POLITÉCNICO DE LEIRIA | ESCOLA SUPERIOR DE ARTES E DESIGN

COMBINING DESIGN AND AUTOETHNOGRAPHY TO IMPROVE VISUALLY IMPAIRED PATIENTS' EXPERIENCE IN HOSPITAL ENVIRONMENT:

A CASE STUDY FOR AWARENESS THROUGH A PATIENT INNOVATOR PERSPECTIVE

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TO ALL VISUALLY IMPAIRED PEOPLE.

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DISCLAIMER

This dissertation represents an original scholarly work, developed to fulfill the requirements to complete my master's degree, with all sources duly acknowledged. Some of the content is derived and expanded from the following publication:

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ABSTRACT

A world where almost every sign is given by visual inputs amplifies the profoundly challenging experience endured by visually impaired people. The absence of vision significantly impacts a person's life, as simple daily tasks can become difficult or even impossible to accomplish. Blind and low-vision individuals face numerous barriers, and one of the most challenging obstacles is physical orientation within public spaces, such as schools and hospitals, in an autonomous way. Hospital facilities represent a critical touchpoint when considering wayfinding systems, even for sighted individuals.

Supported by the Patient Innovation concept, autoethnography methodologies, and design practices, the author, who is simultaneously a designer, researcher, and patient with low vision, explores how personal experiences can assist other visually impaired patients while educating about disability and promoting inclusion in healthcare and design.

This case study for awareness is based on a first-person perspective and aims to address the existing wayfinding elements for visually disabled patients within hospital facilities through an "auto-shadowing" journey – from a hospital's main entrance to the ophthalmology service in Porto (Portugal) – evaluating the ability to reach the ophthalmologist's appointment autonomously.

The research findings reveal the absence of an effective navigation system capable of providing accessible tools to blind and low-vision patients. Considering the issues identified, the author proposes discussions and reflections on how design practices should be oriented to prioritize and facilitate societal change.

Improving the experience of visually disabled patients is critical to providing better healthcare services and promoting a more equal and accessible world where they can have a more active voice in society. Regardless of their disability, healthcare should be accessible to all citizens.

Keywords: Visual Impairment; Indoor Wayfinding; Patient Innovation; Healthcare; Design; Autoethnography.

RESUMO

Um mundo onde quase todos os sinais são transmitidos por meio de estímulos visuais intensifica a experiência profundamente desafiadora vivida por pessoas com deficiência visual. A ausência de visão causa um grande impacto na vida de uma pessoa—tarefas diárias simples podem tornar-se difíceis ou até impossíveis de realizar. Pessoas cegas e com baixa visão enfrentam inúmeros desafios, sendo um dos mais complicados a orientação física em espaços públicos, como escolas e hospitais, de forma autónoma. As instalações hospitalares representam um ambiente crítico em termos de navegação, mesmo para pessoas com uma acuidade visual saudável.

Suportado pelo conceito de *Patient Innovation*, por metodologias de autoetnografia e por práticas de design, o autor, que é simultaneamente designer, investigador e pacinte com baixa visão, explora, nesta dissertação, como as experiências pessoais podem auxiliar outros pacientes com deficiência visual. Ao mesmo tempo educa sobre o capacitismo e os desafios enfrentados, promovendo a melhoria da acessibilidade e inclusão nos serviços de saúde e no design.

Este estudo de caso de sensibilização baseia-se numa perspetiva de primeira pessoa e pretende abordar os elementos *wayfinding* existentes para pacientes com deficiência visual dentro de instalações hospitalares, através de uma viagem de "*auto-shadowing*" - desde a entrada principal de um hospital até ao serviço de oftalmologia no Porto (Portugal) – avaliar a capacidade de chegar à consulta do oftalmologista de forma autónoma.

Os resultados da investigação revelam a ausência de um sistema de navegação eficaz, capaz de fornecer ferramentas acessíveis a pacientes cegos e com baixa visão. Considerando as questões identificadas, o autor propõe discussões e reflexões sobre como as práticas de design devem ser orientadas para priorizar e facilitar a mudança social.

Melhorar a experiência dos pacientes com deficiência visual é essencial para proporcionar melhores serviços de saúde e promover um mundo mais equalitário e acessível, onde estas pessoas possam ter uma voz mais ativa na sociedade. Independentemente da sua deficiência, os cuidados de saúde devem ser acessíveis a todos os cidadãos.

Palavras-Chave: Deficiência Visual, Wayfinding; Patient Innovation; Cuidados de saúde; Design e Auto-Etnografia.

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Author's Note:

Image description is a valuable accessibility feature – similar to audio description – that helps visually impaired individuals access information otherwise inaccessible to them. For example, a person who is blind and uses screen reader software can understand the content of all images with the help of image descriptions.

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INTRODUCTION

INTRODUCTION

Acquiring a Visual Impairment at 27 years old – A Personal Narrative

I started thinking about the issues regarding visually impaired people in 2019 when I was diagnosed with Leber's Hereditary Optic Neuropathy (LHON). This caused me to lose my central vision in both eyes at the age of 27. As a young woman with an entire life ahead of me, I couldn't believe what was happening. It took me several months to process, and I'm still processing it.

I worked as a pattern maker at a textile factory, where I was responsible for transforming sketches into technical/vectorial drawings through rigorous measurement charts. This job required precise accuracy for every detail – one millimetric error could ruin an entire production of thousands of clothes. My journey was always about fashion design – with a fashion design degree and several courses in this field – it was my way of expression by creating fashion-forward, avant-garde, and disruptive designs inspired by emotions. I think fashion design is usually misunderstood and undervalued because of its symbioses with the frivolous celebrity world. Still, fashion is more than that – it has a deep connection to ourselves – our self-confidence, self-esteem, and culture.

At the time I got sick, I had a normative and stable life – a job, a driver's license, a car of my own, a rented apartment, friends, a boyfriend, and a list of dreams to accomplish – dreams that I couldn't do some of those anymore, at least not in the same way.

Vision is our most reliable sense (Viosca, 2018).We experience and learn about the world – from a young age – through visual stimulation. Sight is essential to perform simple daily tasks – from reading a message on our smartphone screen, driving, walking on the street safely (where life-threatening situations could happen), working or looking

for a job, making a payment at a store, preparing a meal – the challenges are endless. On a deeper level, vision is a big part of our social interactions – new friendships, understanding others' behaviors and feelings by seeing their body language (Karagoz, 2023), and even dating. I'm not going to be a hypocrite – social interaction with low vision is extremely hard.

Feeling discouraged, lonely, sad, and angry is inevitable and part of the trauma experience. The healing and acceptance process is more difficult when acquiring a disability rather than an inborn disability – people with acquired impairment have higher depression levels (Kim & Park, 2023). I had experienced life as a normative person, so I'm very aware of what I had lost as a citizen. We all have rights and duties, apart from being disabled or not, but society has yet not provided equitable opportunities and approaches to provide a more dignified life to this group of citizens.

When we are healthy, it is incredibly challenging to imagine what disabled people experience 24 hours a day, seven days a week, of an entire life. In addition to all the physical barriers, significant issues remain to be tackled, including ableism.

On July 13, 2019, I received my diagnosis – an irreversible eye condition. The only treatment available – that could improve a slight sight recovery – didn't have any effect on me. I was lost for some time, thinking: what am I able to do now?

My vision got worse in the first year, during the COVID-19 lockdown. After the first year, it had stabilized. Now, my visual acuity is what doctors call "counting fingers" (Schulze-Bonsel et al., 2006), meaning that I can't recognize anything even within 1 meter away. You can imagine it as if you are taking a shower and you are trying to see through that foggy glass, you just can see large shapes, but you can't identify them; you can't distinguish the toilet from the wall because they are both the same color, it is just a white blur.

I needed to learn how to live with this condition by finding new ways to mitigate visual information requirements.

Throughout my five years as a person with low vision, I have come to realize that the awkwardness and discomfort often encountered in social interactions stem more from the feelings of others rather than my own. While I do experience moments of awkwardness, I have observed that many individuals struggle to comprehend and empathize with people with disabilities. Their lack of understanding inadvertently contributes to the isolation of individuals with impairments, potentially leading to mental health disorders. I'm committed to mitigating these issues by sharing my experiences and conducting research to promote awareness.

I wanted to continue my journey in Design, but I wasn’t sure who I was as a designer anymore. I found that research in health and wellbeing proves that Design isn't always based on visuals; it's a way of thinking, an innovation and intervention tool capable of breaking barriers and improving the quality of life for those affected by health conditions. So, I decided I will use Design and Research to provide impaired people with a more autonomous, accessible, dignified, and equal life and at the same time, when possible, educate about disability and ableism. The process of doing my master's degree and this dissertation has raised profound questions as a patient, designer, and researcher, about design practices, disability representation in design, and the privilege of determining who gets to shape and develop knowledge in the field.

As a patient, I have visited various healthcare facilities – in England, Italy, and Portugal. This experience gave me a perception of the lack of accessibility in this environment.

The choice of the hospital's space is justified because of its importance to people with disabilities. It is often not just a place for medical care, but also for experiencing trauma, as it's where life-changing diagnoses are given — myself included.

I strongly believe that my patient experience and my design skills could help create better accessibility for other visually impaired people and generate empathy throughout my own narrative.

Despite the major impact LHON had on me, this diagnosis doesn't define what I am, at least not anymore.

Life, from now on, is different.

Research Introduction

Hospitals are complex, crowded, large-scale, noisy, and scary environments (Cooper, 2010; Jeamwatthanachai et al., 2019; Rousek & Hallbeck, 2011). Ultimately, healthcare facilities have an extra crucial factor – unlike airports, malls, and university campuses – the emotional component. People often feel anxious, fearful, and stressed when visiting a hospital (Cooper, 2010; Jeamwatthanachai et al., 2019).

Healthcare is an essential part of our lives, even more so when having a diagnosis of incapacity or disability that requires regular follow-up. Hospitals are extremely hard places to navigate, even for sighted people (Fixova et al., 2014). The current wayfinding systems rely on visual cues, creating significant challenges for visually impaired people.

In the past years, there has been an increase in research on hospital accessibility for visually disabled individuals. Of the few articles found (Hosseini, 2021; Jeamwatthanachai et al., 2019; Rousek & Hallbeck, 2011), most were developed in the United States and the United Kingdom. Limited to observational or questionnaires, these studies still have a long way to go in ensuring that the inputs from blind and low-vision patients are more effectively heard.

There is an obvious need for an adapted space for these patients; Babbu & Haque (2021) recognize that physical environments can influence healthcare results, not only for patients but also for the staff. The adaptation of those spaces, just like on pediatric wings, saw improved results (Akinluyi, 2019; Alvaro, 2015; Shepley, 2001; Ulrich et al., 2004 apud Babbu & Haque, 2021). So, a question could be formulated: **if pediatric spaces are designed to suit their patients and improve emotional and physical results, why aren't ophthalmology spaces adjusted to accommodate patients with a high visual disability profile?**

Personally, as a low-vision person, it’s easy to identify the lack of accessible resources for visually impaired patients inside healthcare facilities. An efficient wayfinding system

increases the quality of care, lowers anxiety and stress levels, and optimizes overall services and patients' and visitors' safety. Research shows that visually disabled people get lost very easily inside hospitals where light, sound, and landmarks are key factors to blind and low-vision patients' orientation (Rousek & Hallbeck, 2011).

Every citizen should have the right to equal access to public healthcare services. Knowing this, it seems important that the following research should focus not only on the challenges and difficulties faced by visually impaired people in accessing hospitals but also on the advancements made to improve access. The hope of this document is that it will help raise awareness about visual disabilities.

The image below (Figure 1) represents the core elements of the problem definition.

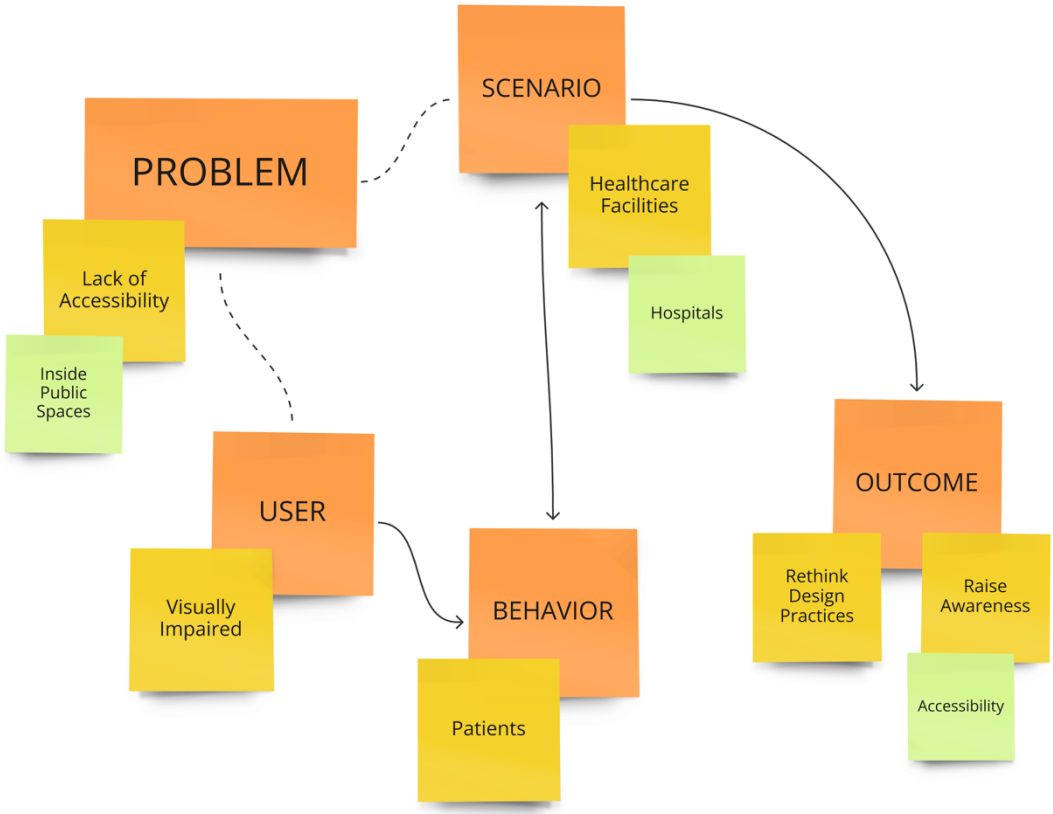

Figure 1 – Infographic description: A set of "post-its" (with orange and yellow shades) connected by arrows about the problem definition – from "Problem – User – Behavior – Scenario and Outcome.

From this, a new question was formulated: **How can autoethnography and socially committed design practices, sustained by first-person perspectives, improve the experience of visually impaired patients in hospital environments?**

Before diving into this document, it's important to have some knowledge of some concepts to understand the significance and impact that these concepts and methods will have on its creation. This research delves into the potential benefits of adopting a first-person perspective to provide better resources for visually impaired individuals seeking improved healthcare and to raise awareness based on personal experience.

What sets this dissertation apart is its incorporation of patient innovation, design expertise, and autoethnography within a healthcare context, all from the viewpoint of someone with low vision. This innovative approach encourages deep exploration of wayfinding systems, design methodologies, and the societal role of disabled individuals. It is important to highlight the existence of ableism and take proactive steps to address it in order to develop more effective solutions for these often marginalized citizens.

The **Patient Innovation** concept (a Portuguese project that began in 2014) was the starting point of my journey as a researcher, providing me a with sense of purpose and belonging. In this concept, patients are given a platform to be part of the solution by developing solutions to cope with their condition and individual needs, offering valuable insights about their illnesses, which contributes to increased awareness (Oliveira et al., 2015).

Autoethnographic design blends rigorous research methods with innovative thinking from designers' own perspectives. Louise Schouwenberg and Michael Kaethler have explored this new design practice in their book “The Autoethnography Turn in Design” (2021) where they consider the true potential of design to “reside in its possibility to make sense of the world and to understand and cope with life's challenges and

demanding circumstances all of which foreground the designer. (…) we considered design a practice of cultural critique" (Kaethler & Schouwenberg, 2021 p.32).

In Design, good intentions do not always result in truly inclusive and non-discriminatory solutions (Costanza-Chock, 2020; Hedditch & Vyas, 2023). From this observation, in this research, **Design Justice** will be used as a critical guideline to observe and analyze other design approaches, such as Universal Design and Inclusive Design. While attempting to reduce inequalities, these approaches often fail to ensure social justice, leading to outcomes that exclude minority groups who lack power in society. In contrast, Design Justice, with its unique ability to address the weaknesses of these approaches, emerges as the most equitable and inclusive approach among all design variants. It is particularly well-suited for this study of visually impaired wayfinding systems, where equal solutions are paramount.
These contributions align closely with my heart and beliefs, integrating social and activism components.

This dissertation is divided into two parts. The first part will consist of three literature review chapters (Figure 2):

1. Healthcare and Patient Innovation: This chapter delves into the medical aspects of visual impairment and describes the Patient Innovation concept.
2. Autoethnography and Design: This chapter explains the autoethnography method and design practices related to social and disability issues, including Autoethnographic Design and Design Justice.
3. Wayfinding: This chapter examines the nature of wayfinding systems, their presence in hospitals, the elements that make them up, and the available resources for visually impaired individuals.

In its second part, the case study for awareness will involve an in-depth exploration of the shadowing process and the application of the autoethnography methodology, while the investigation's findings will be presented and discussed in the final sections, Discussion and Conclusions.

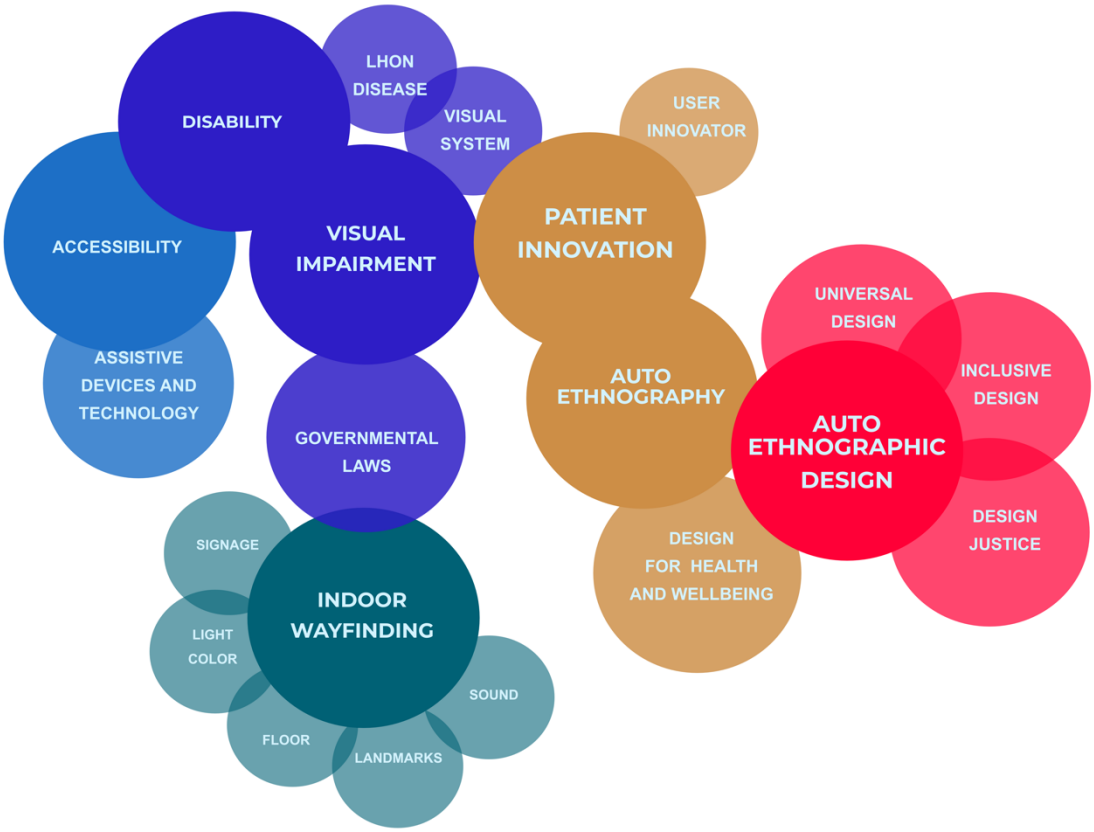

Figure 2 – Infographic Description: A visual representation of a set of interlocking circles with different colors, representing all the subjects to be addressed in this document.

In this research, I will use my personal experience as a patient to identify wayfinding cues while navigating autonomously within an unfamiliar hospital. This study was conducted using an **Autoethnographic** methodology, the **Patient Innovation** concept, an ethical and inclusive approach through Design, such as the **Design Justice** approach**,** and an **auto-shadowing** method for collecting results.

The application of the "auto-shadowing" method will start from the main entrance of Pedro Hispano Hospital Local Healthcare Unit—a public healthcare hospital located in the second-most metropolitan area of Portugal, the Porto region, more specifically in the Matosinho's municipality—and ended at its ophthalmological service. Throughout

this journey experience, I will describe the challenges I faced in finding my way to the doctor's appointment.

In 2023, the Ethics Committee of Pedro Hispano Hospital—Unidade de Saúde Local Matosinhos granted approval for this research (Appendices – Ethical Terms). Initially, this work was encompassed within a broader project focusing on hospital wayfinding with other researchers. However, owing to specific constraints, the study underwent an evolution, diverging from the original product-solving concept.

Before continuing this document, I would like to note that I will write this thesis using the third-person and first-person to reflect my experiences and inputs as an autoethnography designer and based on the work of Sasha Costanza-Chock, Orhan Karagoz, Elisabeth Griffiths, and Annmaree Watharow.

PART I.

LITERATURE REVIEW

PART I. LITERATURE REVIEW

CHAPTER 1. HEALTHCARE AND PATIENT INNOVATION

The Visual Impairment

> *"Disability is defined as a physical or mental impairment that has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities."*
>
> (Brown & Leigh, 2020, p. 128)

The World Health Organization (2023) estimates that 2.2 billion people worldwide are visually impaired. Almost half of these "could have been prevented". Glaucoma, refractive errors, cataracts, age-related macular degeneration, and diabetic retinopathy are among the most frequent causes of blindness and low vision (WHO, 2023).
Sight deteriorates with aging. Therefore, people over 50 are the most affected by a visual impairment condition (J. M. F. de A. Borges, 2018; WHO, 2023). Nevertheless, everyone can be affected.
In Portugal, the National Statistics System (INE) estimates that 3,5% of the population has a visual disability (INE, 2022).

Apart from the constraints of being visually impaired, sight loss also affects overall wellbeing. Disabled people have a higher risk of suffering from other diseases, usually associated with mental health issues – depression and anxiety (Demmin & Silverstein, 2020; Garcia et al., 2017). Visually impaired people feel discouraged and fearful and have low self-esteem to move around autonomously (Jeamwatthanachai et al., 2019). Studies show that these citizens spend most of their lives inside buildings (Li & Lee,

2010), which causes isolation. The genesis of those problems is ableism – which is "discrimination or prejudice against individuals with disabilities" (*Ableism Definition & Meaning - Merriam-Webster*, n.d.) — our society's norm.

Neuroplasticity – Brain's Adaptation to Blindness

Neuroscience research has been dedicated to comprehending the adaptive mechanisms of the human brain in response to vision loss, resulting in an interruption in the activity of the visual cortex. While the biological processes underlying brain modification remain incompletely elucidated, empirical evidence undeniably attests to its adaptive capacity. Considering the deprivation of visual processing, the brain undergoes reorganization, repurposing the visual cortex to accommodate alternative sensory functions, such as those associated with touch and hearing (Sepulcre, 2018).

The Visual System

Sight is the leading player of all senses (Viosca, 2018; WHO, 2023). Most of the human brain's activity is dedicated to processing visual information. (*Vision Is Our Dominant Sense | BrainLine*, n.d.) – This reflects our world, where almost every sign is based only on visuals. Vision plays a major role in the first stages of learning about the surroundings – as babies and throughout one person's life. Learning about colors, shapes, and objects and watching others' behaviors influence social interaction (Cupples et al., 2012).Simple daily life tasks are full of visual cues and necessities – especially activities related to mobility and navigation, throughout cities and indoor spaces (Jeamwatthanachai et al., 2019).

Visual perception begins when light reaches the eyes. The retina's photoreceptors will transform it into visual inputs. Photoreceptor cones process colors, and rods control light intensity (Viosca, 2018). The visual information passes through the optic nerve – a

"cable" that connects the eyes to the brain. The left and the right nerves come across an "X" structure called the optic chiasm. From then, the visual signal goes on opposite hemispheres to be processed on the occipital lobe – the visual cortex, located at the back of the brain/head (Huff et al., 2023).

Although a part of the brain is exclusively dedicated to vision, it doesn't mean it is isolated from the other lobes. The visual cortex is interconnected by steams that enable associations between senses and memories. Depending on the type of visual signal received, these inputs "exit" the primary visual cortex via two steams, the ventral and the dorsal streams, corresponding to the "what" and "where," respectively (Viosca, 2018) The ventral stream – also known as "vision-for-perception" – is involved in image recognition, ultimately accessing the memory field, while the dorsal stream – the "vision-for-action" – is associated with motor actions – connecting to the brain's motor areas (Hebart & Hesselmann, 2012 p. 8107). The brain defines these actions based on the obtained image. If some structure of the visual system is injured, it will result in a lower visual acuity, depending on the damaged area.

Leber's Hereditary Optic Neuropathy

Leber's Hereditary Optic Neuropathy (LHON) is one of those disorders that provokes irreversible visual impairment. It's a rare genetic condition due to optic nerve degeneration, causing the loss of central vision (Figure *3*). The field of vision refers to the area in which objects are visible when looking in a single direction without moving the eyes. The visual field comprises the **central vision**, covering the inner 30 degrees and central fixation – described as "tunnel" vision – and **peripheral vision**, which extends 100 degrees laterally, 60 degrees medially, 60 degrees upward, and 75 degrees downward (Spector, 1990). The central visual field enables the cognitive ability to interpret and identify written information as well as observe and distinguish objects and individuals.

Both are crucial for performing everyday tasks.

The optic nerve comprises approximately 1 million retinal ganglion cell (RGC) layers. Its degeneration is provoked by a mutation in mitochondrial DNA (mtDNA) that enables the RGC to produce energy – resulting in apoptosis, a type of programmed cell death (Meira et al., 2014). The cell's "battery" is the mitochondria, which keeps them alive and healthy. In LHON, the mtDNA mutation enables the electron transportation chain process, resulting in a lower production of adenosine triphosphate (ATP), an essential molecule that conservates and distributes the obtained energy (Dunn & Grider, 2023; Kirkman et al., 2009), and also an increase of reactive oxygen species (Meira et al., 2014; Yu-Wai-Man et al., 2020), resulting in a thinner and pale optic nerve, incapable of working correctly. Ninety percent of LHON cases came from one of these three mutations: m.G11778>A in the MT-ND4 gene – which is the most common – m.3460>A in the MT-ND1 gene and m.T14484>C in the MT-ND6 gene (Meira et al., 2014; Sundaramurthy et al., 2021; Yu-Wai-Man et al., 2020).

Figure 3 —Two 2 images of a child wearing a white dress in a garden and holding a daisy. Left: Vision from sighted people; Right: Vision of LHON patients (LHON Eye Society, 2023)

Not every mtDNA mutation carrier develops LHON. Investigation demonstrates that some environmental issues – e.g., smoking and antiviral medicines – can "awaken" the disease. Still, the exact causes remain uncertain for a carrier developing LHON rather than other carriers.

An Optical Coherence Tomography (OCT) confirms the LHON diagnosis (Figure 4). Ophthalmologists see a pale and thin optic nerve. The remaining inactive RGC cannot be measured.

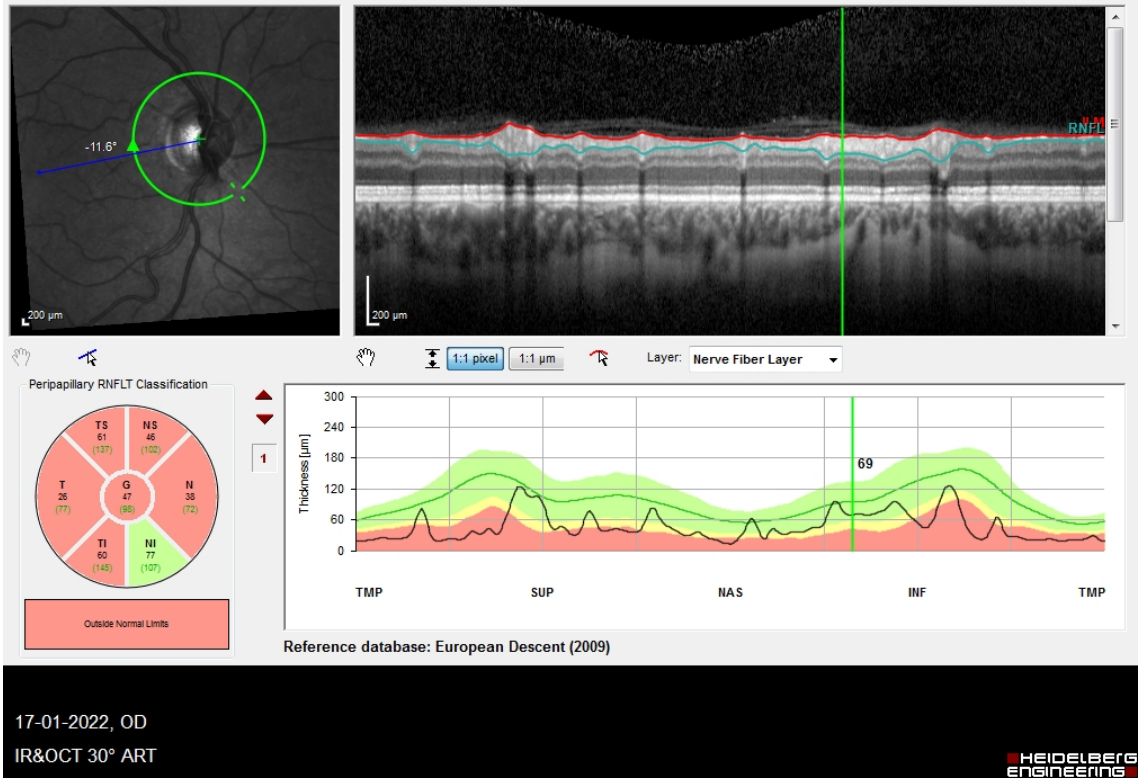

Figure 4 —This is the Optical Coherence Tomography (OCT) of my left eye. This image displays colored charts measuring optic nerve thickness and a black-and-white image of the inside of the eye.

LHON prevalence in Europe is 1:45000 people (Mascialino et al., 2012) – there are no data within Portugal – it is "the most common primary mitochondrial DNA" disorder (Sundaramurthy et al., 2021), mainly affecting young male adults (Meira et al., 2014; Sundaramurthy et al., 2021). The only treatment approved by the European Medicines Agency is with idebenone, a benzoquinone that tries to reestablish retina ganglion cells' electron transportation chain. Some patients with the most common mutations can experience a slight recovery – but not a full recovery – within two years into treatment with idebenone (van Everdingen et al., 2022).

Visual Acuity

Visual acuity measures a person's level of visual sight. According to the Ranges of Visual Loss of International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM), a nominal normal visual acuity is 20/20 (Colenbrander, 2009). The first number (20) refers to the testing distance (usually 20 feet in the US, 6 meters in Europe), and the second number indicates the distance at which a person with normal vision can see the same detail.

This measurement can be divided as (Colenbrander, 2009, p. 15):

Range Normal Vision: From 20/12.5 to 20/25. 20/20 vision is the nominal.
Near-Normal Vision: 20/32 to 20/63.
Moderate Low Vision: 20/70 to 20/160.
Severe Low Vision: 20/200 to 20/400.
Profound Low Vision: 20/500 to 20/1,000.
Near- Blindness: 20/1,250 to 20/2000.
Total Blindness: No light perception.

For low-vision patients, semiquantitative scales are required—counting fingers, hand motion, and light perception (Schulze-Bonsel et al., 2006). Depending on the country, there are several visual acuity charts. Patients with LHON experience a degradation of their visual acuity in the first year of developing the disease (Meira et al., 2014; Sundaramurthy et al., 2021). After that period, vision stabilizes (Figure *5*). In my case, my visual acuity is classified as 0.5/20 or 20/400 in the ICD-9-CM scale.

Color Perception

LHON patients experience a sensitivity deficit that impairs their ability to distinguish colors (Rudolph et al., 2013). While the photoreceptors responsible for capturing colors—cones—remain unaffected, the non-functioning ganglion cells make it impossible for them to differentiate between most of the chromatic spectrum, such as green, red, orange, and pink.

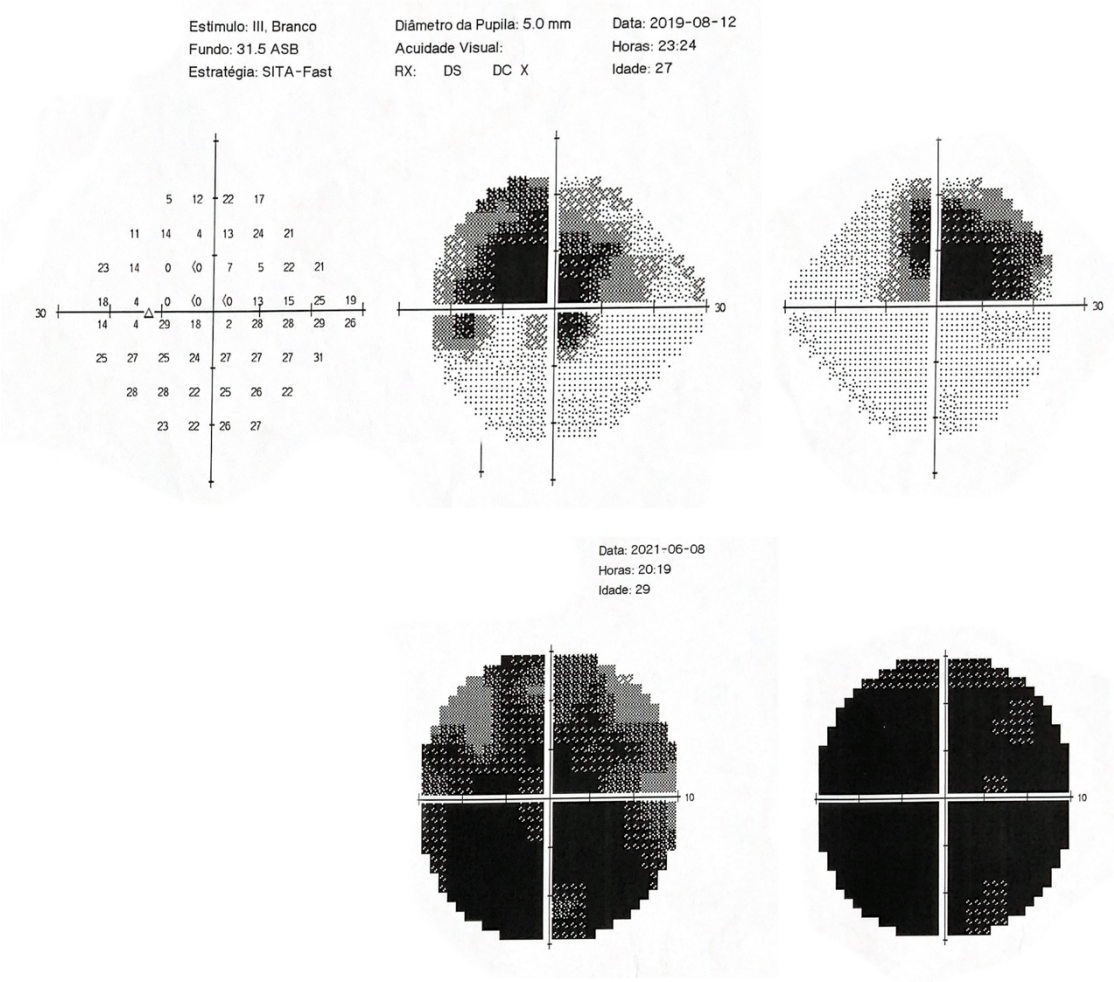

Figure 5—This is my visual field exam. The first image was taken on 12th August 2019, when I was first diagnosed. The image below was taken almost two years later. The amount of vision lost is visible through the dark shadows in the visual field of both eyes.

LHON Plus

Researchers who have studied LHON disease have found that it is a "multi-organ" disorder (Finsterer & Zarrouk-Mahjoub, 2016). Some patients – very few – have developed extraocular symptoms, such as cardiac arrhythmias and multiple sclerosis. In cases where those additional manifestations occur, the condition is referred to as LHON-Plus. A study by J. Finsterer and S. Zarrouk-Manjoub (2016) highlights the importance of close monitoring of LHON patients to detect the onset of organ involvement beyond the eyes.

In the first year, when I was diagnosed with LHON, I avoided seeking more information about it – even if understanding my disease wouldn't change my condition. When I started my master's degree, my curiosity grew. Although initially, I hadn't anticipated delving into LHON, I was disheartened by the lack of consideration for the patient aspect in many scientific studies. It seems that the disease is treated separately from the human suffering from it, neglecting the human dimension of their feelings, neglecting the patient and their humanity.
Wouldn’t it make sense to understand the patient experience?

Patient Innovation

"Patients are increasingly able to conceive and develop sophisticated medical devices and services to meet their own needs."

(DeMonaco et al., 2019 p.81)

The User Innovator Concept: Patient Innovation Roots

In 1976, Eric Von Hippel conceptualized the term "User Innovator". It consists of giving users the power to create solutions for their own needs – "user innovator begins when one or more users of some good recognize a new set of design possibilities – a so-called "design space" – and begin to explore it" (Baldwin et al., 2006).

Von Hippel, a professor of technological innovation at the MIT Sloan School of Management, developed his research around the user innovator concept, revealing a significant paradigm shift in the innovation field. It emphasizes the potential for users to enhance and create products and services based on their insights and experiences, leading to an improved quality of life for both themselves and others (Von Hippel, 1976). In contrast to the methods utilized by manufacturers and companies (DeMonaco et al., 2019), consumers contribute with creative ideas that are not constrained by traditional thinking processes. This free innovation, presented by Von Hippel, represents a mutually beneficial scenario wherein users self-award themselves as they freely disseminate their solutions to fulfill their needs. Simultaneously, companies benefit from this valuable free input, utilizing it to develop and improve their products and services.

Considering the concept presented above, Patients are the user innovators in the healthcare segment. Due to their health conditions, patients and their caregivers face specific medical challenges, ranging from safety concerns to governmental approval. As

a result, they can develop solutions to address their personal needs and enhance healthcare systems for everyone.

Patient Innovation Platform

"Even in cases where there are significant safety risks, we think it would be a mistake for governments to limit patient innovation."

(DeMonaco et al., 2019, p.86)

On February 7, 2024, Pedro Oliveira introduced the user innovator concept into healthcare, where "Patient Innovation" (PI) was born. Patient innovation is a Portuguese initiative that fosters and amplifies solutions developed by patients affected by disease-related conditions, acknowledging their vital role in the healthcare sector. Patients and caregivers are empowered to innovate and generate valuable new ideas that increase the quality of life for them and other patients with the same diseases (Cennamo et al., 2022; DeMonaco et al., 2019).

Patients with rare and chronic diseases struggle to find tools to manage their needs (Oliveira et al., 2015). Their creative solutions are often constricted to their circle of family and friends. Pedro Oliveira and Helena Canhão, co-founders of Patient Innovation, saw an opportunity to help those patients share their unique ideas.

This project started as an academic repository of healthcare solutions created by patients. Since then, it has quickly evolved into a non-profit platform that invites people worldwide to publish, share, and discuss their ideas.

Currently, the PI platform evolved a community of 350 000 members, with more than 1800 healthcare solutions—41% from patients, 39% from caregivers, and 11% from collaborators—from 80 countries (*About Patient Innovation | Patient Innovation*, 2024).

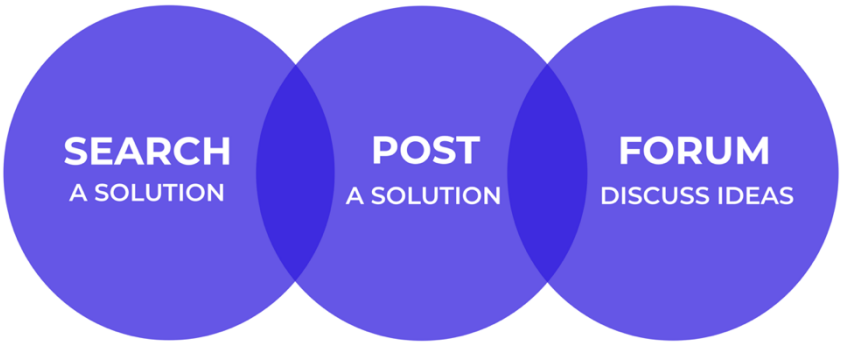

Figure 6 - Three interlocked blue circles representing the three main statements of the Patient Innovation platform: "Search a solution," "Post a solution," and "Forum, discuss ideas."

Everyone interested in healthcare innovation can join the PI community by creating an account on the PI platform. Patents, caregivers, and collaborators can submit their solutions on the platform. The PI medical team will then evaluate their submissions for approval – Figure *6*.

Patient Innovation Bootcamp

Annually, PI promotes the "Patient Innovation Bootcamp"[1] – a worldwide acceleration program aimed at “supporting patients, informal caregivers, and collaborators to implement and scale up the innovative solutions they developed to help them cope with a need imposed by their health condition” (*Bootcamp | Patient Innovation*, 2024), by

[1]More information available here: https://patient-innovation.com/bootcamp

inviting patients' teams to submit their ideas. Under the guidance of the PI team and partners, participants will receive valuable tools to improve their entrepreneurship skills and business knowledge[2].

The Visual Impaired Patient Innovators

Regarding visually impaired patients, the range of innovation possibilities is enormous—patients' and caregivers' solutions could be anything from apps to wearable devices, products, and services. In this health condition, Kaitlyn Kellermeyer and Stacy Cervenka are good examples of patient innovators on the Patient Innovation Platform. Being blind didn't affect their determination to create projects that help themselves and other patients with similar conditions.

Kaitlyn Kellermeyer, wishing to regain more movement independence, invented a 3D map of her university campus with the help of Tyler Wooten, an engineering student. This 3D map provided Kaitlyn with a way to feel a map and guide herself (*Blind Girl Creates Campus Map for the Visually Impaired | Patient Innovation*, n.d.) – Figure *7.*

Stacy Cervenka created the " Blind Travelers' Network"[3] to allow blind individuals to share information about places they have visited, ask questions about places they would like to visit, advise others on orientation and mobility while traveling, and much more (*Blind Woman Creates an Online Community for Personal Tips Sharing by and for Blind Travelers | Patient Innovation*, 2022) – Figure *8*.

[2] Visit https://patient-innovation.com/bootcamp/past-editions to see examples of projects at the PI boot camp.

[3] Promotional video about the “Blind Traveler’s Network” - https://www.youtube.com/watch?v=bgDoMZEVwcI .

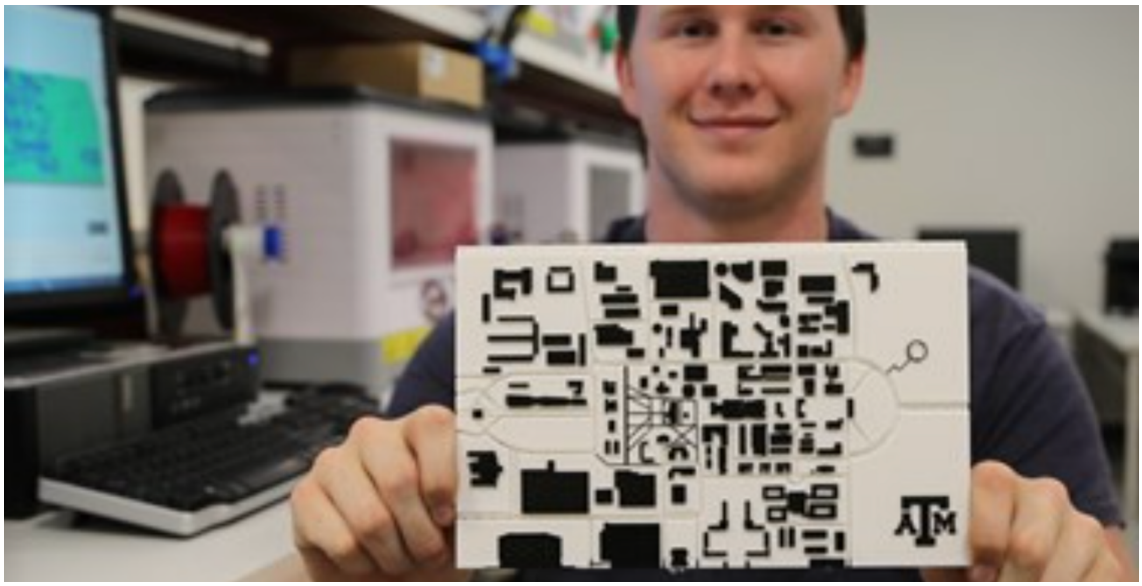

Figure 7 — Photograph of Tyler holding in his hands the 3D Campus Map prototype. *(*Blind Girl Creates Campus Map for the Visually Impaired | Patient Innovation*, n.d.)*

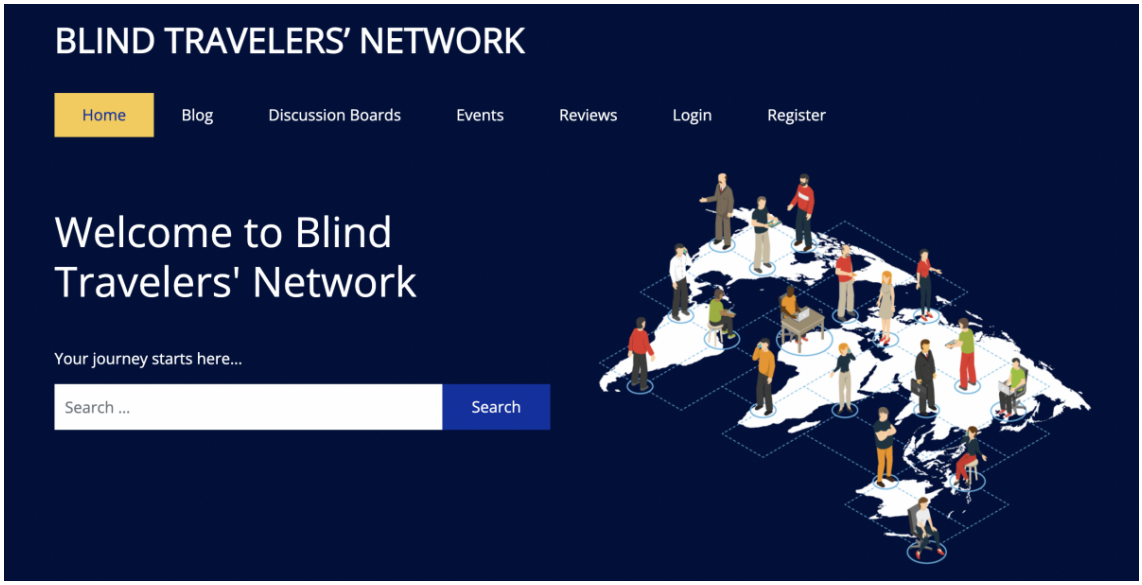

Figure 8 — Image of the home page of "The Blind Traveler's Network", created by Stacy Cervenka *(*Blind Woman Creates an Online Community for Personal Tips Sharing by and for Blind Travelers | Patient Innovation*, 2022)*

Since 2015, at least 113 innovative solutions,[4] for the blind and low-vision, have been added to the PI platform, helping to raise awareness and improve the quality of life and care for these people worldwide.

Patient Innovation in this Research

Patient Innovation provides a strong conceptual foundation for this research, not only by highlighting how my own experience as a patient can contribute to rethinking strategies for improving wayfinding in ophthalmological services for visually impaired patients but also by challenging conventional design practices and the typical role and representation of the designer, particularly in health and well-being projects. Patient Innovation encourages us, as designers and researchers, to work not just for a community but with the community, subverting the hierarchies and structures often embedded in design practices. In this research, I embrace the concept of Patient Innovation as a movement aimed at raising awareness of social change, not only through specific products and solutions but also by addressing the lack of literature, projects, and representation concerning disabled designers. As both a designer and a patient, I aim to contribute to the visually impaired community while also, as a researcher, expanding design practices and enhancing visibility for disabled designers.

[4] List of innovative solutions in the Patient Innovation platform: https://patient-innovation.com/condition/blindness?language=en .

CHAPTER 2. AUTOETHNOGRAPHY AND DESIGN – A New Symbiosis

Autoethnography

Autoethnography is a qualitative method that empowers researchers to use their personal narratives as valuable data sources. This approach integrates aspects of autobiography and ethnography to analyze the researcher's individual encounters within a specific cultural context, aiming to explore broader cultural, social, and political implications (Brown & Leigh, 2020; Fuller, 2024; Griffiths, 2020; Kaethler & Schouwenberg, 2021; Rummery, 2020).

Frequently, Autoethnography is criticized as considered "narcissistic" and "less scientific" due to its focus on the self. However, this argument is unfounded; the aim of autoethnography is not self-revelatory but rather to provide a profound comprehension of the cultural environment and to contribute to academic knowledge and social change: "the emphasis on the self is not a narcissistic or self-indulgent fixation: it is a lens through which the social is explored in order to provide better understanding of cultural phenomena" (Brown & Leigh, 2020 p.165).

Considered a flexible method, Autoethnography has been used in multiple fields, such as anthropology, sociology, psychology, and disability studies. It offers disabled researchers the opportunity to have a legitimate voice, addressing the needs of a frequently disregarded segment of society. As stated by Griffiths (2020, p. 125), "I realized that as an academic with a non-visible disability, doing disability research, a more open discussion about disability as experienced by academics was required."

In the academic world, limited research has been conducted by individuals with disabilities. There are even fewer investigations that include the impact of their disabilities on their research. A few disabled researchers, such as Omar Karagoz (2023),

Annmaree Watharow (2021), Nicole Brown (2020), Kirstein Rummery (2020), and Elisabeth Griffiths (2020), have embraced autoethnography as a methodology. They have used personal storytelling to enhance their respective scientific and academic fields with valuable knowledge and innovative perspectives.

An example of this is Orhan Karagoz. As a blind anthropologist, he chose to do his ethnographic research based on "my senses of hearing and listening, using auditory means to make sense of people and our environment " (Karagoz, 2023,p. 36). Karagoz saw an opportunity to use his blindness meaningfully by replacing the sense of vision with hearing. This allowed him to develop his fieldwork differently from other anthropologists, who depend mostly on vision to conduct their research: "I rely on the tones in people's voices and how they speak in order to judge and interpret character, which many people fail to realize" (Karagoz, 2023 p.37).
As a blind researcher, Karagoz demonstrated alternative methods for collecting valuable data, opening new avenues for practicing and approaching ethnography. Additionally, Karagoz shares the same disease as I do.

Annmaree Watharow, who herself experiences deafblindness— a dual sensory impairment (DBDSI), has made significant contributions to research focusing on individuals with the same health condition. She spearheaded an innovative study that explores the experiences of patients with DBDSI within the context of Australian hospital care. This research, underpinned by patient narratives, seeks to identify and mitigate the adverse experiences encountered by this population. Ultimately, Watharow says, “If I can provide accessibility, so too can hospitals and other social institutions and groups.” (Watharow, 2021, p. 5).

In 2020, Nicole Brown, Kirstein Rummery, and Elisabeth Griffiths contributed to the book titled “Ableism in Academia”, which delves into their personal experiences as disabled individuals and examines how academia is deeply entrenched in ableist practices. The book highlights the pervasive nature of ableism in academic

environments and emphasizes the vital importance of recognizing and amplifying disabled voices.

These academics and more contributors share narratives that illustrate the multifaceted barriers disabled academics face, such as inaccessible physical spaces, exclusionary policies, and attitudes that marginalize disabled scholars.

As Kirstein Rummery states, due to the historical emphasis within disability studies on shifting focus from the body to the social construction of disability, there has been a limited tradition of utilizing autoethnography as an embodied research approach until more recently (Rummery, 2020).

Their work challenges traditional research methods, demonstrating the potential of autoethnography for innovation. Their pioneering research has paved the way for others to adopt this method.

Furthermore, autoethnography serves a critical function in activism and social justice—where Design Justice acts—by employing storytelling to raise empathy, community engagement, and inspiration (Parnther, 2022). In light of this, how can autoethnography be used in design?

The Autoethnography Turn in Design

"A strong positioning and awareness of what Design should be: a genuine engagement by people who truly care for what they claim to care for. Regardless of how we package it, design is always about some aspect of the self, so why not pursue this aspect, foster it, and let the self-speak through Design."

(Kaethler & Schouwenberg, 2021, p.45)

Design has evolved significantly in recent decades (Fuller, 2024), expanding into various fields: from human-centered to people-centered, universal to inclusive, critical to speculative (Mitrović et al., 2021), and more. These practices represent Design efforts to progress with cultural changes, and all share a common characteristic: the design process initiates by looking outward (Fuller, 2024), within a specific context for a hypothetic group target. This means that designers only think and create to solve external issues, enabling them to incorporate their own insights and experiences into the design process.

The concept of **Autoethnographic Design**, presented in the book The Autoethnography Turn in Design (2021) by Louise Schouwenberg and Michael Kaethler, introduces a new framework whereby designers undertake design projects and research from a personal and subjective standpoint, integrating their experiences and positioning themselves "**in the heart of the research**" (Kaethler & Schouwenberg, 2021,p.13).

The Autoethnographic Design emerged from some traditional Design fields—e.g., speculative and relational Design—and ethnography. However, it offers a Design approach unhindered by commercial constraints or well-intentioned altruism (Kaethler & Schouwenberg, 2021). It embraces the "self" as the foundational basis for comprehending the world more effectively. This approach "reveals a sincerity and genuine commitment in the process of design that is too often missing" (Kaethler & Schouwenberg, 2021, p.21).

Like any Design practice, Autoethnographic Design presents its own set of limitations and concerns. According to Kaethler and Schouwenberg (2021), this design approach has roots in art. Within the projects featured in the book, it becomes challenging to clearly distinguish what could also be interpreted as an artistic expression.

In summary, introducing autoethnography to the Design field illustrates how designers can creatively and meaningfully apply rigorous research from a new perspective. However, how can we take that perspective even further socially?

Design Justice

> "Design Justice *goes beyond recent calls for design for good, user-centered design, and employment diversity in the technology and design professions; it connects design to larger struggles for collective liberation and ecological survival."*
>
> (Braman, 2020)

Design Justice is a disruptive approach that reevaluates the role of Design in society. It prioritizes marginalized communities and ensures that their voices and experiences are at the core of the Design process rather than perpetuating inequalities and exclusion. Design Justice questions conventional Design practices (Costanza-Chock, 2020; Hedditch & Vyas, 2023).

This concept was created by a multidisciplinary group of designers, developers, technologists, journalists, community organizers, activists, researchers, and other professionals (Costanza-Chock, 2020). Their deep engagement in social movements and community-based organizations in the United States and worldwide underscores their wealth of practical experience in this field. The Allied Media Conference provided space for those collaborators to begin shaping Design Justice. The Future Design Lab, developed in 2014, functioned as a "practical space" where alternative futures were envisioned and brought to life. Using speculative Design (Mitrović et al., 2021), technology, mapping, and data effectively showcased the necessity and achievability of these alternative futures (Our History — Design Justice Network, n.d.).

Design Justice is rooted in social justice and various social movements, including the disability rights movement. These movements have been instrumental in raising awareness about systemic injustices and advocating for the rights of marginalized groups. They have laid the groundwork for questioning who benefits from Design and who is (not intentionally) excluded.

Design Justice Network

Design Justice Network[5] is a growing platform dedicated to promoting inclusion and equitability through a large community of people devoted to embodying and implementing the Design Justice Principles (*Read the Principles — Design Justice Network*, 2018). It emerged from a workshop titled "Generating Shared Principles for Design Justice," which brought together some of those community members at the Allied Media Conference (AMC) in Detroit, organized by Allied Media Projects. The session aimed to go beyond "social impact design" and "design for good" urging designers to consider that good intention may not be adequate to guarantee that design processes and practices effectively promote inclusion (Costanza-Chock, 2020; Our History — Design Justice Network, n.d.).

During this workshop, the "**Design Justice Principles**" were developed, which comprise a set of guidelines for designers to apply Design Justice in their creative process. The Design Justice Network coordinators revised the original principles over the subsequent years, with the most recent version dated 2018.

Sasha Costanza-Chock (they/them), an Associate Professor of Civic Media at MIT and creator of the MIT Codesign Studio helped spread Design Justice with their book "Design Justice Community-Led Practices to Build the Worlds We Need" (2020), which has

[5] https://designjustice.org for more information.

become an indispensable tool for those interested in understanding and applying Design Justice.

Design Justice Principles

Design Justice has ten principles (2018):

1. *"We use design to sustain, heal, and empower our communities, as well as to seek liberation from exploitative and oppressive systems."*
2. *"We center the voices of those who are directly impacted by the outcomes of the design process."*
3. *"We prioritize design's impact on the community over the intentions of the designer."*
4. *"We view change as emergent from an accountable, accessible, and collaborative process, rather than as a point at the end of a process."*
5. *"We see the role of the designer as a facilitator rather than an expert."*
6. *"We believe that everyone is an expert based on their own lived experience and that we all have unique and brilliant contributions to bring to a design process."*
7. *"We share design knowledge and tools with our communities."*
8. *"We work towards sustainable, community-- led and controlled outcomes."*
9. *"We work towards non-- exploitative solutions that reconnect us to the earth and to each other. "*
10. *"Before seeking new design solutions, we look for what is already working at the community level. We honor and uplift traditional, Indigenous, and local knowledge and practices."* (*Read the Principles — Design Justice Network*, 2018)

Designers have increasingly undertaken critical examinations of the impact of their work on society, exploring how Design can serve as a catalyst for social change and inclusivity.

Universal and Inclusive Design

When designing for people with disabilities, Universal and Inclusive Design are the most frequently employed design approaches.
Universal Design can be defined as one "size" that fits all. This means that products and services must be usable for all users, regardless of age, culture, gender, or disability. (Auernhammer et al., 2022; Ku & Lupton, 2022; O'neill, 2021)

The Principles of Universal Design were established in 1997 by a team composed of architects, engineers, and designers led by Ronald Mace at North Carolina State University. These principles were developed to guide the creation of more inclusive environments and products. The Center for Universal Design at NCSU[6] suggests that these principles can be utilized to evaluate existing designs, guide the design process, and educate designers and consumers about the characteristics of more user-friendly approaches (The 7 Principles - Centre for Excellence in Universal Design, n.d.).

The 7 Principles of Universal Design:

1. *Equitable*
2. *Flexibility*
3. *Simple and Intuitive*
4. *Perceptible Information*
5. *Tolerance for Error*
6. *Low Physical Effort*
7. *Size and Space for Approach and Use*

The attainment of universal design presents a challenge due to the diverse range of users with varying characteristics. Consequently, developing a single product or service that caters to the needs of all consumers is an exceedingly complex task.

[6] Visit https://universaldesign.ie/about-universal-design/the-7-principles

Following the principles of Design for People with Disabilities and Design for All, which emphasize the importance of accommodating all individuals, the concept of Inclusive Design has been developed — "the core value proposition of Inclusive Design is optimizing the design and development of solutions for individuals with specific needs" (Auernhammer et al., 2022, p.233).

As Ku and Lupton (2020) said, Inclusive design is to "look through the eyes of people living with disabilities or chronic conditions that limit mobility. Observe or listen to the challenges that they face on a daily basis" (p. 239).

The key difference between Universal and Inclusive Design is that Inclusive focuses on a specific target group, whereas Universal encompasses a broader scope.
There are numerous examples of inclusive designs in the disability context. The range of assistive devices and technology – from apps to analogical products – for visually impaired individuals is expanding. An example is **tactile surface indicators**, which will be explained in chapter 3.

Disability in Academia

While working on the theoretical part of this dissertation, I found it quite challenging to locate design literature created by disabled researchers, especially those with visual impairments. This is not just a design issue; there is a significant lack of literature produced by disabled researchers, as well as data about their numbers.

Since I couldn't find any data in Portugal, I will use the United States of America as an example to demonstrate the lack of diversity and representation in academia. Statistics highlight that the number is not only low but has also been declining, according to the National Institutes of Health (NIH). The data reveals that the number of disabled principal investigators in academia has dropped from 2% to 1.3% between 2008 and 2022 (NIH, 2022).

Additionally, less than 4 percent of academics working in higher education disclose a disability, neurodivergence, or chronic illness, compared to 16 percent of the working-age public.

The academic environment is increasingly focused on equity, diversity, and inclusion, but disabled researchers often face challenges entering the profession and advancing in their careers (Anbuhl et al., 2023). According to Brown & Leigh (2020), if thriving in academia is difficult for an able-bodied and neurotypical academic, it can be even more challenging for someone who is chronically ill, disabled, or neurodiverse. Admitting to a chronic illness or disability may lead to prejudice, ignorance, and discrimination due to both external and internalized ableism (Brown & Leigh, 2020).

Despite efforts to balance the representation of able-bodied and disabled researchers in this dissertation, it is nearly impossible to achieve. Recognizing the lack of representation in academia, particularly in Portugal and in the design field, this dissertation aims to contribute to filling that gap.

CHAPTER 3. WAYFINDING – Challenges in a Visual World

"Being unable to obtain information about where they are or where to go in public buildings, such as colleges/universities, malls, hospitals, public transportation, and airports, causes problems in their wayfinding process."

(Jeamwatthanachai et al., 2019, p.141)

What is Wayfinding?

Wayfinding "refers to information systems that guide people through a physical environment and enhance their understanding and experience of the space" (*What Is Wayfinding? | SEGD*, n.d.). A wayfinding system provides users with guidelines and orientation elements to navigate the space – knowing where they are and getting from one place to another. It's a helpful tool, even more so in larger and busier environments, such as hospitals, universities, malls, supermarkets, and airports (Gibson, 2009).

Wayfinding in Healthcare Facilities

"Many public facility layouts have been developed with little consideration of the visually impaired, producing difficult and unpleasant wayfinding experiences."

(Rousek & Hallbeck, 2011, p.447)

Hospitals can be complex structures with large buildings and many pathways, often noisy and crowded, creating high-stress environments for healthcare professionals, visitors, and patients (Cooper, 2010; Jeamwatthanachai et al., 2019).

Rousek and Hallbeck (2011) conducted the first study on wayfinding design elements within healthcare settings to identify environmental design deficits. Fifty sighted individuals participated in the study, wearing goggles glasses, simulating the five most common causes of visual impairment. The researchers analyzed the time taken and recorded specific wayfinding tasks. The findings revealed numerous wayfinding design issues, spanning from flooring and lighting to signage. This study highlighted the significant impact of design elements on the wayfinding challenges faced by visually impaired patients, emphasizing the urgent need for better tools.

I recognize the significance of considering the needs of visually impaired patients and individuals with disabilities when conducting research to enhance the wayfinding experience in healthcare facilities. While the contribution provided valuable insights, it's important to acknowledge that involving blind and low-vision patients directly in the study would offer authentic and irreplaceable perspectives. Utilizing goggles glasses disease simulation may not accurately replicate the experiences of someone with glaucoma or dietetic retinopathy. It would be beneficial to consider the inputs of individuals with disabilities to ensure their unique and valuable experiences are considered – arguments corroborated by both Patient Innovation and Design Justice. People with disabilities develop strategies to accommodate their needs, which is an essential factor to analyze and understand in order to provide better assistance.

Navigating unfamiliar indoor buildings – such as hospitals – is particularly difficult for visually impaired people. In 2019, Jeamwatthanachai et al. conducted a study on the wayfinding behavior of visually impaired individuals in unfamiliar indoor environments in Southampton, United Kingdom. The authors segmented the research into five categories to gain deeper insights into the wayfinding obstacles encountered by the visually impaired: utilization of assistance, distance estimation, wayfinding and orientation, unfamiliar environments, obstacles, and hazards.

The findings revealed that visually disabled individuals encounter three primary challenges when navigating unfamiliar indoor spaces: determining their current

location, **finding the route to a specific destination, and establishing and maintaining orientation** (Jeamwatthanachai et al., 2019) – Figure 9.

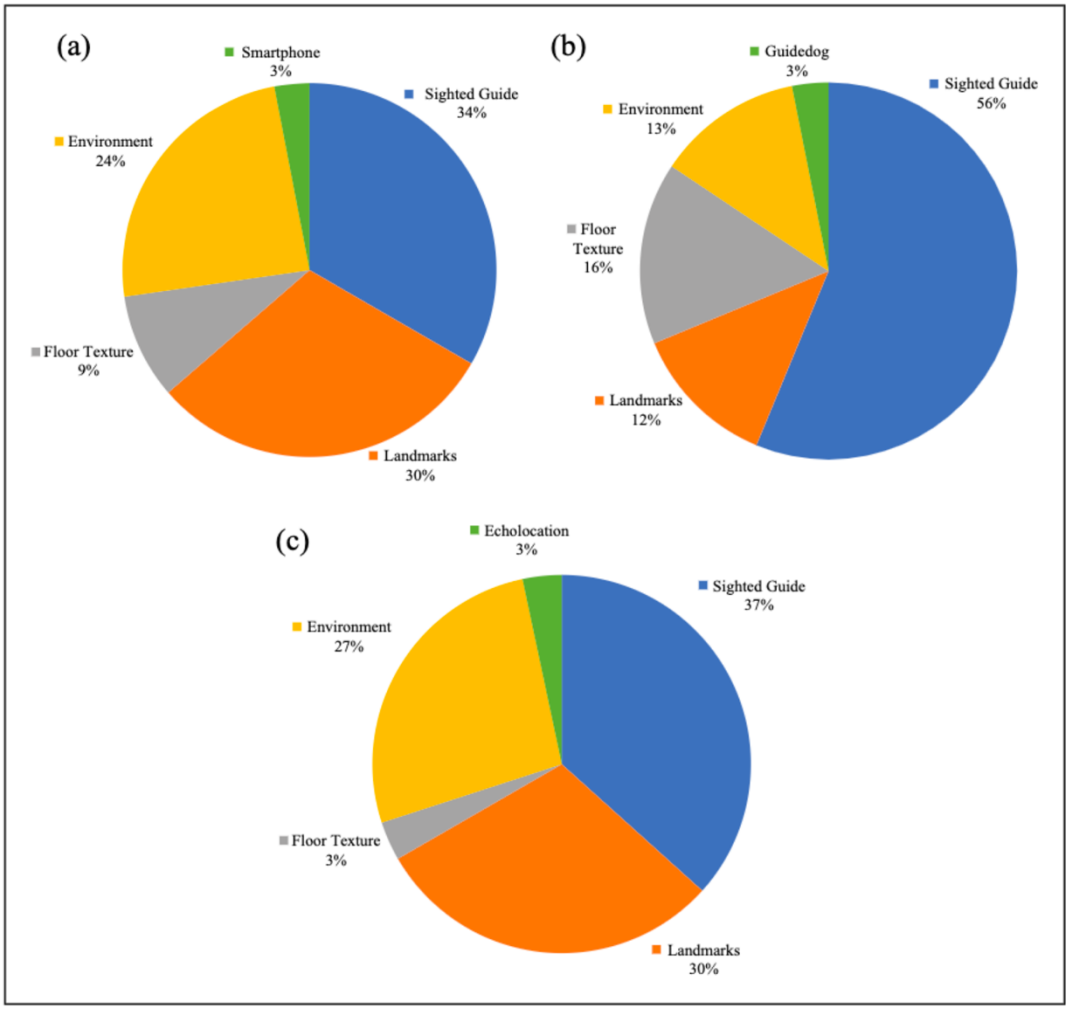

Figure 9 – Three circle charts representing the resources used by visually disabled people in (A) Find current location, (b) find way to destination, and (c) find orientation. (Jeamwatthanachai et al., 2019)

Many buildings, such as university campuses, hospitals, shopping malls, museums, and airports, encounter wayfinding challenges for individuals with visual impairments (Jeamwatthanachai et al., 2019). According to the survey developed by Jeamwatthanachai et al, hospitals and airports are particularly problematic due to their large size, complex layouts, busy open areas, and high foot. Various obstacles like furniture and noise further exacerbate the difficulty of navigation in these environments. This underscores the urgent need for improved wayfinding solutions.

When individuals with visual impairments navigate inside a building on their own, they apply a combination of techniques to be resourceful (Jeamwatthanachai et al., 2019). Initially, they may require assistance from a sighted guide – as illustrated in Figure 9 – to mentally map the indoor space. Subsequently, they can rely on landmarks, light, sound, and odors to locate their destination during the following visits.
Seventy-three percent of participants "agreed walking inside a hospital is very difficult due to population size of patients, nurses, doctors, and visitors, and many obstacles, for example, hospital beds and furniture" (Jeamwatthanachai et al., 2019, p. 146).

Most of the developed studies in the field of visually impaired accessibility inside healthcare facilities – which are very few – don't end up with a possible solution. Instead, they are focused on gathering patient feedback and information about inaccessibility. The only research found that applied a design approach with a tested solution is the Portuguese project "Percept Walk" (2018) by Miguel Aboim Borges. Borges conducted an analogical design project with older people – above 65 – with low vision disorders. The study occurred inside a Portuguese ophthalmological hospital, where Borges built a wayfinding system composed of "boards with written information displayed on walls and haptic textures applied on pavements" (Borges, 2020). The design process helped to understand this group of patients' color, haptic, and visual perception. The results showed an increase in the patient's self-esteem and self-confidence (Borges, 2018; Borges, 2020).

Healthcare facilities are starting to understand that efficient wayfinding improves patient satisfaction (Moa Architecture, 2019; Rousek & Hallbeck, 2011) and ultimately provides a better healthcare service.

Another key factor regarding disabled people is related to healthcare professionals' approaches—"doctors need to consider the emotional journey that visually impaired people take when leaving home to arrive at the healthcare facility" (Cupples et al., 2012,

p. 4). As Author Jamil Zaki says in his book "The War for Kindness: Building Empathy in a Fractured World": "Empathy is something like a muscle: left unused, it atrophies, put to work, it grows" (Zaki, 2019).Empathy plays a critical role in the healthcare setting due to its involvement in addressing sensitive topics – e.g., delivering a diagnosis or prescribing a treatment. An essential aspect of healthcare provision involves recognizing and comprehending the distinctive requirements and obstacles visually impaired patients face.

Authors Cupples et al. (2012) from Queen's University Belfast developed a study enhancing the importance of healthcare professionals in understanding the needs of visually disabled patients to improve healthcare access. The lack of accessibility is reflected in troubled communication between healthcare staff and visually impaired patients, the difficulties they face in accessing written information – about appointments, diagnoses, and treatment – and the navigation issues within the healthcare environment.

They collected several valuable tips for healthcare professionals to apply to blind and low-vision patients, such as keeping in mind that not all patients with vision impairments use dark glasses or have a guide dog or a cane, offering to read any written materials out loud, and specifying the locations where signatures are needed; remembering to be patient and understand that extra time might be necessary for consultations (Cupples et al., 2012).

By understanding their needs, healthcare workers will improve patients' satisfaction and overall healthcare services – “being uninformed compromises patient wellbeing and confers the risk of poorer health outcome” (Watharow, 2021 p.7).

In my personal experience, none of the hospitals or specific ophthalmological clinics, whether public or private, that I visited in Portugal, the UK, and Italy were efficiently accessible for visually disabled patients.

Some buildings are newer, some are larger than others, and some countries invest more in improving their public healthcare facilities. I have noticed that the main difference between the healthcare facilities I visited is their medical devices. In terms of accessibility, it becomes evident that they are all similar.

There are more laws and requirements regarding people in wheelchairs than for those who are deaf or blind, leading to a lack of accessibility tools for these citizens. This is specifically true in Portugal. People with disabilities deserve a better quality of life, which means accessible environments to navigate more autonomously.

Wayfinding Elements for the Visual Disability

"Space is not perceived equally by everyone."

(Borges, 2019 p.229)

Based on the literature review, I identified the key wayfinding elements used by blind and low-vision people to navigate autonomously:

- Signage
- Light and Color
- Floor
- Sound
- Landmarks

Studies reveal that visually disabled people use a mix of these wayfinding elements to navigate—this skill gives them confidence enough to go out by themselves (Jeamwatthanachai et al., 2019).

In this context, aids such as the white cane or the guide dog are excluded from consideration due to their classification as personal-use items. It's important to note

that some individuals with blindness or low vision either lack access to these tools or choose not to utilize them.

Signage

Signage is present everywhere. In the hospital context, signage has a significant responsibility in guiding all the different stakeholders—patients, visitors, and healthcare workers.

For visually impaired people, signage represents a major concern: “It is obvious that signs composed solely of visual text and symbols are useful only to those with sufficient vision to read them, and that those with visual disabilities are at a clear disadvantage” (Arditi, 2017, p.1).

Enacted in 1990, the Americans with Disabilities Act (ADA) introduced a set of guidelines aimed at providing accessibility for American citizens within public services and buildings. These legislative rules mandate architects, engineers, and designers to integrate ADA requirements throughout the design, construction, and renovation stages, ensuring that facilities are accessible to individuals with disabilities. The document entitled "Standards for Accessible Design," which was last revised in 2010, delineates rules concerning signage, as well as lighting and color schemes, to better accommodate individuals with visual impairments (2010 ADA Standards for Accessible Design | ADA.Gov, n.d.; Arditi, 2017; Rousek & Hallbeck, 2011).

According to international laws – including the ADA and the UK’s Disability Discrimination Act (DDA) – the most recommended features regarding visual impairment signage are:

- Non-serif and bold fonts;
- Large-size lettering;
- Color contrasts – e.g. black background with white or yellow lettering;

- Embossed signs;
- Braille.

The ADA Standards also contemplate braille information. While braille is recognized as a beneficial strategy, it is noteworthy that not all individuals with visual impairments know how to read it—especially low-vision people (Arditi, 2017).

Light and Color

Lightning is a major factor for blind and low-vision people. It is important to clarify and demystify that blind people don't see just black. Visual acuity and visual perception depend on the diagnosis, but despite that, most visually impaired individuals can identify the presence of light and darkness.

Light can be present artificially and naturally in hospital settings. It is crucial to "be aware that changing light levels can affect vision: bright sunlight may be a greater problem than dark corridors" (Cupples et al., 2012, p. 4). The presence of natural light can significantly influence the wayfinding abilities of visually impaired individuals, owing to variations in lighting conditions throughout the day.

In Design, it is acknowledged that black represents the absence of light, in opposite to white. As highlighted in the first chapter, certain disorders that lead to vision loss also impact color perception – as it happens with LHON. Therefore, it is imperative to select a color contrast scheme that comprises solid, contrasting colors when designing spaces or signs.

Floor

In compliance with the United States of America and United Kingdom legislation, flooring material is required to exhibit uniform coloration – avoiding overly light or dark shades – and must possess a matte finish.

Tactile walking surface indicators are very helpful for visually impaired individuals to gain information about their surroundings. They have been applied in several contexts, most commonly in outdoor environments.

In 2002, the UK Government developed "Inclusive Mobility: A Guide to Best Practice on Access to Pedestrian and Transport Infrastructure" a set of regulations based on the Disability Discrimination Act 1995. This guidance sought to make public spaces more accessible and navigable for disabled citizens. After its initial inception, the document received an update in 2021, where it was significantly expanded to encompass more rules that consider a broader range of accessible tools. This evolution in policy underscores the government's commitment to fostering inclusivity and equal access within public infrastructures, reflecting a broader societal shift towards recognizing and accommodating the diverse needs of all citizens. One of the accessible features of the Inclusive Mobility guidance is the tactile paving surfaces (Department for Transport UK, 2021).

Although to their utilization in pedestrian crossings and public transport stations, detectable flooring textures are also used in indoor environments, where two main types are deployed:

- **A warning indicator** is provided by the blister surface texture, which consists of a "dot" pattern representing the presence of potential hazards and decision-making points—Figure 10**.**
- **Guidance / Directional indicator** consisting of parallel round bars that guide blind and low-vision people through designated paths – Figure 11.

It is imperative to emphasize that those textures (the dots and the bars) should have a contrasting color scheme with the floor on which they are intended to be installed.

Furthermore, stair edges should also have anti-split bars in color constant.

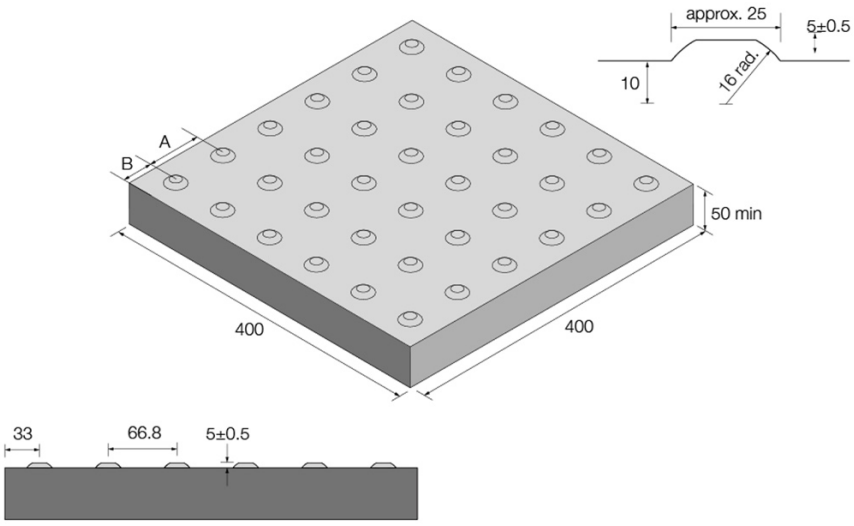

Figure 10 – Warning surface bilster texture surface technical drawing (Department for Transport UK, 2021)

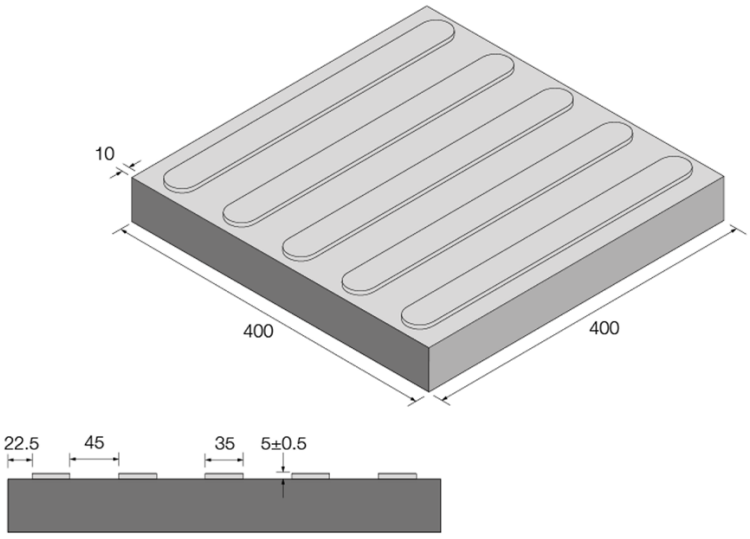

Figure 11 – Guidance surface texture technical drawing (Department for Transport UK, 2021)

With this haptic language, visually impaired individuals can better interpret and perceive their surroundings to navigate more safely. In complex environments such as hospitals, the use of tactile surfaces could be an important element to incorporate into a sensory-motor wayfinding system (Borges, 2019).

Sound

The chaos of sounds inside hospitals is overwhelming for visually impaired people. Noisy spaces prevent blind and low-vision individuals from obtaining information about their surroundings by hearing – a sense that those people usually develop more accurately (Karagoz, 2023).

The impact of noise in mixed function spaces in urban areas, such as hospitals, was studied by Zhang et al. (2022). They found that these spaces have noise levels that cause a negative psychological impact on people with visual impairments. This can lead to feelings of insecurity, discomfort, and confusion. Visually impaired individuals often feel overwhelmed and helpless in these busy environments, and they often seek quieter and simpler urban spaces. Such environments would enable them to make more accurate judgments about their surroundings, fostering a better sense of safety and understanding (Zhang et al., 2022, p. 8).

Described as busy, complex, and noisy, most participants in Jeamwatthanachai et al. (2019) study found it hard to concentrate due to the noise and the many obstacles around them. This caused them to lose their way and orientation as they couldn't rely on landmarks or environmental cues (p. 146). On the other hand, individuals with visual impairments have noted the challenges and mental effort required in navigating hospitals by counting steps, a wayfinding system used by visually impaired people while in unfamiliar spaces (Jeamwatthanachai et al., 2019, p. 144).

Landmarks

Landmarks are reference points that could be any object – architectural elements (e.g. doors and walls) or furniture. It's a helpful tool for low-vision people as their residual visual capabilities enable them to recognize big items: "even those with significantly reduced visual acuity have little trouble locating large objects and architectural features" (Arditi, 2017, p. 1). Landmarks are one of the most used elements (Figure 9) that can assist Individuals with low-vision in getting basic information about their surroundings, thus enhancing their ability to orient themselves more autonomously (Jeamwatthanachai et al., 2019; Rousek & Hallbeck, 2011).

Wayfinding Assistive Devices and Technology

In recent years, the rapid progress in technology miniaturization, coupled with advancements in Artificial Intelligence (AI) and visual recognition technologies, has led to the emergence of new assistive devices for wayfinding. These devices, ranging from smartphone apps to robotics, leverage AI to aid visually impaired individuals in navigating both outdoor and indoor environments. As highlighted by Bhagat et al. (2023), AI will play a pivotal role in the future of assistive technology for blind and low-vision individuals.

AI and Technologies for the Visually Impaired

Some of these innovations, which contribute to a more accessible world, are already in use. One example is "Be My AI[7]", an extension of the "Be My Eyes" app, which connects visually impaired users with volunteers via voice and video calls to help with navigation, reading, and object description. The "Be My Eyes" app was officially launched in 2015

[7] https://www.bemyeyes.com/, a video example of "Be My Ai" - Be My Eyes Virtual Volunteer

by its founder, Hans Wiberg, who himself experiences visual impairment (*The Story about Be My Eyes*, 2024).

The AI-powered "Be My AI" uses GPT-4's capabilities for multimodal understanding and object recognition capabilities, allowing users to receive 24/7 assistance without relying on volunteers.

These AI recognition capabilities also help address the “last-few-meters” problem — for example, navigating inside a hospital from the entrance to a doctor’s office — a challenge identified by Saha et al. (2019). This issue affects both blind and visually impaired users and traditional GPS-based wayfinding systems, which often struggle with accuracy due to tall structures, limited signal penetration in buildings, or satellite access constraints. It’s on these difficulties that AI can bridge these gaps by recognizing surroundings and guiding users more effectively (Saha et al., 2019).

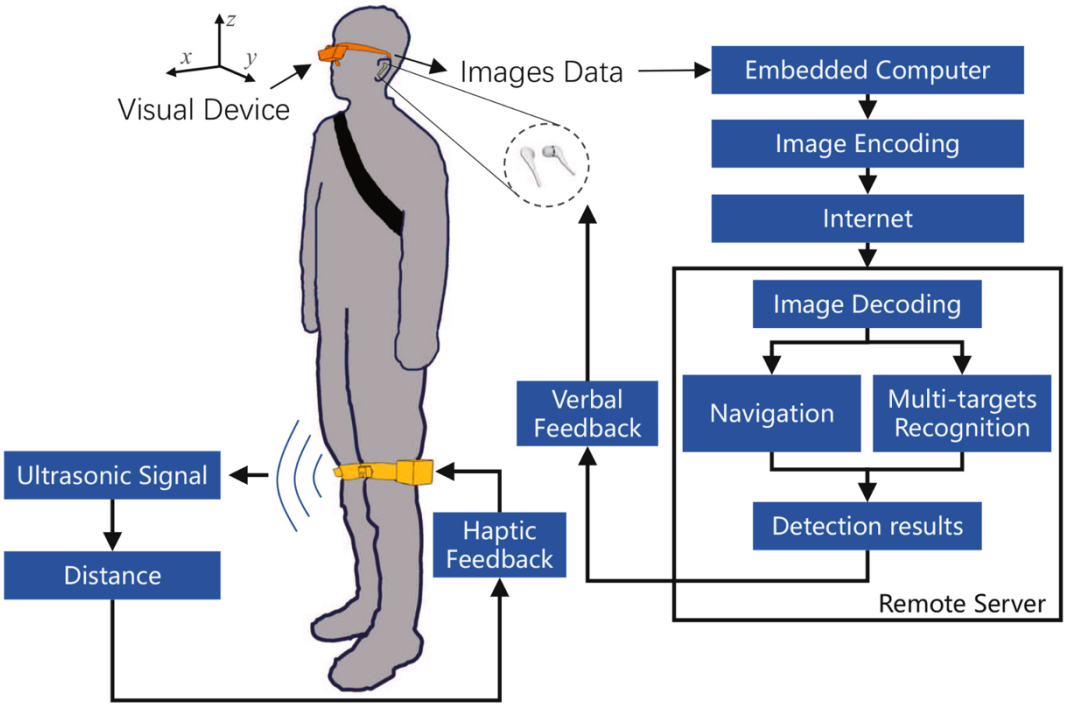

Figure 12 — Overview of the wearable system: This image depicts a person wearing the components of the wearable system, along with the processing sequence of the signals.(Li et al., 2023)

On the medical front, AI is being used in the diagnosis of eye diseases and in AI-assisted wearable devices such as goggles and augmented canes (Wang et al., 2023). These wearables, paired with advancements in hardware, are in the early development stages. For instance, Li et al. (2023) proposes using depth-sensing cameras in goggles, which assist users by providing haptic feedback and voice alerts to help with object localization, text reading, and navigation.

In the field of robotics, outdoor navigation has seen advancements like Zhu et al. (2019), with the creation of a robotic guide-dog equipped with vision and speech capabilities. This innovation addresses the limitations of traditional guide-dogs[8], such as their inability to recognize traffic light colors (since dogs are colorblind) and the high costs and complexity of their training. For indoor wayfinding, Liu et al. (2023) conducted a feasibility study on a small robot that guides users to their destinations through voice commands with the aid of a handle, being particularly useful in unfamiliar indoor spaces where navigation support is needed[9].

As these technologies rapidly evolve, new questions and challenges will arise. However, by enhancing independent navigation, these innovations significantly improve the quality of life for visually impaired individuals, fostering satisfaction, self-confidence, dignity, and more accessible, equitable treatment.

[8] "Guide dogs or service dogs are assistance dogs trained to help blind and visual impaired people to move in complex read situations, such as obstacles and traffic signs." (Zhu et al., 2019)

[9] An example of this robot can be seen here: https://youtu.be/BS9r5bkIass. (Liu et al., 2023)

PART II.

CASE STUDY

FOR AWARENESS

PART II. CASE STUDY FOR AWARENESS

CHAPTER 1. INTRODUCTION AND METHODOLOGIES

This case study for awareness aimed at evaluating the ability of visually impaired individuals to independently reach their ophthalmologist appointment. The research will analyze the effectiveness of the existing wayfinding tools in the chosen hospital environment. The methodology includes conducting an "auto-shadowing" journey from the hospital's main entrance to the ophthalmological service. The study will incorporate personal reflections and autoethnographic appreciations to enhance the depth and enrich the intent of this case study.

The Chosen Environment

A few sets of requirements were procured for the construction of this study. It aimed to access a government-owned and operated hospital under the Portuguese National Health Service (SNS). It would also be essential that it had access to a large and densely populated area since this ophthalmological care is mainly available to large/district hospitals, as it needed to represent the majority of use cases for visually impaired people. While this study doesn't focus on the journey from home to the hospital, as a low-vision person, it's important that the hospital is easily accessible to me from my home. The hospital should also be a good representative of the challenges of indoor wayfinding and navigation.

The Pedro Hispano Hospital

The Pedro Hispano Hospital is situated in Matosinhos – within the second-largest metropolitan area in Portugal. It is a Local Healthcare Unit (ULS) – Figure 13. which means it offers a comprehensive range of healthcare services for the Matosinhos, Póvoa do Varzim, and Vila do Conde municipalities. This hospital is the main healthcare facility for seven smaller healthcare centers (Centro de Diagnóstico Pneumológico; Centro de Saúde Matosinhos; Centro de Saúde São Mamede de Infesta; Centro de Saúde Senhora da Hora; Centro de Saúde de Leça da Palmeira; Unidade de Saúde Pública; SASU Matosinhos) and is an integral part of the local community.

Established on March 20, 1997, the hospital was built to replace the previous District Hospital of Matosinhos, offering more modern and functional facilities. In 1999, it was designated as a Local Health Unit, with a mission to provide primary and ongoing healthcare to the local population and visitors. It is also responsible for public health activities and supports health authorities. The focus is on person-centered care, with an emphasis on promoting research and providing continuous education for both pre- and post-graduate professionals (ULS de Matosinhos, 2023).

The Ophthalmology Service

As I mentioned earlier, there is a pressing need for a better wayfinding system capable of providing visually impaired people with the resources for more autonomous and convenient access to healthcare, especially in large public hospitals.

Many blind and low-vision patients need ongoing follow-up within ophthalmological services, so it is essential to make these spaces as accessible as possible for those who need them the most. As a low-vision person, this is my reality, and it is also the reality of thousands of people who feel neglected in their basic mobility needs.

We must ask ourselves, If pediatric spaces are shaped to their patients (Babbu & Haque, 2021), why aren't the ophthalmology spaces adjusted to receive patients with a high visual disability profile?

Figure 13 - Pedro Hispano Hospital. This is an image of Pedro Hispano Hospital's entrance with signage and the building in the distance. The hospital is mostly made of crude concrete that is dark brownish grey. *(*ULS de Matosinhos*, 2023)*

CHAPTER 2. THE CASE STUDY

In this research endeavor, I will apply a shadowing approach to meticulously analyze and document my personal encounters as a low-vision patient navigating autonomously from the hospital entrance to the ophthalmologist's office.
As its foundation, this study will be based on the fusion of Patent Innovation, Design, and autoethnography, applying an "auto-shadowing" methodology.

This case study was created not only with the intention of observing my experience but also to share how the navigation systems in this experience could be improved. It serves as an example to raise awareness of the difficulties visually impaired people face in hospitals and, at the same time, offers a designer's critique. The case study is divided into two perspectives: first, from my experience as a patient/user, and second, as a researcher analyzing my own experience.

I aim to elucidate the hurdles I encounter, the prevailing design elements, and the efficacy of the existing wayfinding system. I also aim to answer a crucial question: **Will I be able to attend the ophthalmological appointment unassisted in an unfamiliar building?**

Van der Weele & Bredewold (2021) indicate that most healthcare research emphasizes interview-based studies, with few studies utilizing focus groups and hardly any that use ethnographic observational approaches (p. 340). **What types of ethnographic observational methods could I employ to report my own experiences in this research?**

From Shadowing to "Auto-Shadowing"

The shadowing method is a qualitative approach that entails observing users perform a task over a defined, usually prolonged period (McDonald, 2005 apud Van der Weele & Bredewold, 2021). Used in diverse fields, including design, ethnography, and healthcare

research, this technique is important because it allows the researcher to observe the users' experiences of care (Goodrich et al., 2022).
Researchers applying the shadowing method assume an external position in the study, by “figuratively trailing them as their shadow (Van der Weele & Bredewold, 2021, p.341) and consider the participants’ experiences impartially.

This approach originated in organizational studies (Van der Weele & Bredewold, 2021) but differs from traditional observation methods. It involves the researcher closely following and observing an individual over an extended period, focusing on the person rather than the physical surroundings (Meunier & Vasquez, 2008, p. 168, cited in Sirris et al., p. 137). This form of direct non-participant observation, referred to a "shadowing" that aims to collect detailed data by walking in the individual's footsteps and observing their various activities (Sirris et al., 2022, p. 137) taking field notes bring the shadower perspective into view (McDonald, 2005 apud Van der Weele & Bredewold, 2021).

In this research, I’m the researcher and the user/patient.
My experience is of the shadowed and the shadower, and in this is a case study of “Auto-Shadowing” research.

By adopting the shadowing observation method and transforming the observation and note-taking into an absence of vision approach, it was decided that an audio descriptive note-taking report was essential for the development of this study and the most appropriate and adapted to me, the researcher. Also, the journey will consist of a hypothetical appointment at the ophthalmological service of Pedro Hispano Hospital.

This will result in an autoethnographic report, based on audio notes, that contains my experience and perspective as a user/patient, an accessibility specialist, and, most importantly, a low-vision person.

To document my journey, I used my smartphone to capture video footage, accompanying my audio descriptions – Figure 14.

Figure 14 - Myself capturing signs by maxing out the zoom camera on my smartphone.

During the auto-shadowing, photographs were taken to report on the prevailing design and wayfinding elements and navigation experience during the itinerary. The faces of the people in the photographs were blurred to respect their privacy.
This documentation took place on 9th May 2023.

To compile the different conditions encountered, the itinerary has been divided into five milestones (Figure 15). The sequence starts at the hospital's main entrance and ends at the ophthalmological service, and they were named as follows: 1 - Main Entrance; 2 - Hospital Lobby; 3 - Appointment Check-in; 4 – Waiting Room; and 5 – Ophthalmological Service.

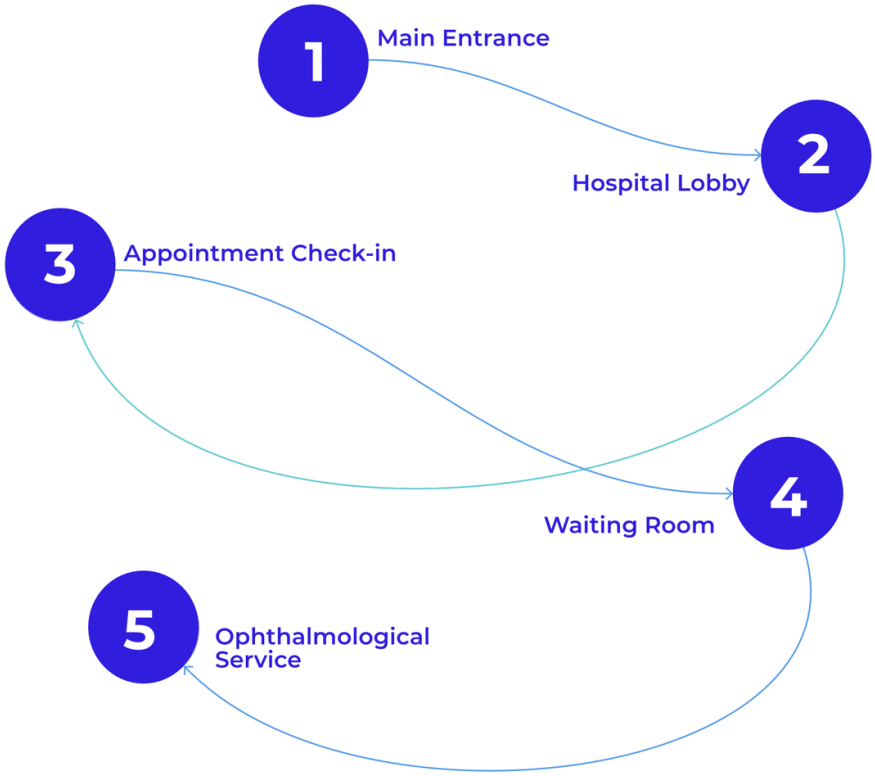

Figure 15 – Five circles representing the five milestone

The following journey and findings will be reported and analyzed according to the five Wayfinding Elements for the Visual Disability. This information will be presented in five sections: Signage, Light and Color, Floor, Sound, Landmarks, and Obstacles.

Before proceeding, it is important to note that the journey to the hospital was excluded from consideration in this study, which exclusively focuses on indoor navigation.

In this context, assistive technology was not utilized, as the objective was to critically examine the current wayfinding system in place within the chosen hospital.

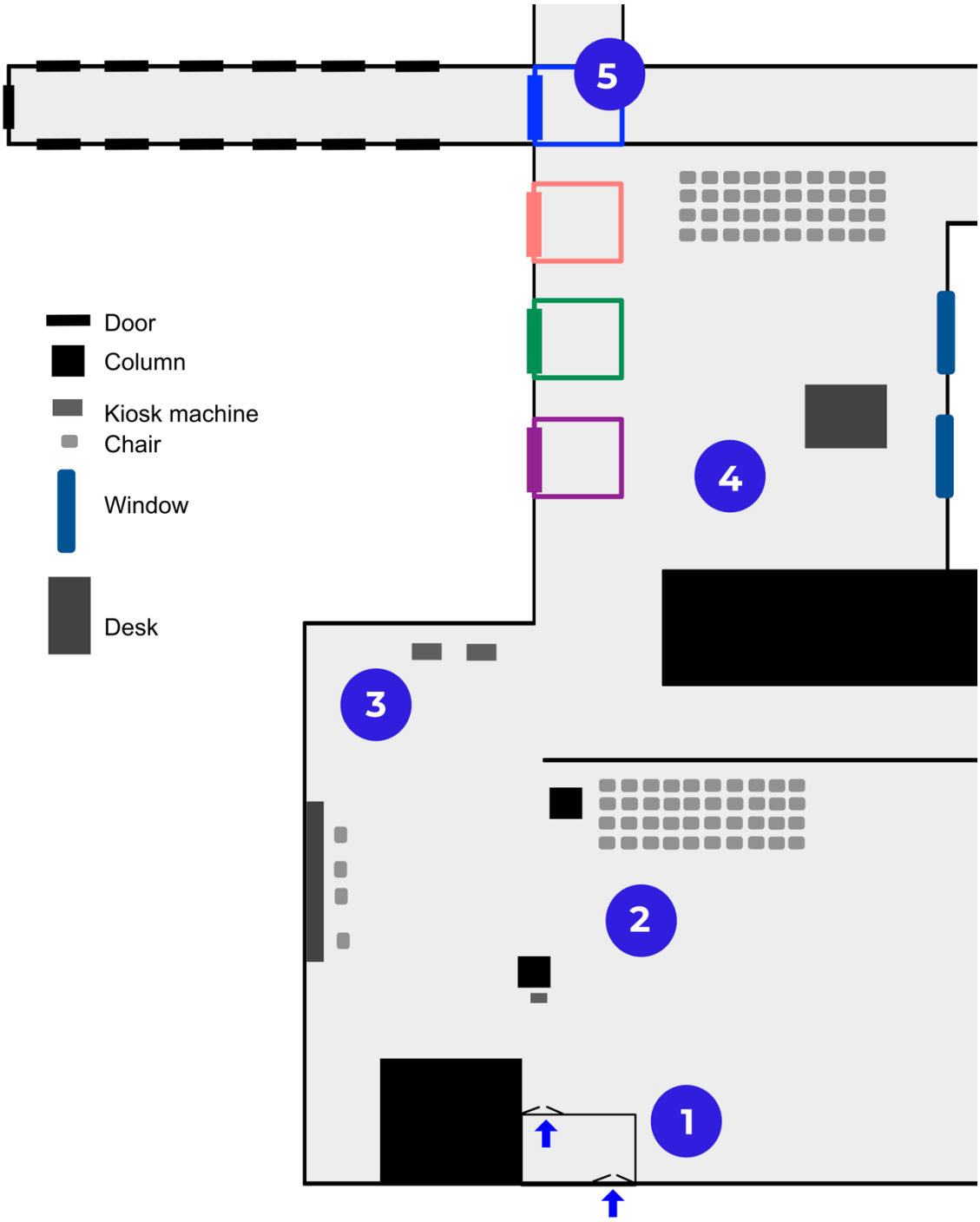

Figure 16 - Simplified hospital building plan - main entrance, lobbies, and ophthalmological service. There was no rigorous scaling involved.

This image (Figure 16) simplifies the hospital building plan – (first floor), intended to provide a clearer understanding of the navigation process involved.

The journey took around 32 minutes from begining to end, excluding waiting times.
In some images will be added a simulated “LHON filter”, to better illustrate the realities of the shadowed.

Auto-Shadowing Journey

It's May 9th, 2023, at 10:30 am. I'm about to start the auto-shadowing, accompanied by my smartphone, which records audio, video, and photos and assists me in locating objects. As a security precaution, my supervisor, Professor Cláudia Pernencar, will accompany me and take some pictures of my journey – Figure 17.

Figure 17 - Beginning of my journey. In this image you can see me, Raquel, standing in front of the hospital doors.

Sept 1 – Hospital's Main Entrance

The hospital's primary entryway is equipped with an automatic door system consisting of two external and two internal doors, thereby creating an enclosed "box" entrance (Figure 18 andFigure *19*). I initiated my exploration at this location and promptly discerned that while users enter through the external right door, they must continue through the internal left door. This configuration presents a significant navigational challenge for blind and low-vision individuals. The black frame of the doors helped distinguish between them.

My awareness of this issue was heightened by auditory cues from the environment, specifically the sounds of other individuals moving behind me and the noise of other doors being utilized. Without that, I would have difficulty knowing which way to go.

I noticed something on the floor next to the left door: a yellow removable obstacle, but I couldn’t figure out what it was or its purpose— Figure 23.

Figure 18 – The "box" entrance from the perspective inside the hospital building - seen by sighted people

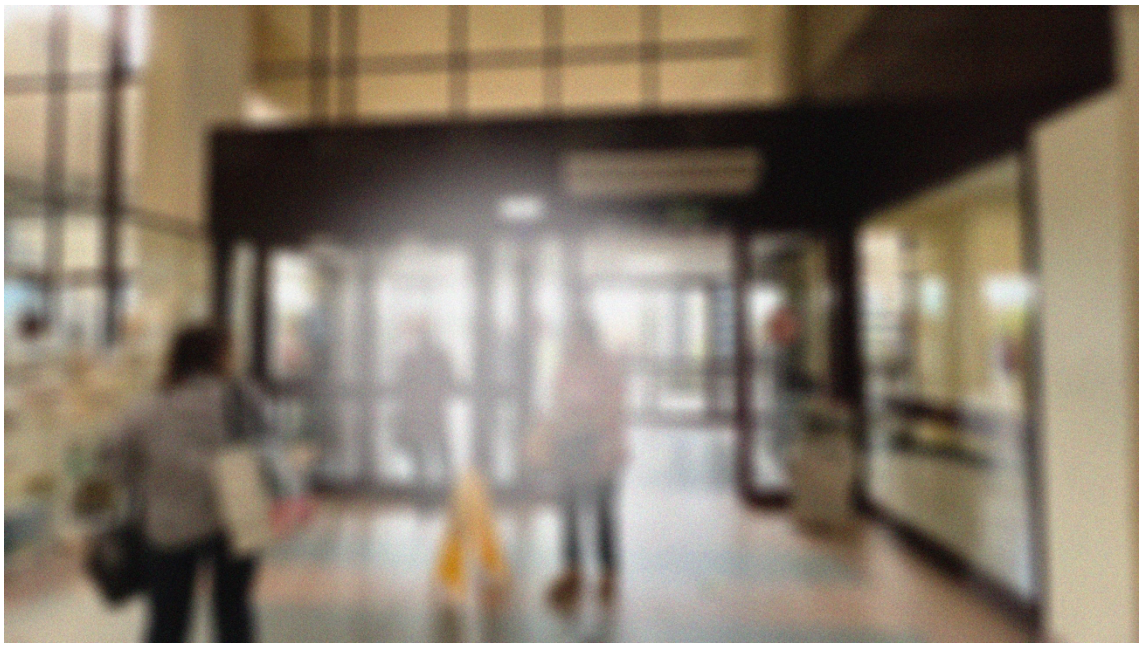

Figure 19 – The "box" entrance The "box" entrance from the perspective inside the hospital building - seen by me (an approximate view)

Step 2 – Hospital Lobby

When I entered the hospital, it was very noisy and overpopulated. The wide-open area had several paths converging with different types of obstacles. It was easy to get lost or go the wrong way.

I attempted to navigate using the floor signage, yet the presence of two horizontal shades of flooring did not aid in this endeavor. It is strange to encounter a floor designed with two color shades that appear to lack any deliberate meaning. Also, the small squares of the tiles are really distracting.

While entering the hospital lobby, there were some yellow objects blocking the entrances, and I couldn't understand their purpose. I just circumvented them to avoid any collisions.

Additionally, I was unable to read the signage positioned above my head – Figure 20 and 24.

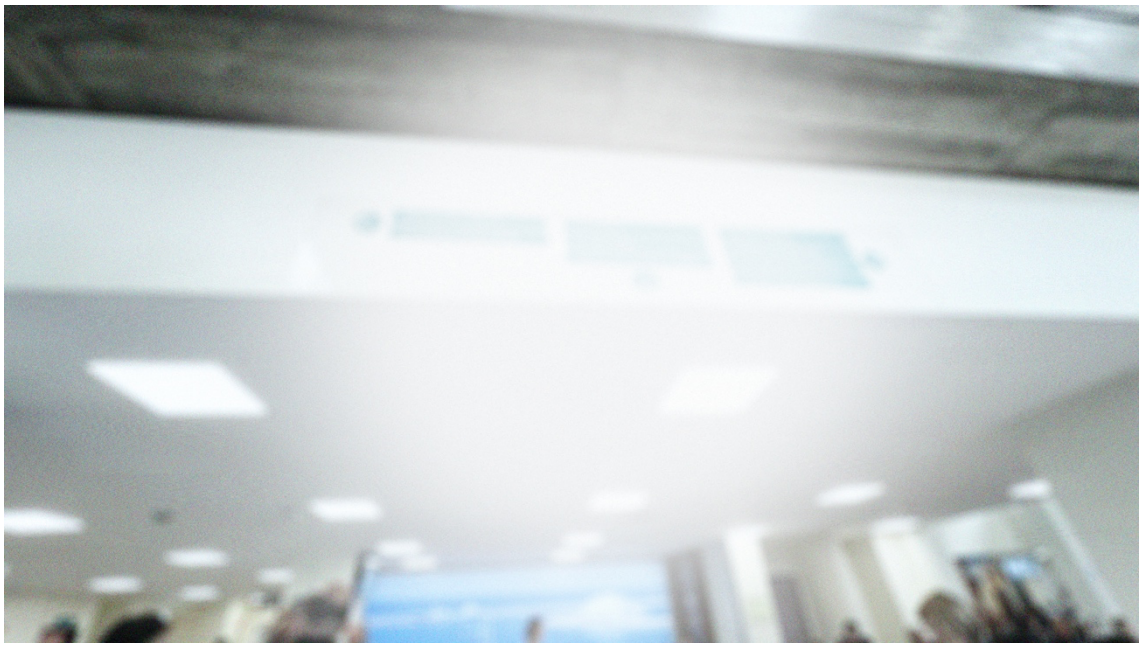

Figure 20 - Signage on the entrance of the hospital lobby - seen by me (an approximate view)

I continued my journey by trying to follow the yellow lines, but being in such an open space can be a little daunting. On the right side, there were some booths with people, and on the left side, there were many rows of people seated.
I tried to locate any landmarks that could help me find my way back in case I got lost, but I wasn't able to. The only landmark was a column in the middle of the lobby.

I was feeling a bit confused at this point. The space was getting more crowded and louder. On the right side, there were loud sounds coming from coffee machines. It seemed like it might be a hospital café. I continued to the left side as I tried to move away from the noise of the people sitting in chairs and from the café.

Confused, I decided to seek help from the hospital staff to see who was available to assist me. As I was looking for help, a hospital staff member approached me. Upon being approached, they were surprised by my request for assistance, attributing their confusion to the fact that I don’t use a white cane or a guide dog, nor do I wear sunglasses—items that are stigmatized and associated with visual impairment.

They informed me of the position of the self-check-in kiosk.

Step 3 – Appointment Check-in

Within the lobby area, at the far-left side, two self-service kiosk machines are provided to facilitate the check-in process for medical appointments. Individuals have the option to utilize these machines autonomously or request assistance from hospital staff.

As I tried to navigate the directions given by the hospital staff, I was able to locate the self-service kiosks thanks to the line of people. They were white with a screen and some sort of code pad, similar to an ATM. I tried to lean on the screen to understand what information it displayed, but because of their reflective surface, I was having difficulty checking if they had any accessibility options and functions. I tried using my smartphone to magnify the screen to help locate them. I had to ask again the hospital staff for assistance. The volunteer was helpful. After I registered for my supposed appointment, I was handed a ticket paper with a number.

After this, I'm supposed to find the waiting room designated for ophthalmological service.

Step 4 – Waiting Room

Upon completing the appointment check-in process, I was instructed to navigate rightward and then turn left (see Figure 17 to understand the flow) to access the waiting area designated for sectors A, B, C, and D.

This corridor had an even higher density of occupants relative to the lobby. Trying to find and guide myself through its architectural layouts, I could understand that it featured a slender corridor that turned left to another lean corridor.

From here, I could see large changes in light and color. The floors were now another color, lighter and with larger tiles, and they contained a reflective coating that was really distracting and affecting me. I became visually confused.

There were many people circulating at the same time, some even just standing in the middle of it. Unable to understand the movement of the people ahead, I bumped into some of them.

There were big, colored areas with big letters (Figure 21). I was able to perceive the differences in contrast and some of the tonalities of the colors. Continuing the corridor, I used these design elements as landmarks, which enabled me to understand where the sector's entrances were located.

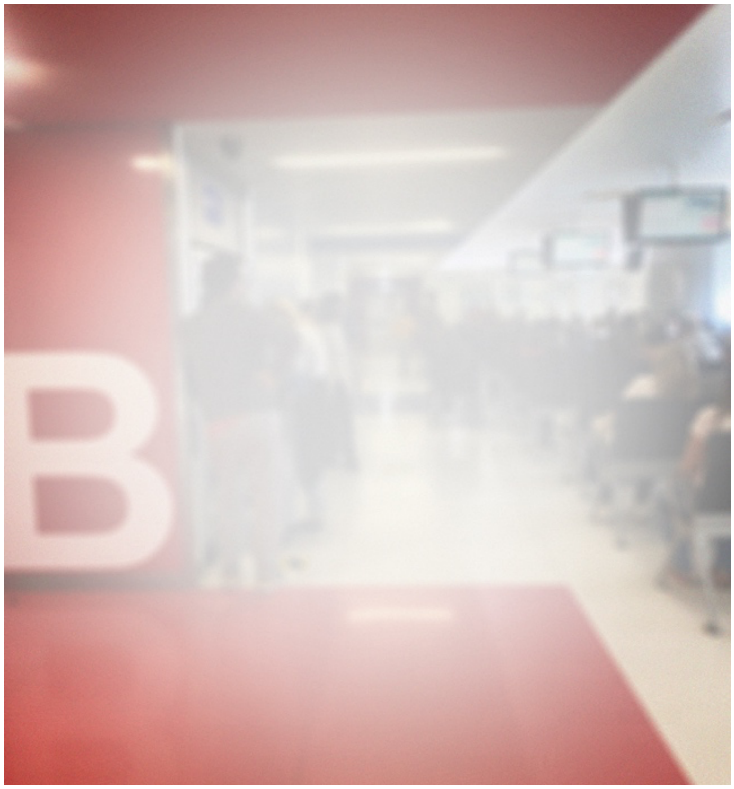

Figure 21 - Sectors entrances - seen by me (an approximate view)

The waiting room was overwhelming – full of obstacles. The space was bright, thanks to the large windows, which had multiple focal lights with different intensities, which, in my case, affected my capability of perception – Figure 22.

Figure 22 – Waiting area - seen by me (an approximate view)

I tried locating any signage boards or screens to understand when I would be called for the hypothetic doctor's appointment. After searching, I was able to locate the display screens. Because of their position and size, I could only see their information if I used my phone as a magnifying tool.

Since the environment was very noisy and with many overlapping sounds, I couldn't tell if the screens had a voice announcement system. I couldn't perceive information about when the doctor would call me.

I just waited there, unaware that I would have clearly missed the appointment.

Step 5 – Ophthalmological Service

Arriving at the ophthalmological service, I encounter a quiet corridor with dark-colored doors, contrasting with the intense white artificial light.
Although uniform in color, the flooring presents a challenge in navigation due to its overly bright surface, which made it hard to perceive the space.

It was difficult to know which door the appointment was supposed to be at. Since I couldn't hear any voice confirmation that the doctor was ready to receive me or information about which room was the doctor's office, I couldn't find it without the help of a sighted person.

I identified the presence of obstacles like hospital beds and other medical equipment, which compromised safety.

Findings

For the purpose of research analysis, I have collected all relevant information to examine the effectiveness of the wayfinding system, particularly from the perspective of individuals with low vision.

The retrieved information is organized in a table to categorize the 5 elements related to wayfinding and design. This is followed by a brief personal summary of each step, and then a more detailed examination and analysis of the findings presented in bullet points. All of these are divided into the same five steps as the auto-shadowing journey, both from a researcher's and a patient's approach.

Step 1 – Hospital's Main Entrance

WAYFINDING ELEMENTS	
General Features	• "Box" entrance with 4 doors - just 2 are open - automatic doors – Figure 18
Signage	• A blue circle with an arrow signal indicates which doors are the ones that open – Figure 20
Light and Color	• Natural light • Glass doors with black structure
Floor	• Floor sign - indication to use the left door (Figure 23)
Sound	• Automatic doors sound
Landmarks and Obstacles	• Removable obstacle indicating wet floor

Table 1 - Hospital main entrance wayfinding elements

Starting from the hospital's main entrance, I immediately noticed how confusing the door system was for someone with visual disability. The alternating pattern of entering

through one external door and then continuing through a different internal one was a challenge, especially without clear auditory cues to guide me. I was immediately confused and discouraged, and I realized how dependent I was on the sounds of others around me to figure out which way to go because I couldn't perceive the existing signage.

- The hospital entrance doors' circulation system is distrustful even for sighted people. Users have to enter the first section of doors on the right (the standard circulation side) and exit the "box" on the left.
- For individuals with visual impairment, distinguishing glass doors from their immediate environment presents a significant challenge. However, in this instance, the door was more readily identifiable, owing to its distinctive black framing.
- The signage was ineffective and not uniform, with different styles and states of condition, like the signage at the entrance that I couldn't understand – Figure 23.
- The presence of unrecognizable objects in the circulation path—the wet floor indicator—represents an issue for visually disabled individuals.
- The presence of other users was helpful in understanding the correct path.
- There was no need to request help; this milestone was possible to achieve alone.

Figure 23 – Main Entrance floor yellow signage and a white arrow inside a blue circle door signage

Step 2 – Hospital Lobby

WAYFINDING ELEMENTS	
General Features	• Crowded • Wide open area
Signage	• Signage with color contrast (white letters in dark background) located very high
Light and Color	• Artificial and natural light
Floor	• Floor with 2 colors and with yellow indicators
Sound	• Noisy
Landmarks and Obstacles	• Removable obstacle indicating the wet floor • Column in the middle of the open area

Table 2 - Hospital lobby wayfinding elements

Inside the hospital lobby, the environment was chaotic and overwhelming. The noise, combined with the open space, made navigation extremely difficult. Floor signage didn't help, and I struggled to understand its purpose. I couldn't read the signs above my head that were supposed to direct me to the ophthalmology department, and I quickly felt lost without landmarks to guide me.

- Like most public healthcare buildings, Pedro Hispano's hospital exemplifies a common issue: a very noisy, overpopulated, and wide-open area where several paths converge. It's easy to get lost or go the wrong way, even for sighted people.
- The wide-open area, usual in healthcare facilities, presents navigational challenges, especially for visually impaired individuals, as it creates

disorientation. Open spaces without distinct boundaries or landmarks make orientation difficult (Vision Australia, 2006 apud Rousek & Hallbeck, 2011).

- At Pedro Hispano Hospital, the services are each identified by a letter. This information can be found on a chart situated in the right corner of the lobby. To view this chart, one must turn right upon entering through the main entrance; otherwise, it remains unseen. In this shadowing process the chart was missed.
- The entrance signage (figure 24), although featuring adequate contrast (white on blue, as recommended by ADA), is placed too high, making it hard to see. The small and thin font size further complicates readability. For my situation it was unreadable.

Figure 24 – Hospital lobby signage located on a high level

- The presence of foreign objects, such as wet-floor markers (Figure 25), is a big challenge. Not only are they harder to spot, but they also don't convey their message to visually impaired people. This becomes a security issue because these individuals wouldn't know they are entering a wet area that could be dangerous. The presence of a collum in the middle of the area was unexpected.
- The leftover COVID-19 markings—yellow lines guiding corridor flow and black foot markers with yellow outlines indicating stopping zones—were one of the few useful wayfinding guides (Figure 25). However, the markings were an afterthought since they weren't maintained.
- The floor color was inconsistent (Figure 25), using two different tonalities that may have led to confusion, as contrasting colors are critical for low-vision

individuals. Also, the size of the tiles added to the confusion, making it harder to concentrate on information. Since low-vision people still maintain some understanding of their surroundings, it is important not to overload them with information.

- The absence of clear, tactile, or visual landmarks increases feelings of insecurity.
- The abundance of conflicting sounds can create confusion (Zhang et al., 2022). This was exacerbated by the lobby's being a mixed-use space: a circulation corridor, a café, a waiting area for patient information, patient information desks, and check-in machines. The high volume of people talking increased the challenge.
- Unlike many other healthcare settings, Pedro Hispano Hospital provides specialized healthcare workers to assist with navigation, which is a positive aspect. In other institutions, support is often relegated to security staff, lacking the same level of care.
- There was a need to request help; this milestone wasn’t achieved alone or without causing a high level of anxiety and stress.

Figure 25 – Hospital lobby flooring – signage representing a “foot” print in black with a yellow background square

Step 3 – Appointment Check-in

WAYFINDING ELEMENTS	
General Features	• Hospital volunteers help patients check-in
Signage	• Not applied
Light and Color	• Artificial light
Floor	• Same as the lobby
Sound	• Noisy
Landmarks and Obstacles	• Not applied

Table 3 - Appointment check-in wayfinding elements

The self-service kiosks are located on the far left side of the hospital lobby. I was quite lost, so I started looking for help. The hospital staff assisted me in this process. I tried to check in at the self-service kiosks, but I realized that the interface wasn't user-friendly, especially for those with visual impairment. Once again, I had to rely on the help of sighted people, which made me feel less independent. The check-in process, which was supposed to be simple, was another reminder of how assistive technologies often fall short in catering to people with disabilities.

- The self-service kiosks are designed with interfaces similar to ATMs. They feature white backgrounds, a screen, and a digital keypad. The screen is reflective, making it difficult to read the information displayed or even to use a magnifier system to access that information.
- There weren't any accessibility features such as audio feedback or magnifier system, making it difficult for low-vision users – Figure 26.
- Braille was not available at any point during this journey, and specifically, these kiosks lacked any touch-accessible information about their functionality.

- The presence of hospital volunteers was crucial for the accessibility of elderly individuals, patients with disabilities, and first-time visitors.
- The check-in system was not user-friendly, even for sighted people, which led to many requesting volunteer assistance. This suggests a broader design issue with the self-service kiosks. This dependency reduced autonomy for visually impaired individuals, who had to rely on sighted individuals to complete the check-in process.
- The registration process generates a paper ticket with a number and section, but lacks information about its whereabouts or content, as the kiosk does not provide any voice feedback.
- Some visually impaired individuals can appear to be sighted, especially if they do not display outward signs of their impairment. It is important to educate hospital staff about this because kiosks and other digital interfaces can be challenging to use without assistance. When the person providing assistance is unsure whether the individual is actually visually impaired, it can unintentionally create additional anxiety and stress for visually impaired individuals (Cupples et al., 2012).
- This milestone would not have been achievable without assistance from a sighted individual, making it undoable independently.

Figure 26 – Hospital staff and patient in front of the kiosk machine

Step 4 – Waiting Room

WAYFINDING ELEMENTS	
General Features	• Crowded with a narrow corridor • Complex environment: 4 hospital services within the same waiting area
Signage	• Digital displays across the waiting area
Light and Color	• Natural and artificial light
Floor	• Distinct colors indicate different services • Same yellow floor signage as the lobby area
Sound	• Very noisy
Landmarks and Obstacles	• People moving back and forward. • People standing in front of the sectors entrance blocking the corridor flow

Table 4 - Waiting room wayfinding elements

Locating and arriving at the waiting room was equally challenging. The narrow corridor, the crowd, and the lack of clear direction made me feel lost. Though I could detect some color contrast on the floor, which helped as a signage and landmark, I still had to count intervals to find my way. The waiting area was noisy and overwhelming, and without being able to hear the voice announcements of the display screens system, I had no way of knowing when my turn would come.

- Navigating through the narrow corridor was particularly difficult due to the crowded environment (Figure 27). Many people stood in front of sector entrances, blocking the corridor and causing congestion. This was further exacerbated by the assumption that others would move out of their way, creating obstacles for visually impaired individuals.

- Above the self-service machine, there was a sign pointing towards the consultation area. While it partially followed ADA recommendations (White on Black lettering and without serifs), its placement on the ceiling made it difficult to notice, contributing to the challenge of finding the sector and waiting room.
- There were reported a multitude of bumps with other people circulating, with the supervisor, in a security role, intervening to prevent accidents. These can also again be attributed to a lack of knowledge of common people, that visually impaired people can appear like others.

Figure 27 – Corridor, sectors entrances and waiting area

- Digital signage systems are designed to assist sighted individuals by displaying appointment steps, such as blood tests or doctor appointments. However, these screens are placed too high for individuals with low vision (Figure 28).

Additionally, many of these screens were not working properly or were glitching (Figure 28), which created difficulties even for sighted people.

- The voice announcement system was extremely deficient. It featured a weak automatic text-to-voice translation with robotic speech that was too fast, overlapping voice commands, and easily mixed with the noisy environment, making it nearly impossible to discern critical information such as doctor calls. This system isn't adequate for the conditions of the space (Figure 29).
- As stated before, sound has a big impact on how surroundings are perceived by visually impaired individuals. During the journey, the high volume of this large waiting area prejudiced the overall experience.
- The different sectors of the Pedro Hispano Hospital, at least on the ground floor, are marked with large letters and various colors (Figure 27). For visually impaired people, this information is only useful for those already familiar with sector designations, such as those who know that ophthalmology is in "Sector D".
- As previously noted, my ability to differentiate colors is significantly impaired; however, my capacity to perceive contrasts in color proved advantageous. This particular characteristic facilitated my utilization of the color discrepancies present on the flooring as navigational aids—as landmarks. These allowed navigation between sectors by counting intervals, which allowed the identification of sector entrances such as Sector D.
- The changes between the flooring in the lobby and the waiting room area were noticeable, confirming a change in the surrounding area.
- Changes in floor materials, such as lighter, reflective tiles, caused significant visual confusion, making it harder to navigate and adding to the disorientation in the space.
- The waiting room was crowded with many obstacles, large groups of people, and an overcapacity of chairs. There was a constant flow of activity, bright natural light from numerous windows, and multiple focal lights, all of which created visual confusion.
- As experienced before, other hospital services usually have a dedicated waiting room area for ophthalmology services, which, in this case, didn't.

- This milestone wouldn’t be possible to achieve alone.

Figure 28 - Signage of the waiting room with half the screens not working properly.

Figure 29 – Waiting room from the sector D perspectivee

Step 5 – Ophthalmological Service

WAYFINDING ELEMENTS	
General Features	• Narrow corridor with color contrast doors
Signage	• Door signage – doctor's office and examination rooms
Light and Color	• Artificial light – white color
Floor	• One uniformly colored and shiny floor
Sound	• Noiseless
Landmarks and Obstacles	• Hospital beds • Medical equipment

Table 5 - Ophthalmological service wayfinding elements

The ophthalmology department itself was much quieter and easier to navigate due to the dark-colored doors standing out against the walls, but finding the right room was still a struggle. The small number plates were unreadable for someone with low vision, and the reflective floor surface made it hard to get visual cues. Also, the existing obstacles—hospital beds and medical equipment—represent a potential safety issue. I would have missed my appointment if I had been on my own, and the overall experience could have had a negative impact on me.

- Although the quiet atmosphere was less overwhelming than other hospital areas, navigation remained difficult due to the lack of clear wayfinding features.
- Without audio cues or tactile signage, I had difficulty identifying which door led to the doctor's office. The absence of voice announcements or auditory confirmation meant that I needed help from a sighted person to find the correct room. This reliance further diminished the sense of independence that blind and low-vision patients, like myself, should have when navigating healthcare environments.

- The floor uniformity is a plus for low-vision patients, but its reflective nature exacerbated visual confusion.
- The contrast of the light color walls and the dark-colored doors helped locate where the doors were and use it as a landmark.
- It wasn't easy to determine which side of the corridor the appointment would take place on, as the number plates were too small for people with low vision to read and located at a high level.
- The doors lacked larger identification numbers, which would help locate them.
- This step would have required intervention from a sighted person, or the doctor to help the patient.
- If, autonomously, especially in a first-time situation, the journey would cause high levels of stress and confusion. This issue can co-occur within other hospital services.
- This research didn’t take into account that low-vision patients may require access to other services or different appointment rooms inside the facility to perform exams. If they are unattended or unfamiliar with their surroundings, the visually disabled patient may fail to complete their journey.

Figure 30 – Ophthalmological service area with dark-colored doors

Observations: Navigating Hospitals with Low Vision

The primary observation from this case study is that, despite some improvements in signage and assistance programs, hospitals remain difficult to navigate autonomously for visually impaired individuals. Hospitals such as Pedro Hispano provide valuable resources like volunteers to assist patients, but this reliance on human intervention undermines patient autonomy.

As Jeamwatthanachai et al. (2019) state, sighted guides are commonly used in hospital settings. While they are valuable, relying on this method of navigation often compromises independence, privacy and can feel disempowering. Not every patient can or should rely on others for assistance, and the absence of tactile systems or clearer wayfinding signage makes it even more crucial to provide alternative solutions. Even though the ophthalmological services were located on the ground floor, it also cannot be ignored that blind and low-vision patients need to access various hospital services, not just ophthalmology, making accessibility essencial. Relying on human assistance, though helpful, shouldn't be the default option.

Like many healthcare facilities, Pedro Hispano lacked essential wayfinding features for visually disabled patients, including tactile floors and auditory cues for appointment information. While large lettering at the sector entrances was a positive feature, the overall design still didn’t account for the needs of visually impaired patients. Waiting areas were cluttered, lacked adjusted signage, even for sighted people, and lacked tactile floors for guidance, adding to the confusion. This experience aligns with Jeamwatthanachai et al.'s (2019) findings that patients struggle with navigation and orientation, particularly in unfamiliar indoor environments.

The five key elements of wayfinding identified to accommodate blind and low-vision patients —signage, lighting and color, flooring, sound, and landmarks—are often overlooked or insufficiently imposed.

As observed, these issues can lead to unnecessary stress and a sense of disempowerment. These findings support the concerns raised in the literature review regarding the limitations of assistive technology and design practices in healthcare environments.

It's here that Van der Weele & Bredewold's (2021) assertion that patient-led ethnographic observation is underutilized in healthcare research is also evident, as the current design standards often fail to account for the lived experiences of disabled individuals.

Sound is a crucial factor for visually impaired people (Karagoz, 2023), and the hospital's ambient noise created significant barriers for me during navigation. As stated by Jeamwatthanachai et al. (2019), understanding the environment is one of the most important methods of navigation for visually impaired people, making sound crucial for the recollection of information. Zhang et al. (2022) highlighted that the chaotic nature of hospital environments, because of overwhelming sound sources, causes negative effects of confusion and helplessness, making auditory navigation more difficult. This was clearly confirmed by my inability to hear the voice announcement system

Lighting was also inconsistent, and fluctuating levels made it difficult to interpret the space. As light poses another challenge for visually impaired people, the brightness of spaces with big windows like the waiting room, is another point of consideration.

The architectural structure of the building seems like a collection of interconnected spaces. The layout of the ground floor is unintuitive and confusing, even for sighted people. This is also evident in the different choices of materials and styles of surfaces. According to Vision Australia (2006, cited in Rousek & Hallbeck, 2021), breaking wide open spaces into smaller spaces can help visually impaired people's orientation.

As technology continues to advance, systems like the guide robots developed by Liu et al. (2023) are becoming closer to reality. Additionally, issues such as the lack of GPS

access inside buildings for systems like the wayfinding googles of Li et al. (2023) will be resolved. However, they are not publicly available and not accessible to public systems for financing. In such cases, we must resort to analog methods, even if they are not sufficient for good and secure navigation, let alone autonomous navigation.

As a researcher, implementing larger signage with bold letters and defined contrast that complies with international regulations and locating them on eye level can be some of the solutions. Additionally, for blind people, the use of braille in certain places should be implemented. To make it easier to locate services, the use of tactile surface indicators, which is an element of design and wayfinding, can help address these challenges.

One major helpful system that designers can implement is the use of landmarks for visually impaired people. According to Arditi (2017), Jeamwatthanachai et al. (2019), and Rousek & Hallbeck (2011), these landmarks can help low-vision individuals become more aware of their surroundings. Utilizing landmarks that can be seen using the residual visual capacities of low-vision people for the purpose of wayfinding can be an easy and inexpensive method for hospitals to better orient their facilities. Those landmarks must be large size items, like architectural features or décor elements.

To help understand how other solutions could be created, the ADA Standards include comprehensive guidelines for signage and tactile elements that cater to visually impaired individuals. These include raised characters on signage for low-vision people to read the text, braille in every system, and uniform lighting throughout the spaces.

In contrast with the United States of America and the United Kingdom's regulations regarding accessibility for citizens with visual impairment, Portuguese legislation focuses mainly on wheelchair access and does not address the specific needs of visually disabled citizens (Decreto-Lei n.o 163/2006). Considering the implementation of international guidelines could improve public services to be accessible for all citizens, regardless of their disability.

It is important to note that since this shadowing process did not include an actual visit to a doctor's appointment, it wasn't possible to understand the empathetic care of the medical staff. Only a very positive reaction from the volunteer staff was reported. Nevertheless, as Cupples et al. (2012) states, it is an important subject to understand in the future.

Recommendations

Based on the ADA standards and in this case study, some recommendations can be applied to improve the overall experience of navigation and orientation in the Pedro Hispano Hospital building:

- Consisting flooring surface throughout the hospital areas – with a matte finish and uniform in color – pastel shades;
- Implementing tactile surface indicators;
- Avoid all obstacles that block the flow and pose a potential hazard;
- Create large-size signage with bold, non-serif, and embossed lettering and color contrast schemes and located at eye level;
- Considering translating information to braille;
- Installing consistent lightning throughout all spaces – yellow-colored;
- Improve the display screens to incorporate a more efficient sound system;
- Break the wide-open area of the waiting room into four spaces – one for each sector.

All of these suggestions are already known and applied in other contexts. It is important to acknowledge that even with these analog tools, hospital wayfinding systems for visually impaired individuals do not ensure the safety and effectiveness needed for these patient profiles. Implementing assistive technology devices and AI could be more beneficial but addressing accessibility issues should extend beyond product-solving solutions.

PART III.

DISCUSSION AND CONCLUSION

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This dissertation aimed to illuminate the significant barriers that blind and low-vision individuals encounter when navigating hospital environments. It also emphasized the importance of developing design approaches and frameworks that promote accessibility and raise awareness of the challenges and ableism faced by visually impaired people.

By delving into my own experience as a low-vision person, designer, and researcher, I have tried to raise vital questions and observations from both theoretical and practical perspectives, which I will discuss in this final chapter.

How long does it take?

Being a person with a visual impairment acquired at 27 years old, I am acutely aware of what I have lost as a citizen. I no longer receive the same equal treatment as before. Living with a rare, non-visible condition is difficult in itself, but in addition, my safety, dignity, and privacy are constantly in question. I face ableism and stigma in most of my social interactions and daily activities. Why? Because I am unable to move autonomously most of the time. But why is that happening? From my perspective, the answer goes deeper than a lack of accessibility.

Current design models for wayfinding and assistive technologies often perpetuate inequality by excluding the perspectives of those who depend on these systems the most. I never dreamed of becoming an activist, but I find myself in that role at times. So, in some ways, this dissertation is a call for action and awareness. I am not proposing, as a designer, to find a specific strategy for this hospital. What I am doing is observing and demonstrating the difficulties that a person with low visual acuity faces when navigating a hospital—a place that should be safe, dedicated to the health and well-being of its patients in all their diversity.

More than highlighting the challenges that people like me face, it is essential to ask: why are we still so far behind in terms of accessibility and social inclusion? Why isn't design thinking more equitable? It’s critical to go beyond merely acknowledging the barriers people encounter.

This is not only a Portuguese issue. As I mentioned in the introduction, I have visited many hospitals across Europe, and none of them provide adequate accessibility for visually impaired individuals.

This underlying question demands urgent attention: Why are there still significant shortcomings in accessibility and social inclusion advancements? Moreover, why is there a lack of focus on ensuring that design thinking processes are more equitable?

While it is undeniably important to implement strategies and elements that enable people with disabilities to navigate hospitals, this is just the beginning. Addressing inclusion and accessibility requires a shift in thinking and a change in attitude, starting with education. A change in attitude is needed from services, designers, and all those working in healthcare support. Equity and accessibility must become more prominent in scientific research on design for health and well-being.

Through this case study for awareness, there’s a reflective aspect that addresses the need to confront structural issues and recognize the multiple socio-political dimensions at play. It is not just about my inability to move efficiently— the absence of accessibility constantly reminds me of my condition. Ableist systems dehumanize people with disabilities, making them invisible, and diminishing their experiences and dignity.

This research explores the intersection between the roles of designer, researcher, and patient. What does it mean to embody each of them, and how do they inform one another? I am in a privileged position, both personally and academically, to conceptualize ideas and practices around navigation and wayfinding for visually

impaired people because I can communicate, mediate, and understand different perspectives from multiple points of view.

At its core, this research has an educational and reflective aspect—design reflecting on design, design thinking about itself. It's more about social awareness and new perspectives, while also combating prejudice and the stigma that comes with being a person with low vision doing this kind of work.

The position I occupy defines this research. I am not a designer who will merely discuss how wayfinding systems can be improved. I am a designer, patient, user, and researcher who questions why these considerations aren't already in place.

When will we start critically reflecting on design, accessibility, and ableism from a transdisciplinary perspective?

Rethink Design Practices for Inclusion, Representation and Equity

As Costanza-Chock (2020) states, good intentions don't always translate into inclusive and non-discriminatory design solutions. There has been progress in how accessibility and inclusivity are approached in design, including for people with disabilities, but there is still a long and urgent path to tread in order to truly address and design not only more accessible infrastructures, products, and services, but also educational systems based on social justice, focused on equity, and dismantling structures of violence and ableism.

Design Justice and similar concepts need to be disseminated and applied to provide space and platforms for new ways of producing knowledge while giving agency to communities that have been socially marginalized.

Design must be more diverse, socially responsible, and inclusive, expanding its interaction with the world by raising awareness, asking the right questions, and

searching for solutions. Additionally, design must become an active voice in transdisciplinary discourses and practices that promote social justice.

Design is in constant dialogue with society and itself, not only in how it exists but also in how it could and should be. The interaction between Design, Education, and Activism is central to addressing accessibility and equality in a sustainable, innovative, and ethical way.

It is also urgent to rethink the role of the designer and how is determined who can be a designer and researcher. Applying autoethnographic methods can be particularly valuable in this regard, providing designers and/or researchers with the opportunity to incorporate their own experience, narrative, and voice into their practice, especially if they are part of a specific community often misrepresented in design and society. Designers who are not often represented are key to developing new, innovative concepts and perspectives in the field of design. As Liebergesell et al. (2023) noted:

“Practitioners who have first-hand experience of being disabled are in a privileged position to reconcile design and disability. Integrating disability (experience) in design can be inclusive, aesthetically worthwhile, and poetic/expressive.”

Accomplished Objectives and Challenges

Doing this research was undeniably challenging, at times deeply rewarding, and at other times, I must admit, overwhelming.

Although there is much to say and explore about the areas investigated, I believe this dissertation has made a relevant and innovative contribution to the field of Health and Wellness Design, particularly within the Portuguese context, where the research gap is still significant—especially for studies conducted by disabled researchers.

Using autoethnography and 'auto-shadowing' allowed me to engage more deeply with the themes of this dissertation, enriching it further. Additionally, using creative design

methodologies and sharing my own narratives and experiences enhances the representation of designers and researchers with disabilities. This is a key element in deconstructing prejudices and evoking new possibilities for designing and discussing design.

The most challenging aspect of this research was balancing my full-time job outside academia with the time required for this dissertation, particularly for reading.

I acknowledge that this dissertation might benefit from a more structured literature on disability studies, representation, and ableism. This could help build bridges and raise questions about how design can engage with critical education and social justice. However, I felt that expanding on these areas would shift the focus away from the core subjects of this dissertation.

Next Steps

Finally, I would like to offer a few suggestions that I believe could be the next steps for continuing research on hospital wayfinding for people with disabilities while incorporating autoethnographic methods.

Following this dissertation, an interesting approach for future research would be the use of collaborative autoethnography. by designers and researchers with disabilities.

This method would incorporate the different experiences and perspectives of various professionals, creating a sociocultural and political understanding of the explored subject. Such an approach could help generate new discourse and potential solutions to the difficulties of navigating wayfinding systems in hospitals.

Future research could also focus on education, challenging current design practices and representation in accordance with the principles of Design Justice.

Additionally, investigations should explore how wayfinding systems and technologies can be designed to promote both independence and privacy for people with disabilities. Integrating new technologies and AI will be essential in reconfiguring hospital wayfinding systems, making them more autonomous, private, and tailored to individual needs.

In Conclusion

This research began by asking how autoethnographic methodologies and socially committed design practices can improve the experience of visually impaired patients in hospital environments. After completing this dissertation, I believe the answer is clear yet complex. It's true that designs for accessibility, created by able-bodied designers, can help improve and facilitate navigation for visually impaired patients in hospitals through signage, apps, and other initiatives. Despite the importance of these solutions, there is a risk of superficiality in that approach, which often overlooks the complex relationship between design, ableism, equity, and representation.

Throughout this dissertation, I demonstrate that personal experiences and autoethnographic methodologies are valuable tools for deepening and rethinking design practices. A designer can occupy multiple roles—not only as a "thinker" or "problem-solver," but also as a mediator within various communities, using personal experience to navigate different needs and struggles. My own experience reinforces the benefits of occupying this role, not just by suggesting strategies already proposed by able-bodied designers, but by questioning those solutions and others that have yet to be applied. I can inhabit the role of a patient while also remaining critical, at a distance, as a researcher and designer—but both perspectives should and must coexist.

In this research, I focus on hospitals as an example of a place that should be equipped to provide equal treatment for everyone, particularly since these spaces are essential for the well-being of communities in vulnerable situations, yet often become sites of re-

traumatization for people with disabilities. However, this inaccessibility is pervasive; this dissertation could easily address many other spaces.

What I propose here is to prioritize a discourse to which I can contribute differently — questioning and raising awareness about why things aren't done differently and how they could be. While I risk being perceived by some as partial or overly activist as a researcher, I believe this approach is necessary to amplify the importance of representation in design and academia and to highlight how ableism profoundly shapes our personal and professional design practices, even unconsciously.

I can only speak from my own experience, recognizing that each voice and experience of living with disabilities is profoundly different and unique. If design is fundamentally about creating a better and more accessible world, these experiences cannot be oversimplified. Some designers contribute by creating signage, others develop apps, and still others question how design itself needs to evolve to be more inclusive for both designers and users. What I have learned through this research is that, despite being all of these types of designers myself, I need to prioritize what I want to amplify with my voice and practice.

So, at the conclusion of this dissertation, I would argue that it's not just about how these methodologies can contribute to the design and well-being of visually impaired patients, but how urgent the representation of first-person perspectives is for design and social change. I believe this research is one more small step in a long journey, especially within the Portuguese context, where design, disability, and transdisciplinarity need to work more closely together.

“Disabled people have always existed, whether the word disability is used or not. To me, disability is not a monolith, nor is it a clear-cut binary of disabled and nondisabled. Disability is mutable and ever-evolving. Disability is both apparent and nonapparent. Disability is pain, struggle, brilliance, abundance, and joy. Disability is sociopolitical, cultural, and biological. Being visible and claiming a disabled identity brings risks as much as it brings pride.”

Alice Wong, 2020
in “Disability Visibility”

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APPENDICES

ETHICAL TERMS

APPENDICES – ETHICAL TERMS

APPENDIX 1

COMISSÃO LOCAL DE PROTEÇÃO E SEGURANÇA DA INFORMAÇÃO

EMISSÃO DE PARECER

Refª xx /CLPSI/2022

1 - ASSUNTO:

Estudo de Campo do projeto "*From a Patient Innovation Perspective: Design as a Tool to Improve Blind and Visual Impaired People Experience in Hospital Facilities"*

2 - RESPONSÁVEL PELO PEDIDO:

Cláudia Alexandra da Cunha Pernencar

3 - DIMENSIONAMENTO DA AMOSTRA:

Atividades 1, 2 e 5 – 5 participantes;

Atividade 3 – 15 participantes;

Atividade 4 – Não se aplica.

Nota: Informação das atividades disponível no cronograma

4 - PERÍODO DE REALIZAÇÃO:

Duração estimada de 3 dias

5 - GARANTIA DA PSEUDOANONIMIZAÇÃO DOS DADOS PESSOAIS:

Não se aplica. Nos instrumentos não são solicitados dados sensíveis tais como nome, e outras informações pessoais.

6 - *PERÍODO APÓS O QUAL OS DADOS SÃO DESTRUÍDOS*:

Os dados recolhidos (não sensíveis) no âmbito deste estudo e partilhados com o Politécnico de Leiria serão mantidos em arquivos seguros, com acesso restrito, sejam eles eletrónicos ou físicos, de acordo com a legislação guardados por 5 (cinco) anos após a conclusão do estudo. Após terminado o período obrigatório de conservação destes, os mesmos serão totalmente destruídos. Os parceiros de investigação que colaboram neste estudo não estão autorizados a partilhar os seus dados com terceiros.

7 - EQUIPA DE INVESTIGAÇÃO:

Cláudia Pernencar (LIDA/ESAD – PLeiria)
Maria João Jacinto (Patient Innovation / NOVA SBE)
Eliana Santiago (ID+/Universidade do Porto)

Raquel Marques (LIDA/ESAD – PLeiria)

8 - PARECER:

1. Qual a licitude para realizar este estudo?

2. Identificar quem é que vai proceder à recolha dos dados na ULSM.

Claúdia Pernencar e Raquel Marques

3. Identificar como vai proceder à recolha dos dados na ULSM.

No primeiro dia será realizado um estudo sombra áudio/descritivo que irá envolver 5 participantes com deficiência visual para relatarem o seu percurso desde a entrada principal do hospital até ao serviço de oftalmologia, como também a orientação nesse mesmo espaço (mais detalhes no documento "CEH_Descrição");

No segundo dia será um realizado um FOCUS GROUP com participantes do estudo de observação. Num ambiente de conversa informal, serão partilhadas coletivamente as experiências relatadas no estudo sombra áudio descritivo, de forma a consolidar quais foram as maiores dificuldades encontradas e extrair ideias sobre possíveis melhorias a aplicar. Este FOCUS GROUP não necessita de acontecer no hospital. Poderá ser realizado no formato remoto.

O envolvimento dos profissionais de saúde irá se dar através de um questionário online, de cariz anónimo, onde serão colocadas perguntas sobre a sua experiência com este perfil de utentes e a sua perspetiva sobre a acessibilidade do hospital (ver documento "INQUERITO_PS"). Num terceiro dia será realizado um estudo de observação ao teste piloto implementado (mais detalhes no documento "CEH_Descrição").

4. A base de dados já existe ou vai ser criada?

Irá ser criada

5. Quem vai introduzir os dados na base de dados?

A equipa de investigação pela mão de Raquel Marques

6. Quais os critérios utilizados para a pseudonimização dos dados?

O estudo não irá levantar dados sensíveis tais como nome e outras informações pessoais dos participantes.

7. Quais os requisitos de acesso à base de dados e quem é que vai ter acesso à mesma durante o estudo?

Os dados não sensíveis serão mantidos de forma protegida pela equipa do estudo, e só estarão acessíveis às seguintes pessoas ou entidades: aos investigadores da equipa, às Comissões de Ética competentes, a outras entidades competentes ao abrigo do disposto na legislação.

8. Onde é que os dados, depois de recolhidos e tratados, vão ser armazenados?

Os dados não sensíveis recolhidos no âmbito deste estudo e partilhados com o Politécnico de Leiria serão mantidos em arquivos seguros, com acesso restrito, sejam eles eletrónicos ou físicos, de acordo com a legislação guardados por 5 (cinco) anos após a conclusão do estudo. Após terminado o período obrigatório de conservação destes, os mesmos serão totalmente destruídos. Os parceiros de investigação que colaboram neste estudo não estão autorizados a partilhar os seus dados com terceiros

9. Identificar qual o equipamento (computador) a utilizar para armazenar e tratar os dados, e, quais os requisitos de segurança a nível informático.

Não se aplica. O estudo não irá trabalhar com dados sensíveis.

10. Está prevista a transferência de dados entre instituições? Se sim, como se vai realizar essa transferência?

Não.

11. O estudo vai ser publicado?

Sim: (1) em formato de dissertação; (2) está previsto também submeter 1 artigo científico a uma conferência.

12. Qual o período de tempo após a realização do estudo em que os dados são destruídos?

Não se aplica. O estudo não irá trabalhar com dados sensíveis.

13. Como é que os dados vão ser destruídos?

Após terminado o período obrigatório de conservação dos dados (5 anos) os mesmos serão totalmente destruídos. Caso sejam físicos, destruição dos papeis. Caso sejam digitais, serão eliminados

14. No caso de envolver promotor externo e/ou entidades externas, deverão ser elaborados os seguintes documentos:

a) Documento relativo ao tratamento de dados onde fiquem definidas as responsabilidades de cada uma das unidades no processo de recolha, armazenamento e tratamento dos dados;

b) Documento onde estejam identificadas as responsabilidades de todos os intervenientes no estudo.

Nota - A ULSM possui modelos os documentos referidos no ponto 14, alíneas a) e b).

Matosinhos, de 2 de março de 2022

P' Comissão Local de Proteção e Segurança da Informação

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(Ana Paula Teixeira – DPO ULSM)

APPENDIX 2

UNIDADE LOCAL DE SAÚDE DE MATOSINHOS HOSPITAL PEDRO HISPANO	INFORMAÇÃO	Nº 21/CES/JAS Data: 10-02-2023

Para: **Serviço de Gestão do Conhecimento**
De: **Comissão de Ética para a Saúde da ULS Matosinhos**

Assunto: Pedido de autorização para realização de estudo- Analysis *of wayfinding for Healthcare facilities*

INFORMAÇÃO

Exmos(as) Srs(as),

A Comissão de Ética para a Saúde apreciou pedido de autorização para realização de estudo, intitulado *"Analysis of wayfinding for Healthcare facilities", cuja* autora é Mónica Kopplin Carrilho, aluna do Mestrado em Design e Bem Estar na ESA. CR Politécnico de Leiria.

A Comissão de Ética para a Saúde da ULS Matosinhos deliberou por unanimidade, nada opor à realização deste estudo.

Com os melhores cumprimentos

Dr. José Alberto Silva
Presidente da Comissão de Ética
da ULSM Matosinhos

Dr. José Alberto Silva
(Presidente da Comissão de Ética da ULSM, E.P.E.)