EHealth | Download Scientific Diagram*, n.d.)

Telemedicine	**eHealth**
Refers to the provision of clinical services remotely, focusing on diagnosing, treating, and monitoring patients.	A broader term that encompasses all aspects of healthcare practices supported by electronic processes and communication.
Initially developed to treat patients in remote areas.	Involves the use of electronic systems to support healthcare delivery and other records.
Activities can include video consultations, remote patient monitoring, and the digital transmission.	Aims to improve the services healthcare practitioners provide to patients.

*Table 1 – Differences between eHealth and Telemedicine (*The Various Forms of Telemedicine within EHealth | Download Scientific Diagram, *n.d.)*

These new eHealth technologies have been increasing significantly in recent years, bringing with it the need for a greater focus on human-computer interaction and graphical interfaces ("Design Principles in the Development of Digital Health Applications," 2021).

To accommodate this digital revolution, the author of Design for Care, Peter H. Jones (2013), discusses the critical role of designers within healthcare environments and how we can ensure a good design practice:

Summary of the critical role of Designers in healthcare (Jones, 2013).

Role of Design	**Description**
Dealing with the complexity of Health Systems	Design manages and breaks down the complexity of healthcare systems, ensuring that digital solutions are easy to use and integrated into workflows, meeting everyone's needs.
Focusing on person-centred care	Design in digital health must shift towards a person-centred approach, considering the overall impact on health and recognising patients as active participants.
Driving innovation in clinical practices and services	Collaboration between designers and clinical teams identifies where digital solutions can improve processes, decision-making and health outcomes.
Improving user experience and usability	Design creates user-friendly interfaces using usability tests and human-centred principles, especially for electronic health records.
Facilitating cultural and organizational change	Designers help promote collaboration, innovation and a focus on the individual, contributing to the smooth integration of digital health into organisations.

Table 2 – Summary of the critical role of Designers in healthcare (Jones, 2013).

3.3 Artificial Intelligence (AI)

3.3.1 What is AI?

AI has been around for over six decades, with the start of the AI research discipline at the Dartmouth Conference in 1956 (Minsky et al., 2006), but only in the last couple of years has it started to be more understood and accessible by the general public (Adamopoulou & Moussiades, 2020).

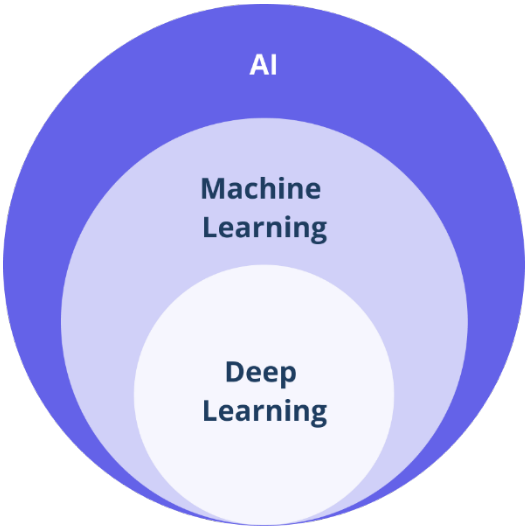


Figure 9 - Overview of AI technology adapted from (Nuzzi et al., 2021)

Artificial Intelligence (AI) refers to the capability of machines or computers to perform tasks, calculations, or actions that would typically require human intelligence (Nuzzi et al., 2021). The core technologies within AI include machine learning and deep learning, along with their subsets, such as conversational AI, large language models, and others (Davenport & Kalakota, 2019).

AI systems first need to learn to perform tasks and other activities. This can happen in different ways, and machine learning plays a crucial role by enabling systems to learn and improve with time and experience with minimal human intervention using different learning methods: Supervised Learning, Unsupervised

Learning, Reinforcement Learning, and Semi-Supervised Learning (Akhtar & Ramkumar, 2024; Carbonell et al., 1983).

Classes of Machine Learning

Learning method	**Description**
Supervised Learning	Trained with data that was already labelled.
Unsupervised Learning	In this type, there is no previously labelled data. The algorithm needs to find patterns among the available data.
Reinforcement Learning	Trial and error approach where successful learning is rewarded
Semi-Supervised Learning	Combines supervised and unsupervised learning by allowing the algorithm to have a small set of labelled data and a big amount of unlabelled data.

Table 3 – Classes of Machine Learning (Akhtar & Ramkumar, 2024; Carbonell et al., 1983).

The chosen learning method will depend on the goal and dataset available, and this can also influence how designers design AI products and interfaces since the data and context can change user perceptions (Akhtar & Ramkumar, 2024).

3.3.2 Artificial Intelligence in IBS

Several studies show that AI has a promising future in diagnosing and managing IBS (Acharjee & Choudhury, 2022; Davenport & Kalakota, 2019; Vulpoi, Luca, Ciobanu, Olteanu, Bărboi, Iov, Nichita, Ciortescu, Prelipcean, et al., 2023; W. Zhang et al., 2021). With technological advancements and increased data availability, AI is expected to become increasingly accurate and personalised, assisting in early diagnosis through cost-effective and non-invasive methods, optimising treatment, and discovering new therapies for IBS (Vulpoi, Luca, Ciobanu, Olteanu, Bărboi, Iov, Nichita, Ciortescu, Prelipcean, et al., 2023).

Figure 10 – Landscape of possible AI IBS applications (Vulpoi, Luca, Ciobanu, Olteanu, Bărboi, Iov, Nichita, Ciortescu, Cijevschi Prelipcean, et al., 2023).

Summary of possible AI IBS applications

AI Application	**Description**
Colonoscopy Assistance	Detects organic lesions and assesses colonoscopy quality, potentially identifying minute changes associated with IBS.
Bowel movement analysis	AI algorithms analyse bowel sounds as a non-invasive diagnostic tool for IBS.
IBS-patient specific diet	AI systems optimize nutritional strategies based on individual gut microbiota

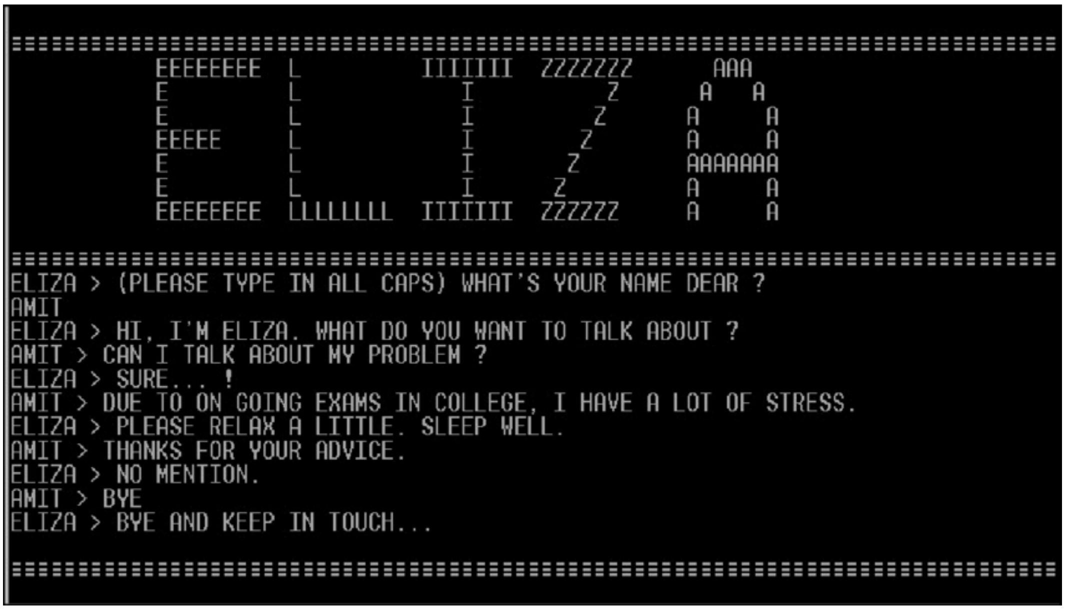
Smart devices	AI-powered mobile applications help patients self-report and track IBS symptoms more accurately.

Table 4 – Landscape of possible AI IBS applications (Vulpoi, Luca, Ciobanu, Olteanu, Bărboi, Iov, Nichita, Ciortescu, Cijevschi Prelipcean, et al., 2023)

3.4 Conversational Artificial Intelligence

3.4.1 What is Conversational AI?

Conversational AI refers to technologies such as chatbots, a computer program or applications that simulate a conversation with human users, whether through text or voice, and virtual assistants that enable the processing and understanding of natural language using large volumes of data and trained models to replicate human interactions (Khatri et al., 2018).



```
===============================================================================
           EEEEEEEE  L         IIIIIII  ZZZZZZZ      AAA
           E         L            I          Z      A   A
           E         L            I         Z      A     A
           EEEEE     L            I        Z       A     A
           E         L            I       Z        AAAAAAA
           E         L            I      Z         A     A
           EEEEEEEE  LLLLLLLL  IIIIIII  ZZZZZZ     A     A

===============================================================================
ELIZA > (PLEASE TYPE IN ALL CAPS) WHAT'S YOUR NAME DEAR ?
AMIT
ELIZA > HI, I'M ELIZA. WHAT DO YOU WANT TO TALK ABOUT ?
AMIT > CAN I TALK ABOUT MY PROBLEM ?
ELIZA > SURE... !
AMIT > DUE TO ON GOING EXAMS IN COLLEGE, I HAVE A LOT OF STRESS.
ELIZA > PLEASE RELAX A LITTLE. SLEEP WELL.
AMIT > THANKS FOR YOUR ADVICE.
ELIZA > NO MENTION.
AMIT > BYE
ELIZA > BYE AND KEEP IN TOUCH...

===============================================================================
```

*Figure 11 – ELIZA, the first chatbot (*3: Interface of Eliza Chatbot (Malykh, 2017) | Download Scientific Diagram*, n.d.)*

ELIZA was the first publicly known chatbot created in 1966 by Joseph Weizenbaum at MIT. This chatbot, is one of the first examples of a natural language processing program (Shum et al., 2018) and it was developed for the health context, designed to simulate and establish a conversation between a therapist and a patient (Minsky et al., 2006; Shum et al., 2018).

Recent research shows that chatbots offer higher user engagement than traditional online forms in health data collection (Soni et al., 2022). Other studies explore the utility and applications of Conversational AI concepts in various healthcare sectors (Adamopoulou & Moussiades, 2020). Although further research is still needed, these two studies highlight the promising future of Conversational AI in the healthcare field.

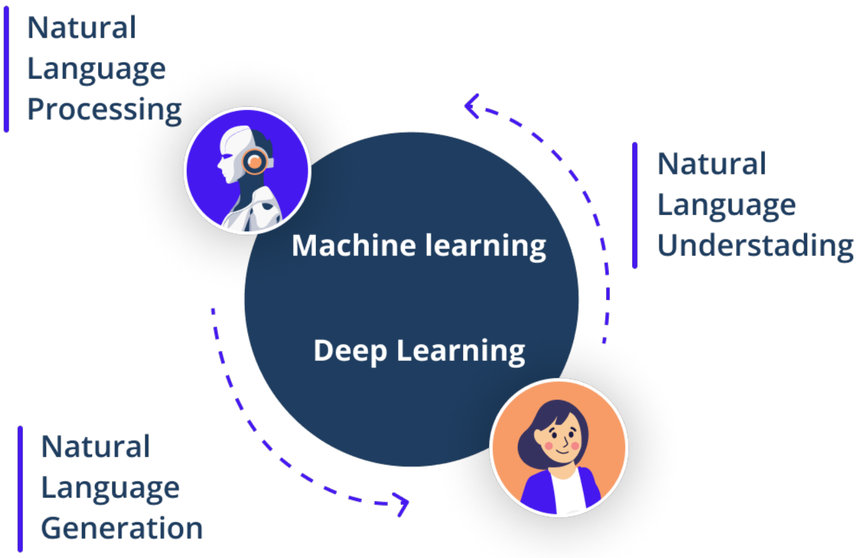


*Figure 12 – Conversational AI adapted from IBM (*What Is Conversational AI? | IBM, *n.d.)*

A conversational AI uses a combination of different technologies such: 1) machine learning (ML), 2) deep learning (DL), 3) natural language processing (NLP), 4) natural language understanding (NLU), and 5) natural language generation (NLG) to allow reasoning, intent understanding and enable a human-like conversation (Kusal et al., 2022a).

Combination of technologies used in Conversational AI (Gao et al., 2019; Kusal et al., 2022a):

- Machine Learning (ML)
- Deep Learning (DL)
- Natural Language Processing (NLP)
- Natural Language Generation (NLG)
- Natural Language Understanding (NLU)

Designing a conversational AI requires considering a range of functionalities and features to support human interaction across different scenarios. The most common Conversational AI functionalities can include: 1) voice-to-voice, 2) text-to-text, and 3) mixed-mode interactions that convert speech to text and vice versa (Kusal et al., 2022). These conversations can happen in voice user interfaces, like Siri or Google Assistant, which are therefore invisible, through graphical user interfaces, or a mix of both.

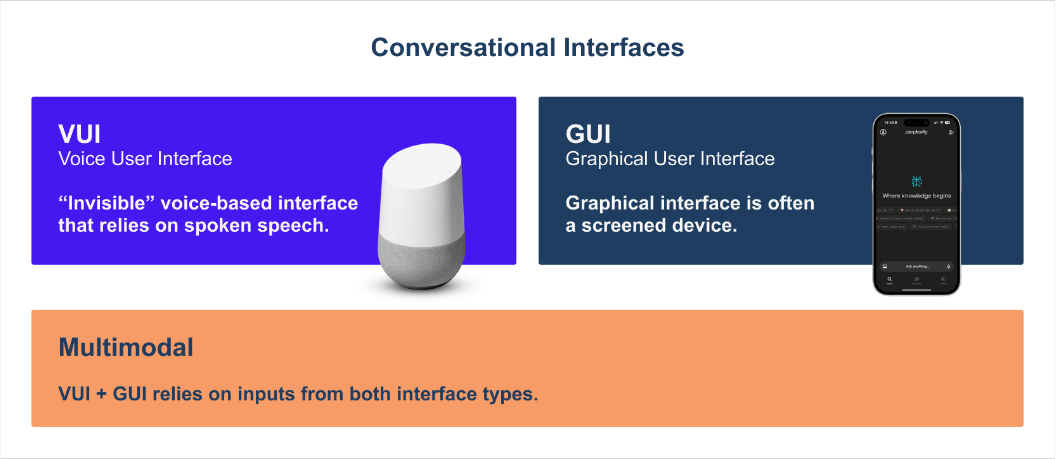


Figure 13 – Adapatation of VUI GUI relationship (Evanhoe & Deibel, 2021).

3.4.2 Conversational AI in IBS

A systematic review by Schachner et al. (2020) identified a literature gap on AI-based conversational agents for chronic conditions. However, a recent study by Mohan et al. (2024) compared two large language models (LLMs), Google Bard and OpenAI Chat GPT, in the context of irritable bowel syndrome (IBS).

Both AI tools demonstrated the ability to analyse various medical images relevant to IBS treatment and interact with IBS patients (Mohan et al., 2024). The study assessed the reliability and accuracy of these chatbots, reporting that Chat GPT achieved 71% accuracy and 58% reliability in providing information. The authors concluded that there is evidence to support the reliability of these chatbots in assisting IBS patients but emphasised the need for further research in this area (Mohan et al., 2024).

The literature gap on this subject reveals an opportunity to better understand and explore the potential of conversational AI for managing chronic conditions such as IBS.

3.4.3 Designing for Conversational AI

Over the last years, design has been used to better develop Conversational AI solutions. Hall and Safari (2018) note the importance of using principles of human communication in the design of interactions with digital systems. What seems to be highlighted here is the importance of understanding how humans interact and communicate in order to create meaningful interfaces that go beyond speaking or sending text messages (Evanhoe & Deibel, 2021).

Designing for conversational AI is a unique and emerging field in design, shifting how we interact with technology, especially in health care, highlighting the need also to understand some of the communication principles like the Grice’s Maxims (Evanhoe & Deibel, 2021; Hall & Safari, 2018).

Grice’s Maxims are a communication principle that addresses the underlying question of what makes a conversation successful. According to Grice, for a conversation to be effective, both parties must collaborate (Westby, 2023).

As Hall & Safari (2018) state in their book “Conversational Design”, these principles should inform the design of conversational AI interfaces, ensuring a positive and usable experience in human-computer interaction.

Grice (1975) divides this principle into four main parts: The maxim of quantity, quality, relevance and manner:

Grice (1975) **maxims:**	
Maxim	**Description**
Quantity	They must provide the right amount of information, no more and no less than necessary
Quality	They should be truthful and avoid saying something for which they don't have adequate evidence
Relation	They must be relevant and keep the focus on the topic of conversation
Manner	Should avoid obscurity and ambiguity by being brief and orderly

Table 5 – Grice’s Maxims – Principles of communication (Grice, 1975)

4. Methodology: Human-Centred Design

4.1 Introduction

This chapter begins by situating this study within a Human-centred design approach to co-develop a conversational AI interface in the context of IBS. Then, I will discuss a range of methods and my intentions for data analysis.

4.2 Human-Centred Design

This project combined the human-centred design methodology with the non-linear and iterative traditional design thinking approach (*IDEO Design Thinking | IDEO | Design Thinking*, n.d.).

Human-centred design is a holistic approach to problem-solving that puts the human being at the centre of the process (*Donald A. Norman, Stephen W. Draper - User Centered System Design_ New Perspectives on Human-Computer Interaction-CRC Press (1986)*, n.d.; IDEO.org, 2015). This methodology focuses on understanding the human experience and solving the correct problems. By prioritising experience, human-centred design seeks to create products, services and systems that are non-functional, intuitive and enjoyable to use.

The norm ISO 9241-210 (2019) defined six main principles to determine Human-Centred Design: 1) The design is based upon and explicit understanding of users, tasks and environments. 2) Users are involved throughout design and development. 3) The designs are driven and refined by user-centred evaluation. 4) The process is iterative. 5) The design addresses the whole user experience. 6) The design team includes multidisciplinary skills and perspectives.

Applying a Human-centred Design methodology may ensure a good adherence to the best design practices, allowing for the creation of better products that fit patient needs and guarantee a fair use of the AI applications (Auernhammer, 2020; Capel & Brereton, 2023; *Donald A. Norman, Stephen W. Draper - User Centered System Design_ New Perspectives on Human-Computer Interaction-CRC Press (1986)*, n.d.).

This methodology has already been used and proven valuable within the IBS context. It draws feedback and gathers insights from IBS patients, allowing for a better understanding of their needs (Kamp et al., 2024).

4.3 Conducting the study

In conducting this study, I intended to begin by understanding the patient's experiences to gather information that would help in exploring the development of a new conversational AI prototype in this context of IBS. Here, a Design Thinking approach and framework was used to conduct the study following four phases: 1) Define, 2) Ideate, 3) Prototype, and 4) Test (*IDEO Design Thinking | IDEO | Design Thinking*, n.d.).

4.3.1 Project Overview: Design thinking approach

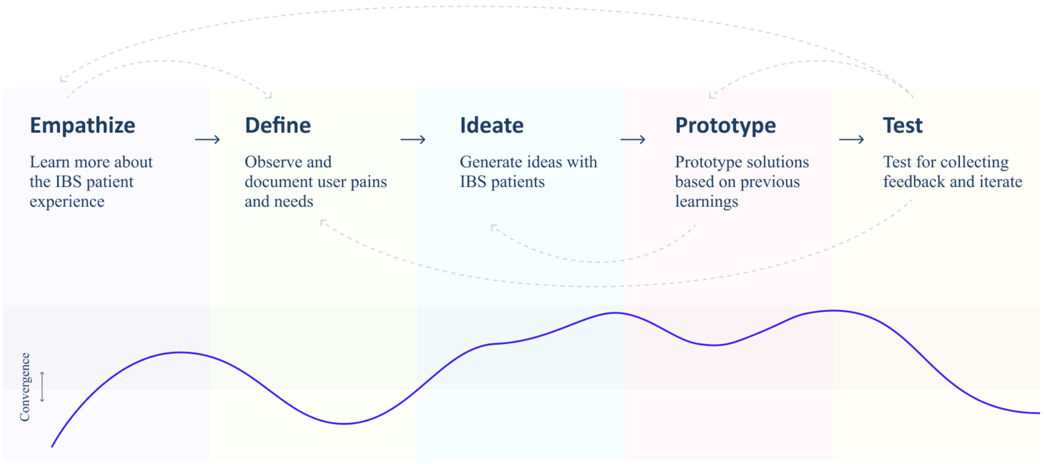


Figure 14 – Design thinking approach visualization

Design thinking is a human-centred design approach (*IDEO Design Thinking | IDEO | Design Thinking*, n.d.). This approach is defined as an iterative, empathic and exploratory way to solve problems while involving the direct participation of users (Razzouk & Shute, 2012).

Next, I will introduce all the different phases of the design thinking approach and this project's methods, techniques, and expected outcomes:

Summary of Design Thinking **phases**, **methods** or **techniques** and **outcomes**

Phase	**Methods / Techniques**	**Expected outcomes**
Empathise	Semi-structured interviews	Learn more about the patient’s experience, pains and needs
Define	Persona	Help document what was learned from the semi-structured interviews and inform the next stages.
	Empathy Map	
	Patient Flow	
	Patient Journey	
Ideate	Co-design Workshop	Learn more about how a conversational interface could help IBS patients and foster idea co-generation with patients.
Prototype	Wireframing	Document previous steps into quick, tangible interfaces.
	High Fidelity Designs	Define and document the UI patterns and overall UX.
	Prototyping	Have a working prototype that can inform the project's next steps and be used to validate designs.
Test	Usability test	Learn insights about the usability of the system and new product opportunities.

Table 6 – Summary of Design Thinking phases, methods or techniques and outcomes

4.3.2 Selecting and Inviting Participants

Patients' participation is a core part of the human-centred design in healthcare (Lyon et al., 2019). I recruited the participants to participate in the interview sessions, the co-design workshop, and the validation of the prototypes.

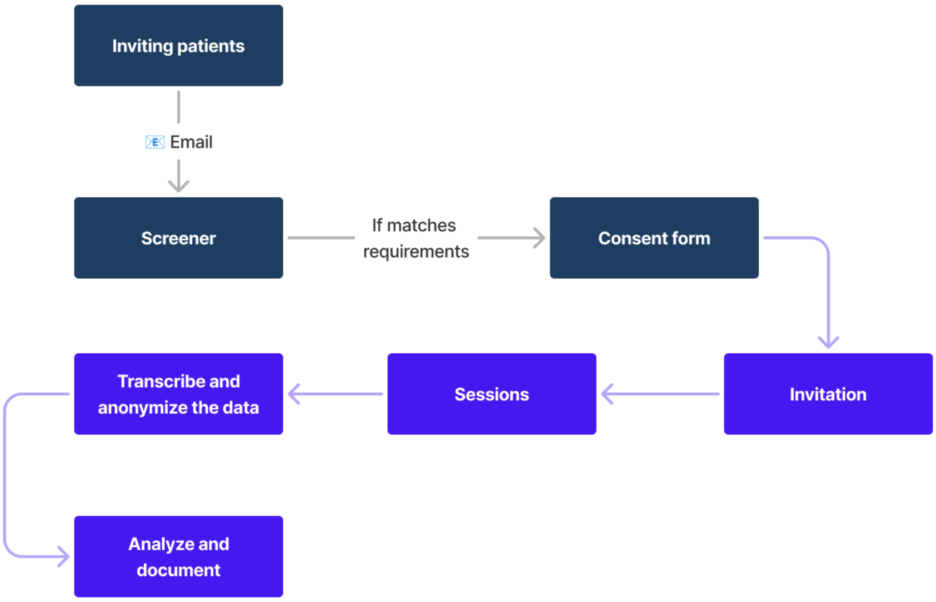


Figure 15 – Participants recruitment process

The direct participation of patients living with IBS is important not only to better understand their current experiences and needs, but also to gather their ideas and aspirations for co-developing a new conversational AI interface.

Ninety-nine IBS patients were invited to participate in this study, but only eight were recruited through a screening process (appendix I) that determined their eligibility.

The following table will show the recruitment criteria for this study:

Recruitment criteria	
✅ Selected	All genders, 18-50 years old
	Patients who have been diagnosed with IBS
	Have been followed by a doctor for at least 12 months.
	The current health state is not sensitive.
❌ Excluded	Patients with other inflammatory diseases but not IBS.
	Patients with low digital literacy

Table 7 – Recruitment criteria for patients for this project

Ethics and Protocol

This project did not involve public or private organisations. All the participants were invited through a network of contacts that had already been set up and did not require the approval of an ethics board.

Nevertheless, several measures were taken during the recruitment phase to protect the participants' individual data, safety, and privacy. These include completing an informed consent form (as shown in appendix III) and anonymising the data and transcripts.

The informed consent explains the nature and scope of the project and guarantees the free right of all participants to withdraw from the project at any time without prejudice, explains the guarantees of confidentiality and anonymity and shares the contact details of the person responsible for processing all the information.

Due to the health condition of participants living with IBS, it was decided that all activities should be conducted remotely for patients' convenience.

All participants involved in this project agreed and signed the informed consent form.

4.3.4 Project Plan

As mentioned in the previous Chapter 4, Section 3.1, the design thinking approach is not linear (IDEO Design Thinking | IDEO | Design Thinking, n.d.), meaning that this project also took advantage of small iterations.

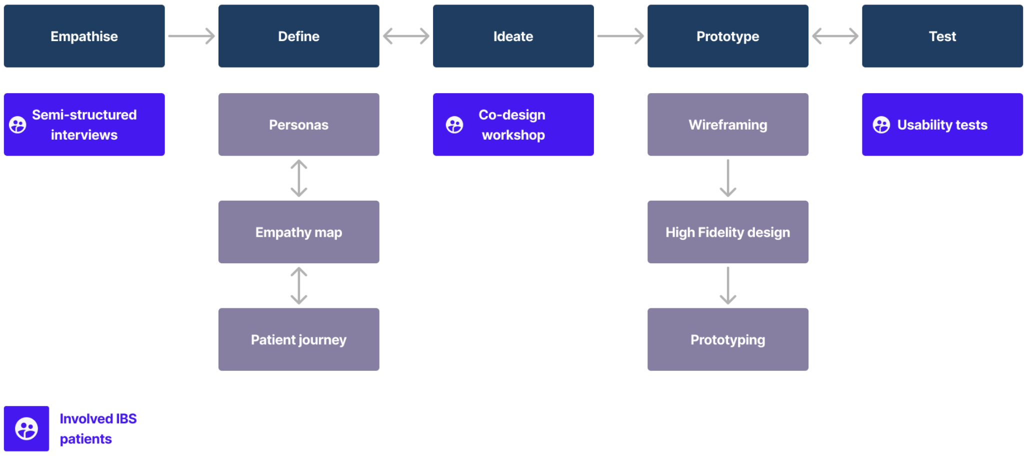


Figure 16 – Project plan overview

It followed the typical design thinking phases and included a strong contribution from the IBS participants during the empathise, ideate, and test phases.

5. Empathise: Exploring Patients Experiences in Living With IBS

5.1 Introduction

This chapter will present the patients' voices through semi-structured interviews. Interviews are a relevant method for gathering information to better understand people's mental models, pain points, experiences, and motivations (Pernice & Rosala, 2023).

This chapter aims to shed light on patients' experiences, including how they navigated their path to diagnosis, their coping strategies, and their main frustrations with their health condition. The findings from these interviews will contribute to a deeper understanding of the patient experience and support the next phases of the Design Thinking process.

5.2 Who Participated?

A total of five patients living with IBS participated in these semi-structured interviews. These participants had a combination of different life and patient experiences.

User	**Gender**	**Diagnosed when**	**Currently followed by**
P1	Female	3-5 years ago	Discharged
P2	Female	5-10 years ago	NHS GP
P3	Female	3-5 years ago	Private Hospital or Clinic
P4	Female	1-2 years ago	Private Hospital or Clinic
P5	Female	1-2 years ago	Private Hospital or Clinic

Table 8 – Participants involved in the Empathize part of the project.

5.3 Conducting and Analyzing Interviews

As mentioned in Chapter 4, section 4.3.2, all these sessions were conducted remotely due to the unpredictability of IBS symptoms and for the participants' better convenience and comfort.

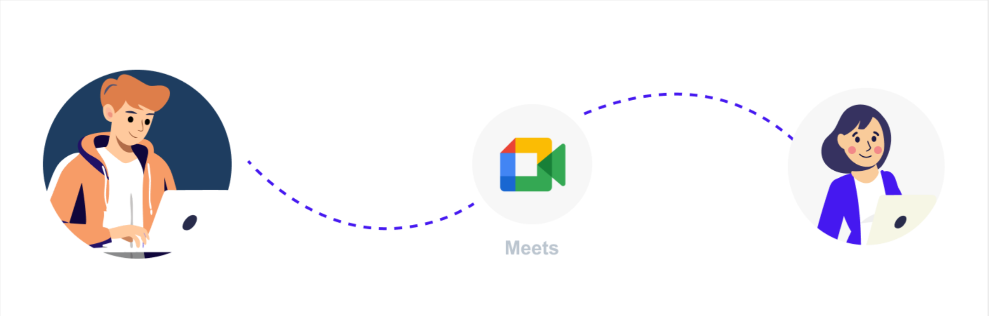


Figure 17 – Remote interview setup

The following table shows the participants, date and duration of the semi-structured interview sessions:

User	Date	Duration (mm:ss)
P1	12/03/2024	**31:14**
P2	24/03/2024	**59:40**
P3	19/03/2024	**32:14**
P4	9/03/2024	**42:46**
P5	17/03/2024	**33:10**

Table 9 – Participants and duration of interviews

I interviewed several participants through a video call handled by the Google Meets platform. At the beginning of each interview, there was an initial protocol where participants were re-introduced to the topic, their rights, and how the conversation would work, allowing space for any questions before starting.

By this time, participants had already signed the consent form, and permission for recording was double-checked via that document and in-call during the recorded moment.

5.4 Findings

5.4.1 Participant 1

Patient experience

Using the interview guide (see Appendix IV), the first issues explored were about the journey about getting a diagnosis.

Participant 1 revealed her experience in living with IBS, the fact she felt frustrated that they had gastrointestinal problems from very early age, and highlighted the main impacts of IBS and care pathway. She said:

> *P1: I've had bowel problems since I was born. In other words, I think my mum says that ever since I was born, I've always had many problems here. I've been to many doctors, endoscopies, colonoscopies, a thousand things, and it was always nothing". (lines 24-30)*
>
> *P1: (...) I'd wake up at night and pass out. Oh, and in a lot of pain. Then I started to get used to it (...), then I would end up having a very large discharge, and it would normalise, but not the pain, and that's when I sought help again. (...) I went back for several tests, even to check for any intolerance, and that was that! That's when it was diagnosed.* (lines 33-40)

Following this, his/her views demonstrated her/his experience through a care journey. She revealed:

> *P1: Now, this time, I've found a doctor who could guide me (...) because I was already getting scared. The fainting part was starting to scare me. Not before that. Before that, many of the suggestions I heard were to take what's good for you, what's good for you, from the GP. And I didn't go looking for specific help; it was only when I got scared that I actually went to a gastroenterologist. (...) As far as the NHS was concerned, they never paid much attention to me. (...)* (lines 58-72)
>
> *P1: It was a bit frustrating because I did a lot of the things I was told, and it didn't normalise at all. But then I didn't know where to turn either, because I'd already done it... I thought I'd done all the exams and that it was nothing. Maybe it really wasn't me who had something, but yes, it was frustrating; it was very desperate at times, not least because the pain is sometimes quite awful* (lines 87-88)

Through the dialogue, Participant 1 revealed her experience in looking for health expertise to understand what is going on with her bowel as she was experiencing a lot of pain and discomfort at the time. She also expressed her view regarding the lack of communication, perhaps "attention" from her GP regarding her symptoms at that time. However, a lack of communication seems to trigger emotional impacts on people, in particular, people who are in a lot of pain. She also added:

> *P1: I even tried the GP, but it was always her only. She never referred me because of my age, because she thought it was just my diet, that I wasn't doing the right things. (lines 75-77)*
>
> *P1: (...) Yes, I just gave up on the NHS. (line 303)*

This view from Participant 1 shows how the lack of communication in healthcare services can also encourage feelings of mistrust in the context of healthcare services. In discussing the context of private healthcare services, the participant revealed her experience of communication associated with her getting advice and strategies to deal with eating food from the doctor. The participant expressed her toughs in this way:

> *P1: Oh, I also did what that doctor advised me to do, to try the low fodmap diet, which helped a lot. I was completely unaware of the fodmap, and it's definitely what's helped me balance my diet now. There are still better and worse times. The nervous system has a huge, huge influence. It's automatic. (lines 39-44)*

After abandoning the NHS route, Participant 1 shared a positive experience at a private hospital consultation. There, her new doctor introduced them to the Low FODMAP diet, which significantly improved her condition following this tailored approach and dietary changes.

Coping strategies and managing IBS

We then explore the coping strategies for managing IBS where Participant 1 began by sharing her coping strategies for managing IBS symptoms, emphasizing the pivotal role of dietary control in her daily life:

> *P1: There are better and worse situations (...) I've even bought recipe books sometimes, also when I feel like I'm under attack, so to speak. (lines 280-283)*

Her proactive strategy of utilizing recipe books illustrates a tailored approach to dietary management, demonstrating a deep understanding of how crucial personalized diet planning is for mitigating IBS symptoms.

This approach to managing her diet transitions into how she deals with acute flare-ups, which are an inevitable part of her condition:

> *P1: I immediately became very bloated with a very hard belly, more than a day like this. And there was a lot of pain from having to lie there... Oh well. Then, I had to go on laxatives to help me normalize and control what I was eating on those days. (…) And cramps, lots of cramps. (lines 126-129 and 141-142)*

The severity of these flare-ups necessitates immediate medical intervention, such as laxatives, underscoring the challenges of balancing proactive dietary measures with reactive medical treatments.

This discussion of symptom management led then to the exploration of her experiences with the healthcare system:

> *P1: (...) Where else would I go? Making an appointment with the doctor who follows me wasn't an appointment for that day or probably two or three days later. Maybe only a week or two, at best. Going to the emergency room because I was in pain. That's unthinkable; I don't do it because I know they won't take any notice, and I don't think it's worth it; no, no, I don't have much place to go for immediate help. (lines 174-179)*

> *P1: Maybe something or someone that would be easy to access in times of crisis other than, I'm going to have to go to the hospital and say: 'I've got cramps' because I think that nowadays doctors just send a 'person for a walk' and they don't even care. (lines 309-313)*

Her frustration with the healthcare system's lack of responsiveness highlights a crucial gap in the support available to IBS sufferers. The need for more accessible and empathetic medical care is clear, as timely interventions can significantly alleviate the severity of her symptoms and improve her quality of life.

Within this context of seeking more effective healthcare solutions, Participant 1 also emphasizes the importance of her daily routines:

> *P1: I think I know. I also know how to avoid them (flare-ups) and I don't always avoid them. That's true (...) in the morning I have a routine every day when I wake up that if I don't do it, I know it won't go well and I'll be uncomfortable that day. Which is to wake up and drink a glass of warm or hot water and then have a coffee. Ah, even before having breakfast! Ah, if I don't do that, I won't be able to go to the loo that day and I'll be even more uncomfortable. (lines 154-196)*

Her meticulous morning routine not only aids in physical symptom management but also provides a sense of control and normalcy, illustrating how critical such rituals are to her overall strategy for managing IBS.

Finally, the discussion of coping mechanisms ends with Participant 1 sharing her SOS medications used in particular during social events:

> *P1: Aero-OM usually helps; it's always with me, in my bag, so when I know I'm having dinner or lunch, when I know I'm going to eat a bit more, I take it straight away ah, (...) I don't know if it's psychological or not, but I try... it helps me a bit. (lines 154-157 and 190-196)*

Her use of SOS medications not only addresses the physical aspects of IBS but also reduces social anxiety, enabling her to engage more freely in social activities. This dual approach underscores the importance of comprehensive management strategies that address both the physical and psychological impacts of the condition.

Experience of living with IBS

Participant 1 discussed her experiences with digital health tools designed to manage diet and IBS symptoms, expressing dissatisfaction with the current offerings:

> *P1: I have already installed those low fodmap apps (...) I tried it, but then I gave up, because the problem with it was that the whole thing was paid for and I didn't think it would bring any great advantages. (...) Well, I've used it, but then I always give up because I don't think they're very practical. (lines 338-343)*

This feedback highlights the lack of utility Participant 1 found in health management apps, particularly low FODMAP diet apps. Her frustration with the practicability and cost of these tools reflects a common barrier faced by individuals seeking digital solutions for chronic health conditions.

Furthermore, Participant 1 expressed a broader concern with the focus of many health apps:

> *P1: The others I haven't tried yet, I haven't found one that satisfies me. I think it's all too much about calories and calories. Or maybe there are, and I don't know about them! (lines 349-352)*

What she shares in this testimonials show a disconnection between the needs of IBS patients and the features offered by most dietary apps, which tend to concentrate more on calorie counting than on managing food sensitivities or IBS-specific dietary needs. This gap suggests a market opportunity for more targeted, health-centric apps that address the unique dietary challenges faced by individuals with IBS.

In concluding the interview, Participant 1 shared her ideal vision for a tool that would allow them to manage her condition more effectively, emphasizing the importance of enjoying food without the repercussions of IBS:

> *P1: I'd love you to invent something so that I could eat what I want without having a flare-up, without having pain afterwards. But I know that's impossible. I mean, I don't say anything these days. You never know. But something that would create a filter there, a barrier that I could enjoy savoring, (…) (lines 373-381)*

This aligns with scientific evidence, on the article “The Pleasures and Memory of Food and Meals” (Rozin & Gohar, 2011) authors argue about the contemporary eating habits that serve more than just nutritional purposes, they also provide pleasure and contribute to creating memories.

Participant 1	
Formally diagnosed when	4 years ago
Main symptoms	Severe constipation, abdominal pain, fainting, cramps
Main frustration when living with IBS	Inability to control severe crises, leading to a significant impact on daily life
Coping strategies	Low FODMAP diet, having a morning routine, having Aero-OM with them
Experiences with Healthcare System	Frustration with GPs, better care from private specialists
Use of digital resources	Tried using FODMAP and diet apps, but stopped due to cost and practicability
If everything was possible…	Ability to eat everything without the drawbacks of IBS

Table 10 – Key summary comparison from the session with P1

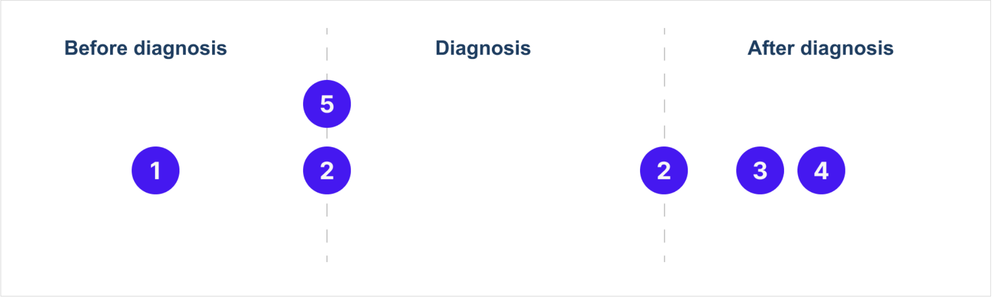


Figure 18 – P1 Emerging questions by patient journey phase

Emerging questions

1. Late diagnosis
2. Emotional impact
3. Lack of diet adherence and need for dietary guidance
4. Need for more digital solutions
5. NHS did not reply as expected

5.4.2 Participant 2

Patient experience

Participant 2 started by sharing her journey to receive a proper diagnosis for her symptoms, which began as early as 2015 but was not formally recognized until two years later:

> *P2: It was in two thousand and seventeen, although the symptoms started more or less in two thousand and fifteen, in two thousand and seventeen I was diagnosed for the first time. I had to be reinvestigated, in quotes, because they wanted to make sure it wasn't Crohn's disease or another inflammatory disease. And I'm still going through this process, after a few years I'm still going through it, but it's already certain that it's Irritable Bowel Syndrome. Sometimes I come across new doctors who find it strange that my symptoms persist so long after so much medication. And they say, 'Oh, but isn't it Crohn's disease? Isn't it? Is it an inflammatory disease?'. Oh, and they prescribe the tests I've done a thousand times and I do them again and they say 'Oh no, it's Irritable Bowel Syndrome!'. So that's it for now. Ninety-nine point nine per cent. (lines 24-35)*

This narrative highlights the frustration and redundancy in healthcare interactions that Participant 2 faced, with repeated tests and initial misdiagnoses reflecting a common challenge in distinguishing IBS from other gastrointestinal disorders. The repeated questioning by healthcare professionals indicates a significant lack of continuity in care and understanding within the healthcare system.

Participant 2 also recounted her initial symptoms, which were misdiagnosed multiple times as gastroenteritis:

> *P2: I started having a lot of bloating, a lot of abdominal pain, a lot of gas and I thought it was strange. I went to my GP to find out what was going on and she said I'd probably caught gastroenteritis. A month passed, two months... and the gastroenteritis persisted. I went to the family doctor again and she said it was gastroenteritis. For about half a year, I even went to the hospital and they said it was gastroenteritis. (lines 45-50)*

The persistence of symptoms mistakenly attributed to gastroenteritis exemplifies the challenges in diagnosing IBS, where symptoms overlap with many other conditions. This prolonged misdiagnosis delayed appropriate treatment and likely exacerbated Participant 2's discomfort and uncertainty.

Afterwards, Participant 2 recalls her journey in the emergency room and how started to be followed by a doctor:

> *P2: But one day I was really full with stomach pains; I couldn't stand it, I was in unbearable pain, and I went to São João again. Oh, and by chance, the person who saw me in the emergency room was a gastroenterologist. She said it probably wasn't gastroenteritis; it was another gastrointestinal problem and she'd like to investigate. (lines 50-55)*

This serendipitous encounter underscores the importance of specialized care in diagnosing complex conditions like IBS, which often get overlooked in general practice settings.

Participant 2 then tells about her experience with the NHS gastroentrologist and the nutrition challenges:

> *P2: (...) at the moment, the whole hospital process is a bit of a pain and sometimes I feel like I'm waiting there for two hours to get an appointment. And I leave there the same or worse off than I was." (lines 134-137)*

> *P2: (…) she gave me a piece of paper with forbidden foods and foods I could eat and I tried to follow it a little bit to the letter. Giving me a piece of paper with the forbidden foods and the foods I can eat was a bit wrong. (…) Lettuce, for example. I used to eat lettuce, it never did me any harm and the nutritionist said 'Oh, it's better to cut down on lettuce, because lettuce is usually bad for you' and now I don't eat lettuce. But I know perfectly well that lettuce is not bad for me. (Lines 61-62, 132-133, 223-227)*

These experiences reflect a lack of tailored care in the management of IBS, particularly in dietary guidance, where broad and non-individualized advice fails to meet the specific needs of the patient. The frustration with generalized dietary lists that do not align with her personal experience calls for a more customized approach to diet management in IBS treatment, potentially leading to better patient outcomes and satisfaction.

Coping strategies and managing IBS

Participant 2 described her comprehensive regimen for managing IBS, utilizing a combination of medications that address various aspects of the syndrome:

> *P2: I'm currently taking a probiotic, I'm taking Librax, I'm taking Duspatal, I'm taking Aero-OM, Imodium and I'm taking the antidepressant (...)" (Lines 341-343)*

> *Analysis: This mix of probiotics, antispasmodics, anti-diarrheal, and antidepressants illustrates the multifaceted approach often necessary to manage IBS effectively. Each medication targets different symptoms or underlying causes of IBS, showcasing the complexity of treatment and the need for personalized therapy strategies in chronic gastrointestinal disorders.*

Furthermore, Participant 2 shared a striking detail about her dependence on one specific medication:

> *P2: So I take a box of Imodium a day. And that's what I literally work for, right now I work for Imodium. (Lines 148-149)*

This comment reveals a concerning level of reliance on Imodium, a medication used to manage diarrhoea symptoms associated with IBS. The fact that Participant 2 consumes a box daily highlights the severity of her symptoms and the drastic measures they resort to for relief. This dependence not only underscores the extreme challenges faced by some IBS patients but also raises questions about the long-term sustainability and safety of such high dosage use. It reflects the urgent need for more comprehensive, perhaps even multidisciplinary, approaches to treatment that could better address the underlying factors of IBS and reduce reliance on symptom-specific medications.

Experience of living with IBS

Next, Participant 2 shared how IBS has disrupted her professional life, particularly during a shift at a supermarket:

> *P2: I got to the [supermarket], it was a Saturday, there were loads, loads of people in that supermarket (...) and then there were loads of customers at my till and I thought 'either I go to the loo now, or I'll pass out here again' and my stomach started hurting so badly, so badly, so badly. And I started crying. I couldn't... because it was stronger than, in other words, I didn't cry and I didn't ask to cry. Tears literally fell. And I had to go to the loo and I left the clients there... because there were no other colleagues to replace me. That's why I didn't call anyone and that was that. I left a huge queue at my till. I went to the loo and left. I had to leave at that moment. I said to my boss. Look, take charge of my till and close it when you can, because I can't be here in so much pain any more. (Lines 373-383)*

This narrative shows the sudden and overwhelming symptoms of IBS that forced Participant 2 to abandon her responsibilities at a critical moment. The intensity of her pain and the emotional distress it caused were so severe that they overcame her ability to maintain professional composure, leading to a direct impact on her job performance and customer service. The absence of immediate support from colleagues further exacerbated the situation, leaving her no choice but to prioritize her health over her duties.

Technology and digital health

After this, Participant 2 discussed the use of technology in managing her IBS, particularly highlighting the utility of a hospital's app for appointment management and the role of online patient groups:

> *P2: I use it, for example, when I have an appointment to check the appointments, because the letters take ages to arrive and sometimes, I only know the day before that I'm going to have the appointment. And if I have the app, I know straight away when the doctor has booked it. (Lines 655-658)*

This use of digital appointment management tools demonstrates how technology can enhance the efficiency and convenience of healthcare interactions for individuals with chronic conditions like IBS. By providing timely access to appointment schedules, the app significantly reduces the uncertainty and stress associated with waiting for postal communication, which can often be delayed. This immediate access is crucial for patients who need to manage her schedules around frequent medical visits.

Furthermore, Participant 2 elaborated on her engagement with online communities dedicated to IBS:

> *P2: I'm in a lot of irritable bowel syndrome patient groups (...) I mean, I'll be honest: I've never asked any questions or anything. But for example, let's say I have a question: I search in the search bar to see if anyone has already asked that question and also tried to get a bit of information from those who are going through the same thing as me. (Lines 168-173)*

The use of online patient groups underscores the value of peer support and shared knowledge in managing chronic health issues. Although Participant 2 does not actively engage in discussions, they benefit from the collective wisdom of the community. This passive engagement still allows them to access a wealth of information and experiences that can aid in understanding and managing her condition better. It highlights a form of digital solidarity where users can gain insights without direct interaction, which can be particularly valuable for those hesitant to share personal health challenges openly.

As we concluded our conversation, Participant 2 expressed the desire for a radical change in her health management approach to alleviate the burdens of IBS. They shared a wish that they would consider to improve her quality of life:

> *P2: I've always told my parents that I don't ever want to have an operation, I've never had one and I never want one, but right now I'm so desperate that I'm willing to have an operation so that I can get a good new intestine so that I can stop having these symptoms and stop taking ten medications a day (...) if I could do everything: I'd have an operation and a new intestine. (683-695)*

This statement illustrates the lengths to which Participant 2 would go to find relief from her chronic condition. Her willingness to undergo a significant surgical procedure, despite a previous aversion to surgery, highlights the severity of her daily struggles with IBS. The idea of obtaining a "new intestine" symbolizes her desire for a fresh start, free from the pain and medications currently dominating her life.

Participant 2	
Formally diagnosed when	6 years ago
Main symptoms	Diarrhea, abdominal pain, bloating, gas
Main frustration when living with IBS	Fear of eating, restrictive diet, difficulty working and socializing
Coping strategies	Low FODMAP diet, Imodium (up to 10 per day), tea, hot water bottle
Experiences with Healthcare System	Long waiting times, lack of personalized care, sees four specialists (gastro, neuro gastro, psychiatrist, nutritionist)
Use of digital resources	Uses hospital app to manage appointments, searches for information online and in patient groups

If everything was possible…	A new, healthy intestine through surgery

Table 11 – Key summary comparison from the session with P2

Figure 19 – P2 Emerging questions by patient journey phase

Emerging questions

1. Need for early and accurate diagnosis
2. Challenges in accessing immediate medical care
3. Overreliance on medication
4. Psychological impact
5. Need for digital tools that can be more useful
6. Need for better patient education

5.4.3 Participant 3

Patient experience

Participant 3 begins her story by recounting the initial confusion and misdiagnosis surrounding her symptoms, which were first thought to be gastroenteritis:

> *P3: The symptoms... initially, I thought it was gastroenteritis, so an intestinal upset. (...) I saw, a day passed. Two. It didn't pass. I went to the GP, who prescribed at the time, I don't remember very well, but some things like a gastric protector and some other normal things. (Lines 23-26)*

This early misunderstanding highlights the challenges often faced in correctly diagnosing IBS, as symptoms can closely mimic those of less severe gastrointestinal issues. The initial treatment with general medications such as gastric protectors further underscores the complexity of accurately identifying IBS based solely on early symptoms without a thorough investigation.

As symptoms persisted, Participant 3 took a proactive approach by consulting a specialist as she shares:

> *P3: At that point, I decided on my own to go straight to a gastroenterologist, because, meanwhile, perhaps two, three weeks had passed and the symptoms, as I tell you ..... the gastro examines the endoscopy, says that there really is a chronic gastritis there, but that it's not the reason for those symptoms I have of excessive gas, as if I were exploding and always with my stomach making lots of noises and constipation like this (lines 37-42)*

> *P3: At least I think that from the moment there is a diagnosis, even if it is this one, in my case, it helped me immensely because I understood what was happening... Because I think the worst of all is until you understand what is happening (lines 62-65)*

The visit to the gastroenterologist not only clarified the presence of chronic gastritis but also led to the critical insight that it was not the root cause of the more troubling symptoms. The relief expressed by Participant 3 upon receiving a correct diagnosis highlights the significant psychological impact of understanding one’s health condition, which can often be as crucial as the physical treatment itself.

Participant 3 also adds to the last diaologue:

> *P3: [Getting the diagnosis] The worst phase, because normally, and I'm like this... when I realised I wasn't getting things sorted out at the GP, I started imagining the worst case scenario in my head (...) because, unfortunately, bowel cancer is becoming more and more common, (...) all of this was open to me and that's when, of course, the symptoms got even worse. And with this anxiety thing... I was completely out of control until I got this diagnosis and had the colonoscopy. (...) And that period was very dramatic for me, very dramatic (lines 87-96)*

The anxiety and stress associated with the unknown elements of her health condition exacerbated Participant 3's symptoms, demonstrating how psychological factors can significantly influence the severity and management of IBS. The fear of serious diseases such as bowel cancer reveals the deep psychological distress that can accompany the diagnostic process for chronic conditions.

Coping strategies and managing IBS

When exploring coping strategies Participant 3 shared insights into how she manages IBS, which prominently include the use of anxiety medication as a long-term treatment:

> *P3: Strategies for example: I've been taking the anxiolytic Victan for many years. I've been taking it for over twenty years (...) I take it at night just to, well, but on the gastro's advice, I was added an anxiolytic. (Lines 223-226)*

Participant 3's use of the anxiolytic Victan, which has been part of her routine for over two decades. The additional anxiolytic prescribed by her gastroenterologist underscores a tailored approach to managing the intertwined symptoms of anxiety and IBS. This dual strategy reflects a growing understanding within the medical community of the psychosomatic connections in IBS, where anxiety not only exacerbates the gastrointestinal symptoms but also emerges as a focal point of treatment.

The incorporation of anxiety management into IBS treatment aligns with current research that suggests a biopsychosocial model is essential for effective management of IBS. Understanding and treating the psychological aspects of IBS can lead to significant improvements in the physical symptoms, affirming the need for comprehensive approaches that address both mental and physical health components.

Experience of living with IBS

We then spoke about how Participant 3 experiences living with IBS, where she described the social pressures and personal compromises involved:

> *P3: I tell you, there's a family dinner, everyone drinks coffee and I order a coffee too, because, well, everyone drank and I drank. (Lines 170-173)*

The decision to engage in typical social dining practices, such as drinking coffee, despite knowing the potential consequences, underscores the complex interplay between social belonging and health management.

Despite these challenges, Participant 3 maintains that IBS does not drastically impede her daily routines, claiming minimal impact on major life activities as she states:

> *P3: But I can't say that it's something that, for example, I've never had to stop going to work." (lines 204-298) "I'm more careful when I'm like this, when I'm feeling a bit more in crisis. OK, I'm honest too, aren't I? Otherwise, I practically eat everything, come on." (Lines 277-278)*

These statements suggest a level of adaptation where Participant 3 has found a balance that allows them to continue with her daily activities, albeit with caution during more severe episodes. Her approach indicates a degree of normalization of her condition, where they have learned to manage symptoms to the extent that it does not significantly disrupt her work or broader lifestyle.

However, Participant 3 also acknowledges making notable dietary adjustments to minimize symptom flare-ups:

> *P3: I avoid pulses... because I know they give me a lot of gas and it'll change me. I avoid pulses as much as possible, I avoid green things, for example bananas. (Lines 271-282)*
>
> *P3: If it's feijoada, imagine... I'll have feijoada! I know it's okay, I don't want to be a killjoy, but I'll take a spoonful of feijoada. I prefer people to say Ah, you're not eating anything. No, I don't feel much like it because I already know that it's going to happen to me... I've learnt to deal with it that way. (Lines 198-204)*

Here, Participant 3 details specific dietary strategies to manage her IBS, like avoiding certain high-risk foods known to cause discomfort. Her pragmatic approach to social eating situations, such as choosing to have a small amount of problematic foods like *feijoada*, demonstrates a nuanced management strategy that prioritizes social engagement while still mitigating risk. This strategy represents a compromise, aiming to blend in socially without fully disregarding her dietary needs.

Technology and digital health

Afterwards, we explored the technology and digital health topic where Participant 3 highlighted the use of email as a primary method of communication with her gastroenterologist:

> *P3: We communicate a lot by e-mail, which I think is very quick and fast (...) when I'm worse or when there's an abnormal situation or it's already happening. I write and say that this is happening or I'm feeling this way. Do you think I can take Normatal or do you think I can take I don't know how many? And he advises me and I've got it somewhat under control. (Lines 68-72)*

This method of communication proves to be particularly beneficial for Participant 3, it allows for timely advice and adjustments to treatment plans based on current symptoms, providing Participant 3 with a sense of control and immediate access to medical support. This ongoing, remote interaction with her doctor not only enhances the management of her condition but also minimizes the disruptions to her daily life caused by in-person consultations.

Participant 3 further elaborated on the benefits of this modern approach to healthcare communication:

> *P3: The only thing I can say is how easy it is to be ready, to correspond with my doctor and to be constantly informed, if necessary, via email (...) I can say that these new technologies have helped, they've avoided a lot of consultations, because often it was just to show the results of tests or even analyses. I'd send him the results and he'd just say, "everything's fine, don't worry, that's all. (Lines 250-257)*

The ease and efficiency of email communication not only streamline the process of health management but also contribute significantly to reducing the logistical burden of chronic illness management. By sending test results electronically and receiving quick feedback, Participant 3 avoids unnecessary travel and waiting times, which can be particularly taxing for individuals dealing with frequent or severe symptoms.

During the conversation, Participant 3 expressed a clear preference for minimizing medication usage, reflecting a common sentiment among patients who are concerned about the long-term effects and dependence associated with pharmaceutical treatments, as she mentions:

> *P3: I don't have to take anxiolytics or antidepressants, because I really am... I avoid medication as much as possible, but I always make the same mistake. (lines 337-338)*

This statement reveals Participant 3's reluctance to rely on medications such as anxiolytics or antidepressants, despite possibly needing them at times. The mention of "making the same mistake" implies a cycle where attempts to avoid medications result in situations that ultimately necessitate her use.

When questioned further about her aversion to medication, Participant 3 articulated her concerns about the pervasive nature of pharmaceuticals in modern healthcare:

> *P3: I really believe that nowadays we've gone overboard, because there's a medicine for everything and if I were to take everything that the doctor prescribes, I'd be worse off than my grandmother, who takes thirty pills a day. And maybe I'd choose not to take them... to have more natural solutions. I don't know... Like how it is used to be. (lines 352-355)*

Participant 3's viewpoint reflects a broader skepticism about the over-medicalization of health conditions and a yearning for a return to more natural remedies. Her reference to a simpler, presumably healthier time "like how it used to be" underscores a desire for treatments that do not just address symptoms but also harmonize with the body's natural processes.

Participant 3	
Formally diagnosed when	3-5 years ago
Main symptoms	Obstipation, bloating, intestinal noise, some pain

Main frustration when living with IBS	Choosing what to eat at restaurants or social events
Coping strategies	Healthy diet with fiber and avoiding trigger foods like coffee, spicy and gassy foods
Experiences with Healthcare System	Took initiative to see private gastroenterologist after feeling dismissed by GP, now has good follow-up
Use of digital resources	Communicates with doctor via email, reducing need for in-person visits
If everything was possible…	Not needing to take any medication

Table 12 – Key summary comparison from the session with P3

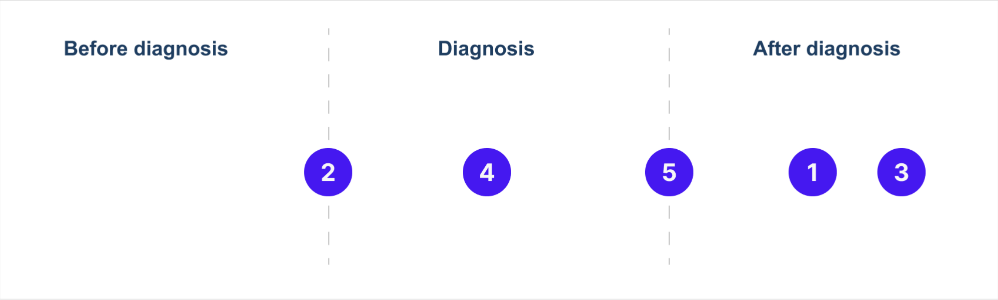


Figure 20 – P3 Emerging questions by patient journey phase

Emerging questions

1. Need for Better Patient Education
2. Need to improve the Initial medical support and diagnosis psychological impact
3. Integration of Mental Health Support in IBS Management
4. Allow access to specialised dietary guidance and support
5. Communication channels between patients and healthcare providers

5.4.4 Participant 4

Patient experience

We started by Participant 4 sharing her frustrating experience in seeking medical help for her symptoms, which were often dismissed by healthcare professionals, as she states:

> *P4: I felt that the doctors didn't take my complaints seriously, which only increased my anxiety. (Lines 22-24)*

This dismissal can heighted the participant feelings of being misunderstood and not taken seriously.

The struggle to obtain a clear diagnosis not only heightened Participant 4's anxiety but also had a broader impact on her mental health:

> *P4: The difficulty in obtaining a clear diagnosis has greatly affected my mental health, increasing my stress levels. (Lines 30-32)*

The uncertainty surrounding her health condition contributed to increased stress, illustrating how integral a timely and empathetic diagnostic process is to the overall health care experience. Delays and miscommunication in diagnosing can exacerbate the patient's existing symptoms and create new health issues, such as stress and anxiety.

The turning point in Participant 4's diagnostic journey came after experiencing significant weight loss:

> *P4: (...) so I went to a gastro doctor to find out what the problem really was, why I was losing weight, Eh and that was it. I had a colonoscopy, an endoscopy, and after several tests, I was diagnosed with irritable bowel syndrome. (Lines 38-40)*

This narrative highlight that the diagnosis of IBS often follows significant and alarming symptoms that cannot be ignored, such as abrupt weight loss. The necessity for multiple tests, typical in diagnosing IBS due to its classification as a diagnosis of exclusion (Saha, 2014), underscores the complexities and challenges in accurately identifying this disorder.

Coping strategies and managing IBS

Afterwards. Participant 4 outlined her approach to managing IBS, which includes a combination of daily and as-needed medications:

> *P4: There's one thing that usually helps me, and that's a ready-made medicine. Every day I take a medicine for irritable bowel, dospatal, which I think is what it's called. I take a medicine for that every day and then I have a medicine that helps relieve the spasms, which is buscopan, which I usually take when I'm a bit more irritable. (Lines 131-136)*

This share from Participant 4 highlights the reliance on pharmacological interventions to control the symptoms of IBS. Duspatal, used daily, helps regulate bowel movements and reduce irritation, while Buscopan is used on an as-needed basis to alleviate abdominal cramps.

In addition to medication, Participant 4 has implemented significant dietary changes under professional guidance to further manage her condition, as she says;

> *P4: I started seeing a nutritionist and exercising. (Line 104)*

Working with a nutritionist and engaging in physical exercise signify a holistic approach to health management.

The specifics of Participant 4's diet further emphasize the personalized nature of IBS management:

> *P4: (...) It's personalised, it really is. It's a diet that says I have to eat a certain number of grams of meat. I don't know how many grams of fish, the soup has to have those ingredients, it really has to, and that's it. And basically I have to drink a lot of fluids, which is to help. I also have to take protein to help me gain weight. That's it. (Lines 377-381)*

The focus on specific food quantities and types is aimed at avoiding triggers while ensuring nutritional balance.

However, maintaining such a strict diet presents challenges, especially in social situations or when dining out as Participant 4 shares:

> *P4: The challenges are when I'm away from home because when I'm away from home, it's extremely difficult to fulfil the challenges. It's not that I can't carry my soup around with me because he's determined not to eat soup in the restaurant. And I can't eat soup in a restaurant? I can't eat it, so I can't carry my soup behind me. Ah, but on those days! I try to eat something like a baked potato with grilled fish and try to make up for the lack of what I can't eat. (Lines 385-392)*

This dialogue shared the difficulty in adhering to a strict diet in unfamiliar environments, pointing to a significant gap in the availability of suitable dietary options for individuals with IBS when outside her controlled home setting.

Experience of living with IBS

When it comes to the experience of living with IBS Participant 4 shares the profound effect IBS has had on her ability to maintain a consistent work schedule:

> *P4: I even missed work because of it. So I don't know, I don't know what medication they gave me, I know that after a while I was a bit better and that was it, but I went to the emergency room several times. (Lines 242-245)*

This testimony reveals the severe implications of IBS on Participant 4's professional life, where frequent absences and emergency room visits become necessary to manage acute symptoms

The conversation further explores Participant 4’s troubled relationship with food, driven by anxiety over potential symptom flare-ups:

> *P4: It was a bit complicated, because I used to look at food and I still do today. I'd look at the food, I'd look at the food and I'd start to be afraid to eat. I was really afraid to eat because I knew that I was going to eat this, and then I'd go to the loo and it would give me a crisis and I'd feel sick. (Lines 61-65)*

The anticipatory anxiety described here highlights the psychological toll associated with eating.

Participant 4 also discusses how IBS has led to social isolation, particularly during events where food plays a central role:

> *P4: Ah, it affects me because there are lots of things I don't do. Like I don't go, I don't go to certain places. No, I don't. I don't go to weddings, for example, because I think it's very difficult for me or other kinds of things to look at food and not be able to eat. (Lines 255-258)*

This avoidance of social gatherings where Participant 4 cannot control her diet highlights another dimension of IBS's impact — social isolation. Avoiding such events helps manage symptoms but at the cost of missing significant personal interactions and experiences.

Moreover, the challenges extend to vacations and travel, as Participant 4 shared:

> *P4: Sometimes I have problems when I go on holiday, because I can't always find restaurants or places to go that suit me. I always try to find accommodation where I can eat my meals, which is much easier. (lines 218-221)*

Travel often requires careful planning to ensure dietary needs are met, as unpredictable meal options can exacerbate symptoms. This need for meticulous preparation can limit the freedom and spontaneity typically associated with travel, adding yet another layer of difficulty to living with IBS.

Technology and digital health

Participant 4 then shares her reservations about seeking information on health conditions online, highlighting a common concern regarding the reliability and impact of such data:

> *P4: I've never really looked for much, I've never really looked for much help on the internet. No, I'm not. I'm not much of a Google person or anything and look up symptoms. I think sometimes you get more scared when you try to read (...) because then you try to associate it with what you have, And then you say "I have this" and then people become a bit hypochondriacal. (Lines 450-454)*

This reluctance to engage with online health resources shared by Participant 4 in this dialogue comes from a fear of misinterpretation and the potential for exacerbating anxiety. Participant 4's testimony reflects a broader issue with health information on the internet: the overwhelming amount of content that can sometimes be inaccurate or misleading, leading to increased worry rather than providing relief or actionable guidance.

In the end of the conversation Participant 4 expressed a strong wish to overhaul her current way of managing IBS, by mitigating the severe limitations imposed by the condition on her daily life, as she said:

> *P4: I'd change everything, without a doubt, this is very limiting. It's like this: I go to eat at someone's house or something and it's like 'I can't eat this, I can't eat that'. (...) It's all very intense. (Lines 591-600)*

This share from reveals the profound frustration and constraints Participant 4 experiences due to IBS. The need to constantly monitor and restrict her diet, especially in social settings like dining at someone else's home. Her language—"*I'd change everything*"—reflects a deep-seated desire for a life free from the burdens of IBS, where they could enjoy social interactions and meals without the constant worry about triggering symptoms.

Participant 4	
Formally diagnosed when	2 years ago
Main symptoms	Diarrhea, nausea, abdominal pain, weight loss
Main frustration when living with IBS	Eating out, traveling, socializing, working during flare-ups
Coping strategies	Low FODMAP diet, probiotics, stress management, seeing nutritionist and psychologist
Experiences with Healthcare System	Dismissed by doctors initially as gastroenteritis, eventually diagnosed by gastroenterologist, now well supported

Use of digital resources	Participates in online patient groups, follows low FODMAP resources and accounts
If everything was possible…	Not having to work to reduce stress-triggered symptoms

Table 13 – Key summary comparison from the session with P4

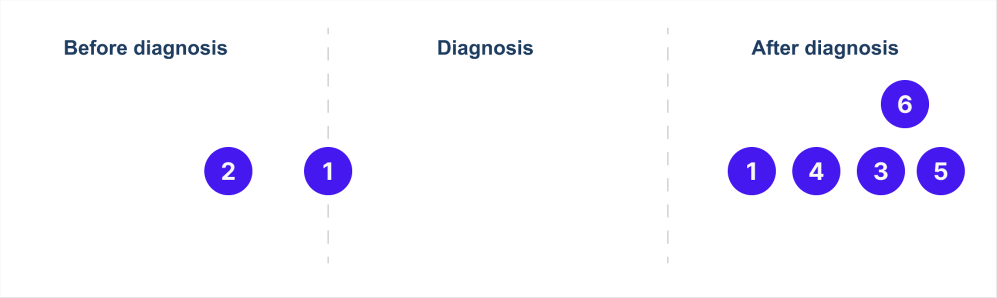


Figure 21 – P4 Emerging questions by patient journey phase

Emerging questions

1. Importance of addressing the psychological impact
2. Need to improve Initial medical support and diagnosis
3. Integration of Mental Health Support in IBS Management
4. Allow access to specialized dietary guidance and support
5. Communication channels between patients and healthcare providers
6. Potential for digital health tools in IBS symptom tracking and management

5.4.5 Participant 5

Patient experience

Participant 5 began by recounting her long history of intestinal issues, which were frequently misinterpreted, as she states:

> *P5: Oh, I've always had intestinal problems. More than anyone else in the family, for example, the festive food was bad for me, but it wasn't for anyone else. I used to go to hospital all the time with stomach pains, which were supposed to be gastroenteritis... I've always had it. (Lines 24-27)*

In this share we can notice that Participant 5 talks about her early experience of being more susceptible to food-related discomfort than others in the family highlights the longstanding nature of her symptoms. The repeated misdiagnosis as gastroenteritis illustrates a common challenge in the recognition of IBS, where intermittent, severe symptoms are often misunderstood as less complex digestive issues.

Participant 5's then shares:

> *P5: Every time I went to the doctor, it was always: 'Why? That was something you took. It was something.... that…' there was never anything really. Until I had to punch the table and say look, I'm sorry, I haven't eaten for three weeks. Something's not right here. (Lines 45-48)*

This dialogue highlights the struggle extended into Participants' 5 adult life, particularly in how they interacted with healthcare providers. The frustration expressed here underscores the difficulty IBS patients often face in having her symptoms taken seriously. Participant 5's needs to advocate forcefully for themselves highlights a significant issue within healthcare interactions.

The participant also recounted her reluctance to use emergency services due to the expectation of not being taken seriously:

> *P5: I didn't think it was something that needed to go to an emergency room, did you? If you have diarrhoea, you don't go to the emergency room, unless it's something bloody, something really violent, that you can't stop. But I even went to the emergency room when*

> *I was desperate for three weeks in a row. I went to the emergency room and the man gave me Ultra Levure and told me to go home and go on a diet. I asked him: what part didn't you realize that I haven't eaten for three weeks, and that this can't be? (Lines 95-105)*

This experience reveals the critical gaps in emergency care for chronic conditions like IBS, where symptoms may not always appear life-threatening but significantly impact quality of life.

Amidst systemic delays exacerbated by external factors such as the COVID-19 pandemic, Participant 5 turned to private healthcare:

> *P5: Oh, and then I had to make an appointment to see a gastroenterologist and, like the public one, on top of that it was Covid times. So I didn't have any appointments, I had to go to the private one and I had to get it done and from then on the doctor realised that yes, this can't be. (Lines 50-53)*

After extensive testing and consultations Participant 5 shares her testimonial when she got a correct diagnosis:

> *P5: It was exams, everything. And even in areas other than gastroenterology. That's why I also went to the gynaecologist, because since the place is similar, there couldn't be a gynaecological thing that would cause this. (Lines 53-56)*

This Participant 5's narrative illustrates the arduous path many IBS sufferers undergo to obtain a proper diagnosis and effective treatment.

Coping strategies and managing IBS

We then explored the coping strategies in managing IBS where Participant 5 shared:

> *P5: I always take Imodium, because that's what can stop the diarrhoea as quickly as possible and then I always take this medication, because after the Imodium, it's like the system stops completely and then you start to feel sick because it's not working properly. So you go back on the probiotics, back on the three-day medication and you'll be fine. (Lines 235-240)*

In this dialogue Participant 5 shares her proactive measures for coping with IBS, which encompass a variety of medical and lifestyle adjustments aimed at mitigating symptoms and improving overall well-being.

Participant 5 then adds:

> *P5: Ah, now it's a lot about managing stress. I've realised it's one of the big triggers. Apart from food being a big trigger for me, certain types of food, stress is a big trigger, that's it! And then the part of using essential oils to calm down, meditating, doing breaths, that kind of thing, which I didn't think would work, but actually does, is what I've been using more to try and control it. (Lines 272-277)*

> *P5: I've just started at the gym and I can feel a big difference, not physically, but mentally it's a really big difference. (Lines 287-289)*

Participant 5 recognises stress as a significant exacerbator of her IBS symptoms and has incorporated various stress-relief techniques into her daily routine to mitigate it. The use of essential oils, meditation, and breathing exercises, alongside regular gym sessions, shows her commitment to addressing the psychological factors that impact her physical health.

She also shares more into the psychologic side:

> *P5: In the meantime, I've also started seeing psychologists, which I think has made a big difference, because the emotional stress and all this is a trigger for a crisis to appear, which I didn't realise at the time, but that's it. Now I realise that all these areas have to be very integrated. (Lines 71-74)*

Engagement in psychotherapy has enabled Participant 5 to better understand and manage the emotional dimensions of living with IBS.

Experience of living with IBS

Participant 5 then described the profound effects of IBS on her professional life:

> *P5: In the past, it was everything. Because it's like this: a person who's been in the bathroom for four hours at dawn is in no condition at eight in the morning to go to work! Doing a job that requires mental effort is impossible. And that was very painful, very painful. I often went to work crying and came home from work crying. (lines 349-353)*

This testimonial emphasizes the difficulty in maintaining a normal work schedule and the direct impact of IBS symptoms on Participant 5's ability to perform her job, particularly when the condition demands significant time in the bathroom during early hours, impairing her ability to function effectively at work later in the day. The emotional toll is equally significant, with the stress of managing symptoms in a professional environment leading to distress both before and after work.

Further discussion revealed Participant 5's anxiety about experiencing symptoms in public places:

> *P5: It's fear. It's the constant fear that this will happen outside the home, because while it's happening, everything is under control at home? No? You can do it. You have access to a bathroom, you have access to your things, that's it. Now, if it happens in the middle of public transport or if it happens at work or whatever, it's always that panic that it's going to happen. (lines 220-224)*

The fear of having an IBS episode in public significantly constrains Participant 5's ability to engage in activities outside her home. This anxiety limits her mobility and participation in everyday activities.

Further into the conversation Participant 5 adds to the social isolation point:

> *P5: There were many dinners that I didn't go to. There were many things I didn't go to, there were others that I really had to go to and everyone was eating, and I had a bucket of tea, which was my food during dinner. This kind of thing interferes a lot, everything about socializing interferes a lot. (lines 311-314)*

Here we can understand the restrictions on what Participant 5 can safely eat contribute to her sense of being different or excluded in social settings, particularly during meals which are central to social interactions. Opting for a bucket of tea instead of participating in a meal highlights the significant modifications they must make, which can feel isolating and impact her social life and relationships. This aspect of IBS management—navigating social situations with dietary limitations—poses its own challenges.

Technology and digital health

We then explored the technology and digital health tools where Participant 5 shared:

> *P5: (...), I don't even know anything that exists. (...) Look, the lists of foods that there are with the tables on the low food maps help a lot because a person gets there and sees them and then there's a lot hidden in the food that sometimes we don't realise, because it comes in a code and any layperson can't understand what's written there. (lines 402-405)*

In this statement Participant 5 expressed interest in digital health solutions for managing IBS, though they noted a lack of familiarity with specific applications designed for this purpose. However, they acknowledged the usefulness of digital resources like FODMAP lists in managing diet-related aspects of the condition.

In conclusion to our conversation Participant 5 shared what she would change if everything was possible:

> *P5: I'd change the stress part. If I could switch that switch off a bit, but unfortunately I can't because apart from work, I'm also studying, so there's a lot going on. And if I could choose not to work, I wouldn't. (Lines 492-495)*

This share highlights her desire to significantly alter how she manages stress, which she identified as a primary trigger for her IBS symptoms. Participant 5's current life situation, juggling both work and study, significantly contributes to her stress levels, suggesting that her daily activities and responsibilities are closely intertwined with her health challenges. The wish to "switch off" stress indicates a longing for a more tranquil and manageable lifestyle, which they believe could alleviate her condition.

Participant 5	
Formally diagnosed when	2 years go
Main symptoms	Severe abdominal pain, frequent diarrhoea, nausea, bloating and abdominal distension
Main frustration when living with IBS	The constant fear of symptoms occurring in public and feeling misunderstood by others
Coping strategies	Low FODMAP diet. Stress management techniques. Always carrying medication (Imodium). Probiotics and psychotherapy
Experiences with Healthcare System	Initially dismissed, they had a long journey to a proper diagnosis. Had to strongly advocate for herself to get proper attention. Found more support in private healthcare.
Use of digital resources	Uses digital food lists and FODMAP tables for diet management
If everything was possible…	They would reduce stress levels, potentially by not working

Table 14 – Key summary comparison from the session with P5

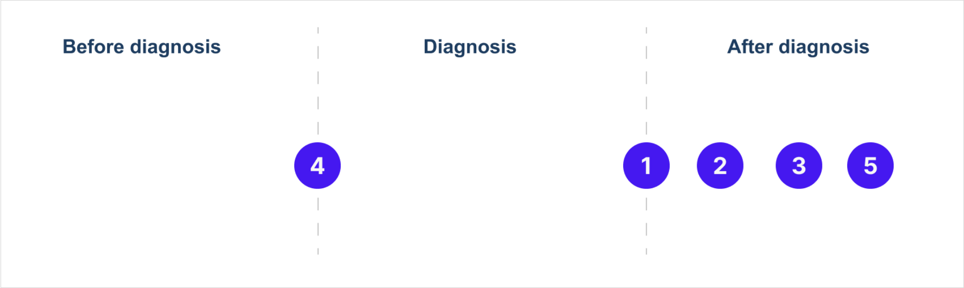


Figure 22 – P5 Emerging questions by patient journey phase

Emerging questions

1. Need for better patient education
2. Potential for digital health tools in IBS management
3. Impact of dietary restrictions on quality of life and social occasions
4. Need for more IBS awareness
5. Workplaces need to be more inclusive to help IBS patients manage their condition

6. Define: Materializing Initial Research

6.1 Introduction

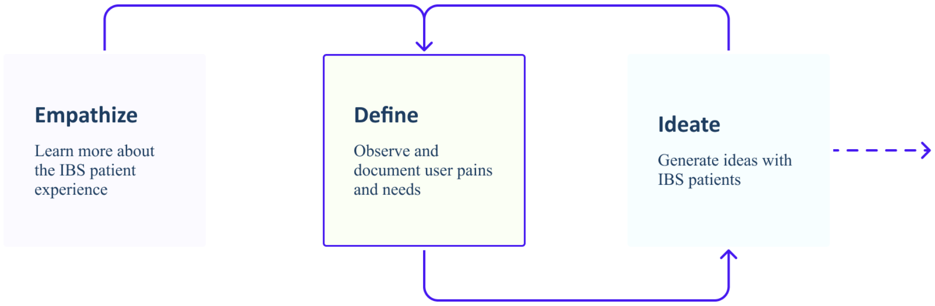


Figure 23 – Define stage of the Design Thinking approach

Building on the empathise phase, this chapter synthesises the key findings related to patients' experiences of living with IBS. After examining these insights in-depth, we can define a problem statement as the foundation for the following design stages.

The persona, empathy, and journey map presented in this chapter were used to help prepare the workshop and mainly to inform the interface design practice, enabling it to be more human-centred.

6.2 The present patients experiences of living of IBS

Themes:

- Challenging diagnostic journey
- Multidimensional impact on quality of life
- Diet and Low fodmap
- Technology and digital health

Highlights Overview Across Different Participants

	P1	P2	P3	P4	P5
Diagnosed	4 years ago	6 years ago	3-5 years ago	2 years ago	2 years go
Main symptoms	Severe constipation, abdominal pain, fainting, cramps	Diarrhea, abdominal pain, bloating, gas	Obstipation, bloating, intestinal noise, some pain	Diarrhea, nausea, abdominal pain, weight loss	Severe abdominal pain, frequent diarrhoea, nausea, bloating and abdominal distension
Main frustration when living with IBS	Inability to control severe crises, leading to a significant impact on daily life	Fear of eating, restrictive diet, difficulty working and socializing	Choosing what to eat at restaurants or social events	Eating out, travelling, socializing, working during flare-ups	A constant fear of symptoms occurring in public and feeling misunderstood by others
Coping strategies	Low FODMAP diet, having a morning routine, having Aero-OM with them	Low FODMAP diet, Imodium, tea, hot water bottle	Healthy diet with fibre and avoiding trigger foods like coffee, spicy and gassy foods	Low FODMAP diet, probiotics, stress management, seeing nutritionist and psychologist	Low FODMAP diet. Stress management techniques. Always carry medication. psychotherapy
Experiences with Healthcare System	Frustration with GPs, better care from private specialists	Long waiting times after being referred	Took initiative to see private gastroenterologist after feeling dismissed by GP, now has good follow-up	Initial dismissed by doctors initially as gastroenteritis, eventually diagnosed by a gastroenterologist, now well-supported	Long journey to proper diagnosis. Had to strongly advocate for herself to get proper attention. Found more support in private healthcare.

Use of digital resources	Tried using FODMAP and diet apps, stopped due to cost and practicability	Uses hospital app to manage appointments, searches for information online and in patient groups	Communicates with doctor via email, reducing need for in-person visits	Participates in online patient groups, follows low FODMAP resources and accounts	Uses digital food lists and FODMAP tables for diet management
If everything was possible…	Ability to eat everything without the drawbacks of IBS	A new, healthy intestine through surgery	Not needing to take any medication	Not having to work to reduce stress-triggered symptoms	Would reduce stress levels, potentially by not working

Table 15 – Combined view of summary highlights of all the five interviews.

6.2.1 Challenging Diagnostic Journey

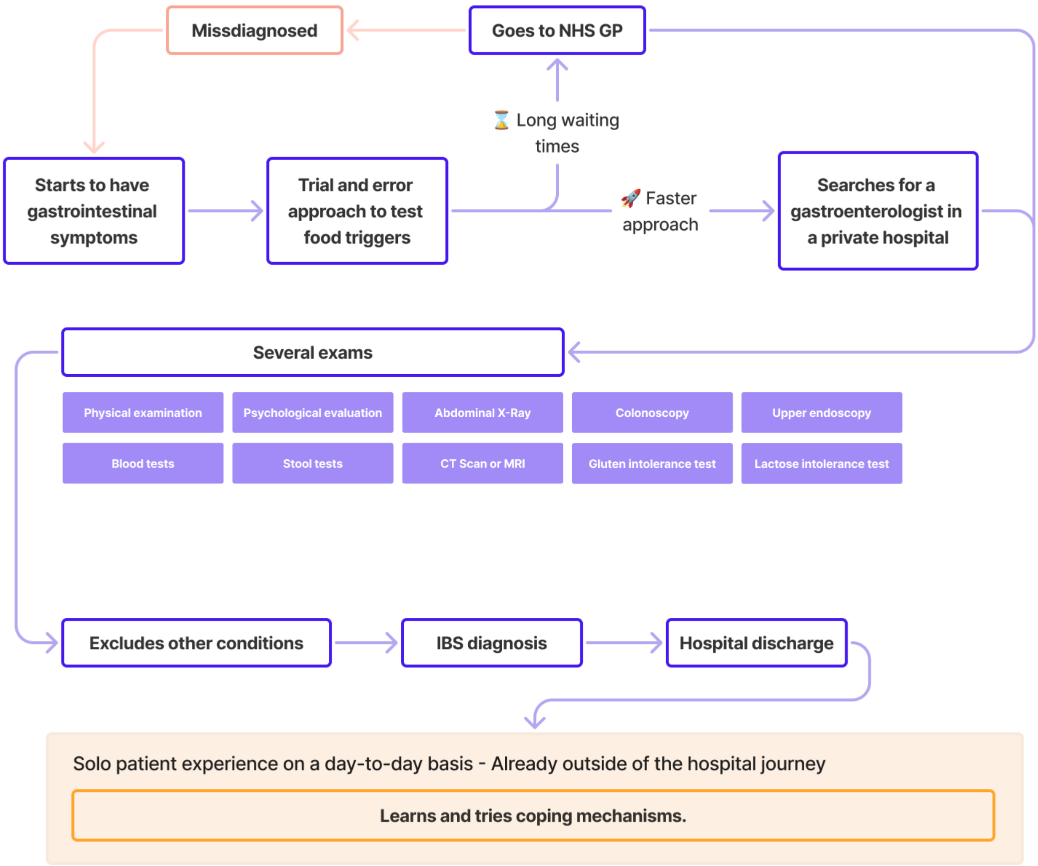


Figure 24 – Diagnostic patient journey

Several participants expressed frustration with their healthcare system experiences, particularly in relation to the lack of understanding or action on the part of healthcare professionals and the long waiting times for appointments and treatments as observed in Figure 24. Besides this frustration, they also report that they often suffer from misdiagnosis before receiving the IBS diagnosis.

6.2.2 Multidimensional Impact on Quality of Life

Irritable Bowel Syndrome (IBS) severely impacts the quality of life, especially in social situations, both in professional and personal life.

Eating

Figure 25 – Eating at home versus outside

Participants revealed a pattern of anxiety and avoidance in contexts that involve eating, both in their professional and personal lives. Many patients develop a fear of eating in public, anticipating potential flare-ups. This often results in the refusal of invitations and possible social isolation.

The constant need to adjust food choices creates an additional mental burden, forcing patients to negotiate between their dietary needs and social expectations. This concern permeates everyday life, affecting everything from work meals to casual encounters. Still, it also opens doors to new opportunities for conversational AI products such as real-time support and meal management.

Work-life

Figure 26 – Working with IBS

IBS symptoms often result in absences from work, difficulty keeping to schedules, and reduced productivity, as shown by the participants. Patients also report going to work in poor physical and emotional condition, often after poor nights' sleep due to symptoms leading to emotional distress.

6.2.3 Diet and Low FODMAP

Figure 27 – Searching for foods that are low fodmap

The low FODMAP diet emerges in almost all patient conversations as a crucial management strategy for patients with IBS. Three participants reported significant positive experiences with this dietary approach.

We can learn from these testimonials that the implementation of the low FODMAP diet helped IBS patients, with one participant describing an "abysmal" change. Some of the patients were initially unaware of this option, but after introduction by healthcare professionals, they recognised its positive impact.

The low FODMAP diet reduces fermentable carbohydrates that can aggravate IBS (Catassi et al., 2017). This is achieved by temporarily eliminating certain foods and gradually reintroducing them to identify individual triggers and personalise the diet over the long term, which shows great results (Eswaran, 2017).

Although the low FODMAP is a good starting point, each individual has their tolerances, demonstrating the need for a personalised diet (Barrett, 2017).

6.2.4 Technology and Digital Health

Communication between patient and hospital

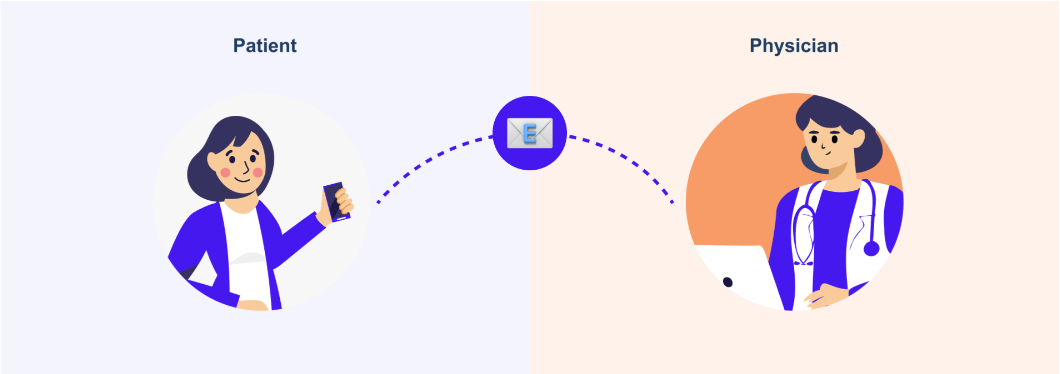


Figure 28 – Electronic communication between patient and physician (hospital)

Two participants mentioned communication-related positive experiences while using email and an app to check medical appointments instead of waiting for a letter from the hospital.

Other apps and digital health management

Figure 29 – Other apps for digital health management

Patients reported using other apps to join patient groups where they can learn from previous interactions. Although some patients are not aware of IBS-specific apps, they sounded happy to explore those opportunities.

6.3 Outcomes and Outputs

As mentioned at the beginning of this chapter, the following techniques were created based on the findings shared in the previous section and with the aim to help prepare the workshop and mainly inform the interface design practice, enabling it to be more human-centred.

6.3.1 (IBS Patient) Persona

Personas are a technique that aims to create a consolidated view of the audience that will benefit from the product or service being developed. This ensures that product teams consider user needs and goals throughout the project. To ensure good personas, they should be derived from research and not fictional (Martin & Hanington, 2019).

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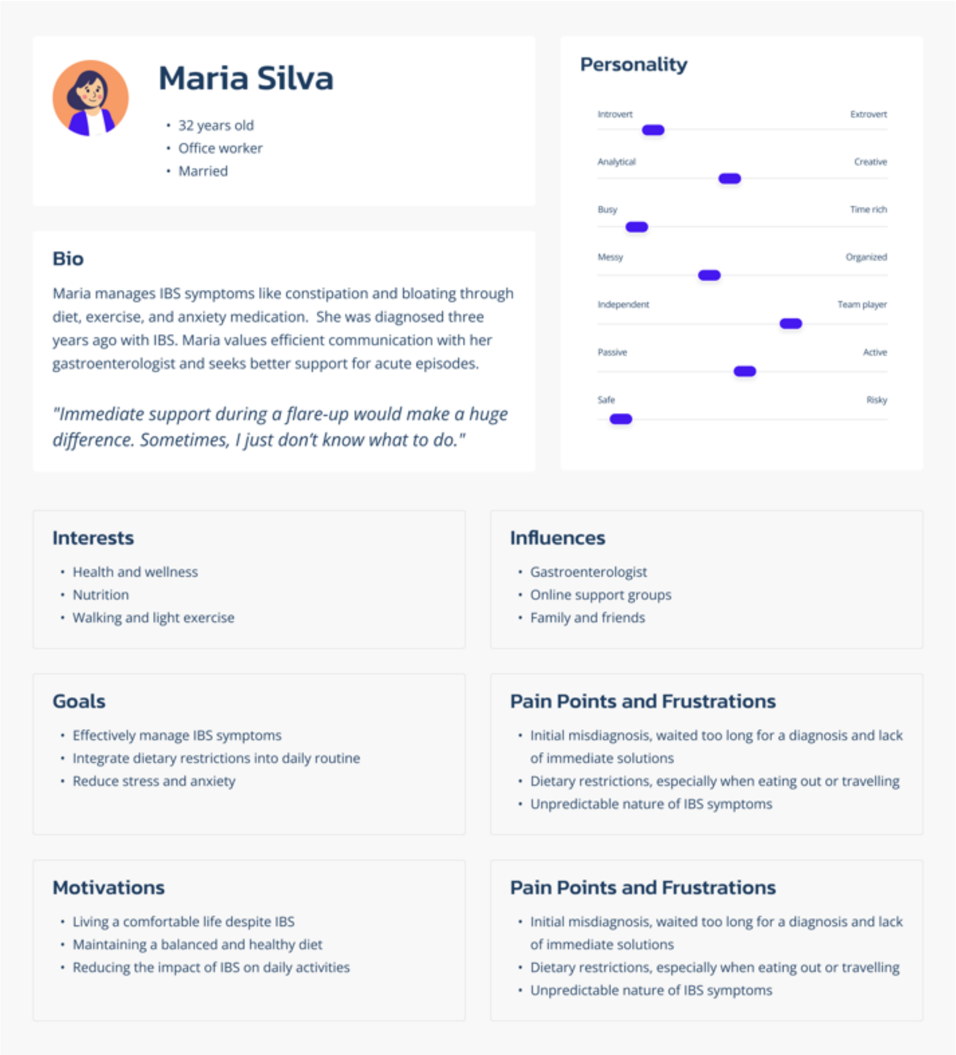

Maria Silva

- 32 years old
- Office worker
- Married

Bio

Maria manages IBS symptoms like constipation and bloating through diet, exercise, and anxiety medication. She was diagnosed three years ago with IBS. Maria values efficient communication with her gastroenterologist and seeks better support for acute episodes.

"Immediate support during a flare-up would make a huge difference. Sometimes, I just don't know what to do."

Interests

- Health and wellness
- Nutrition
- Walking and light exercise

Influences

- Gastroenterologist
- Online support groups
- Family and friends

Goals

- Effectively manage IBS symptoms
- Integrate dietary restrictions into daily routine
- Reduce stress and anxiety

Pain Points and Frustrations

- Initial misdiagnosis, waited too long for a diagnosis and lack of immediate solutions
- Dietary restrictions, especially when eating out or travelling
- Unpredictable nature of IBS symptoms

Motivations

- Living a comfortable life despite IBS
- Maintaining a balanced and healthy diet
- Reducing the impact of IBS on daily activities

Pain Points and Frustrations

- Initial misdiagnosis, waited too long for a diagnosis and lack of immediate solutions
- Dietary restrictions, especially when eating out or travelling
- Unpredictable nature of IBS symptoms

Figure 30 – Patient persona.

6.3.2 (IBS Patient) Empathy Map

Similar to personas, empathy maps allow designers to summarise what they have learned from research into four quadrants: what people think, feel, do, and say. This is useful for getting a deeper understanding of the hidden motivations of IBS patients (*Empathy Map – Why and How to Use It | IxDF*, n.d.).

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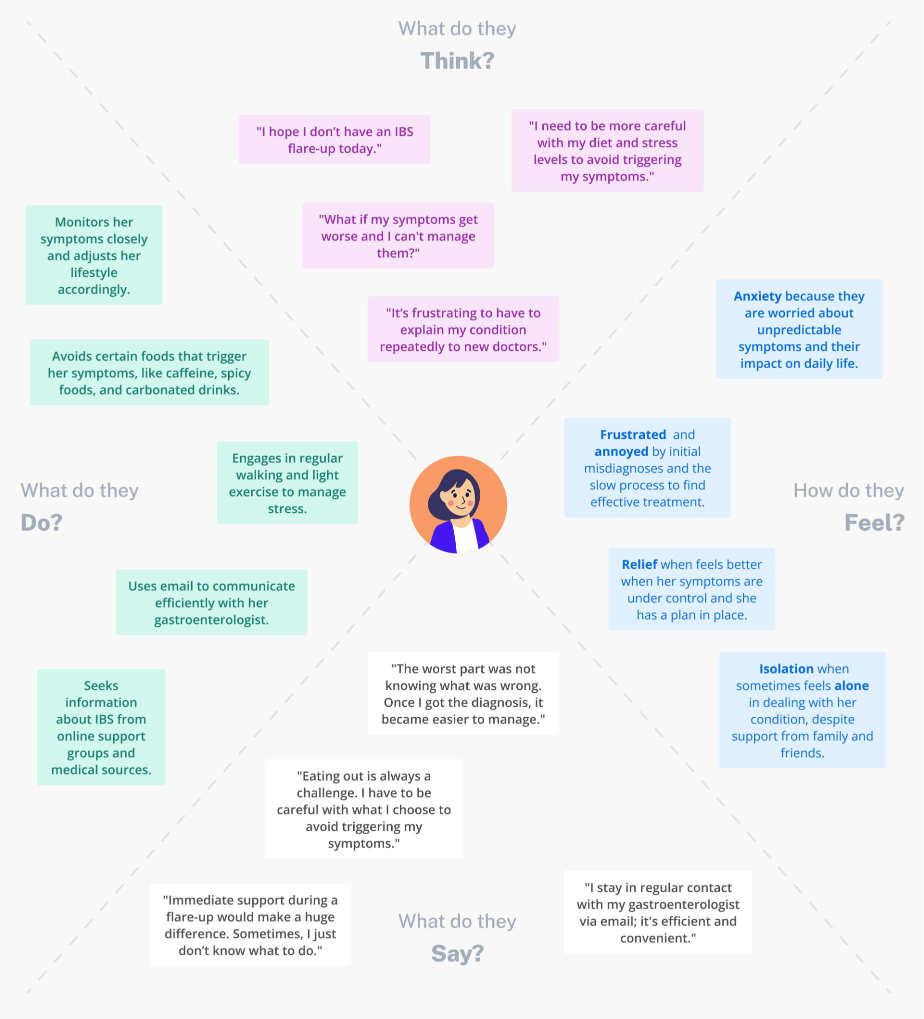
What do they
Think?

"I hope I don't have an IBS flare-up today."

"I need to be more careful with my diet and stress levels to avoid triggering my symptoms."

"What if my symptoms get worse and I can't manage them?"

"It's frustrating to have to explain my condition repeatedly to new doctors."

What do they
Do?

Monitors her symptoms closely and adjusts her lifestyle accordingly.

Avoids certain foods that trigger her symptoms, like caffeine, spicy foods, and carbonated drinks.

Engages in regular walking and light exercise to manage stress.

Uses email to communicate efficiently with her gastroenterologist.

Seeks information about IBS from online support groups and medical sources.

How do they
Feel?

Anxiety because they are worried about unpredictable symptoms and their impact on daily life.

Frustrated and **annoyed** by initial misdiagnoses and the slow process to find effective treatment.

Relief when feels better when her symptoms are under control and she has a plan in place.

Isolation when sometimes feels **alone** in dealing with her condition, despite support from family and friends.

What do they
Say?

"The worst part was not knowing what was wrong. Once I got the diagnosis, it became easier to manage."

"Eating out is always a challenge. I have to be careful with what I choose to avoid triggering my symptoms."

"Immediate support during a flare-up would make a huge difference. Sometimes, I just don't know what to do."

"I stay in regular contact with my gastroenterologist via email; it's efficient and convenient."

Figure 31 – Empathy map

6.3.3 (IBS Patient) Journey Mapping

A journey map provides a visualization of a person’s experience and interaction over time with a product or service. These maps also allow for the documentation of patients’ pains, tasks, and opportunities that can inform the project’s next phases (Stickdorn et al., 2018).

As part of this phase, the IBS patient journey was mapped, summarising the patients’ experiences collected during the interviews.

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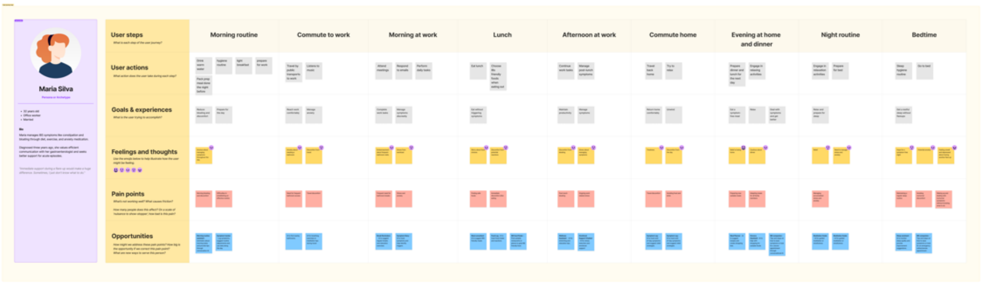


Figure 32 – Journey map zoomed out view

6.4 Problem statement

A problem statement is a foundational element of a design project, created from a deep understanding of user needs, typically gathered through research (*How To Write a Problem Statement: A Step-By-Step Guide | FigJam*, n.d.), as I did in this project. The problem statement guides the design process, ensuring that the focus remains on solving the right problems.

Based on the findings collected in Chapter 5 and summarised in this chapter, I developed the following problem statement, which will inform the subsequent phases of the design thinking process:

Problem statement

Patients with Irritable Bowel Syndrome (IBS) face significant challenges in managing unpredictable symptoms, adhering to dietary restrictions, and accessing consistent, ongoing support. These factors greatly affect their quality of life, highlighting the need for practical and personalised digital solutions to improve the management of their condition.

7. Ideate: Co-design Workshop with IBS Patients

7.1 Introduction

In the previous chapter, a representation of the patients' needs was illustrated through a range of visual tools that identified touchpoints based on patients' voices. In this chapter, I will show the patients' voices, revealing their ideas and perspectives about digital possibilities that might help to develop a conversational AI interface to support patients living with IBS. In doing so, a co-design workshop was created to engage a group of individuals living with IBS in collective creativity.

This phase should inform the next stage of the Design Thinking process, the prototyping phase.

Figure 33 – Zoom-out view of the workshop in Figjam

Link to access:

https://www.figma.com/board/BWXNzvNS3YuXTm9EDvSdPC/Master-Thesis---Jo%C3%A3o-Ferr%C3%A3o-3220046?node-id=1-13&t=uQtZ4W7PQ4opDfUT-4

7.2 Who Participated?

The co-design workshop was conducted online to better accommodate participants. As discussed in Chapter 5, people living with IBS may struggle to meet people in a more presential environment.

Initially, I intended to develop this workshop with all five participants who participated in the Empathise phase, as described in Chapter 5. However, just three people agreed and attended on the day to take part in the workshop (see Table 16). The reason why two of them did not attend was unknown. This seems to happen in design research related to other healthcare contexts (Neves, 2014).

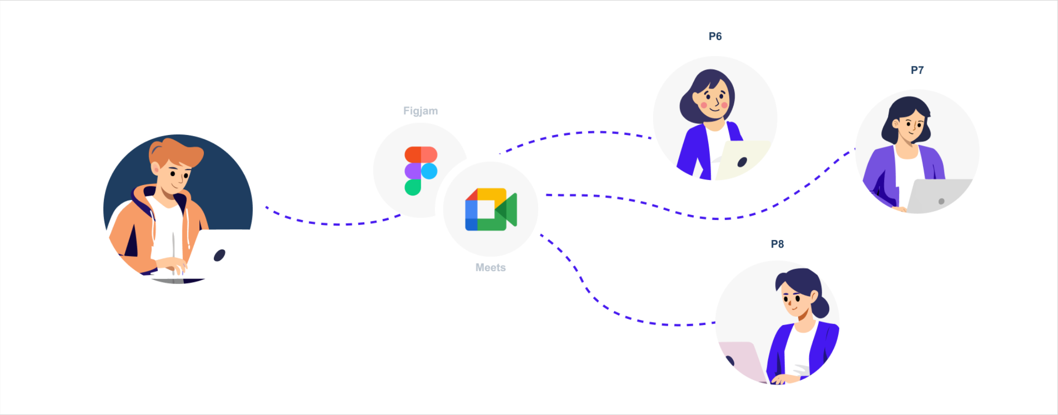


Figure 34 – Remote workshop setup

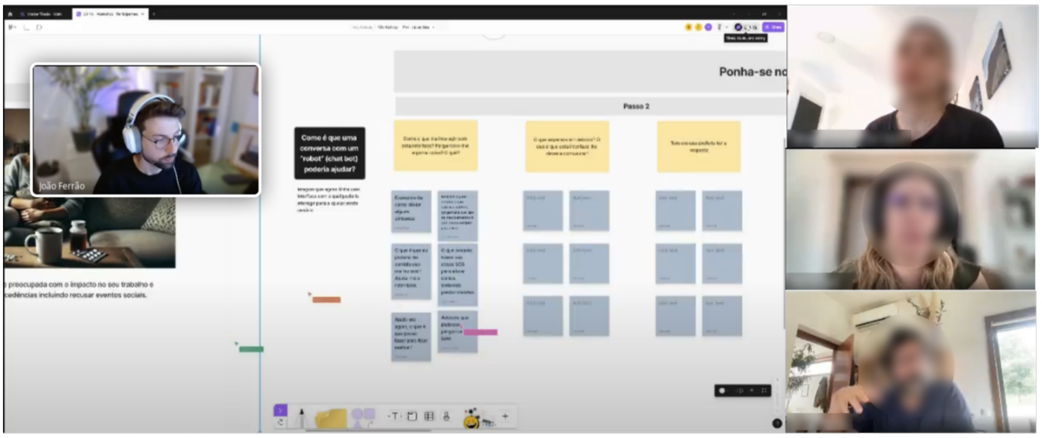


Figure 35 – Remote workshop real setup

User	Diagnosed when	Currently followed by	Duration
P6	1-2 years ago	Private Hospital or Clinic	1:56:33
P7	1-2 years ago	NHS GP	
P8	3-5 years ago	Private Hospital or Clinic	

Table 16 – Participants involved in the Ideate part of the project.

7.3 Preparation

In previous chapter 6, section 6.1, we defined the problem statement alongside the materialization of the initial interview's findings as follows:

Problem statement

Patients with Irritable Bowel Syndrome face difficulties in managing unpredictable symptoms, navigating dietary restrictions and ongoing support that significantly impact their quality of life, requiring practical and personalised digital solutions to better manage the condition.

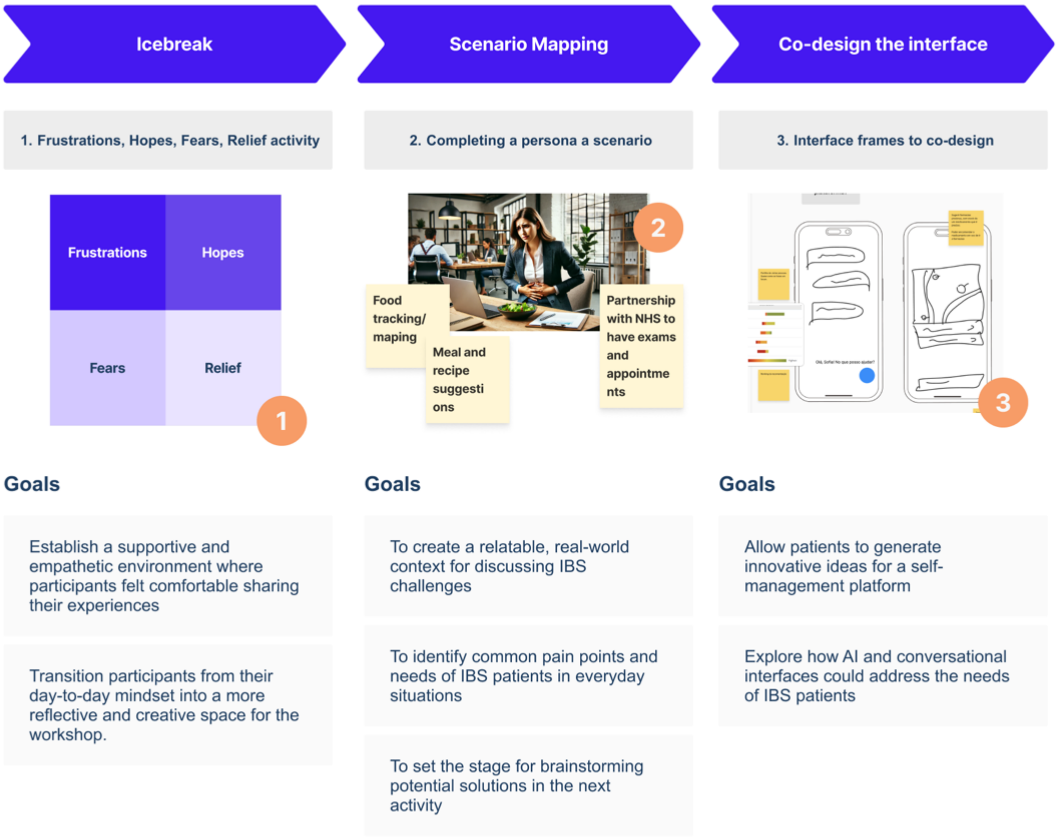
↓

Then, it was defined the aim of the workshop:

Aim of the workshop

How might we promote better quality of life and self-management for IBS patients through a Conversational AI interface

This workshop engaged participants in three main activities: 1) icebreaker, 2) scenario mapping and 3) interface co-design activity as shown in Figure 36.



Icebreak

1. Frustrations, Hopes, Fears, Relief activity

Goals

Establish a supportive and empathetic environment where participants felt comfortable sharing their experiences

Transition participants from their day-to-day mindset into a more reflective and creative space for the workshop.

Scenario Mapping

2. Completing a persona a scenario

Goals

To create a relatable, real-world context for discussing IBS challenges

To identify common pain points and needs of IBS patients in everyday situations

To set the stage for brainstorming potential solutions in the next activity

Co-design the interface

3. Interface frames to co-design

Goals

Allow patients to generate innovative ideas for a self-management platform

Explore how AI and conversational interfaces could address the needs of IBS patients

Figure 36 – Workshop Overview

In the icebreaker activity, I began by asking the participants to share a personal story. Here I used a map illustrating four emotional stages: frustrations, hopes, fears and reliefs as a framework to get participants to reflect about experiential considerations (see Figure 36). Fundamentally, this first activity was about emphasising how these inter-related emotions can be relevant in getting participants to reflect on designing the patient experience, in order to evoke emotional quality, and perhaps, trust.

Afterwards, I used a user scenario mapping (Salazar, 2021), already created beforehand (Figure 37), to drive the conversation and find opportunities for conversational AI. After participants had carefully reviewed the scenario, I shared a set of prompts (Table 17) to explore their thoughts and lead the group discussion.

Figure 37 – Scneario mapping overview

Prompts used during the scenario mapping
How would you interact with this interface? Would you ask it anything? What?
What did you expect in return? What should this interface communicate to you?
Tone in which I'd rather have the answer
What would be your favourite format for interaction?
What other things could you imagine asking of this platform? (think of all the possibilities, from your symptoms to your day-to-day activities or managing your health in a hospital)

Table 17 – Prompts used during the scenario mapping

Lastly, the workshop concluded with a co-design activity, where participants used wireframes to design, write, and visually represent their ideas, based on what had been discussed earlier. Additionally, they also attempted to align each idea with specific parts of the scenario (Figure 38) while sharing their thoughts out loud.

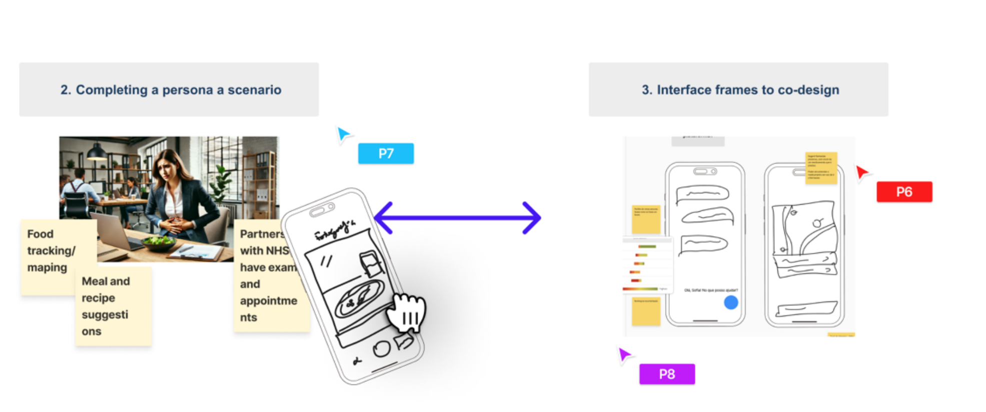


Figure 38 – Co-design activity

7.4 Findings

The icebreaker activity offered some preliminary insights into the experiences and emotions of people living with Irritable Bowel Syndrome (IBS). These initial reflections revealed participants' views on frustrations related to three main aspects: 1) dietary restrictions, 2) the unpredictability of symptoms, and 3) challenges with the diagnosis process. They expressed views about fears related with IBS being linked to more serious conditions and its impact on social and professional relationships. Experiences of hope were associated with medical advancements, particularly treatments that could allow for symptom-free eating. Participants also highlighted the need for more information and community support to help manage their condition. Experiences of relief were related to understanding IBS triggers and gaining control over symptoms, leading to improved well-being.

Afterwards, I invited participants to complete the scenario mapping based on the prompts provided (Table 17) while also co-designing parts of the interface and features of this conversational AI interface. We started by understanding how participants would interact with this interface.

How would they interact with this interface

Two major themes were identified within this prompt: medication-related questions, such as where to find the nearest pharmacy and what medication to take to feel better; and symptom-specific coping strategies, where participants expressed a desire to ask the interface to help them recall what they ate that may have contributed to the flare-up and to suggest next steps for improving their health condition:

> *Q8: Examples of how to relieve some symptoms (...) What you could take in SOS cases to relieve certain predominant symptoms (Lines 371-375).*

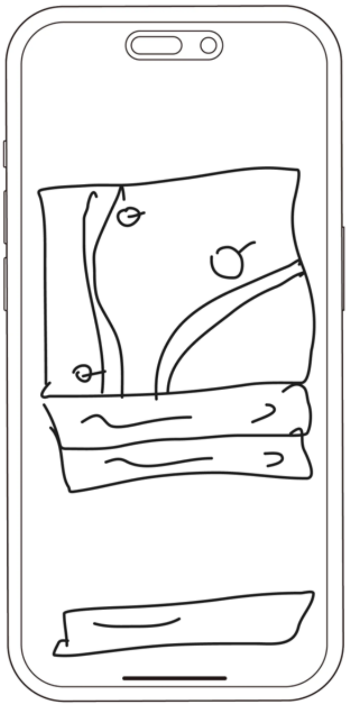


Figure 39 – Co-designed In-chat Map with Pharmacies

P7: I'd point out some of the symptoms I was feeling and ask what kind of medication I could buy to relieve them. I'd love it if I could ask for the nearest pharmacy with the medicines I need available at that moment (...) (Lines 387-393)

P6: What could I have eaten that was bad for me? Help me remember. (...) Help me now, what can I do to get better? (...) What are the good medical practices within the IBS to get better now? (Lines 376-385)

What they expect in return

Participants expect the interface to provide feedback that combines empathy, clarity and practical information based on medical evidence. They value communication that is easy to understand, reliable and actionable, avoiding complex medical jargon as Participants 8 and 6 share:

> *P8: I would like the interface to be simple to facilitate communication with it [...] With medical foundations, in order to increase confidence in it (Lines 395-397, 438-441)*
>
> *P6: I expect to be able to trust the app's recommendations 100 per cent. (...) That it clearly communicates what I should do, without the complicated jargon of doctors or drug leaflets or scientific papers. (Lines 400-412)*

In addition, Participant 7 shares an expectation that the interface will be able to give back not only general advice but also personalised and specific recommendations, including drug suggestions and information on availability at nearby pharmacies:

> *P7: (...) I'd love the app to be intelligent enough to be able to see the stock of pharmacies and be able to identify the nearest pharmacy that could identify what the medication was for those symptoms. (Lines 344-350)*

Participant 7 also shares the importance of this interface of being able to provide emotional comfort and empathy along with practical guidance:

> *P7: I'd like it to be a bit like ChatGPT, that when you 'tell the episode' to start with you give a word of comfort/empathy (e.g. Sofia I'm sorry you're feeling like this, but I'm going to help you) - Something more informal and in a friend/counsellor tone (almost like a doctor figure) (...) (Lines 414-428)*

Tone of voice

The participants all express a clear preference for a tone of response that balances empathy and professionalism. They value a friendly, informal approach that makes them feel comfortable and understood but that also conveys confidence and medical knowledge by sharing:

> *P7: Use a more informal/friendly tone so that the person feels more confident and comfortable sharing their symptoms and asking questions. But at the same time convey a clear and succinct message (Lines 358-364)*

> *P8: Friendly and empathetic tone, but assertive [...] Who we trust (Lines 489-492)*

> *P6: Empathetic, understanding, friendly, clear, trustworthy, guiding. who doesn't judge my wrong choices." (Lines 496-501)*

Participant 6 adds that this interface should transform the complex into something easier to understand, pointing out that in flare-up scenarios, cognitive faculties may not be at their best, with this interface playing an even more important role in clear communication with the patient:

> *P6: (…) Turn everything, what is complexity into simplicity, and tell it to me that way. And I'd like this application to have that too, to talk to me in a simple way. In a way that I can understand, because typically, right? When we're in the state that Sofia is in, these cognitive capacities are much more reduced, right? In other words, all that technical language about medicines and how the doctor speaks to us at the time, When the doctors*

> *spoke to me, they were doing all the exams! I didn't understand half of what they said (Lines 442-454)*

Type of format to communicate

A preference for flexible and multifaceted interaction formats was demonstrated here. Participants value an interface that can adapt to different contexts and needs, offering text and voice interaction options. The ability to use the interface discreetly in professional or public environments is seen as crucial, as is the option to interact more freely in private environments:

> *P6: You can write when I'm in a situation where I can't speak, for example in a meeting with clients, or at work without being remote, or in another environment where I can't speak. And I can talk when I'm more alone, or at home." (Lines 479-486)*

Figure 40 – Co-designed Multi profile AI

> *P6: I'd also like to see (...) that this friend of ours kind of changes. Now it's my PT for my physical exercises about A or B, or now it's my chef, you see now it's my doctor, you see he transforms himself and he changes according to the things I need. He has several personalities, doesn't he, he's my chef, he's my doctor, he's my assistant, when I need to find a prescription he's my pharmacist. He changes all the time, he's a magician, he knows everything, he has access to everything (Lines 950-959)*

There is also strong interest in a mobile application that can follow the user throughout the day, potentially integrating with wearable devices for continuous symptom monitoring, as Participant 8 shares:

P8: Mobile app that can track our daily lives. Have a chat bot (written and dialogue). (Lines 474-477)

Figure 41 – Co-designed Tracking feature

Presenting information in a visual and summarised way, with the option of audio content, is seen as an effective way of making information more accessible and easier to understand.

> *P7: Mobile app, simple interface. The information could come in audio (like WhatsApp where you can even increase the speed). Or in text but summarised (using graphic elements that make it easier to read). Or it could be an app that we could use on smartwatches (that recognises symptoms, like heartbeat for example)" (Lines 465-473).*

Participant 7 also adds the idea of having a wearable that could pre-detect IBS flare-ups as well as an interface page that could summarize the food they have been eating.

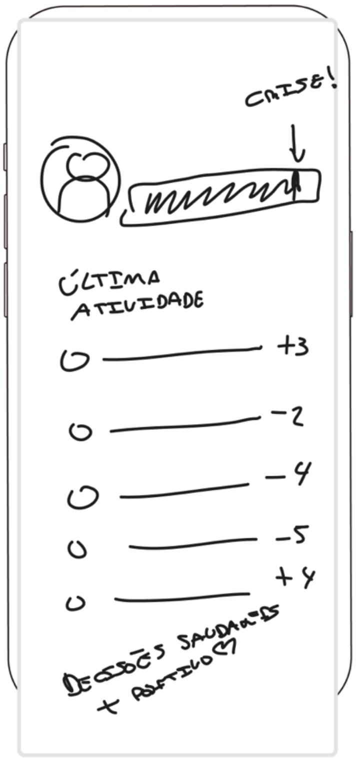


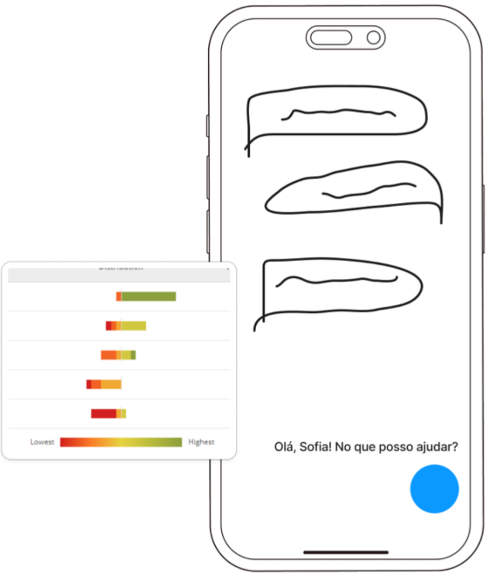
Figure 42 – Co-designed feature to track and predict a flare-up based on historic or symptoms

P7: (…) it could also identify some symptoms as you were saying and tremble, for example, something to alert the person. (Lines 569-575)

P7: What did she do? Or what kind of food did she eat? And have an area dedicated just to her. (Lines 997-1001)

We then explored other ideas during the co-design activity, like the one on the right (Figure 43), where we probed the concept of having group messages besides AI only.

Other patients also mentioned this feature as helpful, as reported during the interview findings in Chapter 5.



Olá, Sofia! No que posso ajudar?

Figure 43 – Co-designed feature to have group conversations with rating.

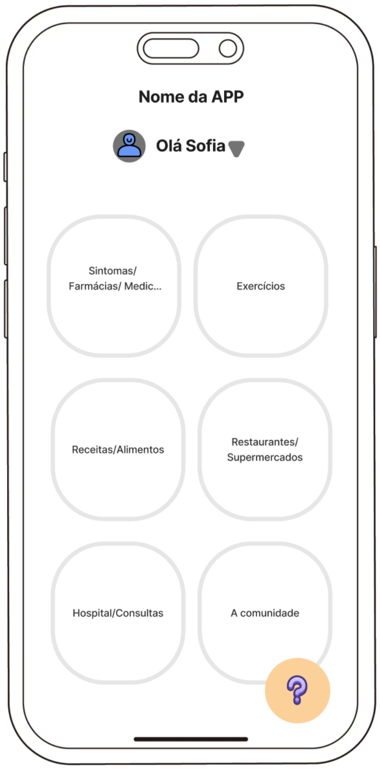


Figure 44 – Co-designed feature to have group conversations with rating.

Lastly, Participant 7 designed and shared with the group a concept about a "health hub" encompassing all the areas they felt were important: symptoms and pharmacies, exercises, recipes and food, IBS-friendly restaurants, personal medical appointments, and community access.

> *P7: (...) in the ideal world, it would almost be an application that you could choose from, almost as if you had several menus, several areas (...) possibly being able to book appointments either at the hospital or with the family doctor through this app (...) (Lines 660-670)*

8. Prototype: Turning Ideas into Tangible Interfaces

8.1 Introduction

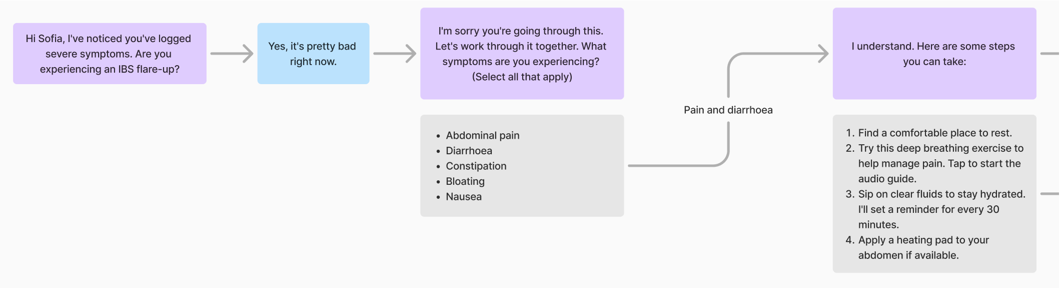
In this chapter, I will present a prototype of the conversational AI interface, taking into consideration the views and ideas of the participants from the ideate phase, as demonstrated in Chapter 7.

The participats' ideas were translated into a combination of prompt flows, wireframes, and high-fidelity prototypes, allowing me to translate abstract concepts into tangible interfaces.

8.2 Outcomes and outputs

8.2.1 Prompt flows

The prototyping process began with the creation of prompt flows, which served as a foundational tool to envision and map out the interactions between humans and AI systems. These prompt flows were designed to capture user inputs and the AI's corresponding actions, ensuring that the interaction would be intuitive and aligned with the users' needs.
These flows were built based on the learnings from the previous phases and using the use cases explored by the participants in the previous chapter.



Hi Sofia, I've noticed you've logged severe symptoms. Are you experiencing an IBS flare-up?

Yes, it's pretty bad right now.

I'm sorry you're going through this. Let's work through it together. What symptoms are you experiencing? (Select all that apply)

- Abdominal pain
- Diarrhoea
- Constipation
- Bloating
- Nausea

I understand. Here are some steps you can take:

1. Find a comfortable place to rest.
2. Try this deep breathing exercise to help manage pain. Tap to start the audio guide.
3. Sip on clear fluids to stay hydrated. I'll set a reminder for every 30 minutes.
4. Apply a heating pad to your abdomen if available.

Figure 45 – Example of a part of a prompt flow

Link to access:

https://www.figma.com/board/BWXNzvNS3YuXTm9EDvSdPC/Master-Thesis---Jo%C3%A3o-Ferr%C3%A3o-3220046?node-id=7-910&t=uQtZ4W7PQ4opDfUT-4

8.2.2 Wireframes

Following the prompt flows, wireframes were developed to provide a visual structure of the interface and to quick experiment different approaches. These wireframes helped to organise the high-level layout acting as a blueprint to inform the high-fidelity designs.

These wireframes took into consideration what was shared by the participants in the ideate phase, exploring concepts like the health score, pharmacy finder and day-to-day companion.

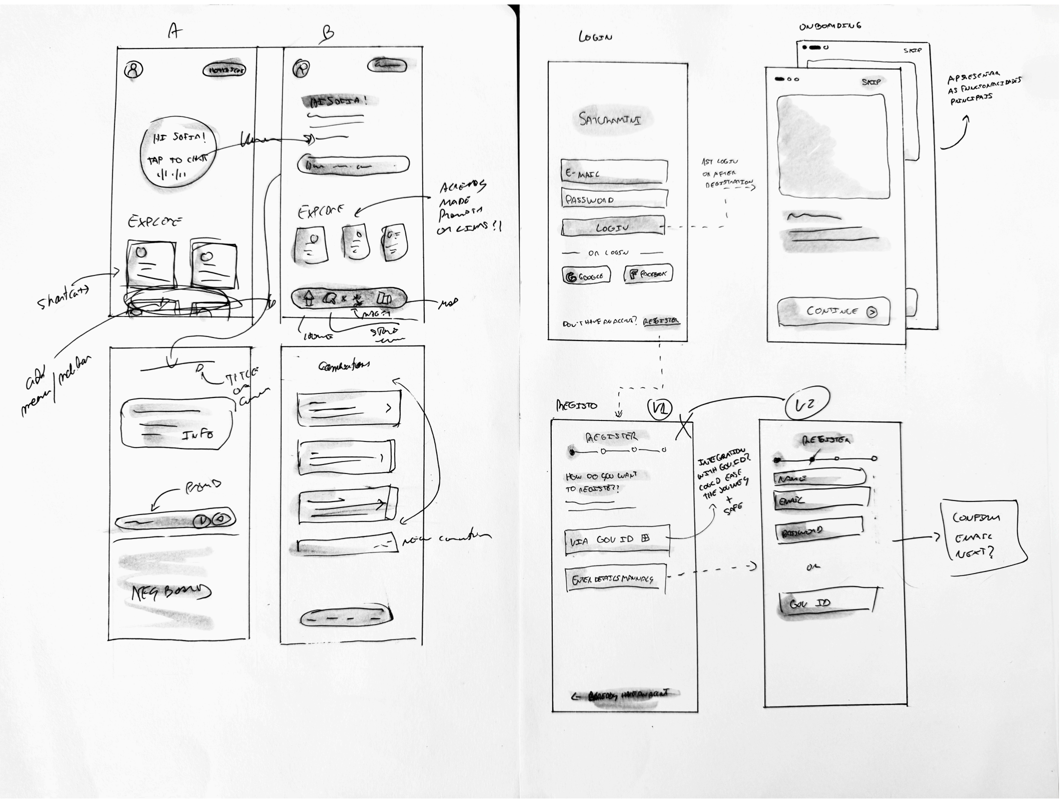


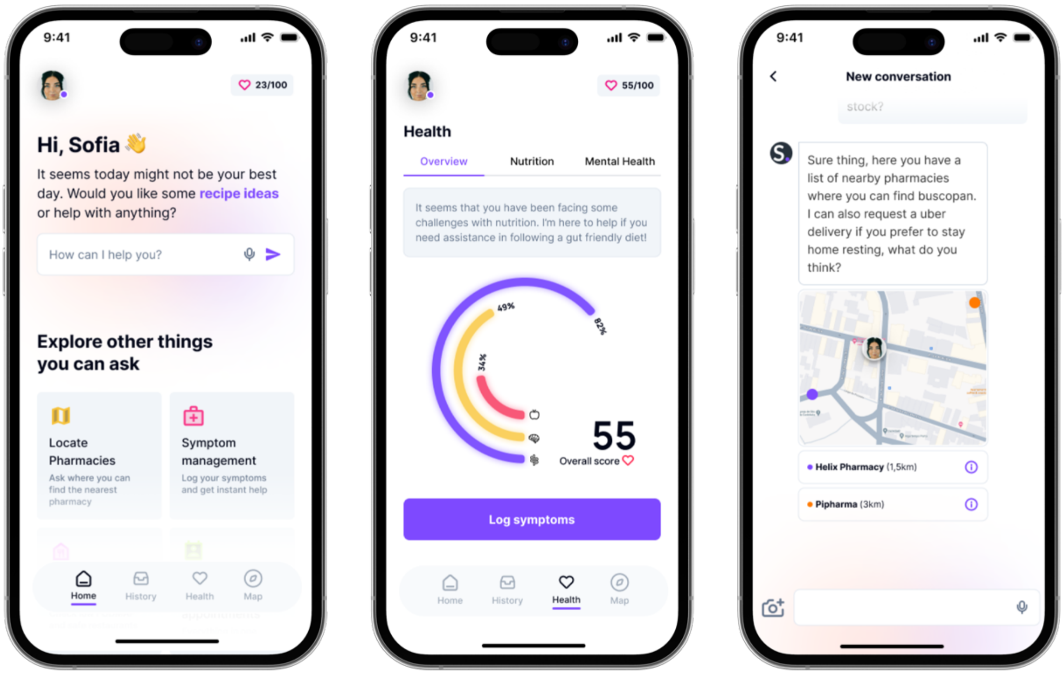
Figure 46 – Selection of wireframes

Link to access:

https://www.figma.com/board/BWXNzvNS3YuXTm9EDvSdPC/Master-Thesis---Jo%C3%A3o-Ferr%C3%A3o-3220046?node-id=1-543&t=uQtZ4W7PQ4opDfUT-4

8.2.2 Prototyping

The final stage involved creating high-fidelity prototypes that brought the wireframes closer to the final solution from an interaction and user interface standpoint. Therefore, they allowed for a realistic representation of the interface, enabling usability testing.



It seems today might not be your best day. Would you like some recipe ideas or help with anything?

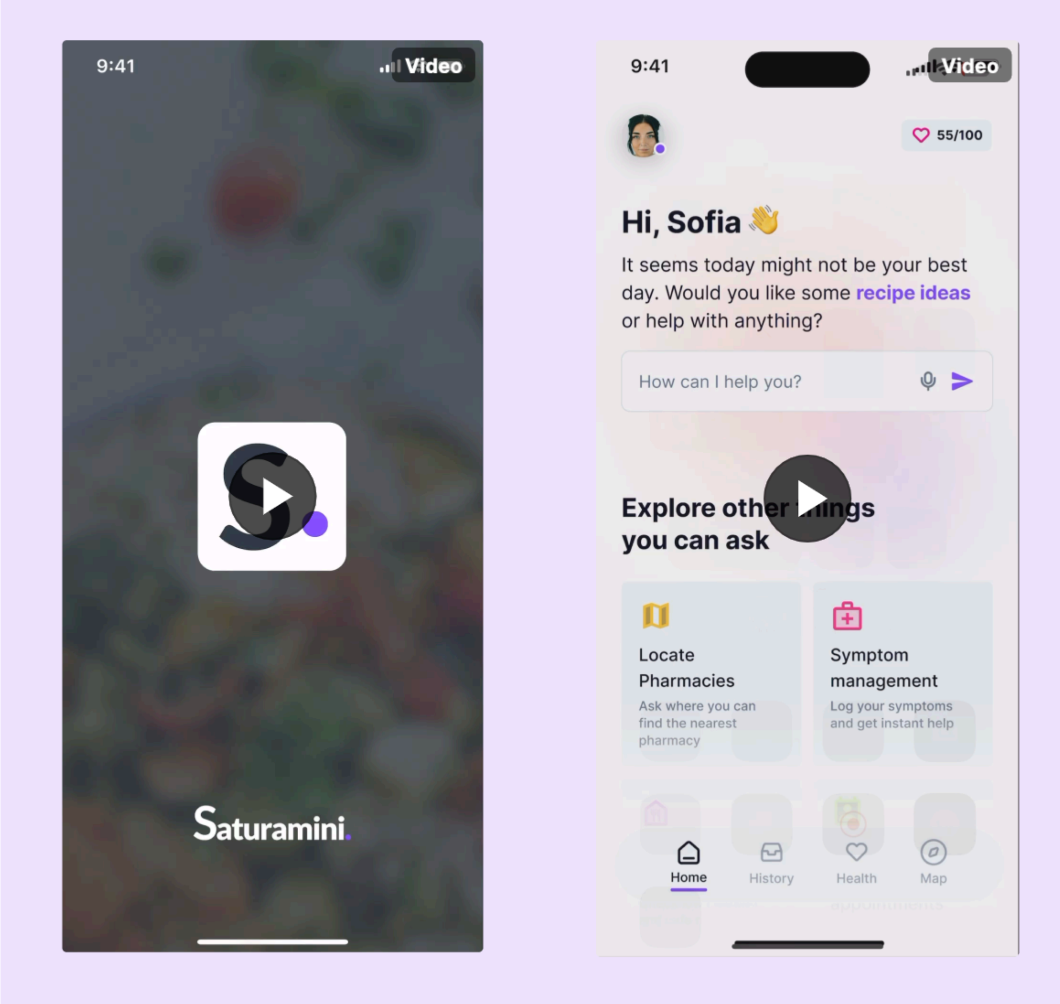
It seems that you have been facing some challenges with nutrition. I'm here to help if you need assistance in following a gut friendly diet!

Sure thing, here you have a list of nearby pharmacies where you can find buscopan. I can also request a uber delivery if you prefer to stay home resting, what do you think?

Figure 47 – Selection of prototyping screens. (Homepage, health score, chat with integrated map feature)

Link to access:

https://www.figma.com/board/BWXNzvNS3YuXTm9EDvSdPC/Master-Thesis---Jo%C3%A3o-Ferr%C3%A3o-3220046?node-id=11-1838&t=uQtZ4W7PQ4opDfUT-4



Hi, Sofia 👋

It seems today might not be your best day. Would you like some recipe ideas or help with anything?

How can I help you?

Explore other things you can ask

Locate Pharmacies

Ask where you can find the nearest pharmacy

Symptom management

Log your symptoms and get instant help

Link to prototype videos:

https://www.figma.com/board/BWXNzvNS3YuXTm9EDvSdPC/Master-Thesis---Jo%C3%A3o-Ferr%C3%A3o-3220046?node-id=17-27274&t=kgBH9QvdF5Edqrx3-4

9. Test: Understanding how participants perceive the interface

9.1 Introduction

The testing phase is a critical step in evaluating the usability and effectiveness of a prototype (Moran, 2019). In this chapter, I will outline how the prototype of the conversational AI interface was evaluated and tested with people living with IBS.

Subsequently, I will present the key findings, some of which have been addressed, while others will be considered for refining the prototype in the future.

9.2 Who participated?

A total of five participants were recruited, as Nielsen states (2012) this is the best benefit-cost ratio for these kinds of studies, allowing to uncover up to 75% of the usability issues.

User	**Duration**
P7	38:48
P9	52:57
P10	42:40
P11	27:35
P12	24:18

Table 18 – Participants involved in the Test part of the project.

9.3 Conducting the test

The usability tests were conducted remotely using Google Meets and Figma to better accommodate participants' needs. As participants were from different locations, online sessions seemed to be more appropriate and comfortable for them.

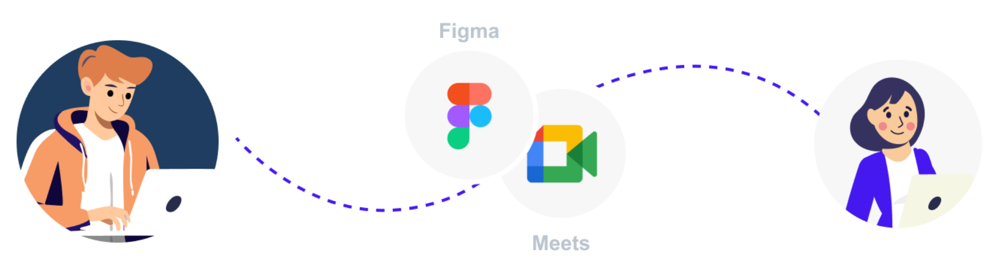


Figure 48 – Usability tests setup

The usability tests were conducted following a test guide (see Appendix V), designed to simulate common scenarios that individuals with Irritable Bowel Syndrome (IBS) might face when using the app. These tests were planned to be more exploratory, and participants were encouraged to verbalise their thoughts throughout the process, following the think-aloud protocol (Nielsen, 2012b). This allowed for real-time insights into their decision-making processes, expectations, and reactions while interacting with the interface.

Main task	Description
Registration and onboarding	Participants create a new account and complete the onboarding process. They explore the app and the available features.
Log symptoms and get a recipe	Participants log their IBS symptoms, rate their discomfort, and interact with the AI for a tailored recipe suggestion.

Log symptoms during a crisis	Participants simulate a severe IBS flare-up, report symptoms like abdominal pain and diarrhoea, and assess the app's response, including recommendations and self-help tools.
Access an audio guide experience	Participants had to find an audio guide, a suggestion from this AI.
Find a pharmacy and request a delivery	The last task involved users to go through finding a pharmacy nearby and request a delivery.

Table 19 – Usability test main tasks

9.4 Findings

Scenario 1, Task 1: Onboarding and registration

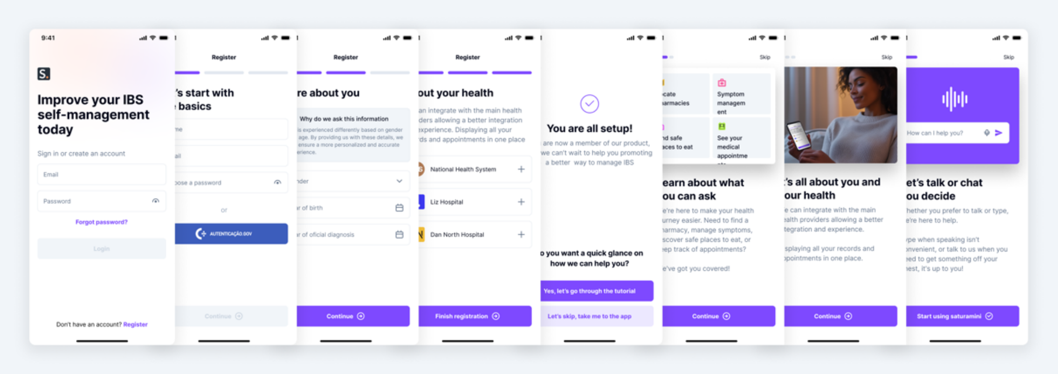


Figure 49 – Registration and onboarding screens

The first task involved participants to go through the registration and onboarding screens until they would reach the App homepage.

> *P7: I find it interesting that the registration process is easy and straightforward.*

> *P9: It was super easy, I didn't need much time to start using the app.*

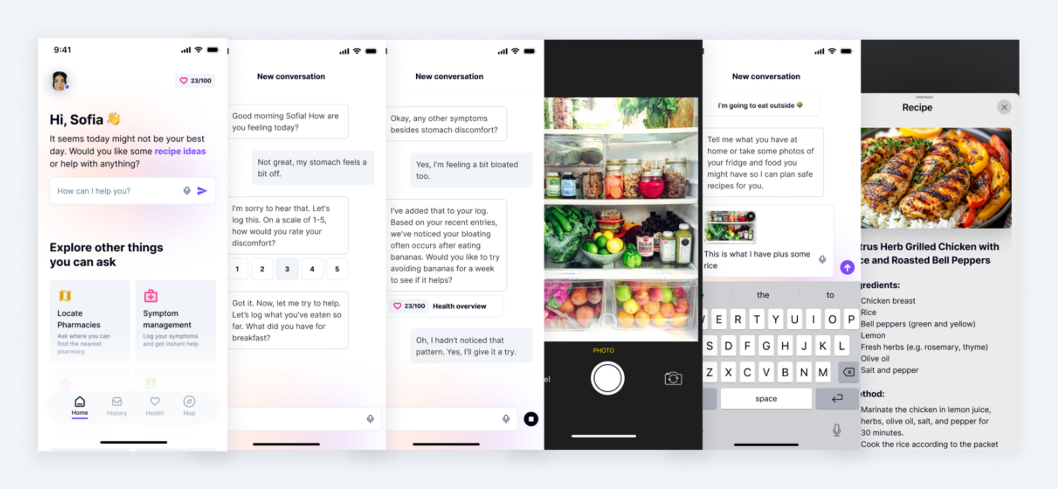
P11: I liked how the app guided me at the beginning, I felt well-oriented.

Overall, all users mentioned the registration and onboarding to be easy and straightforward with no usability problems found. At least two users suggested the expectation of having option to login with third parties like Google.

Description	**Recommendation**	**Users**
The registration process is simple and straightforward, easy to start using.	-	5/5
Suggestion to allow login with external accounts like Google or Facebook	Add option to login via Google	2/5

Table 20 – Findings of Scenario 1, Task 1: Onboarding and registration

Scenario 1, Task 2: Morning log with symptoms and get a recipe



Hi, Sofia 👋

It seems today might not be your best day. Would you like some recipe ideas or help with anything?

How can I help you?

Explore other things you can ask

Locate Pharmacies Ask where you can find the nearest pharmacy

Symptom management Log your symptoms and get instant help

Good morning Sofia! How are you feeling today?

Not great, my stomach feels a bit off.

I'm sorry to hear that. Let's log this. On a scale of 1-5, how would you rate your discomfort?

Got it. Now, let me try to help. Let's log what you've eaten so far. What did you have for breakfast?

Okay, any other symptoms besides stomach discomfort?

Yes, I'm feeling a bit bloated too.

I've added that to your log. Based on your recent entries, we've noticed your bloating often occurs after eating bananas. Would you like to try avoiding bananas for a week to see if it helps?

23/100 **Health overview**

Oh, I hadn't noticed that pattern. Yes, I'll give it a try.

I'm going to eat outside

Tell me what you have at home or take some photos of your fridge and food you might have so I can plan safe recipes for you.

This is what I have plus some rice

trus Herb Grilled Chicken with ce and Roasted Bell Peppers

jredients:

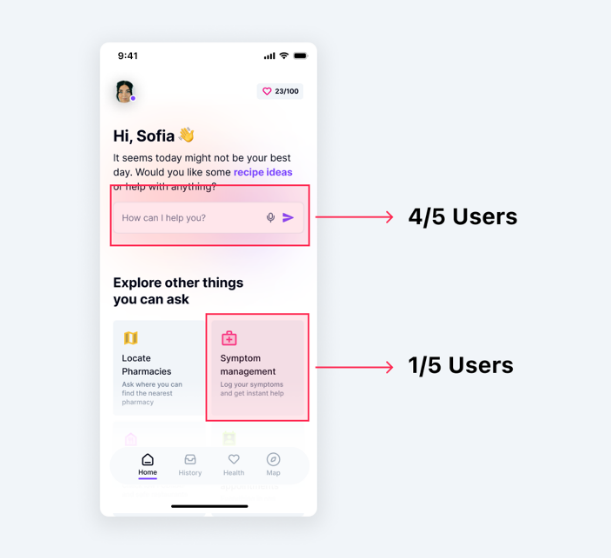
Chicken breast
Rice
Bell peppers (green and yellow)
Lemon
Fresh herbs (e.g. rosemary, thyme)
Olive oil
Salt and pepper

thod:

Marinate the chicken in lemon juice, herbs, olive oil, salt, and pepper for 30 minutes.
Cook the rice according to the packet

Figure 50 – Morning log and getting a recipe screens

Next, participants were asked to imagine they were not feeling well and wanted to request help from the application. Afterwards, participants received subtasks to further explore the conversation, such as asking for assistance with a recipe to cook at home.



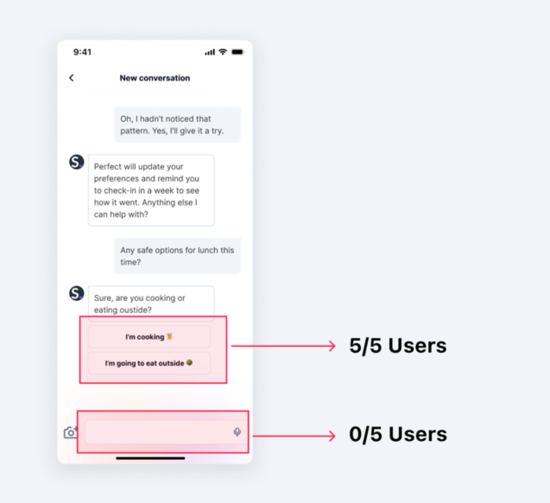
It seems today might not be your best day. Would you like some recipe ideas or help with anything?

Figure 51 – Homepage entry points

It was observed that most of the users prefer to start the journey through the conversational route, selecting the text input as the starting point for this task.

Besides the entry points, it was also found that participants would value a better way to save the recipes, with two users out of five asking for image thumbnails on the listing and wishing for a separate area just for recipes, as participant 7 says:

> *P7: It would be useful to have just one part of the income already structured.*



Oh, I hadn't noticed that pattern. Yes, I'll give it a try.

Perfect will update your preferences and remind you to check-in in a week to see how it went. Anything else I can help with?

Any safe options for lunch this time?

Sure, are you cooking or eating oustide?

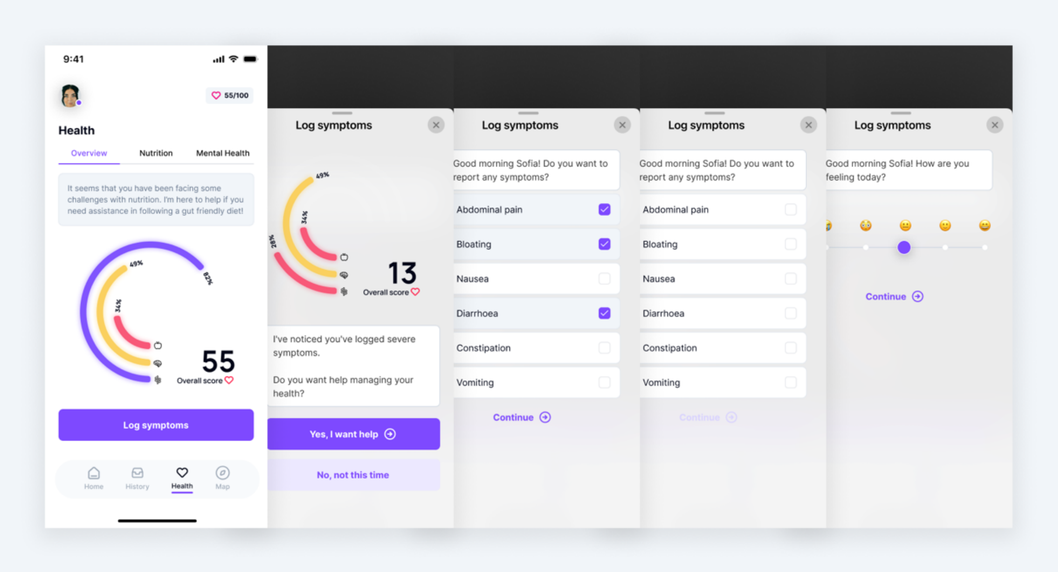
Figure 52 – Choice scenario screen

It was also found that five participants out of five preferred interacting with the AI through traditional buttons instead of writing when presented with a choice scenario (Figure 52).

Description	**Recommendation**	**Users**
Participants asked for a quick view of the recipes images in the listing view.	Add Image thumbnails	2/5
Participants mentioned the importance of saving the recipes. They were afraid that the recipes would get lost or that they would	Add a way to save recipes for future reference	2/5
Participants prefer traditional design components over interacting by text in choice scenarios.sz	Keep traditional components, such like buttons, in choice scenarios.	5/5

Table 20 – Findings of Scenario 1, Task 2: Morning log with symptoms and get a recipe

Scenario 2, Task 1: Symptom log



It seems that you have been facing some challenges with nutrition. I'm here to help if you need assistance in following a gut friendly diet!

I've noticed you've logged severe symptoms.

Do you want help managing your health?

Good morning Sofia! Do you want to report any symptoms?

- Abdominal pain ☑
- Bloating ☑
- Nausea ☐
- Diarrhoea ☑
- Constipation ☐
- Vomiting ☐

Good morning Sofia! Do you want to report any symptoms?

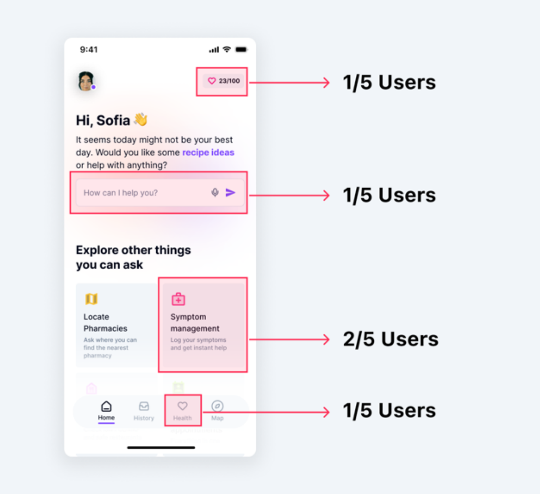
- Abdominal pain ☐
- Bloating ☐
- Nausea ☐
- Diarrhoea ☐
- Constipation ☐
- Vomiting ☐

Good morning Sofia! How are you feeling today?

Figure 53 – Symptom management screens

This scenario was aimed at understanding how participants would log their symptoms and explore how they would use a feature to request a medicine delivery.

The first task of this scenario was about the symptom log. It was observed that almost every participant chose a different entry point to start their journey (Figure 55).



It seems today might not be your best day. Would you like some recipe ideas or help with anything?

Figure 54 – Home page Log symptoms entry points

All participants understood the concept of the Health Score (Figure 54). However, some required additional time or interaction with the element to grasp its function, as two of the participants mentioned thoroughly:

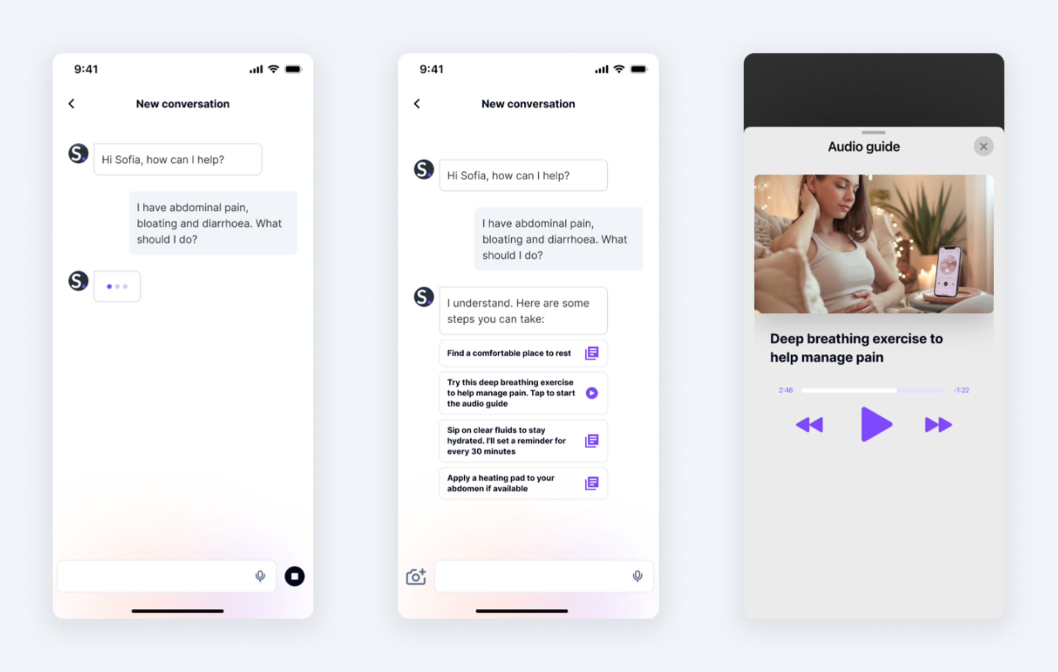
> *P7: The higher the percentage, the better off I am, that's what I was hoping for.*

> *P8: I think it's within a hundred per cent. She'll be a healthy person (...)*

Description	**Recommendation**	**Users**
Participants found the process to log symptoms relatively straightforward and simple.	-	5/5
Participants mentioned the need to add other customisable options when the AI asks about their symptoms.	Add “other” option and let users add their symptoms manually in the symptom log screen	2/5

Table 20 – Findings of Scenario 2, Task 1: Morning log with symptoms and get a recipe

Scenario 2, Task 2: Access an audio guide experience



Hi Sofia, how can I help?

I have abdominal pain, bloating and diarrhoea. What should I do?

Hi Sofia, how can I help?

I have abdominal pain, bloating and diarrhoea. What should I do?

I understand. Here are some steps you can take:

Find a comfortable place to rest

Try this deep breathing exercise to help manage pain. Tap to start the audio guide

Sip on clear fluids to stay hydrated. I'll set a reminder for every 30 minutes

Apply a heating pad to your abdomen if available

Deep breathing exercise to help manage pain

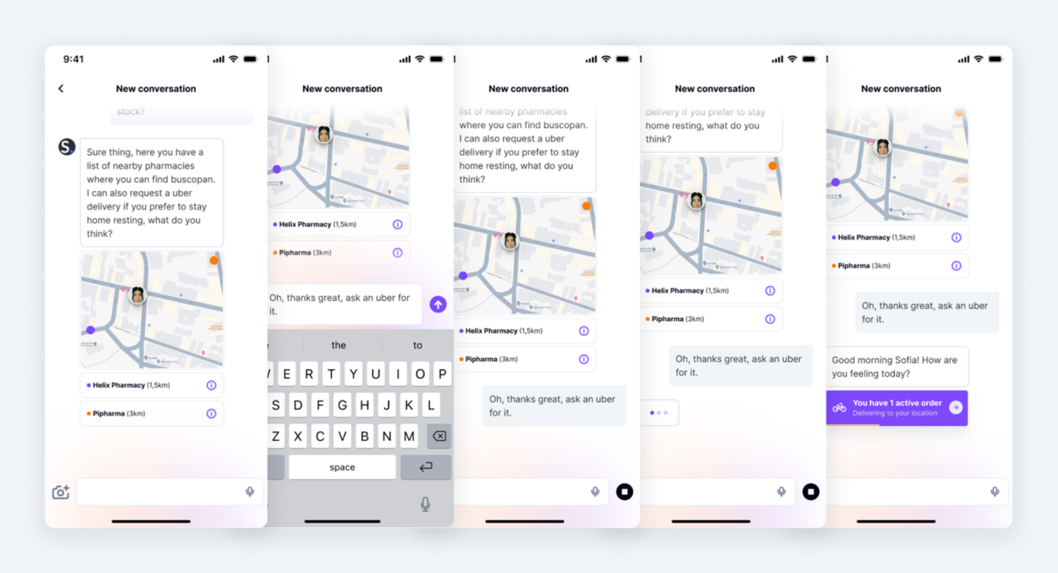
Figure 55 – Audio guide screens

All participants were able to easily identify and interact with the audio guide. One participant also suggested the addition of "subtitles" or "text" to accompany the audio guide, allowing users to follow along with visual instructions.

Description	**Recommendation**	**Users**
All participants could find and perceive how to access the audio guide	-	5/5
One participant recommended adding text or subtitles to follow along with the audio	Add text to the audio guide	1/5

Table 21 – Findings of Scenario 2, Task 2: Morning log with symptoms and get a recipe

Scenario 2, Task 3: Find a pharmacy and request a delivery



Sure thing, here you have a list of nearby pharmacies where you can find buscopan. I can also request a uber delivery if you prefer to stay home resting, what do you think?

Oh, thanks great, ask an uber for it.

Good morning Sofia! How are you feeling today?

Figure 56 – Pharmacy locator screens

Requesting nearby pharmacies was straightforward, but all participants missed the AI's suggestion to request a delivery. Based on observation, it is believed that this occurred because the map took center stage, drawing participants' attention more toward the map representation and buttons throughout the flow.

It was also noted that this was perceived passively by the participants, as they stated:

> *P11: I think it's good, because I avoid the stress of having to leave the house when I'm ill and unwell.*

> *P12: I'd like the app to do it for me, instead of me having to leave the app and go to another Uber app, I'd like the app to coordinate it for me.*

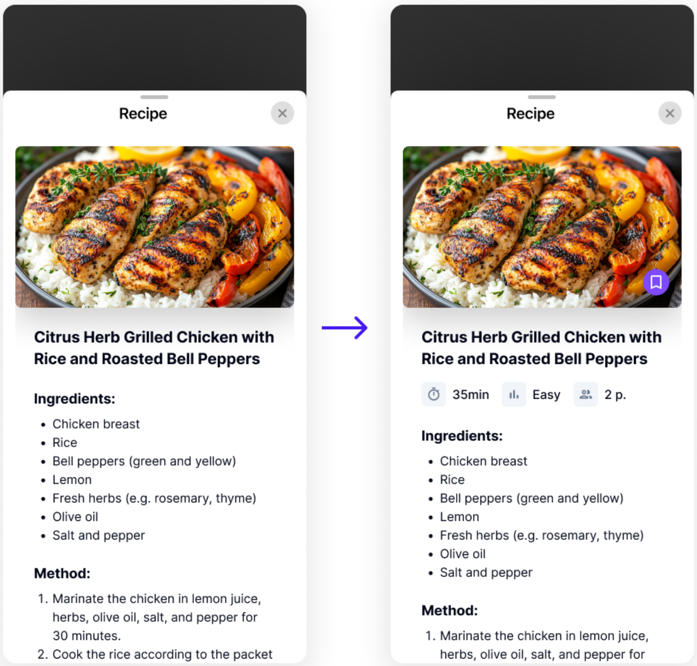
Description	Recommendation	Users
A quicker and more effective way to request delivery was lacking. Participants expected a button for this function, as they did not realize they could request medicine delivery.	Add button to the interface to enable faster and better affordance	5/5
Participants expected the opening hours of the pharmacies to be available, as well as a map with directions on how to get there.	Add information details accordingly to user expectations	2/5
Lack of clarity about the payment process when coordinated with third parties.	This is a result of the absence of these screens in the prototype. The final experience should encompass the payment gateway flow.	2/5

Table 21 – Findings of Scenario 2, Task 2: Morning log with symptoms and get a recipe

9.5 Design iteration

The feedback gathered during the testing phase contributed to iterate the initial designs. The following figures provide a visual representation of these changes, showcasing how the collected feedback was incorporated into the design to address specific pain points and improve the functionality of the prototype.

The following figures exemplify some of the changes taken after the tests. First, it was added to the recipe detail the option to save, as well as the details of duration, effort and portion of recipe.



Recipe

Citrus Herb Grilled Chicken with Rice and Roasted Bell Peppers

Ingredients:

- Chicken breast
- Rice
- Bell peppers (green and yellow)
- Lemon
- Fresh herbs (e.g. rosemary, thyme)
- Olive oil
- Salt and pepper

Method:

1. Marinate the chicken in lemon juice, herbs, olive oil, salt, and pepper for 30 minutes.
2. Cook the rice according to the packet

Recipe

Citrus Herb Grilled Chicken with Rice and Roasted Bell Peppers

35min Easy 2 p.

Ingredients:

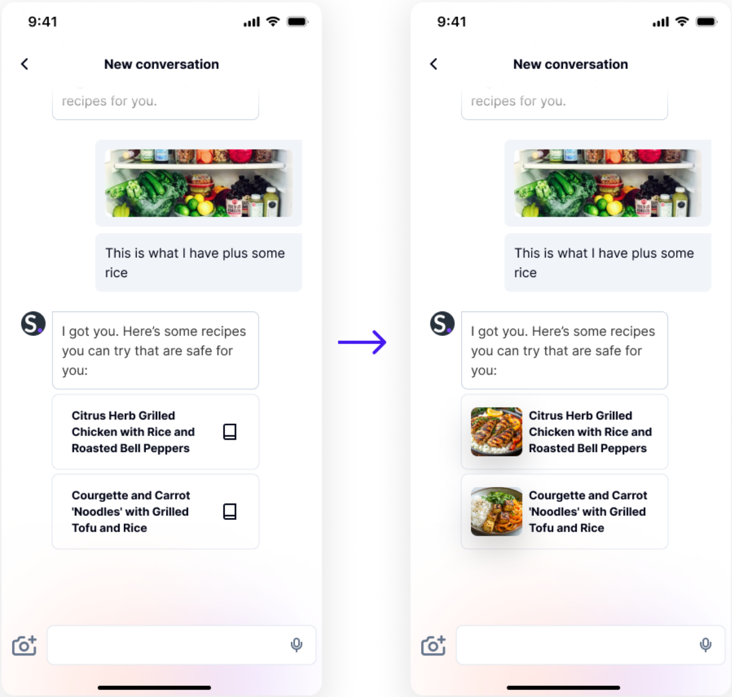
- Chicken breast
- Rice
- Bell peppers (green and yellow)
- Lemon
- Fresh herbs (e.g. rosemary, thyme)
- Olive oil
- Salt and pepper

Method:

1. Marinate the chicken in lemon juice, herbs, olive oil, salt, and pepper for

Figure 57 – Recipe detail page after iteration

In the chat view it was added thumbnails to the recipe list to accommodate a preview of the recipe before opening the detail page.



recipes for you.

This is what I have plus some rice

I got you. Here's some recipes you can try that are safe for you:

Citrus Herb Grilled Chicken with Rice and Roasted Bell Peppers

Courgette and Carrot 'Noodles' with Grilled Tofu and Rice

recipes for you.

This is what I have plus some rice

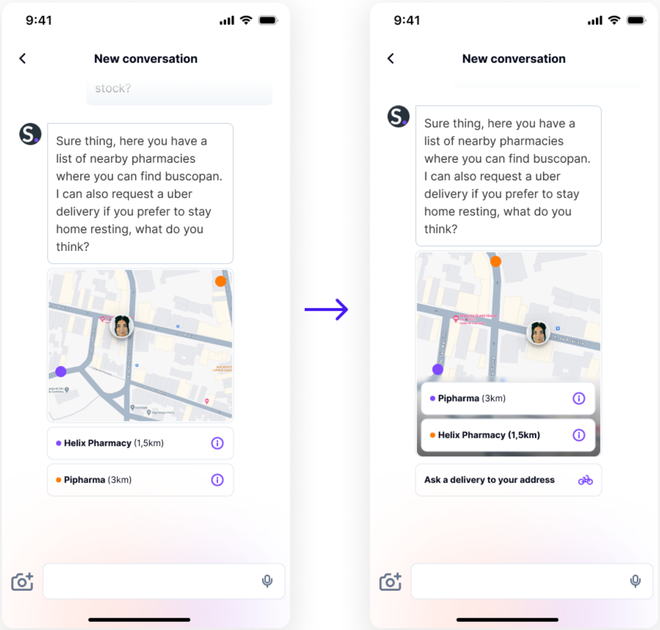
I got you. Here's some recipes you can try that are safe for you:

Citrus Herb Grilled Chicken with Rice and Roasted Bell Peppers

Courgette and Carrot 'Noodles' with Grilled Tofu and Rice

Figure 58 – Recipe thumbnail in the chat

Another change was regarding the available interaction with the map, adding an option to request a delivery instead of relying only in the text interaction.



Sure thing, here you have a list of nearby pharmacies where you can find buscopan. I can also request a uber delivery if you prefer to stay home resting, what do you think?

Sure thing, here you have a list of nearby pharmacies where you can find buscopan. I can also request a uber delivery if you prefer to stay home resting, what do you think?

Figure 59 – Recipe thumbnail in the chat

10 Discussion

10.1 Introduction

This project aimed to promote critical thinking and explore how AI conversational interfaces can better support IBS people living with IBS.

This chapter will reflect on how engaging people living with IBS in creative dialogues offers a meaningful AI conversational interface prototype. In other words, we will discuss how design thinking as an approach supported the creation of a conversational interface.

This chapter will also discuss the achievements and limitations of this project and share the tools and techniques used in designing for digital prototyping.

10.2 Design Thinking as an Approach to Develop a Conversational Interface

Using design thinking as an approach and an integral part of human-centred design proved adaptable and helpful in developing a conversational AI interface for IBS patients. Applying this methodology allowed for an in-depth understanding of people's needs, particularly those with IBS. It also contributed to a better understanding of the main challenges people face daily and what they expect to improve in the future.

The empathy phase, conducted through semi-structured interviews, provided rich information about the lived experiences of IBS patients. This phase revealed the multifaceted impact of IBS on people's lives, from dietary restrictions to social and professional challenges. These insights were instrumental in shaping the subsequent phases of the design process.

The definition phase, which involved the creation of personas, empathy maps, and journey maps, was not only crucial for consolidating interview findings but also for guiding the iterative development of the project. These tools facilitated the active involvement of IBS patients. This iterative process allowed for continuous exploration and synthesis of information, where each research phase informed and shaped subsequent stages.

The ideation phase, through a co-design workshop, was particularly valuable in fostering a collaborative environment and generating ideas directly from IBS patients.

Lastly, the prototyping and testing phases were characterised by a commitment to iterative refinement of the interface design, which ensured that it continuously met the users' needs and expectations.

Overall, the design thinking approach facilitated the exploration of a conversational AI interface to support the self-management of IBS.

10.3 Design Tools and Techniques for Digital Prototyping

Digital prototyping relies on a combination of design techniques that work together to create an effective and intuitive user experience. Each technique plays a role in different phases of the design process, from initial ideation to final testing.

Prompt design

Prompt design is essential for defining the instructions used in conversational AI models, ensuring the responses are relevant, accurate, and aligned with specific user needs. This informs both interface design and interaction strategies, as discussed by Evanhoe & Deibel (2021).

Mapping prompt flows

Mapping prompt flows involves visualizing and planning the conversation paths. It helps define how the user's inputs lead to different outcomes, giving structure to the interaction and enhancing the AI model's responsiveness.

Wireframing

Wireframing allows designers to create low-fidelity representations of the interface. It provides a basic structure for organizing the flow and gathering feedback early on, ensuring that the design fits user needs before moving into more detailed phases.

High-fidelity designs

In this stage, high-fidelity designs bring the interface closer to the final product. These include refined visuals and more precise interaction details, providing a clearer sense of how the final AI interface will look and behave.

Interactive prototyping

Interactive prototyping with tools like Figma is crucial for testing the usability of the interface. It enables designers to simulate user interactions, making adjustments based on real-time feedback to ensure the final design is both functional and intuitive.

10.4 Challenges and the Future Landscape of Designing for Conversational AI

Designing conversational AI interfaces, particularly in healthcare applications such as managing Irritable Bowel Syndrome (IBS), presents unique challenges and opportunities (Davenport & Kalakota, 2019; Schachner et al., 2020). These include effectively integrating natural human interactions with AI systems and adapting to patients' complex and individual needs with IBS.

Reflecting on my journey working on this project, one of the most significant lessons learned was the importance of personalisation. The variation in symptoms and daily experiences among patients means that more than one-size-fits-all solution is needed. Usability testing further highlighted the need to explore the concept of hyper-personalisation, allowing the AI to respond more dynamically to patients' needs.

Another key finding was the patients' preferred interaction method with the AI interface. When presented with two options — manually typing or selecting a pre-defined button — patients consistently showed a clear preference for the button option. This is perhaps the quicker method and aligns with more traditional interface components that users are familiar with. This preference indicates a need to design interfaces that minimise cognitive load and efficiently offer quick and accessible choices.
This insight is crucial for the future of conversational AI design, as it demonstrates that users value simplicity and speed in their interactions, especially in a healthcare context where timely responses can be urgent.

Furthermore, I realised that the future of conversational AI design, particularly in healthcare, hinges on strong integration with existing healthcare systems, which can be challenging due to institutional resistance to change and the complexity of these systems.

The development of prototypes and iterative testing proved essential in ensuring that the final interface was functional and intuitive but also adaptable to the user's reality. Each iteration provided valuable insights into how to improve the experience and better understand its value to IBS patients.

Another crucial aspect for the future of design is the balance between conversational interactions and using physical widgets, such as sensors or wearable devices. These can provide real-time data to inform AI and further personalise the patient experience. This opens a window of opportunity to expand functionality and enhance the management of chronic conditions like IBS.

As we move forward, conversational AI design for healthcare, and specifically for IBS, has the potential to transform the way patients manage their condition. By navigating the challenges and embracing the emerging opportunities, we can create systems that provide information and offer real support, empowering the condition self-management for IBS patients.

10.5 Limitations

The limitations of this project, as I see them, are related to its broad scope, which is natural given that these are interfaces with various ramifications and that it was not possible to cover them all within this project's scope. Therefore, only a limited set of flows was explored, and a selection of screens was designed. However, there are other issues, such as the limitation of the number of participants involved and the process of selection of these participants, which must be discussed here. Although the participants of this study possessed the key illustrative characteristics of the population being studied, the small number of participants might limit the findings and might not be indicative of general trends in the data.

Despite these limitations, this study pave the way for future work that should aim to conduct more extensive, longitudinal trials to validate the interface long-term effectiveness, explore integration with wearable devices for real-time symptom monitoring, investigate ways to safely and effectively integrate the solution into existing healthcare systems, and further research into the ethical and regulatory implications of using AI in the management of chronic health conditions.

11 Conclusion

Research shows that the future of AI is full of potential and use cases where artificial intelligence can improve patient care and obtain health outcomes (Vulpoi, Luca, Ciobanu, Olteanu, Bărboi, Iov, Nichita, Ciortescu, Prelipcean, et al., 2023). As such, this research project was dedicated to exploring the design of a conversational AI interface, adopting a design thinking approach, to engage people with IBS in discussions about what could be done to improve self-management of IBS, in particularly during crises.

The iterative process allowed for continuous refinement of the concept, culminating in a prototype that authentically responds to the needs demonstrated and shared by people living with IBS. Its adaptability ensures it can meet the evolving needs of IBS patients.

This study not only demonstrated the potential of conversational AI interfaces to provide personalised and accessible support to IBS patients, especially during periods of crisis but also underlined the crucial importance of personalisation in these solutions. The variable and individual nature of IBS calls for approaches that use hyper-personalisation.

This work's contributions to the emerging field of conversational AI in healthcare are manifold. We have provided a model for the user-centred design of AI interfaces for chronic health conditions, offered valuable insights into the specific needs of IBS patients, and demonstrated the practical application of design thinking and prototyping techniques in the context of AI for healthcare. In addition, the project raised important questions about ethics, privacy, and systems integration in implementing AI solutions in healthcare.

In short, this project demonstrates the transformative potential of conversational AI in improving the quality of life of IBS patients. By combining a deep understanding of patient needs with innovative technologies, we can create solutions that not only manage symptoms, but also provide emotional support and empowerment to patients.

11.1 Future Developments

The future of this project centres on continuing to develop what has already been explored. The following steps include deepening the design phase, assessing the feasibility of implementation, and analysing the market potential.

The investment could be derived from pharmaceutical and insurance companies interested in gastrointestinal conditions. Although the public sector is a priority, the possible budgetary constraints are recognised. For insurers, the product offers an opportunity to provide continuous patient support, potentially reducing hospital and treatment costs and standing out in the market.

A key innovation will be the development of a wearable that detects bowel movements and predicts crises, representing a significant advance in managing IBS.

Initial validation will be done through a control group in early access, allowing adjustments based on honest feedback. In the long term, we aim for the product to become the standard recommendation for IBS patients, with the potential to be adapted to other medical conditions.

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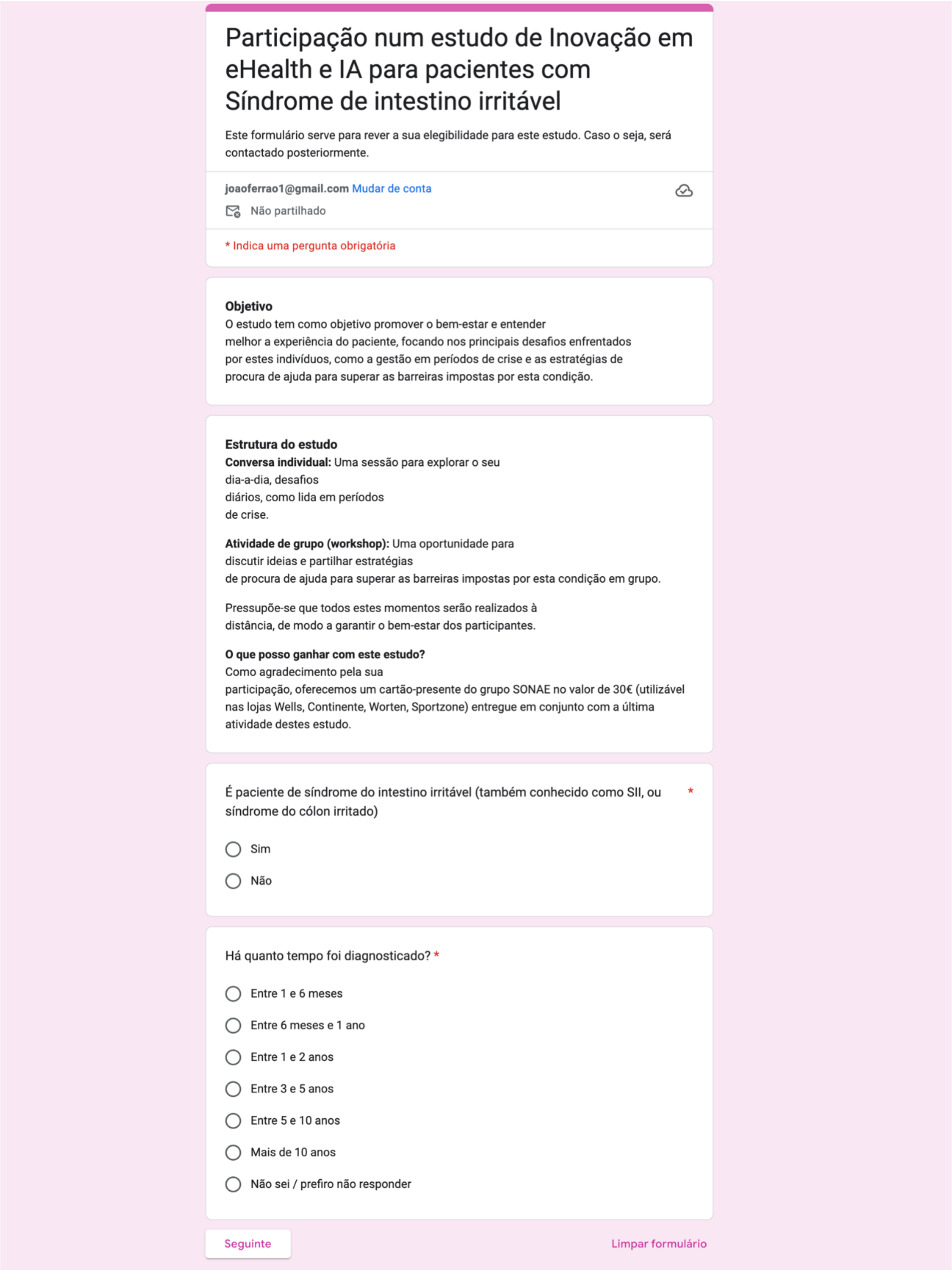
Appendices

Appendix I: Form sent to IBS patient community (screener)



Participação num estudo de Inovação em eHealth e IA para pacientes com Síndrome de intestino irritável

Este formulário serve para rever a sua elegibilidade para este estudo. Caso o seja, será contactado posteriormente.

joaoferrao1@gmail.com Mudar de conta

Não partilhado

* Indica uma pergunta obrigatória

Objetivo
O estudo tem como objetivo promover o bem-estar e entender
melhor a experiência do paciente, focando nos principais desafios enfrentados
por estes indivíduos, como a gestão em períodos de crise e as estratégias de
procura de ajuda para superar as barreiras impostas por esta condição.

Estrutura do estudo
Conversa individual: Uma sessão para explorar o seu
dia-a-dia, desafios
diários, como lida em períodos
de crise.

Atividade de grupo (workshop): Uma oportunidade para
discutir ideias e partilhar estratégias
de procura de ajuda para superar as barreiras impostas por esta condição em grupo.

Pressupõe-se que todos estes momentos serão realizados à
distância, de modo a garantir o bem-estar dos participantes.

O que posso ganhar com este estudo?
Como agradecimento pela sua
participação, oferecemos um cartão-presente do grupo SONAE no valor de 30€ (utilizável nas lojas Wells, Continente, Worten, Sportzone) entregue em conjunto com a última atividade destes estudo.

É paciente de síndrome do intestino irritável (também conhecido como SII, ou síndrome do cólon irritado) *

○ Sim

○ Não

Há quanto tempo foi diagnosticado? *

○ Entre 1 e 6 meses

○ Entre 6 meses e 1 ano

○ Entre 1 e 2 anos

○ Entre 3 e 5 anos

○ Entre 5 e 10 anos

○ Mais de 10 anos

○ Não sei / prefiro não responder

Sobre si e a sua saúde

Numa escala de 1 a 5 como define o seu estado de saúde atual

	1	2	3	4	5	
Muito mau	○	○	○	○	○	Controlado

Numa escala de 1 a 5 como define a sua literacia digital? (Se está habituado a usar app móveis, computador, etc)

	1	2	3	4	5	
Pouco à vontade	○	○	○	○	○	Muito à vontade

Usa ou já usou no passado alguma APP ou website para ajudar a gerir o seu síndrome de intestino irritável?

○ Sim
○ Não

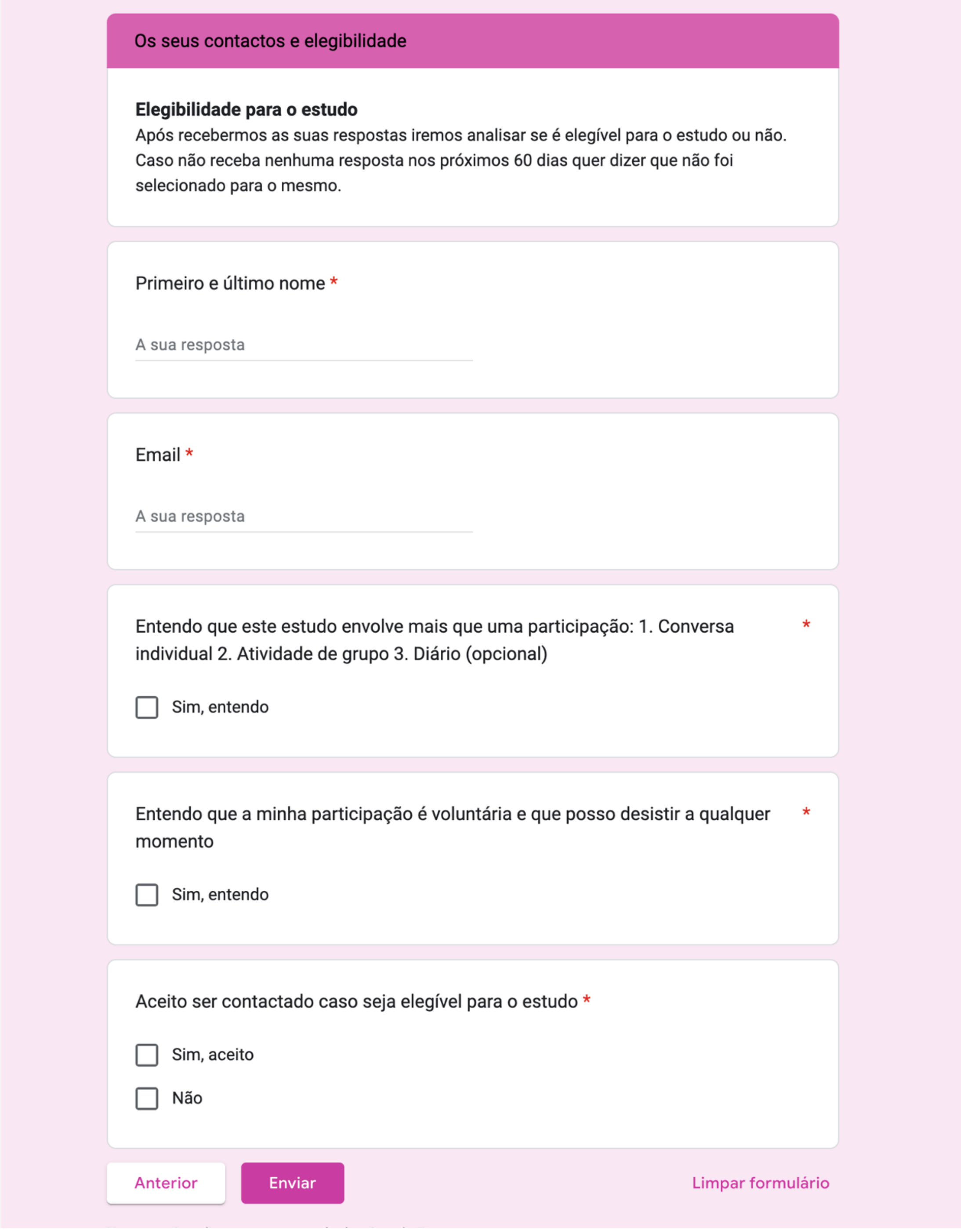
Se respondeu **sim** na questão anterior, qual?

A sua resposta

É atualmente seguido por algum médico ou hospital no âmbito do síndrome do intestino irritável?

Escolha as várias opções que se apliquem

☐ Sou seguido pelo meu médico de familia
☐ Sou seguido por um médico no hospital público
☐ Sou seguido por um médico no hospital ou clinica privada
☐ Não sou seguido atualmente



Os seus contactos e elegibilidade

Elegibilidade para o estudo

Após recebermos as suas respostas iremos analisar se é elegível para o estudo ou não. Caso não receba nenhuma resposta nos próximos 60 dias quer dizer que não foi selecionado para o mesmo.

Primeiro e último nome *

A sua resposta

Email *

A sua resposta

Entendo que este estudo envolve mais que uma participação: 1. Conversa individual 2. Atividade de grupo 3. Diário (opcional) *

☐ Sim, entendo

Entendo que a minha participação é voluntária e que posso desistir a qualquer momento *

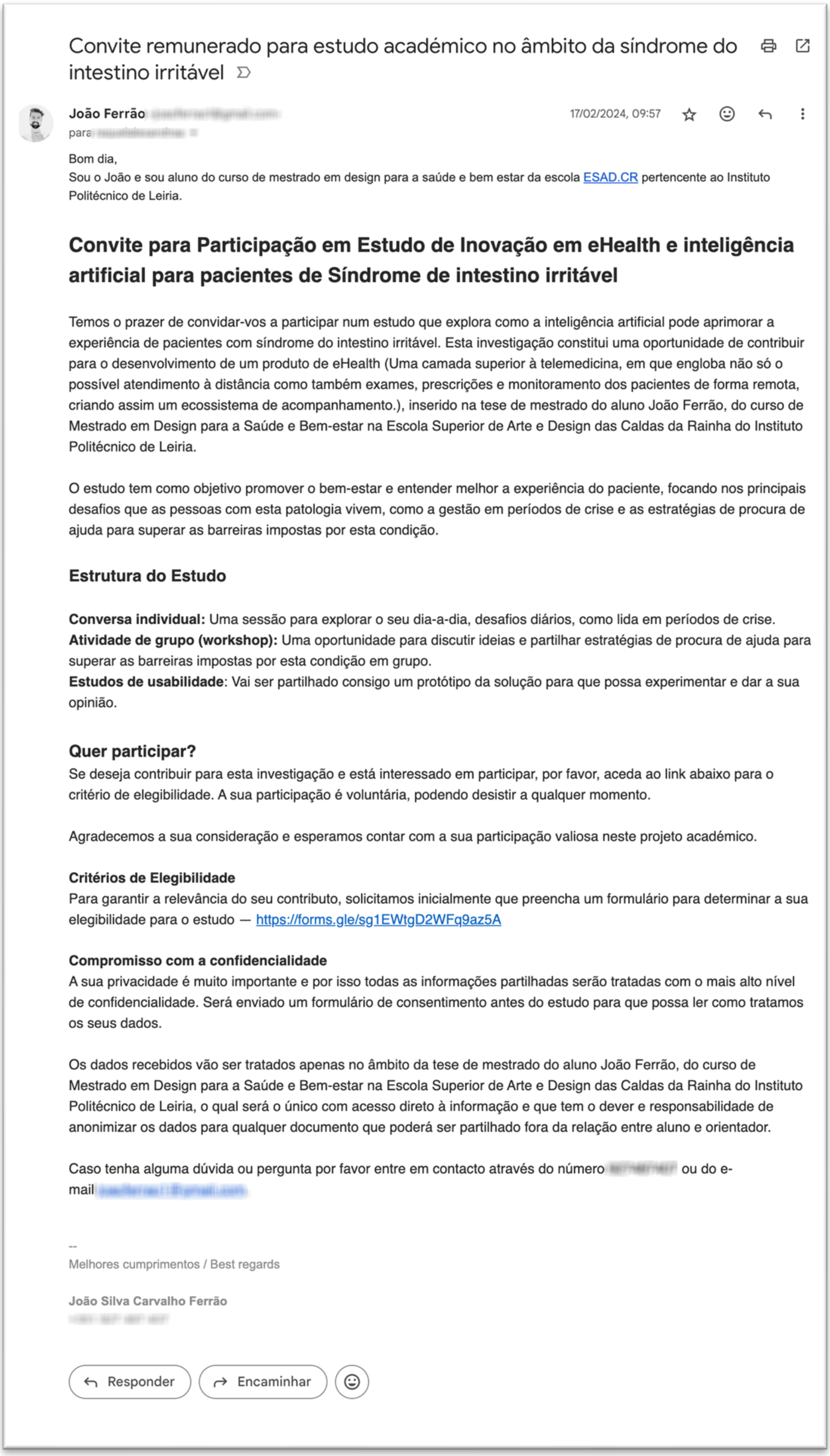
☐ Sim, entendo

Aceito ser contactado caso seja elegível para o estudo *

☐ Sim, aceito

☐ Não

Appendix II: Email invitation



Convite remunerado para estudo académico no âmbito da síndrome do intestino irritável

João Ferrão [redacted]
para [redacted]

17/02/2024, 09:57

Bom dia,
Sou o João e sou aluno do curso de mestrado em design para a saúde e bem estar da escola ESAD.CR pertencente ao Instituto Politécnico de Leiria.

Convite para Participação em Estudo de Inovação em eHealth e inteligência artificial para pacientes de Síndrome de intestino irritável

Temos o prazer de convidar-vos a participar num estudo que explora como a inteligência artificial pode aprimorar a experiência de pacientes com síndrome do intestino irritável. Esta investigação constitui uma oportunidade de contribuir para o desenvolvimento de um produto de eHealth (Uma camada superior à telemedicina, em que engloba não só o possível atendimento à distância como também exames, prescrições e monitoramento dos pacientes de forma remota, criando assim um ecossistema de acompanhamento.), inserido na tese de mestrado do aluno João Ferrão, do curso de Mestrado em Design para a Saúde e Bem-estar na Escola Superior de Arte e Design das Caldas da Rainha do Instituto Politécnico de Leiria.

O estudo tem como objetivo promover o bem-estar e entender melhor a experiência do paciente, focando nos principais desafios que as pessoas com esta patologia vivem, como a gestão em períodos de crise e as estratégias de procura de ajuda para superar as barreiras impostas por esta condição.

Estrutura do Estudo

Conversa individual: Uma sessão para explorar o seu dia-a-dia, desafios diários, como lida em períodos de crise.
Atividade de grupo (workshop): Uma oportunidade para discutir ideias e partilhar estratégias de procura de ajuda para superar as barreiras impostas por esta condição em grupo.
Estudos de usabilidade: Vai ser partilhado consigo um protótipo da solução para que possa experimentar e dar a sua opinião.

Quer participar?
Se deseja contribuir para esta investigação e está interessado em participar, por favor, aceda ao link abaixo para o critério de elegibilidade. A sua participação é voluntária, podendo desistir a qualquer momento.

Agradecemos a sua consideração e esperamos contar com a sua participação valiosa neste projeto académico.

Critérios de Elegibilidade
Para garantir a relevância do seu contributo, solicitamos inicialmente que preencha um formulário para determinar a sua elegibilidade para o estudo — https://forms.gle/sg1EWtgD2WFq9az5A

Compromisso com a confidencialidade
A sua privacidade é muito importante e por isso todas as informações partilhadas serão tratadas com o mais alto nível de confidencialidade. Será enviado um formulário de consentimento antes do estudo para que possa ler como tratamos os seus dados.

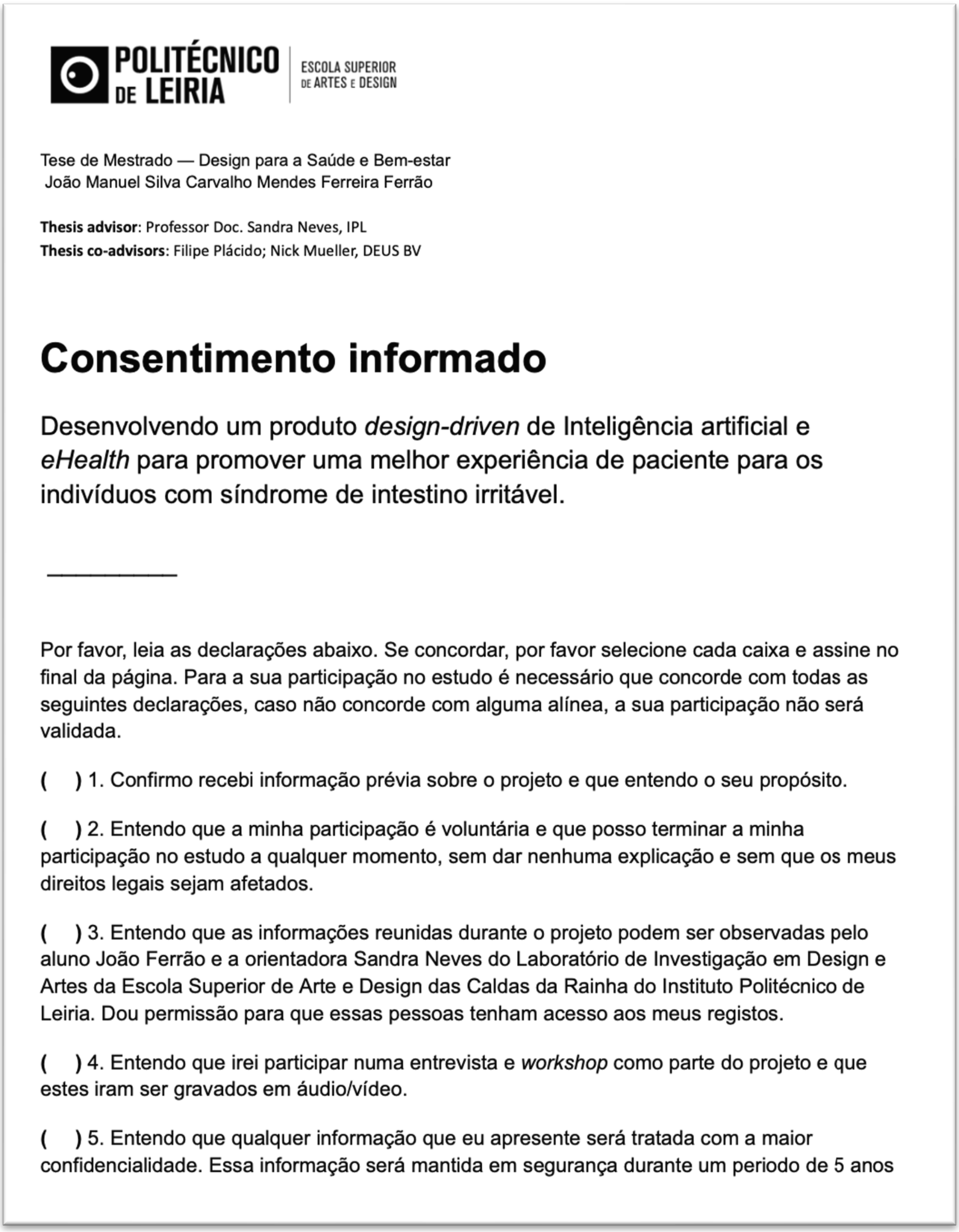
Os dados recebidos vão ser tratados apenas no âmbito da tese de mestrado do aluno João Ferrão, do curso de Mestrado em Design para a Saúde e Bem-estar na Escola Superior de Arte e Design das Caldas da Rainha do Instituto Politécnico de Leiria, o qual será o único com acesso direto à informação e que tem o dever e responsabilidade de anonimizar os dados para qualquer documento que poderá ser partilhado fora da relação entre aluno e orientador.

Caso tenha alguma dúvida ou pergunta por favor entre em contacto através do número [redacted] ou do e-mail [redacted]

--
Melhores cumprimentos / Best regards

João Silva Carvalho Ferrão
[redacted]

Appendix III: Informed consent sent and signed by the participants



POLITÉCNICO DE LEIRIA | ESCOLA SUPERIOR DE ARTES E DESIGN

Tese de Mestrado — Design para a Saúde e Bem-estar
João Manuel Silva Carvalho Mendes Ferreira Ferrão

Thesis advisor: Professor Doc. Sandra Neves, IPL
Thesis co-advisors: Filipe Plácido; Nick Mueller, DEUS BV

Consentimento informado

Desenvolvendo um produto *design-driven* de Inteligência artificial e *eHealth* para promover uma melhor experiência de paciente para os indivíduos com síndrome de intestino irritável.

Por favor, leia as declarações abaixo. Se concordar, por favor selecione cada caixa e assine no final da página. Para a sua participação no estudo é necessário que concorde com todas as seguintes declarações, caso não concorde com alguma alínea, a sua participação não será validada.

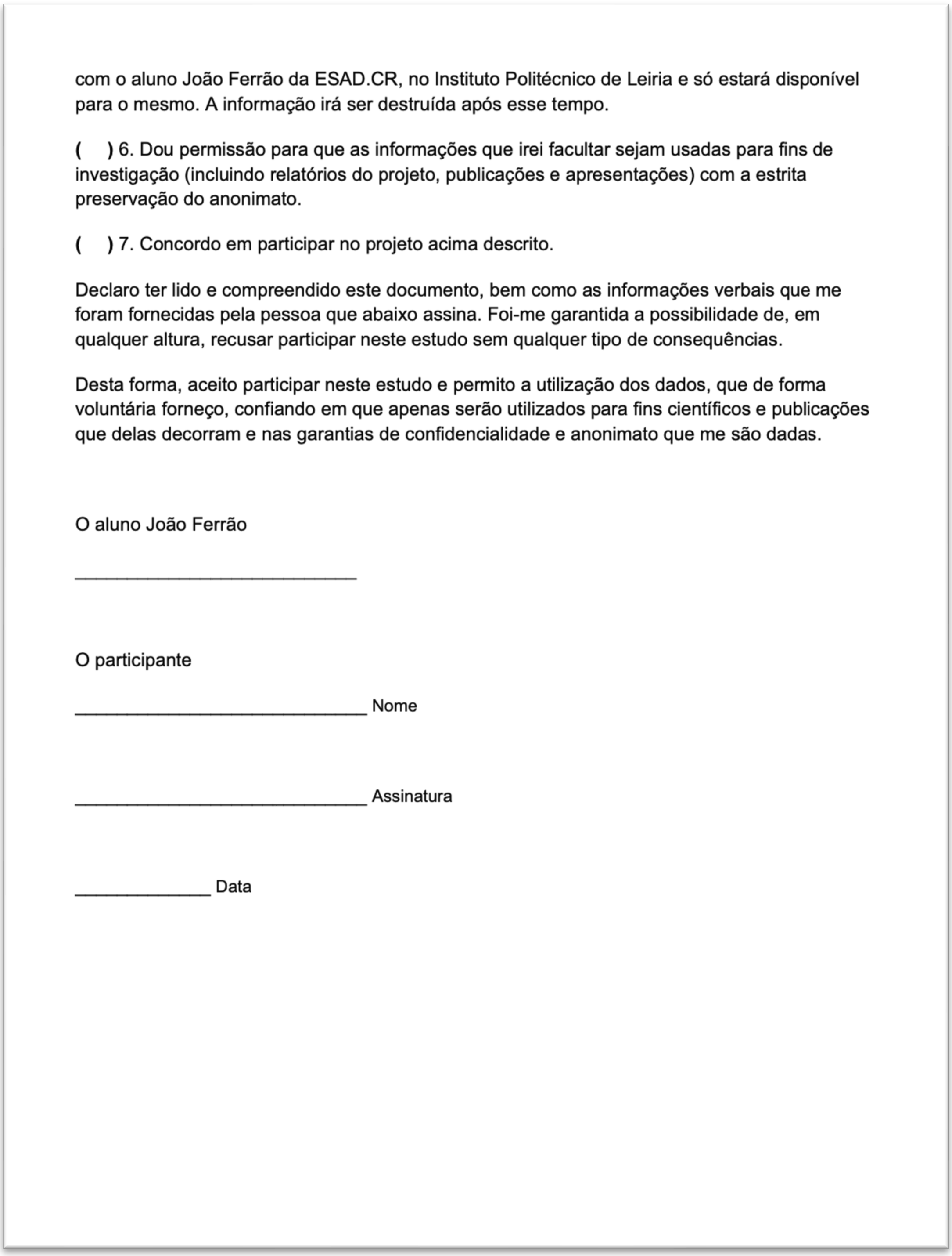
(   ) 1. Confirmo recebi informação prévia sobre o projeto e que entendo o seu propósito.

(   ) 2. Entendo que a minha participação é voluntária e que posso terminar a minha participação no estudo a qualquer momento, sem dar nenhuma explicação e sem que os meus direitos legais sejam afetados.

(   ) 3. Entendo que as informações reunidas durante o projeto podem ser observadas pelo aluno João Ferrão e a orientadora Sandra Neves do Laboratório de Investigação em Design e Artes da Escola Superior de Arte e Design das Caldas da Rainha do Instituto Politécnico de Leiria. Dou permissão para que essas pessoas tenham acesso aos meus registos.

(   ) 4. Entendo que irei participar numa entrevista e *workshop* como parte do projeto e que estes iram ser gravados em áudio/vídeo.

(   ) 5. Entendo que qualquer informação que eu apresente será tratada com a maior confidencialidade. Essa informação será mantida em segurança durante um periodo de 5 anos



com o aluno João Ferrão da ESAD.CR, no Instituto Politécnico de Leiria e só estará disponível para o mesmo. A informação irá ser destruída após esse tempo.

(   ) 6. Dou permissão para que as informações que irei facultar sejam usadas para fins de investigação (incluindo relatórios do projeto, publicações e apresentações) com a estrita preservação do anonimato.

(   ) 7. Concordo em participar no projeto acima descrito.

Declaro ter lido e compreendido este documento, bem como as informações verbais que me foram fornecidas pela pessoa que abaixo assina. Foi-me garantida a possibilidade de, em qualquer altura, recusar participar neste estudo sem qualquer tipo de consequências.

Desta forma, aceito participar neste estudo e permito a utilização dos dados, que de forma voluntária forneço, confiando em que apenas serão utilizados para fins científicos e publicações que delas decorram e nas garantias de confidencialidade e anonimato que me são dadas.

O aluno João Ferrão

____

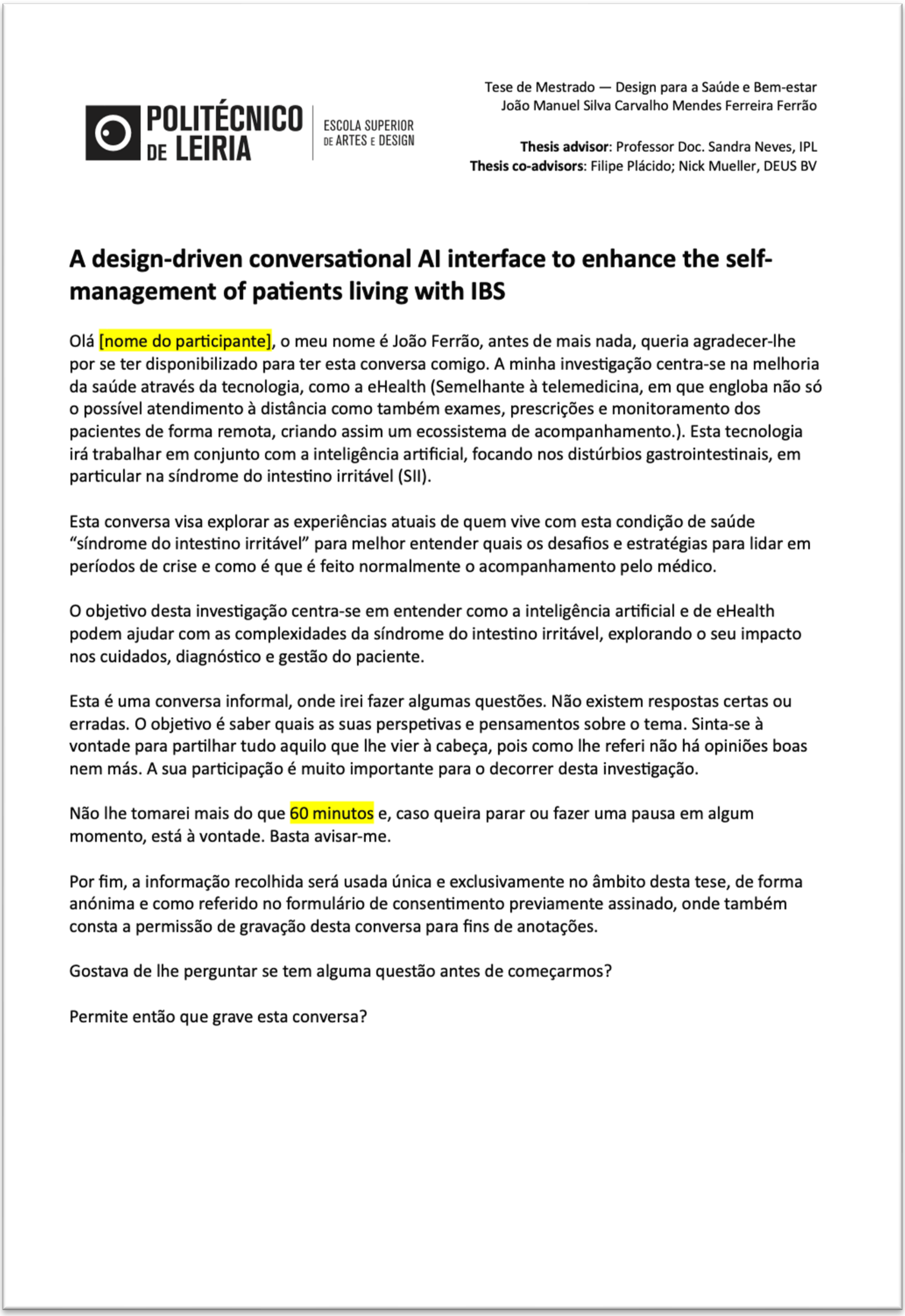
O participante

______________________________ Nome

______________________________ Assinatura

______________ Data

Appendix IV: Interview guide



POLITÉCNICO DE LEIRIA | ESCOLA SUPERIOR DE ARTES E DESIGN

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João Manuel Silva Carvalho Mendes Ferreira Ferrão

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Thesis co-advisors: Filipe Plácido; Nick Mueller, DEUS BV

A design-driven conversational AI interface to enhance the self-management of patients living with IBS

Olá [nome do participante], o meu nome é João Ferrão, antes de mais nada, queria agradecer-lhe por se ter disponibilizado para ter esta conversa comigo. A minha investigação centra-se na melhoria da saúde através da tecnologia, como a eHealth (Semelhante à telemedicina, em que engloba não só o possível atendimento à distância como também exames, prescrições e monitoramento dos pacientes de forma remota, criando assim um ecossistema de acompanhamento.). Esta tecnologia irá trabalhar em conjunto com a inteligência artificial, focando nos distúrbios gastrointestinais, em particular na síndrome do intestino irritável (SII).

Esta conversa visa explorar as experiências atuais de quem vive com esta condição de saúde "síndrome do intestino irritável" para melhor entender quais os desafios e estratégias para lidar em períodos de crise e como é que é feito normalmente o acompanhamento pelo médico.

O objetivo desta investigação centra-se em entender como a inteligência artificial e de eHealth podem ajudar com as complexidades da síndrome do intestino irritável, explorando o seu impacto nos cuidados, diagnóstico e gestão do paciente.

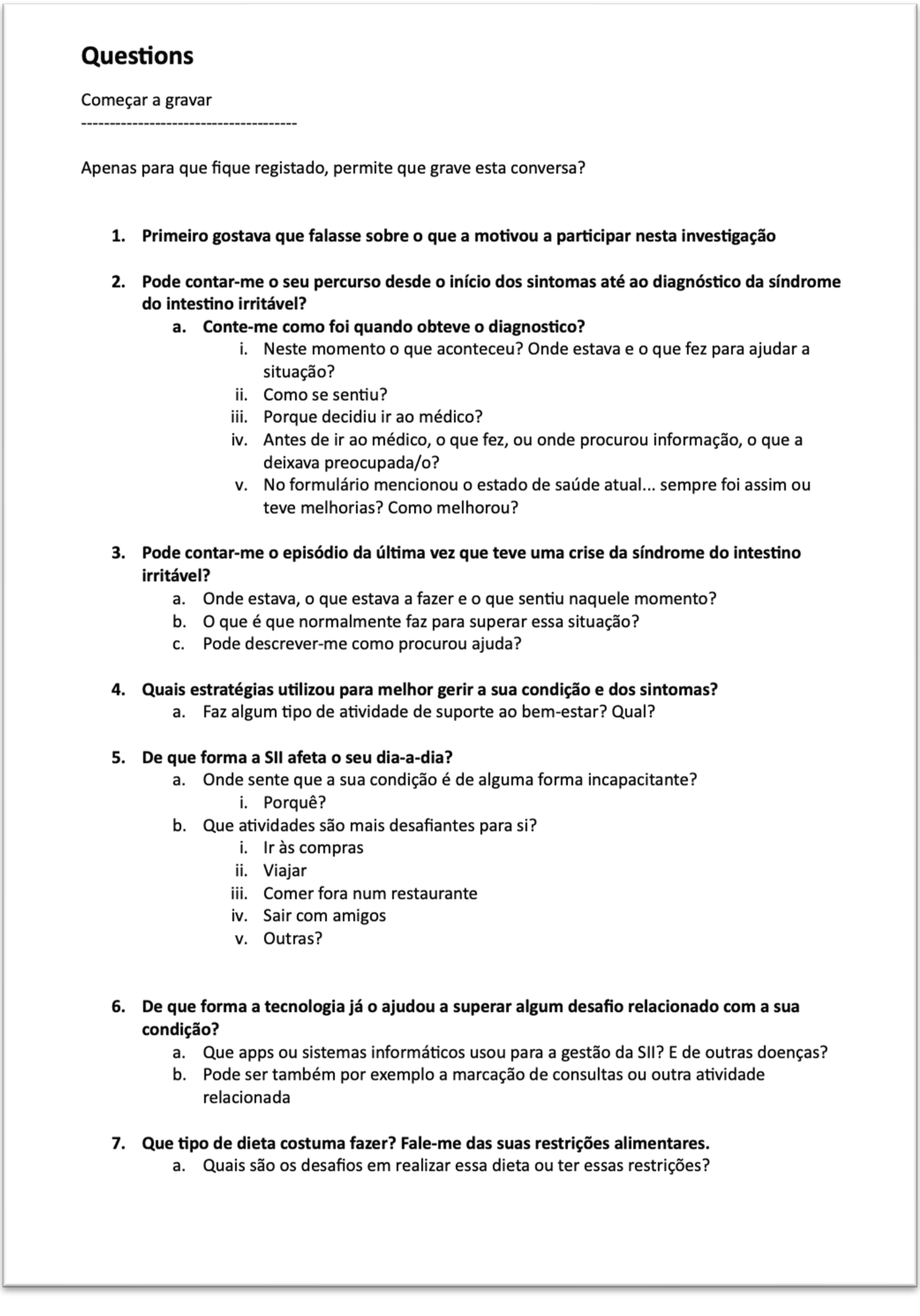
Esta é uma conversa informal, onde irei fazer algumas questões. Não existem respostas certas ou erradas. O objetivo é saber quais as suas perspetivas e pensamentos sobre o tema. Sinta-se à vontade para partilhar tudo aquilo que lhe vier à cabeça, pois como lhe referi não há opiniões boas nem más. A sua participação é muito importante para o decorrer desta investigação.

Não lhe tomarei mais do que 60 minutos e, caso queira parar ou fazer uma pausa em algum momento, está à vontade. Basta avisar-me.

Por fim, a informação recolhida será usada única e exclusivamente no âmbito desta tese, de forma anónima e como referido no formulário de consentimento previamente assinado, onde também consta a permissão de gravação desta conversa para fins de anotações.

Gostava de lhe perguntar se tem alguma questão antes de começarmos?

Permite então que grave esta conversa?



Questions

Começar a gravar

Apenas para que fique registado, permite que grave esta conversa?

1. **Primeiro gostava que falasse sobre o que a motivou a participar nesta investigação**

2. **Pode contar-me o seu percurso desde o início dos sintomas até ao diagnóstico da síndrome do intestino irritável?**
    a. **Conte-me como foi quando obteve o diagnostico?**
        i. Neste momento o que aconteceu? Onde estava e o que fez para ajudar a situação?
        ii. Como se sentiu?
        iii. Porque decidiu ir ao médico?
        iv. Antes de ir ao médico, o que fez, ou onde procurou informação, o que a deixava preocupada/o?
        v. No formulário mencionou o estado de saúde atual... sempre foi assim ou teve melhorias? Como melhorou?

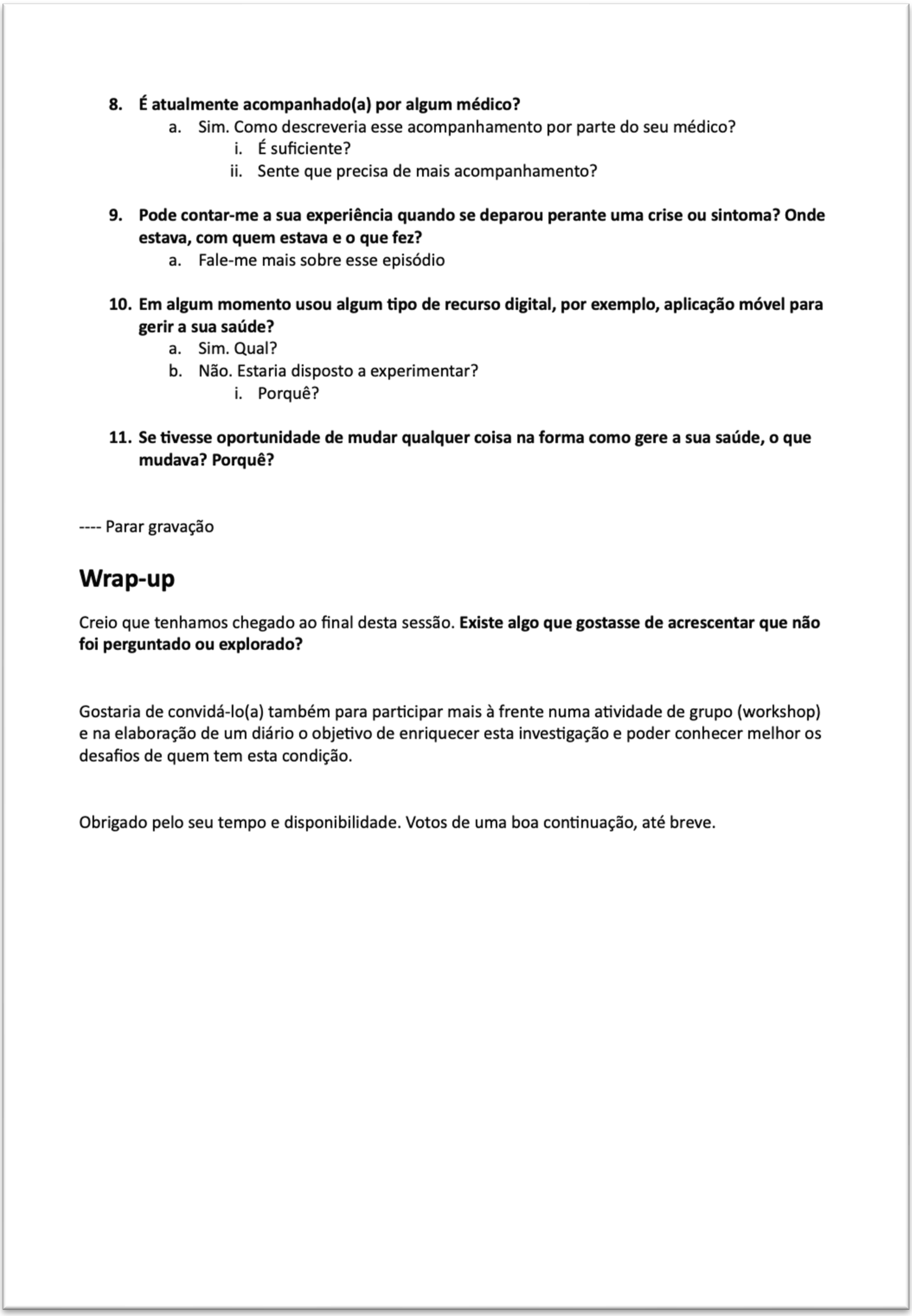
3. **Pode contar-me o episódio da última vez que teve uma crise da síndrome do intestino irritável?**
    a. Onde estava, o que estava a fazer e o que sentiu naquele momento?
    b. O que é que normalmente faz para superar essa situação?
    c. Pode descrever-me como procurou ajuda?

4. **Quais estratégias utilizou para melhor gerir a sua condição e dos sintomas?**
    a. Faz algum tipo de atividade de suporte ao bem-estar? Qual?

5. **De que forma a SII afeta o seu dia-a-dia?**
    a. Onde sente que a sua condição é de alguma forma incapacitante?
        i. Porquê?
    b. Que atividades são mais desafiantes para si?
        i. Ir às compras
        ii. Viajar
        iii. Comer fora num restaurante
        iv. Sair com amigos
        v. Outras?

6. **De que forma a tecnologia já o ajudou a superar algum desafio relacionado com a sua condição?**
    a. Que apps ou sistemas informáticos usou para a gestão da SII? E de outras doenças?
    b. Pode ser também por exemplo a marcação de consultas ou outra atividade relacionada

7. **Que tipo de dieta costuma fazer? Fale-me das suas restrições alimentares.**
    a. Quais são os desafios em realizar essa dieta ou ter essas restrições?



8. **É atualmente acompanhado(a) por algum médico?**
    a. Sim. Como descreveria esse acompanhamento por parte do seu médico?
        i. É suficiente?
        ii. Sente que precisa de mais acompanhamento?

9. **Pode contar-me a sua experiência quando se deparou perante uma crise ou sintoma? Onde estava, com quem estava e o que fez?**
    a. Fale-me mais sobre esse episódio

10. **Em algum momento usou algum tipo de recurso digital, por exemplo, aplicação móvel para gerir a sua saúde?**
    a. Sim. Qual?
    b. Não. Estaria disposto a experimentar?
        i. Porquê?

11. **Se tivesse oportunidade de mudar qualquer coisa na forma como gere a sua saúde, o que mudava? Porquê?**

---- Parar gravação

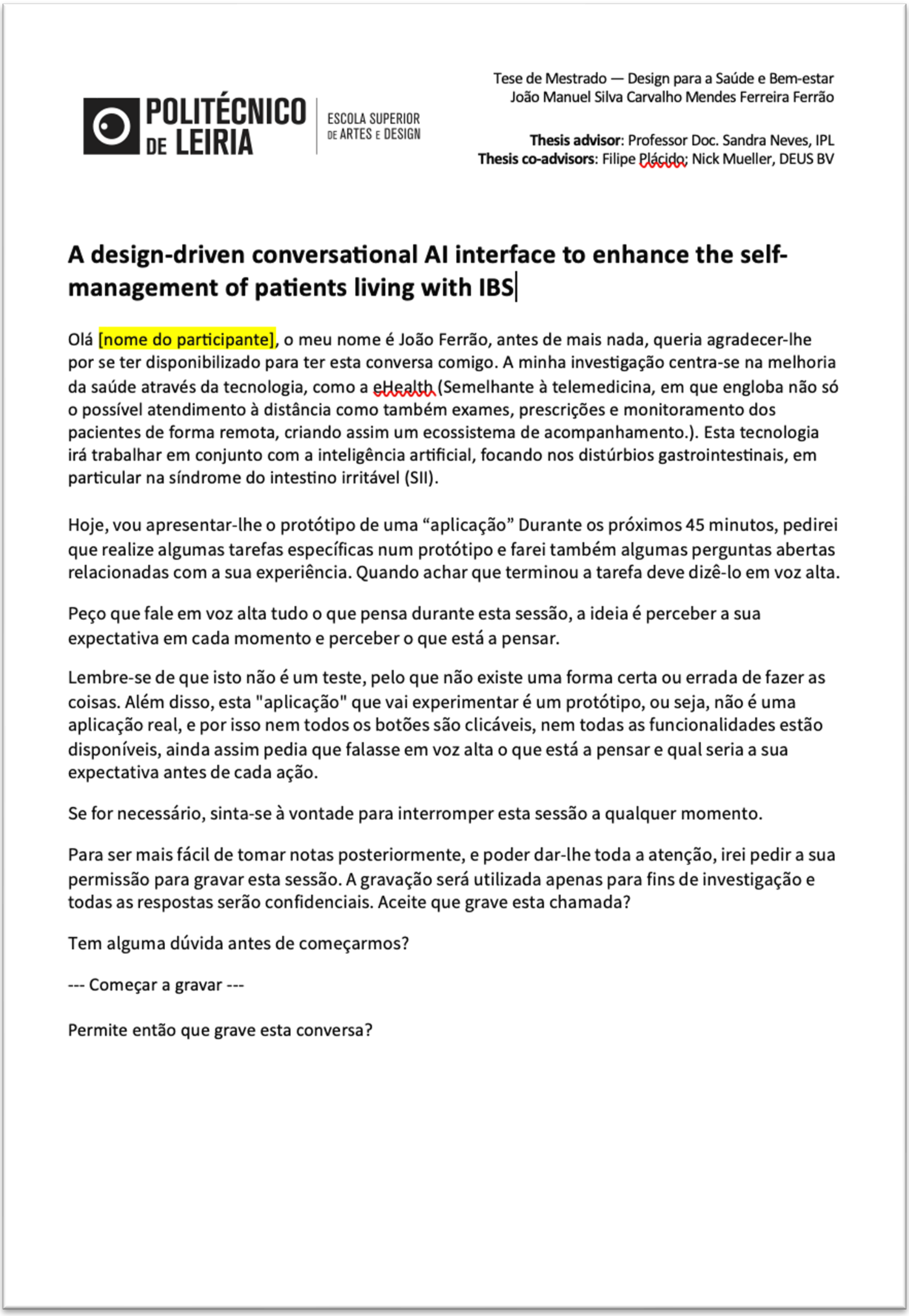
Wrap-up

Creio que tenhamos chegado ao final desta sessão. **Existe algo que gostasse de acrescentar que não foi perguntado ou explorado?**

Gostaria de convidá-lo(a) também para participar mais à frente numa atividade de grupo (workshop) e na elaboração de um diário o objetivo de enriquecer esta investigação e poder conhecer melhor os desafios de quem tem esta condição.

Obrigado pelo seu tempo e disponibilidade. Votos de uma boa continuação, até breve.

Appendix V: Usability test guide



POLITÉCNICO DE LEIRIA
ESCOLA SUPERIOR DE ARTES E DESIGN

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Olá [nome do participante], o meu nome é João Ferrão, antes de mais nada, queria agradecer-lhe por se ter disponibilizado para ter esta conversa comigo. A minha investigação centra-se na melhoria da saúde através da tecnologia, como a eHealth (Semelhante à telemedicina, em que engloba não só o possível atendimento à distância como também exames, prescrições e monitoramento dos pacientes de forma remota, criando assim um ecossistema de acompanhamento.). Esta tecnologia irá trabalhar em conjunto com a inteligência artificial, focando nos distúrbios gastrointestinais, em particular na síndrome do intestino irritável (SII).

Hoje, vou apresentar-lhe o protótipo de uma “aplicação” Durante os próximos 45 minutos, pedirei que realize algumas tarefas específicas num protótipo e farei também algumas perguntas abertas relacionadas com a sua experiência. Quando achar que terminou a tarefa deve dizê-lo em voz alta.

Peço que fale em voz alta tudo o que pensa durante esta sessão, a ideia é perceber a sua expectativa em cada momento e perceber o que está a pensar.

Lembre-se de que isto não é um teste, pelo que não existe uma forma certa ou errada de fazer as coisas. Além disso, esta "aplicação" que vai experimentar é um protótipo, ou seja, não é uma aplicação real, e por isso nem todos os botões são clicáveis, nem todas as funcionalidades estão disponíveis, ainda assim pedia que falasse em voz alta o que está a pensar e qual seria a sua expectativa antes de cada ação.

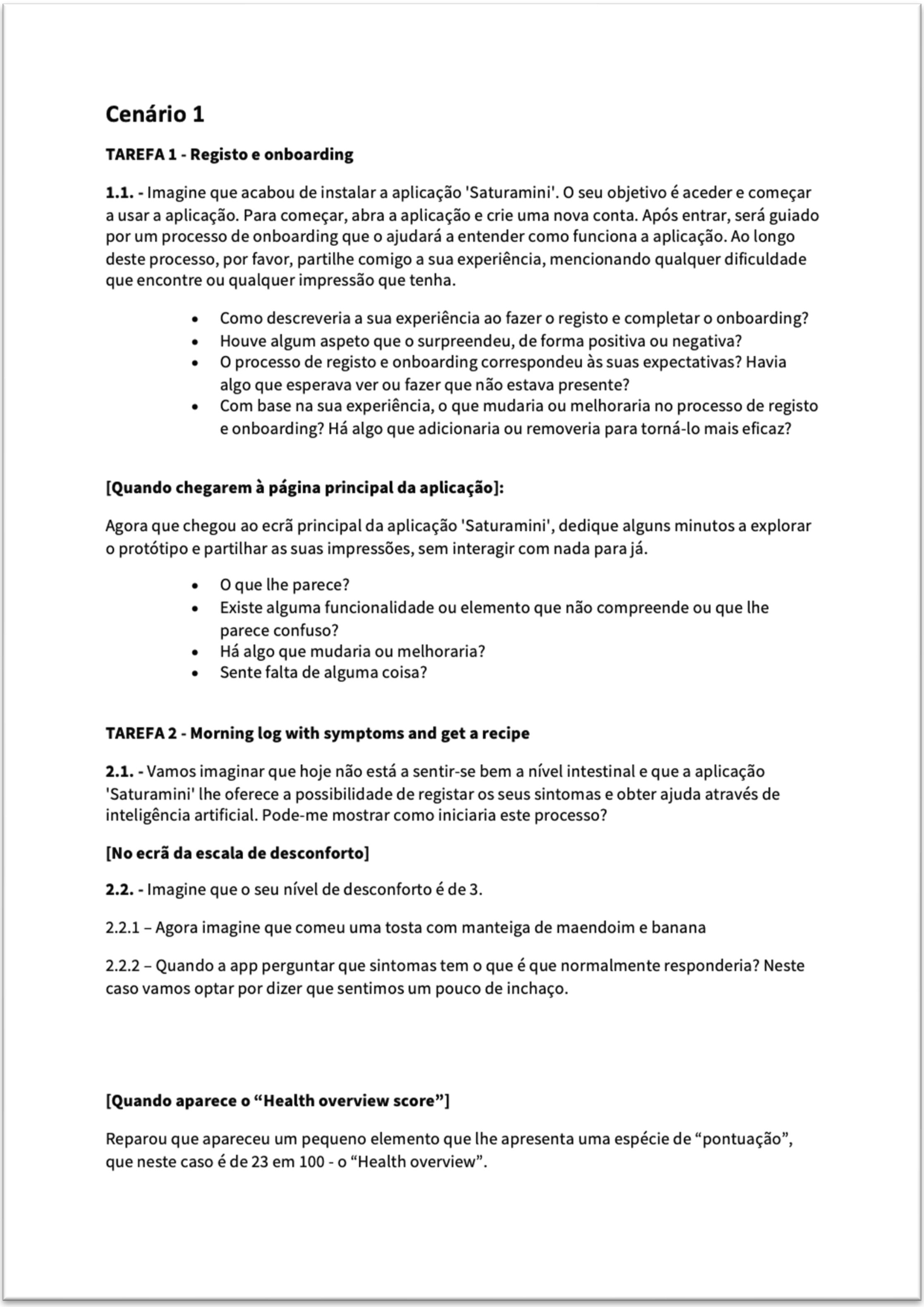
Se for necessário, sinta-se à vontade para interromper esta sessão a qualquer momento.

Para ser mais fácil de tomar notas posteriormente, e poder dar-lhe toda a atenção, irei pedir a sua permissão para gravar esta sessão. A gravação será utilizada apenas para fins de investigação e todas as respostas serão confidenciais. Aceite que grave esta chamada?

Tem alguma dúvida antes de começarmos?

--- Começar a gravar ---

Permite então que grave esta conversa?



Cenário 1

TAREFA 1 - Registo e onboarding

1.1. - Imagine que acabou de instalar a aplicação 'Saturamini'. O seu objetivo é aceder e começar a usar a aplicação. Para começar, abra a aplicação e crie uma nova conta. Após entrar, será guiado por um processo de onboarding que o ajudará a entender como funciona a aplicação. Ao longo deste processo, por favor, partilhe comigo a sua experiência, mencionando qualquer dificuldade que encontre ou qualquer impressão que tenha.

- Como descreveria a sua experiência ao fazer o registo e completar o onboarding?
- Houve algum aspeto que o surpreendeu, de forma positiva ou negativa?
- O processo de registo e onboarding correspondeu às suas expectativas? Havia algo que esperava ver ou fazer que não estava presente?
- Com base na sua experiência, o que mudaria ou melhoraria no processo de registo e onboarding? Há algo que adicionaria ou removeria para torná-lo mais eficaz?

[Quando chegarem à página principal da aplicação]:

Agora que chegou ao ecrã principal da aplicação 'Saturamini', dedique alguns minutos a explorar o protótipo e partilhar as suas impressões, sem interagir com nada para já.

- O que lhe parece?
- Existe alguma funcionalidade ou elemento que não compreende ou que lhe parece confuso?
- Há algo que mudaria ou melhoraria?
- Sente falta de alguma coisa?

TAREFA 2 - Morning log with symptoms and get a recipe

2.1. - Vamos imaginar que hoje não está a sentir-se bem a nível intestinal e que a aplicação 'Saturamini' lhe oferece a possibilidade de registar os seus sintomas e obter ajuda através de inteligência artificial. Pode-me mostrar como iniciaria este processo?

[No ecrã da escala de desconforto]

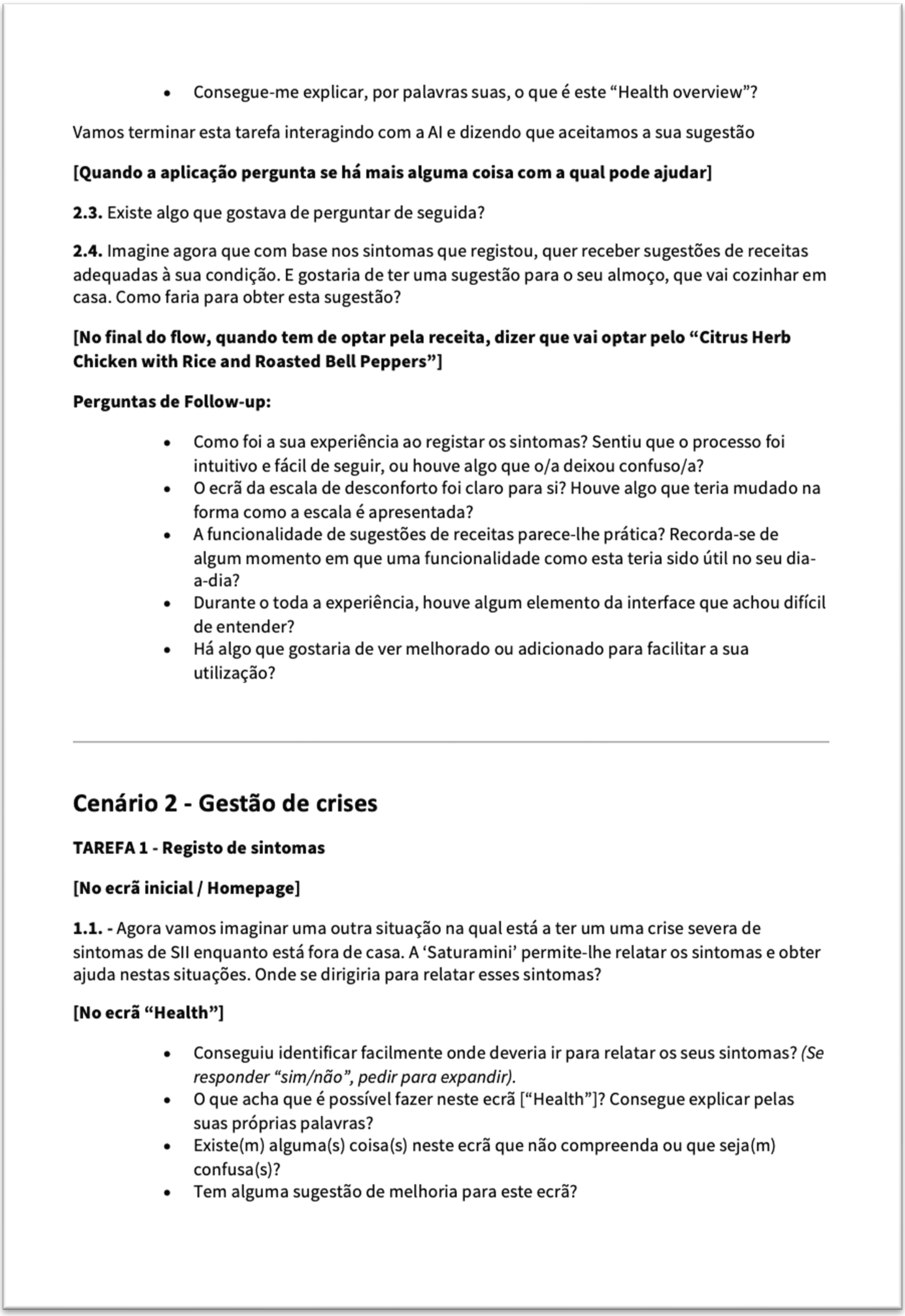
2.2. - Imagine que o seu nível de desconforto é de 3.

2.2.1 – Agora imagine que comeu uma tosta com manteiga de maendoim e banana

2.2.2 – Quando a app perguntar que sintomas tem o que é que normalmente responderia? Neste caso vamos optar por dizer que sentimos um pouco de inchaço.

[Quando aparece o “Health overview score”]

Reparou que apareceu um pequeno elemento que lhe apresenta uma espécie de “pontuação”, que neste caso é de 23 em 100 - o “Health overview”.



- Consegue-me explicar, por palavras suas, o que é este “Health overview”?

Vamos terminar esta tarefa interagindo com a AI e dizendo que aceitamos a sua sugestão

[Quando a aplicação pergunta se há mais alguma coisa com a qual pode ajudar]

2.3. Existe algo que gostava de perguntar de seguida?

2.4. Imagine agora que com base nos sintomas que registou, quer receber sugestões de receitas adequadas à sua condição. E gostaria de ter uma sugestão para o seu almoço, que vai cozinhar em casa. Como faria para obter esta sugestão?

[No final do flow, quando tem de optar pela receita, dizer que vai optar pelo “Citrus Herb Chicken with Rice and Roasted Bell Peppers”]

Perguntas de Follow-up:

- Como foi a sua experiência ao registar os sintomas? Sentiu que o processo foi intuitivo e fácil de seguir, ou houve algo que o/a deixou confuso/a?
- O ecrã da escala de desconforto foi claro para si? Houve algo que teria mudado na forma como a escala é apresentada?
- A funcionalidade de sugestões de receitas parece-lhe prática? Recorda-se de algum momento em que uma funcionalidade como esta teria sido útil no seu dia-a-dia?
- Durante o toda a experiência, houve algum elemento da interface que achou difícil de entender?
- Há algo que gostaria de ver melhorado ou adicionado para facilitar a sua utilização?

Cenário 2 - Gestão de crises

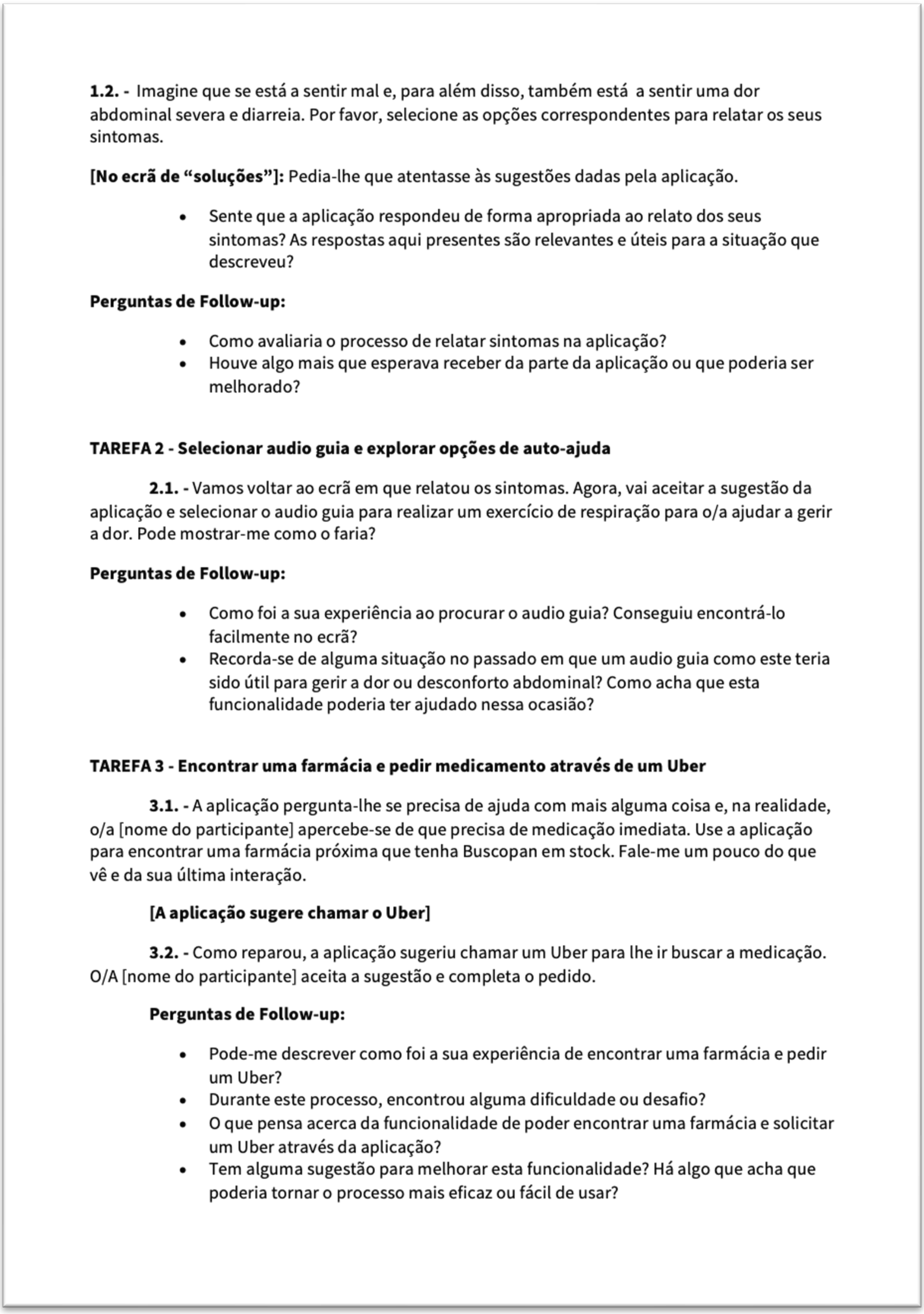
TAREFA 1 - Registo de sintomas

[No ecrã inicial / Homepage]

1.1. - Agora vamos imaginar uma outra situação na qual está a ter um uma crise severa de sintomas de SII enquanto está fora de casa. A ‘Saturamini’ permite-lhe relatar os sintomas e obter ajuda nestas situações. Onde se dirigiria para relatar esses sintomas?

[No ecrã “Health”]

- Conseguiu identificar facilmente onde deveria ir para relatar os seus sintomas? *(Se responder “sim/não”, pedir para expandir).*
- O que acha que é possível fazer neste ecrã [“Health”]? Consegue explicar pelas suas próprias palavras?
- Existe(m) alguma(s) coisa(s) neste ecrã que não compreenda ou que seja(m) confusa(s)?
- Tem alguma sugestão de melhoria para este ecrã?



1.2. - Imagine que se está a sentir mal e, para além disso, também está a sentir uma dor abdominal severa e diarreia. Por favor, selecione as opções correspondentes para relatar os seus sintomas.

[No ecrã de "soluções"]: Pedia-lhe que atentasse às sugestões dadas pela aplicação.

- Sente que a aplicação respondeu de forma apropriada ao relato dos seus sintomas? As respostas aqui presentes são relevantes e úteis para a situação que descreveu?

Perguntas de Follow-up:

- Como avaliaria o processo de relatar sintomas na aplicação?
- Houve algo mais que esperava receber da parte da aplicação ou que poderia ser melhorado?

TAREFA 2 - Selecionar audio guia e explorar opções de auto-ajuda

2.1. - Vamos voltar ao ecrã em que relatou os sintomas. Agora, vai aceitar a sugestão da aplicação e selecionar o audio guia para realizar um exercício de respiração para o/a ajudar a gerir a dor. Pode mostrar-me como o faria?

Perguntas de Follow-up:

- Como foi a sua experiência ao procurar o audio guia? Conseguiu encontrá-lo facilmente no ecrã?
- Recorda-se de alguma situação no passado em que um audio guia como este teria sido útil para gerir a dor ou desconforto abdominal? Como acha que esta funcionalidade poderia ter ajudado nessa ocasião?

TAREFA 3 - Encontrar uma farmácia e pedir medicamento através de um Uber

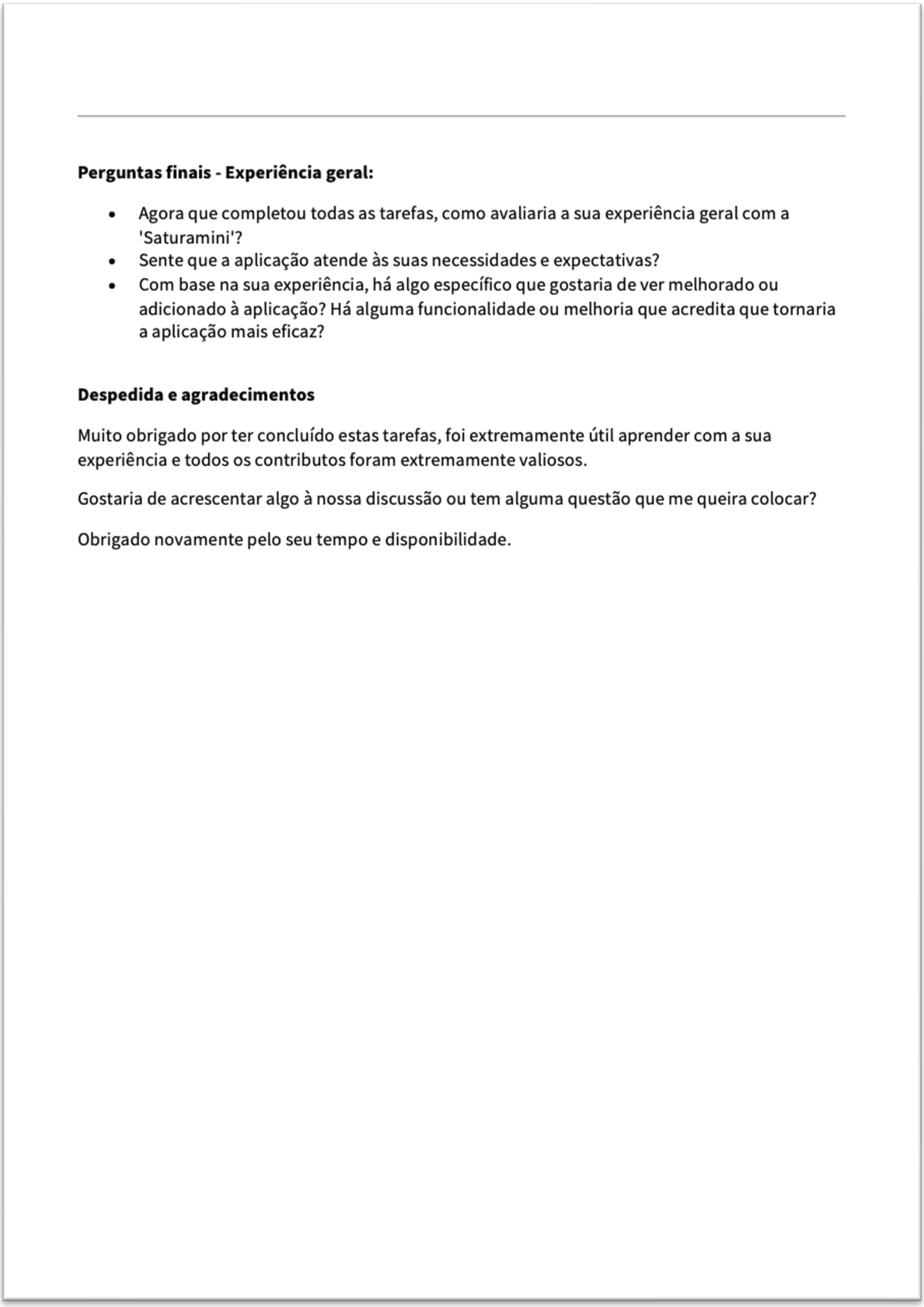
3.1. - A aplicação pergunta-lhe se precisa de ajuda com mais alguma coisa e, na realidade, o/a [nome do participante] apercebe-se de que precisa de medicação imediata. Use a aplicação para encontrar uma farmácia próxima que tenha Buscopan em stock. Fale-me um pouco do que vê e da sua última interação.

[A aplicação sugere chamar o Uber]

3.2. - Como reparou, a aplicação sugeriu chamar um Uber para lhe ir buscar a medicação. O/A [nome do participante] aceita a sugestão e completa o pedido.

Perguntas de Follow-up:

- Pode-me descrever como foi a sua experiência de encontrar uma farmácia e pedir um Uber?
- Durante este processo, encontrou alguma dificuldade ou desafio?
- O que pensa acerca da funcionalidade de poder encontrar uma farmácia e solicitar um Uber através da aplicação?
- Tem alguma sugestão para melhorar esta funcionalidade? Há algo que acha que poderia tornar o processo mais eficaz ou fácil de usar?



Perguntas finais - Experiência geral:

- Agora que completou todas as tarefas, como avaliaria a sua experiência geral com a 'Saturamini'?
- Sente que a aplicação atende às suas necessidades e expectativas?
- Com base na sua experiência, há algo específico que gostaria de ver melhorado ou adicionado à aplicação? Há alguma funcionalidade ou melhoria que acredita que tornaria a aplicação mais eficaz?

Despedida e agradecimentos

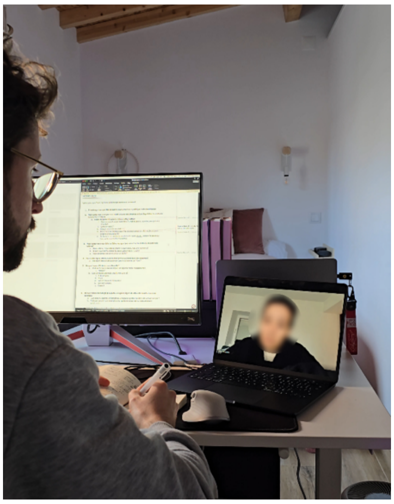
Muito obrigado por ter concluído estas tarefas, foi extremamente útil aprender com a sua experiência e todos os contributos foram extremamente valiosos.

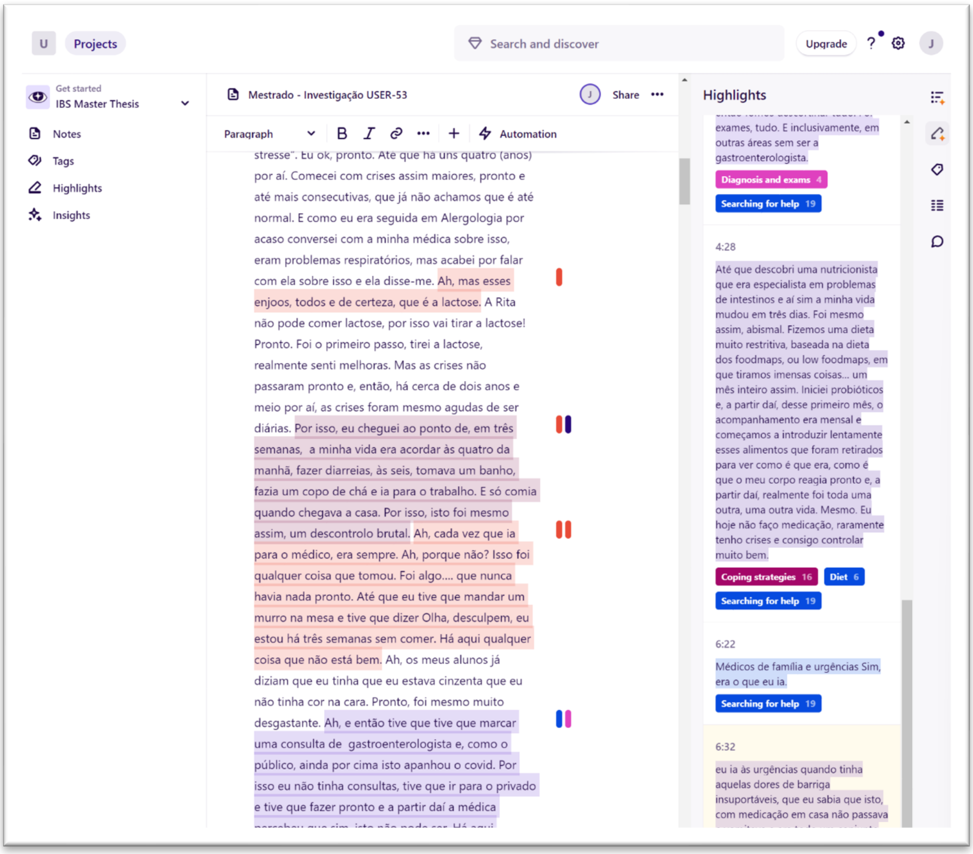
Gostaria de acrescentar algo à nossa discussão ou tem alguma questão que me queira colocar?

Obrigado novamente pelo seu tempo e disponibilidade.

Appendix VI: Framework to analyse the collected data

Regarding analysis, the sessions were transcribed, and the flexible thematic analysis method was used to analyse all the qualitative data collected during these semi-structured interviews and tests. This method, in short, is a systematic way of breaking down and organising research by tagging individual observations that might make it easier to find important patterns and themes across the different sessions (Braun & Clarke, 2006).





Mestrado - Investigação USER-53

stresse". Eu ok, pronto. Até que há uns quatro (anos) por aí. Comecei com crises assim maiores, pronto e até mais consecutivas, que já não achamos que é até normal. E como eu era seguida em Alergologia por acaso conversei com a minha médica sobre isso, eram problemas respiratórios, mas acabei por falar com ela sobre isso e ela disse-me. Ah, mas esses enjoos, todos e de certeza, que é a lactose. A Rita não pode comer lactose, por isso vai tirar a lactose! Pronto. Foi o primeiro passo, tirei a lactose, realmente senti melhoras. Mas as crises não passaram pronto e, então, há cerca de dois anos e meio por aí, as crises foram mesmo agudas de ser diárias. Por isso, eu cheguei ao ponto de, em três semanas, a minha vida era acordar às quatro da manhã, fazer diarreias, às seis, tomava um banho, fazia um copo de chá e ia para o trabalho. E só comia quando chegava a casa. Por isso, isto foi mesmo assim, um descontrolo brutal. Ah, cada vez que ia para o médico, era sempre. Ah, porque não? Isso foi qualquer coisa que tomou. Foi algo.... que nunca havia nada pronto. Até que eu tive que mandar um murro na mesa e tive que dizer Olha, desculpem, eu estou há três semanas sem comer. Há aqui qualquer coisa que não está bem. Ah, os meus alunos já diziam que eu tinha que eu estava cinzenta que eu não tinha cor na cara. Pronto, foi mesmo muito desgastante. Ah, e então tive que tive que marcar uma consulta de gastroenterologista e, como o público, ainda por cima isto apanhou o covid. Por isso eu não tinha consultas, tive que ir para o privado e tive que fazer pronto e a partir daí a médica

exames, tudo. E inclusivamente, em outras áreas sem ser a gastroenterologista.

Diagnosis and exams 4

Searching for help 19

4:28

Até que descobri uma nutricionista que era especialista em problemas de intestinos e aí sim a minha vida mudou em três dias. Foi mesmo assim, abismal. Fizemos uma dieta muito restritiva, baseada na dieta dos foodmaps, ou low foodmaps, em que tiramos imensas coisas... um mês inteiro assim. Iniciei probióticos e, a partir daí, desse primeiro mês, o acompanhamento era mensal e começamos a introduzir lentamente esses alimentos que foram retirados para ver como é que era, como é que o meu corpo reagia pronto e, a partir daí, realmente foi toda uma outra, uma outra vida. Mesmo. Eu hoje não faço medicação, raramente tenho crises e consigo controlar muito bem.

Coping strategies 16

Diet 6

Searching for help 19

6:22

Médicos de família e urgências Sim, era o que eu ia.

Searching for help 19

6:32

eu ia às urgências quando tinha aquelas dores de barriga insuportáveis, que eu sabia que isto, com medicação em casa não passava