DESIGN BEYOND THE EYES:
A WEB-BASED TOOL FOR DESIGNERS WORKING WITH PEOPLE
WITH VISUAL NEEDS

BY

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THESIS
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ABSTRACT

The proportion of the global population who are elderly is growing which will lead to more people with physical conditions including vision loss. Every person with visual needs has different lived experiences considering their living condition, vision condition, and how long they have been living with vision loss or no vision.

There is a gap between the needs of adults experiencing vision loss and the addressing of those needs by existing products and services, due to the lack of a deep understanding of their needs and challenges by designers. Designers who are not familiar with working with people with visual needs have to gain a deeper understanding of their lived experiences and their variety of needs to be able to design for them effectively. Designers need tools and techniques that will prevent them from generalizing the experiences and challenges of their user group, which can lead to considering only one solution for everyone without understanding and considering their individual and different needs.

Although the focus of this project is on the communication between designers and people with visual needs, the individuality of each participant as a human being with different characteristics and experiences played an important role in the path of this project. The primary research included several online interviews and co-creation sessions with people with visual needs and those who have daily communication with them to understand their needs and experiences comprehensively. As a result of the experimental phase, the author realized that there is a need for improving the interactions between designers and individuals with visual needs which would result in a deeper understanding of the real needs of the users to be considered in the design process.

To meet this goal, journey maps (explained below) were found to be the most effective tools that would give the opportunity to the participants to share their experiences safely, openly, and in detail. Therefore, a web-based tool was created for use by designers who are new to the area of visual needs. It provides them with the required information about this area, as well as guidelines for how to proceed with the design process to produce flexible, adaptable, and accessible journey maps that would give space to everyone to share their personal journey.
The components of this tool help designers in the process of creating journey maps with participants with low or no vision. First, designers get familiar with the common definitions that they need to know before starting the interaction with participants including the kinds and causes of vision loss, and existing assistive technologies. Then, they receive guidelines about how to identify their user group by asking the right questions, as well as guidelines for conducting the interviews which would lead to creating the journey maps. The guidelines for creating the visual and non-visual journey maps provide the designers with the characteristics of the maps and how to make them accessible for the participants considering their vision level and their accessibility to technology.
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# TABLE OF CONTENTS

1. INTRODUCTION ....................................................................................................1
2. NATURE OF VISION IMPAIRMENT .................................................................3
3. NATURE OF DESIGN AND DESIGN THINKING ..............................................7
4. HISTORY OF DESIGNING FOR PEOPLE WITH VISUAL NEEDS .................16
5. RESEARCH QUESTIONS/PROBLEM DEFINITION .........................................26
6. EXPERIMENTAL WORK .................................................................................30
7. INSIGHTS FROM EXPERIMENTS .....................................................................68
8. DESIGN PROCESS ...............................................................................................71
9. FINAL DESIGN PROTOTYPE- DESIGN BEYOND THE EYES ......................84
10. CONCLUSION AND THOUGHTS FOR THE FUTURE .................................130

REFERENCES ...........................................................................................................133
APPENDIX A: IRB DOCUMENTATION ..................................................................139
CHAPTER 1: INTRODUCTION

1.1 THE POPULATION WITH VISUAL NEEDS IS GROWING

The proportion of the elderly within the general population is changing in the world and the U.S. People are living longer and there will be fewer children around so that elder care will need to respond to this new condition.

Today, the proportion of older adults in the world population is more than any time (Ejdys & Halicka, 2018). This can be aligned with what Colman (1993) has predicted that in the near future, adults over 50 will comprise about 40–50% of the UK population. Due to these changes in demography, dealing with diversity in physical abilities is gaining more importance. The fact that “the balance between the old and young has fundamentally and permanently changed” cannot be ignored (Clarkson et al. 2013). Although aging is a normal part of human beings’ lives, people generally are experiencing a longer old age than previously in history due to many developments in medicine, science and technology. The elderly population will develop more and different kinds of physical impairment including vision/hearing loss and decline in motor function.

The rapid growth of the population from ages 65 to the mid 80s will cause dramatic increases in the prevalence and costs of vision problems (Wittenborn & Rein, 2014). Horowitz (2004) believes that vision loss has been often accepted as an inevitable and common age-related condition, so people are not aware of its physical and emotional consequences. A survey was conducted by Harris Poll on behalf of the American Academy of Ophthalmology in August 2019 among more than 3,500 U.S. adults age 18 and older. It shows that less than 1 in 5 (19%) can correctly identify glaucoma, age-related macular degeneration (AMD) and diabetic eye disease which are the three main causes of blindness in the USA. Vision loss can also increase social isolation, depression and risk of falls and injuries. It can worsen other chronic illnesses in older adults (Tooley, 2020). Under these circumstances, it is important that the needs of this population are considered in to make a safer environment for them to communicate and get around.
Accordingly, this project looks at data collection methods used as a part of the design thinking process to develop a toolkit to help designers identify and address the needs of the elder population with vision loss or no vision. The aim is to improve their quality of life by designing better products. Through this toolkit, people with vision loss would be able to share their stories and needs with designers to build empathy and help increase the designers’ understanding of the situation. This will then lead to better design proposals to address those needs. End-users will also be consulted to test the solutions and provide feedback.
CHAPTER 2: NATURE OF VISION IMPAIRMENT

2.1 DEFINITION

According to the American Foundation for the Blind a wide range of visual function, from low vision through total blindness can be included in the term visual impairment (American Foundation for the Blind, n.d.).

When conventional glasses, contact lenses, medicine, or surgery cannot fully correct a reduced level of vision, it is considered low vision when it is insufficient to complete daily tasks (The Chicago Lighthouse, n.d.). Macular degeneration, glaucoma, cataract, and diabetic retinopathy are among the eye diseases which contribute to vision loss in older adults (America & Tielsch,1994).

2.2 TYPES OF VISION LOSS

There are two groups of vision impairment, near and distance vision impairment. The latter comes in different levels including mild, moderate, severe, and blindness (World Health Organization, 2021).

Vision loss can vary from low vision to severe vision loss or no vision with a range of visual needs which can even change from day to day (Clarkson et al. 2013). There are different types of low vision including central vision loss, peripheral vision loss, night blindness, colour blindness, blurry or hazy vision (National Eye Institute, 2020). Designers need to learn about different kinds of vision loss to be able to design properly for the relevant users.

![Spectrum of vision loss](image)

*Figure 1: Spectrum of vision loss.*
2.3 EYE DISEASES

The common eye diseases that can lead to vision loss are the following (The Chicago Lighthouse, n.d.):

- Albinism, Corneal Dystrophies & Degeneration, and Cataracts can result in reduced contrast and glare.
- Glaucoma, Retinitis Pigmentosa, and Hemianopsia can result in Peripheral Visual Field Loss
- Macular Degeneration, Stargardt Macular Dystrophy, and Diabetic Retinopathy can result in Central Visual Field Loss.

2.4 PROJECTIONS FOR INCREASES IN VISION LOSS

Vision loss can affect the quality of life in many ways, including finding a healthy lifestyle. It may take some time for those who have lost their vision after childhood to adapt themselves to the new condition. Gradual or sudden vision loss for middle aged and senior people is a challenging situation, and the impact of an unhealthy lifestyle on them would be more serious than for younger adults. According to the National Health Interview Survey (2016), 7.3 million (or 15.1%) of adults ages 65 and up in the U.S experienced vision loss, and 356,000 (or 0.7%) were blind. Although we need more authentic data, it is clear from the stories shared by seniors that the needs of individuals with vision loss are typically not considered by society, and they need more support to make their life safer and better.

Considering the rapidly increasing proportion of the aging population in Unites States, it has been predicted that by 2030, rates of vision loss will double while the risk of severe eye diseases increases particularly in people over the age of 65 (American Foundation for the Blind, 2013). According to Vision Health Initiative (VHI), there are around 12 million people of 40 years old and over in the United States who currently live with vision impairment including:

- 1 million: blind
- 3 million: vision impairment after correction, and
- 8 million: vision impairment due to uncorrected refractive error (i.e., requiring glasses) (Centers for Disease Control and Prevention, 2020).

Figure 2: Projections for blindness in the USA (2010-2030-2050) (National Eye Institute, 2019).
2.5 CHALLENGES FACING PEOPLE WITH VISION LOSS

There are different challenges that older adults who are experiencing vision loss face every day. Cimarolli et al. (2012) have done research on three hundred and sixty-four older adults aged 65 with significant vision impairment due to age-related macular degeneration. The result has been reflected in the following table.

![Table](image)

**Figure 3:** Number/percentage of participants reporting challenges and sample quotes.

In addition to these challenges, independent living (IL) and inclusion are two key concepts that should be considered while designing a product or service in the area of visual needs or any other physical conditions (Institute on Disability/UCED, n.d.).
CHAPTER 3: NATURE OF DESIGN AND DESIGN THINKING

3.1 DESIGN THINKING- A HUMAN CENTERED APPROACH

Tim Brown, the executive chair of IDEO, considers design thinking as an approach to innovation. He stated, “Design thinking relies on our ability to be intuitive, to recognize patterns, to construct ideas that have emotional meaning as well as functionality, to express ourselves in media other than words or symbols” (Brown & Katz, 2009, p. 4).

Design thinking grew out of various strands in industrial design practice, relating to human centered design and Inclusive / Universal design. The term has come to be used to identify those elements of design practice that can be transferred and used across a wide spectrum of human activity, beyond the traditional confines of industrial and product design.

Foster (2021) believes that design thinking as a human centric approach helps the process of problem solving by gaining a better understanding of the users’ needs, brainstorming, reframing the problem, prototyping, and testing the ideas.

Design thinking includes empathy and storytelling. It utilizes various tools to collect authentic data from the target users of a product or service by having them involved in the design process and getting their feedback in the process to make necessary changes throughout the design process rather than only at the end.
3.2 HUMAN CENTERED DESIGN

3.2.1 Definition

As opposed to the traditional design process which focuses on the designers’ personal creative process, the focus of human-centered design techniques is on the questions, insights and activities that are directly related to the end users of the product or service. Human-centeredness focuses on the identity of a product which is defined by how the users perceive the product and how they interact with it (Giacomin, 2014).

Changing from expert to participatory mindset, from designing for people to designing with people is the main goal of human-centered design when design researchers work with people as true experts and co-creators instead of them being just a subject in the design process. Transformation in the focus of design from product to problem when the target users are actively
involved in the process is another characteristic of a human-centered approach which has impacted significantly on the research methods of this project (Sanders, 2014).

3.2.2 Human-centered design tools

Since human experience is not always easy to perceive directly, there are different kinds of tools including verbal and non-verbal to be able to investigate the users’ needs and desires and analyze the information collected from the research (Giacomin, 2014).

A partial list of the most frequently deployed human centered design tools has been provided in figure 5 (Giacomin, 2014, pp 616).

<table>
<thead>
<tr>
<th>Human Data and Models</th>
<th>Capture of Needs, Desires and Meanings</th>
<th>Simulation of Possible Futures</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Anthropometric data sets and models</td>
<td>Verballly based</td>
<td>- Focus groups</td>
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<tr>
<td>- Biomechanical data sets and models</td>
<td>- Ethnographic interviews</td>
<td>- Lead user design</td>
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<td>- Psychophysical data sets and models</td>
<td>- Questionnaires</td>
<td>- Co-design</td>
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<td>- Cognitive data sets and models</td>
<td>- Day-in-the-life analysis</td>
<td>- Storyboard futures</td>
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<tr>
<td>- Emotional data sets and models</td>
<td>- Activity analysis</td>
<td>- Experience prototypes</td>
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<td>- Psychological data sets and models</td>
<td>- Cognitive task analysis</td>
<td>- Para-functional prototypes</td>
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<td>- Sociological data sets and models</td>
<td>- The five whys</td>
<td>- Role playing</td>
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<td>- Philosophical data sets and models</td>
<td>- Conceptual landscape</td>
<td>- Real fictions</td>
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<td>- Word-concept association</td>
<td>- Think aloud analysis</td>
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<td>- Be your customer</td>
<td>- Metaphor elicitation</td>
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<td>- Customer journey</td>
<td>- Extreme users</td>
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<td>- Personas</td>
<td>- Scenarios</td>
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<td>- Contextual inquiry</td>
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<tr>
<td>Non-verballly based</td>
<td>Game playing</td>
<td></td>
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<tr>
<td>- Cultural probes</td>
<td>Visual journals</td>
<td></td>
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<tr>
<td>- Error analysis</td>
<td>- Fly-on-the-wall observation</td>
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<tr>
<td>- Customer shadowing</td>
<td>- Body language analysis</td>
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<tr>
<td>- Facial coding analysis</td>
<td>- Physiological measures</td>
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<td>- Electroencephalograms</td>
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</tbody>
</table>

Figure 5: Human centered design tools.
3.3 DESIGN MODELS AS INSPIRATIONS

Considering the goal of this research, a variety of design models have been studied as an inspiration to get more familiar with different design processes, tools and techniques that can be used in different design projects.

Although the author was inspired by the following models in the design process of this project, it should be noted that some of their features and characteristics were borrowed and were adapted to the nature of this project and the users’ needs.

Two design models that I used to investigate different steps of my design and research process were the Empathy Map and Kumar’s Model of Design Innovation Process.

3.3.1 Empathy map

To create the empathy map, designers pay more attention to what the user says does, thinks, and feels during an interaction with a product or service.

Designers should consider what people:

- Say – quotes and key words.
- Do – actions and behaviors; pictures and drawings.
- Think – motivations, goals, needs, desires, beliefs.
- Feel – emotions, body language, their choice of words, tone of voice (Kelley, 2018).

![Figure 6: Stage 1 in the design thinking process: empathize with your users (Mortensen, n.d.)](image-url)
Inspired by this empathy model, the interview questions were designed to pay more attention to and draw out information about what people do, think, feel and say during the interviews and their daily routine experiences.

3.3.2 Kumar’s design innovation process

As a human-centered design process, the author found Kumar’s model of the design innovation process very helpful and inspiring due to introducing different possible phases of the design process and what tools and techniques can make this process more in-depth. There was a lot of back and forth in the research that this model helped to consider different possible methods of primary data collection specifically to know people and know content.

Figure 7: Model of the design innovation process (Kumar, 2013).

3.4 EMPATHY IS THE KEY IN A HUMAN CENTERED APPROACH

Given the role of designers in increasing the quality of experience for people, they need to understand how individuals feel and respond to different situations. It becomes more important when designers have not had any previous exposure to the situation. Under these circumstances, understanding the target group and the situation requires authentic information.
The challenge for designers in the design process is to elicit authentic needs while appreciating that individuals may not always be able to communicate their needs, or they may be unaware of mundane challenges or embarrassed to share insights into their life experiences (McDonagh 2016, 2017a). As a means for sharing experiences, storytelling and narrative methods can be highly beneficial to meet the goals of understanding real needs. Having individuals share their daily life through open-ended questions or observing them while doing an activity would be examples of storytelling as a qualitative research method for gathering closer-to-authentic information (Corcoran & Stewart 1998, McCormack 2004). Stories can provide design researchers with a deeper understanding of their experience and support designer-user empathy.

Having the end users involved in the design process improves the collection of information and experiences from the end users by direct and constant interactions. Empathic ability helps designers to find the users’ needs and develop solutions for them (Chung & Joo, 2017).

To have the users share their experiences, designers use different storytelling generation methods in the process. This process is also used to tell the story of the products, end users and the interactions between them for gaining a deeper understand of the situation. Considering the importance of storytelling in the design realm, it needs to be discussed further.

### 3.5 STORYTELLING- DEFINITION AND VALUE

Director of the Center for Neuroeconomic Studies, Paul Zack believes “Stories are powerful because they transport us into other people’s worlds but, in doing that, they change the way our brains work and potentially change our brain chemistry, and that’s what it means to be a social creature” (Popova, n.d.).

Storytelling has been used as a communication tool throughout history since the human brain has an innate tendency to form information into stories automatically (Reamy, 2002). The value of storytelling becomes more explicit when it comes to the value of social interaction for sharing knowledge and understanding others. Unlike stories, traditional interview and questionnaire-based approaches have not shown enough capability in understanding patterns of
culture and behavior. Therefore, over the last two decades, there has been a tremendous increase in using different forms of storytelling in organizational levels for sharing knowledge and communicating all details of a situation including emotional aspects (Reamy, 2002; Snowden, 2001).

Storytelling and narrative methods can be highly beneficial in understanding the real needs of users. Having them share their daily life through open-ended questions or observing them while doing an activity are examples of storytelling as a qualitative research method for gathering better data. Narrative methods can provide researchers with a deeper understanding of the user experience and support designer-user empathy. It can be considered not only as a self-reflection tool but also as a method for having others empathize with the storyteller (Goodman & Newman 2014).

Storytelling is a way of sharing experiences and to support communication in user experience design. Story-based thinking helps designers gain a better understanding of the user experience which can lead to developing design ideas within an imagined context (Peng, 2017).

### 3.6 JOURNEY MAPS – A STORYTELLING TOOL

Journey maps are also known as experience maps or customer experience maps and are used to visualize what a person goes through in the process of doing a task. The advantage of journey maps over conventional focus groups is that the journey maps add time as an effective factor to the understanding of user experience. For this reason, the popularity of journey maps has been growing in the design field over the past 30 years. Journey maps show the significant changes of the user’s experience including changes in the emotional level and the user’s needs (Howard, 2014).

Customer journey mapping was created as a means for eliciting emotional responses of consumers to products and services, as well as understanding consumers’ motivations and behaviors. The use of Journey maps is a technique that helps to improve the understanding of the user experience by documenting the different steps they undertake in the process (Crosier & Handford, 2012).
3.7 EXAMPLES OF EXISTING USER JOURNEYS

Characteristics – User journey maps are most commonly visual and use different signs, colors, shapes, and text to communicate users’ experiences. Normally, designers use them collaboratively with the users to get direct real-time feedback on them, but this process is not accessible for people with low vision.

Figure 8: Example 1 (Hanington & Martin, 2019).
As shown in the above images, there are different ways of mapping the various factors that comprise user experience. Depending on what the designer needs to explore, they pay more attention to the factors that affect it such as people and products that are somehow involved in the experience (example 1 and 2), or specific emotions that the user experiences in the process (example 3).
CHAPTER 4 – HISTORY OF DESIGNING FOR PEOPLE WITH VISUAL NEEDS

To address the imbalance between the design of mainstream products and the consumers’ needs, it is preferable that designers expand their perspective from designing the products for a majority of people to considering needs of the entire range of users (Olbrich et al. 2015). The definition of inclusive design defined by the British Standards Institute (2005), inclusive design is “The design of mainstream products and/or services that are accessible to, and usable by, people with the widest range of abilities within the widest range of situations without the need for special adaptation or design,” which results in a better design that satisfies the needs of a larger population.

As mentioned above, poor design can affect some of the user population negatively in a way because they not only do not receive what they need but also feel themselves being excluded and isolated. Although some of the needs of people with low or no vision are addressed by advanced technology, these frequently do not respond to everyone’s needs because of high price or limited access.

Exploring the existing products, services and tools that have been designed for people with different physical abilities can always be inspiring for a design project to see what works or does not work and how the users have been interacting with those products.

4.1 ASSISTIVE TECHNOLOGY PRODUCTS FOR VISUAL NEEDS

- Accessible Mobile Apps
- Tactile Signs- Braille labels and bump dots
- Braille Printers/ Translators
- CCTVs (Closed Circuit Television)/Video Magnifiers
- Deafblind/Multiple Disabilities
- Digital Talking Book Players (Hardware)/ (Software)
- Educational Technology
- Electronic Notetakers (Braille)/ (Speech)
- Refreshable Braille Displays
- Games and Activities
- GPS (Hardware)/(Software)
- Household, Personal and Other Independent Living Products
- Lighting- provide higher levels of lighting.
- Low Vision Optical Devices- a variety of devices, such as stand and handheld magnifiers, strong magnifying reading glasses, loupes, and small telescopes.
- Optical Character Recognition Systems- scan printed text and then have it spoken in synthetic speech or saved to a computer file.
- Screen Magnification Systems
- Screen Readers
- Speech to text- on cell phones and computers
- Independent Living: talking clocks and watches, kitchen items, large-button phones and cell phones, and sunglasses with low vision UV filters.
- Low vision keyboards
- Speech-to-text software voice-activated GPS (American Foundation for the Blind, n.d.).

4.2 DISCONNECTION BETWEEN USERS’ NEEDS AND THE CURRENT PRODUCTS

There are many products on the market that have been designed for people with low or no vision, but often the biggest barrier to adoption is the high cost of specialized design solutions. In many cases, people continue using familiar products by adapting their behavior.

Clarkson et al. (2013) have been investigating a wide range of mainstream products such as cars, telephones, and vacuum cleaners which showed a gap between the design and the consumers’ real needs. They realized that there are a lot of products which do not consider the needs of older people or the needs of people with different physical abilities.
Here are some examples of the mismatch between the products and the users’ needs.

4.2.1 Smart oven for people with visual needs

Although it is designed for the people with no vision using braille buttons, it is expensive and not affordable for individuals with visual needs; they may have lost their job due to vision loss or do not want to spend money on buying new or expensive products. In addition, fewer than 10% of the people who are legally blind in the USA can read braille (Jernigan Institute, 2009).

This is a microwave, conventional oven, air fryer, and food warmer offering accessibility in the kitchen for the visually impaired when paired up to an Amazon Echo. In addition to the accessibility the customer gets by connecting it to the Echo via the Alexa voice interface, they can get a free braille overlay for the keypad. Despite the improvement that this product offers to a person with visual needs, it is relatively expensive and so unlikely to be widely implemented.

*Figure 11: An accessible $250 oven connecting to Alexa for voice control.*
4.2.2 Exercising equipment

Exercising equipment such as treadmills and stationary bikes which are supposed to give feedback to the users are mostly not accessible for people with visual needs. One of the most important components of the treadmill is the panel with which the user is supposed to enter and receive the information. They are mostly designed with a flat surface and digital screen which makes it impossible for people with visual needs to work with them without getting any help especially if they are new users.
4.2.3 Packaging

Packaging is another example of inappropriate design for people with visual needs. Packaging companies do not usually consider making the information about the product accessible for people with no vision. A lot of them are not even accessible for people with low vision due to not considering appropriate contrast between the text and the background as well as the size of the text.

Figure 13: This almond package is not accessible for people with low or no vision – the nutritional facts table is too small to read even for people who do not experience any kind of vision loss. People with low vision are not able to read anything on this package unless they get help from someone else.
4.3 ADJUSTMENT STRATEGIES

Individuals with low/no vision use different strategies such as tactile labeling or change of size or color to make the environment and existing products accessible.

Figure 14: Tactile labeling with bump dots using Velcro, hi-marks, and spotters (Fairbairn, 2014).

A selection of tactile labels including waterproof tape, HI Marks tactile paints and letters, Velcro strip and dots, Touch Dots, and black squares are used to indicate cold warm and hot, or low medium and high on the microwave panel. They are also used to indicate the numbers and power on the TV remote.
There is another level of difficulty in using these strategies. Depending on their vision level, users may need someone else to help them with attaching the tactile labels to the product to make sure they are in the right place. Some companies will offer to do the tactile labeling at extra cost before sending it to the customer.

4.4 HUMAN-CENTERED DESIGN TOOLS

There are a variety of tools for designers to improve their interaction with the users to better address their needs by involving them in the process. Although the following toolkits have not been designed for people with visual needs, they are great sources for designers to generally explore what should be included in designing a toolkit for designers.

4.4.1 A designer's critical alphabet

This alphabet is a deck of cards that designers and design students can use to understand critical theory and reflect on their design process.

Figure 15: A designer's critical alphabet designed by Lesley-Ann Noel.
4.4.2 Design the life you love

This resource is an interactive journal that provides principles and a creative process for the user to build a meaningful future in a joyful and inspirational way.

Figure 16: Design the life you love designed by Ayse Birsel.

4.4.3 Designercise

As an active ideation toolkit for professional play, it is designed to increase flexible, divergent, and creative thinking.

Figure 17: Designercise designed by Leyla Acaroglu.
4.4.4 Racism untaught

Due to an identified gap and opportunity for educators, Racism Untaught has been designed as a toolkit to break down racialized design in the classroom by providing a learning environment focused on diversity and inclusion.

Figure 18: Racism untaught designed by Lisa Mercer and Terresa Moses.

4.5 EXISTING TOOLS FOR PEOPLE WITH VISUAL NEEDS

In addition to studying the existing toolkits for designers, there are tools and guidelines designed by centers or organizations that work in the area of visual needs. Due to their close interaction with people with low or no vision, they can be valid sources for what should be considered in the design of the physical and digital environment.

Here are some examples of the existing tools provided by centers for visual needs. They are more like a document including instructions for people who are going to work in this area.
4.5.1 Wisconsin council for the blind

Accessibility Toolkit
If you’re working to engage people, making your information more accessible helps everyone learn, enjoy and take action. Don’t wait until you get a complaint -- be proactive.

Alt Text
Describe photos or graphics in a document, social media post, or web page. When writing alt text follow these guidelines:
- Context (what are they doing?)
- Concise (use as few words as possible)
- Decrease redundancy (don’t repeat in title or caption)

Figure 19: Accessibility Toolkit for digital documents (Wisconsin Council of the Blind & Visually Impaired, n.d.).

Clear Print Accessibility Guidelines
Print that’s easy on the eyes

Figure 20: Accessibility guidelines (CNIB Foundation, n.d.).
CHAPTER 5: RESEARCH QUESTIONS/PROBLEM DEFINITION

5.1 PROJECT’S GOAL

To design more effective products and services to maintain a fulfilling lifestyle for adults with low or no vision, designers can benefit from a toolkit comprising different data collection methods to help them better understand the needs of users. This project aims at developing and testing such a toolkit by finding and addressing the challenges that the particular user group of people with low vision face.

5.2 GENERAL RESEARCH QUESTION

*How might we design products/services that would help users with low/no vision maintain a fulfilling lifestyle?*

5.3 FOCUSED RESEARCH QUESTIONS

*How might we facilitate the communication between designers and this user group in a design process to collect authentic data?

1. How can designers conduct remote interviews with participants with visual needs to collect authentic data?
2. How can designers create journey maps of users' daily routines to ensure they won’t make unreal assumptions about user’s experiences?

5.4 RESEARCH AREAS

These are the research areas that have been identified based on the final research questions.
5.4.1 Experiment design process

The following techniques were suggested in the beginning for data collection although some of them changed or were tailored based on the participants’ preferences and convenience.

1. Observe remotely via audio/video recording of users doing their daily routines.
2. Semi-structured interviews
3. Remote cocreation sessions

5.4.2 Design process model

Inspired by the existing design process models, this model was developed and adapted to the needs of this project considering the characteristics of the context of the challenges that would be addressed and the participants’ needs.
5.4.3 Storytelling

Storytelling as an experience sharing tool has been used in the design process to collect information from people with visual needs since it helps to:

- Nurture empathy
- Share experiences
- Collect authentic data from the users

5.5 USER GROUP

5.5.1 Primary users

The focus of this project is on designers, design thinkers and design practitioners as the target users who are going to design for people with low or no vision.
5.5.2 Adults with low/no vision – the target users of the primary users

Although the main users of this project are designers, adults with low/no vision were interviewed as well since they are the target users whom these designers are going to work with by using the output of this project to understand their needs and experiences. The interviews were started with people who lost their vision in adulthood, but the author realized that their experiences are different in many aspects although they are all adults with visual needs. Even two different individuals diagnosed with cataract have different experiences depending on how long they have been living with it and what kind of cataract they are experiencing. There is a spectrum for each vision loss disease which can lead to different needs and expectations.

The author tried to make the design process as inclusive as possible by including the experiences of people with different kind and level of vision loss, different years of living with vision loss or even people who were born blind to provide the possibility of looking at this experience from different perspectives. The characteristics of this group include:

- Adults over 40 years old
- Those living with sudden or gradual vision loss or born with no vision.
- People who may also be living with other physical conditions such as hearing loss or declines in motor function.

5.5.3 Secondary users

Although this project is focusing on professional designers as the main users, the toolkit has the potential to be utilized by design students, social workers, activists, policy makers, urban designers, or in general anyone interested in learning about visual needs or working with people with low or no vision.
CHAPTER 6: EXPERIMENTAL WORK

6.1 CONTEXT

The proposed solution of this project is based on the author’s primary research including the meetings and co-creation sessions with the participants and their feedback based on their personal preferences. The toolkit solution of this project is one way to address the identified issue. The guidelines and examples of this toolkit may not be applicable to all users because the lived experiences of individuals with visual needs can be different depending on their vision condition and how long they have been experiencing it. The users of this toolkit are invited to create journey maps with their participants and add them to the journey map collection of this web-based tool. This would help other designers to see how diverse the experiences of people with visual needs can be and consider that in their design process.

The design process of this project was started with investigating the quality of interaction between the existing products and services with individuals with visual needs and how designers are responding to the needs of this user group. The disconnection found between users with visual needs and their environment was the incentive to explore and develop tools. These tools will help design practitioners/ thinkers/ researchers gain more awareness about the area of visual needs and gain more confidence to make the design process more inclusive.

6.2 DATA COLLECTION

Since the primary research took place during COVID19, all data were collected remotely via Zoom, phone, email, and google document/form.

Different resources were used in the data collection phase including people and existing toolkits. This phase of research expanded and developed step by step with the help of initial participants to find more resources and reach out to more people and communities. Those resources included:

1. Participants with visual needs- living with no vision or different levels of vision loss.
2. **Designers**- including design students, professional designers, and design educators.

3. **Communities and centers**- providing free or paid services for people with visual needs and/or other physical conditions. The following Centers were involved.

   - The division of disability resources & educational services at UIUC (DRES)
   - Center for independent living in Urbana, Illinois (PACE)
   - Chicago Lighthouse
   - Illinois Department of Human Services; Bureau of Blind Services
   - Wisconsin Council of the Blind & Visually Impaired

4. **Toolkits**- Existing human centered toolkits with a variety of goals including helping designers to identify exclusiveness and inequity in designed products and services and address them.

### 6.2.1 Recruitment

Terminology: O&M training means orientation and mobility training which gives instructions to individuals with visual needs to travel through their environment safely.

To find potential users who were willing to participate in the research, the author reached out to local or national centers and organizations that provide services for individuals with visual needs. Finding an advocate in in these centers or foundations would help to get connected to some of their customers if they are willing to:

- Vision rehabilitation therapists
- Orientation & Mobility specialists
- Braille teachers
- Occupational therapists
- Social workers, rehabilitation counselors or mental health counselors
### 6.2.1.1 Participants with visual needs

*Terminology: User Experience (UX) designers focus on the whole journey of a user’s interaction with a product and how to improve this experience.*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Vision Condition</th>
<th>Career</th>
<th>Living Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 1</td>
<td>55</td>
<td>Legally blind, color blind but her vision is functional, and she can still see things.</td>
<td>Associate professor</td>
<td>Lives with her husband and daughter.</td>
</tr>
<tr>
<td>Participant 2</td>
<td>57</td>
<td>Legally blind, He can see things, but things are foggy.</td>
<td>Use to do forestry. Lost his job due to vision loss 2 years ago.</td>
<td>Lives with his wife and his toddler.</td>
</tr>
<tr>
<td>Participant 3</td>
<td>60</td>
<td>Born blind</td>
<td>Associate professor</td>
<td>Lives on her own.</td>
</tr>
<tr>
<td>Participant 4</td>
<td>62</td>
<td>Retinitis Pigmentosa (RP), Tunnel Vision</td>
<td>Artist and instructor</td>
<td>Lives with her sister.</td>
</tr>
<tr>
<td>Participant 5</td>
<td>33</td>
<td>Born blind</td>
<td>Media Producer</td>
<td>Lives with her family.</td>
</tr>
<tr>
<td>Participant 6</td>
<td>68</td>
<td>Born blind due to Retinopathy of Prematurity (ROP)</td>
<td>Retired, volunteering at a center providing services for people with visual needs</td>
<td>Lives alone. His daughter lives close by and helps with some daily tasks.</td>
</tr>
<tr>
<td>Participant 7</td>
<td>21</td>
<td>Ashur syndrome—profoundly deaf at birth and lost his</td>
<td>Senior college student</td>
<td>Lives alone at college.</td>
</tr>
</tbody>
</table>

*Table 1: Participants with visual needs.*
was his mom). Vision in 2 years old due to Retinitis Pigmentosa.

| Participant 8 | 50 | Went blind in adulthood about 10 years ago. | Teaches individuals with visual needs | Lives with her husband and teenage children. |

Table 1: Participants with visual needs.

### 6.2.1.2 Designers, trainers, and occupational therapists

<table>
<thead>
<tr>
<th>Career</th>
<th>Number of people</th>
<th>Experience of working with individuals with visual needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>UX designer/researcher</td>
<td>4</td>
<td>2 of them are inclusive designers experienced in vision impairment</td>
</tr>
<tr>
<td>Designers and educator</td>
<td>4</td>
<td>One of them lives with severe vision loss</td>
</tr>
<tr>
<td>Industrial designer</td>
<td>2</td>
<td>They have no experience in this specific area.</td>
</tr>
<tr>
<td>Master’s student in Industrial design</td>
<td>3</td>
<td>They have no experience in this specific area.</td>
</tr>
<tr>
<td>Orientation and mobility trainer</td>
<td>1</td>
<td>She has been working with people with vision loss for 20 years.</td>
</tr>
<tr>
<td>Professional occupational therapist and students in occupational therapy</td>
<td>4</td>
<td>They work with people with visual needs.</td>
</tr>
</tbody>
</table>

Table 2: Designers, trainers, and occupational therapists.
6.3 PREPARATION

In preparation for starting the primary research including the interviews with the participants, the IRB approval was the first step. Institutional Review Board protects the welfare of human subjects in any research conducting within a university. While working on the IRB materials, the ongoing secondary research was taking place to investigate the current situation.

6.3.1 Ethics in human-centered research

Using a human centered approach to collect authentic data about the target users and for the primary research required the participation of the users in a number of ways. Online interviews and phone calls were conducted as two main methods of communications considering participants’ technology access and the need to not having face to face interactions during COVID19. Although no in person observation or communication happened in the research and design process, there was still the need for keeping the participants’ information safe and ensure them that they would not be exposed to any by taking some ethical actions. Institutional Review Board protocols help in building the trust between the researcher and the participant to provide a safe space for them to share their experiences.

6.3.2 IRB (Institutional Review Board)

Since the information and experiences of human beings involved in this research as participants were shared with the researcher, on the rights and welfare of the participants their information should be kept anonymous. The IRB protects the rights of research subjects or participants by reviewing all the research documents and activities that somehow include the participants. There are different documents that the IRB reviews including application or protocol, the consent/assent document(s), research equipment form, tests, surveys, questionnaires, measures, and recruitment documents (The Urbana-Champaign Office for the Protection of Research Subjects, n.d.). These documents should be submitted and confirmed for conducting any primary research in affiliation with the university.

The IRB process of this project including preparation the materials, getting feedback from the IRB staff, the review process and required modifications, and getting approved took
about one month and a half. Although it took a while to get it done and start interviewing the participants, the IRB really helped to organize the whole research process and figuring out what tools, techniques and vocabulary should be used in communication with the participants.

All participants with visual needs received a consent form with the first email that was sent to them. The whole process was explained in the form including the goal and process of the research, what was expected from the participants to do and how many times they would be engaged in an activity or conversation. However, it was mentioned in the consent form as well as the first meeting that all the data collection methods will be adapted to the participant’s preference, and they were free to stop their collaboration anytime at any stage.

6.4 IDENTIFYING THE USER GROUP

The process of identifying the user group started from the beginning during collecting the background data and continued during the time that the interviews were conducted. After getting the IRB approval, the primary research was started with the initial interviews.

Narrowing down the direction of the project to a toolkit for designers who are going to design for people with low or no vision helped to identify the user group. Although the main user group are design practitioners and design thinkers, the needs, and characteristics of participants with low/no vision should be considered in the process due to the interactions between them and the primary users.

Figure 23: The user group diagram.
6.5 EMPATHY INTERVIEWS

In the discovery phase of this project, interviews were aimed at gaining a deeper understanding of the participants’ experiences and feelings to prevent making biased assumptions and to help identify the main user group and their characteristics. Asking open-ended questions in one-on-one conversations with the participants during the empathy interviews would help to elicit stories about specific experiences (Nelsestuen & Smith, 2020).

The following criteria have been considered in designing the interview questions to get an unbiased result as much as possible:

- **Give space** to the participant to share their own stories. Be aware of the questions that could trigger a past trauma.
- **Stay Neutral** during the interview and do not suggest an answer.
- **Be aware of your own bias** before, during and after the interview (Nelsestuen & Smith, 2020).

6.5.1 Interviewees

The interviews were initiated by reaching out to professional designers, design students, and experts in vision impairment. The interviewees helped to make connections with potential participants and resources including individuals, centers and communities who are somehow related to the area of visual needs.

6.5.1.1 Designers and design students

These interviews included Industrial designers and UX designers who have been working on relevant projects or have no experience in working on visual needs.

6.5.1.2 Experts in vision loss

The initial interviews with orientation and mobility trainers, and braille teachers were meant to give a general understanding of the area before talking directly with individuals with low or no vision.
6.6 INTERVIEW’S STRUCTURE AND QUESTIONS

Semi structured interviews included some questions to make sure the required information was collected. All the interviews started with some basic questions about participant’s age and career and continued with what they wanted to share about their experiences and if there were any significant questions left with no answer, they were asked directly.

Based on the participants’ preferences, different media were used for the interviews. Although all the interviews with designers and trainers were conducted in Zoom, participants with low or no vision had other preferred ways of communication including phone calls, emails, and sending messages which needed various tools to be able to share the information and give feedback in cocreation sessions.

6.6.1 Zoom interviews

Participants were asked in the first meeting if they were comfortable with sharing screen and working online collaboratively. It was interesting that video conferencing was often not comfortable for participants with low vision.

6.6.2 Phone interviews

Some participants preferred to talk on the phone because they did not have access to laptops, or because they felt more comfortable with a phone call.

Different questionnaires were designed for individual and group meetings with the interviewees.

The suggested questions that were shared with the participants before, during or after the meetings are discussed in the following sections.
a. Questions for O&M trainers

In addition to designers and individuals with visual needs, people who have been working directly with this user group have plenty of knowledge about their daily experiences. They spend a lot of time with people with low or no vision so that they gain a deeper understanding of their challenges to find appropriate strategies to address them.

**Questions**

- What is your career?
- What kind of training your clients get?
- Do you teach a certain age?
- How long does it take them to finish their trainings? What are the factors that change the length of the trainings?
- What are the specific needs and challenges that they have in different ages?
- Any differences between teaching someone who lost their vision recently and people who have been living with it for a longer time?
- How COVID19 has impacted the training process?
- Anything else you want to share?

b. Questions for designers

Interview with designers at this stage helped to understand what they know or do not know about the area of visual needs and what they need to increase their expertise in this area.

**Questions**

- What is your career?
- What does vision impairment mean to you?
- Have you ever worked on any projects related to people with visual needs? If yes, what was it?
If you are going to design for people with visual needs, what would help you to do that?

What would you need in the research and design process?

c. Questions for participants with low or no vision

Vision loss varies from low vision to severe vision loss/ no vision. Asking the following questions from the users before getting started would help identify the user group and their needs. If these questions were not already answered, they were asked at the end of the conversation. The interview was attempted to be an open and friendly conversation and let the participant take the lead in terms of what to share.

Questions

If you do not want to answer any of these questions, please let me know and we can skip that one, or we will remove that activity.

Your age, degree of vision loss, and other health related conditions will be disseminated anonymously in the research.

- Given the description of the project that I shared with you in the email, is there anything you want to talk about or share in the beginning? I am going to talk less and hear more about your experiences and what you would like to share with me.
- Tell me about a usual day of your life …
- Tell me about a time when you experienced something unexpected or unusual in your daily routine…

The following questions were asked or considered during the interview to understand the participant’s vision condition.

- How old are you?
- Do you have any vision experience?
- If so, when did the vision loss happen/start?
- What type of vision loss are you experiencing?
- Is it partial or complete vision loss?
- Was it sudden or gradual?

The following questions were considered through the whole conversation to understand the participant’s living condition:

- What is your career?
- Do you live alone or with others?
- Do you have any assistant to help you with your daily routines or any other activities?

The following question meant to help the author get more information about the daily challenges of the participant:

I am interested in learning more about the quality of interactions between people and their environment to be able to the environment more inclusive and accessible for everyone, so I would like to ask you about some aspects of your daily routine.

- What can you tell me about challenges in doing some daily tasks like cooking, shopping, using transportation, doing exercise, etc.?
- Is there anything else you would like to share?

These questions were adapted to each participant’s preference and responses during the meeting. Although it was preferred to have more than one meeting with each participant, the number of meetings changed based on their availability. The first and second interview questions were combined for those who were available for just one meeting.

d. Sample email sent to the participant for the first interview

To ensure that the language and vocabulary were appropriate, an expert in visual needs gave feedback on the content and language of the email to make it more welcoming and less
scientific. This is a sample email that was sent to the participant to ask if they are interested in participation.

**Content of the Email**

“Hi,

I am Shafagh, a graduate student working toward creating a tool for healthcare providers or any other individuals who work with adults with vision loss in the process of providing a more accessible environment for them. I am researching how vision loss affected the daily routines of adults to live a healthy lifestyle. What does a healthy lifestyle mean and how do adults with vision loss adapt themselves to this new routine?

I would love to interview you, or others you might think of who lost their vision in adulthood, and your family members and/or paid support workers to gain a deeper understanding of the situation to be able to improve the quality of products or services so that they play their roles in an effective way.

In the interview, I would introduce you to the next step, and if you are willing to do that, I will explain the details which is going to be audio/video recording some of your daily routines and give feedback on the challenges in communication with your environment. This would be like a daily or weekly journal that can happen one time or multiple times. Making this journal for a couple of days could be very helpful for me to understand what should be changed in the surrounding environment or the products to improve the experience in connection with them.

I would say, this is a learning journey for me when I would listen to your stories and experiences which can lead me to a better understanding of what should be provided to improve your experiences in connection with the environment. I hope we can take this journey together because without your help I will not be able to do it.

I would appreciate your participation and I am looking forward to hearing from you and working with you soon.
e. Feedback questions for a group meeting with occupational therapists

A group meeting was conducted with some occupational therapists who have worked with people with visual needs. The goal of the project was presented to them, and they shared their experiences and ideas about the proposed solution. An activity was designed for the meeting, but it did not happen because the number of participants were not enough to do that, so only a group discussion was conducted instead, and the participants answered the google form questions at the end.

**Google Form Questions**

*I would appreciate your feedback on the whole session including the presentation, activity, and discussion.*

**Background information**

- What is your career?

- Have you been working with individuals with visual needs? If yes, how long?

- What kind of interactions have you had with individuals with visual needs?

**Feedback on the Meeting**

- The presentation was concise and informative.

| Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
- The purpose was communicated clearly and was easy to follow during the presentation.

Strongly Agree  Agree  Neutral  Disagree  Strongly Disagree

- What did you like most about this meeting?

- Say a couple of sentences about each part of the meeting including the presentation, discussion, and the Jam board activity. What did you or did not you like about them? How can they be improved?

- Please share any related stories or experiences if you would you like to.

Thank you for your participation and helping me through this journey!

Please reach out to me with any questions at shafagh2@illinois.edu.

6.7 SELF-DOCUMENTATION THROUGH VIDEO/AUDIO RECORDING

The next step in the data collection process was the observation to gain a better understanding of what the users with visual needs experience in their daily routines. Since the in-person observation was not possible during pandemic, the participants were asked to video/audio record their activities. However, no information was received from the participants for different reasons including COVID19 and technology accessibility. It was difficult to send appropriate video/ audio recording equipment to the participants during pandemic which made the task difficult to perform and needed more time and energy. Therefore, it did not happen although the participants seemed to be interested in doing it in the first meeting.

To focus on the experience and revealing the unexpected, collecting data by video recording has been adopted from the field of visual anthropology (Kumar, 2013). It is utilized to capture people’s behaviors and interaction with their environment including products, services, and other individuals. It should be noted that using this method requires a consent form from the participant who is going to be recorded even if the collected information is going to be used anonymously.
The following questions were designed for the self-documentation task by video/audio recording. They were asked from 3 interviewees with visual needs in their first meetings, but they were removed for the other interviewees because no recordings were received from the participants.

**Interview Questions- They were removed from the research process.**

*Thank you again for participating in this study. The next stage is collecting information about your daily routines while you are doing them. To be able to gain a better understanding of your daily routines remotely, I was wondering if you are willing to self-document some of your daily routines including cooking, using transportation, doing exercise, and healthcare tasks using any of the following methods.*

- Audio recording the activity during or after doing it.

- Video recording the activity by yourself or someone else.

- Taking pictures (by yourself or anyone else) of any changes that you have made in the environment to make them accessible.

- Answering daily questionnaire about the activities.

*You can do it in two different ways depending on your preference:*

- Choose two or three activities from the list and record them in 3 different days including the beginning of the week, the middle of the week and on the weekend.

- Make a list of your daily routines and choose some of them to record based on your preference in any days. You can even include some unexpected and unusual activities.

- If you are going to do this activity, is there any other task that you consider more important or more challenging that should be included in the list of tasks?

- Do you have any concerns or questions about this activity?
Although the participants showed interest in doing this activity, nothing was received from them in the next 3 weeks. Only one participant sent a few sentences about each task which was not what was needed for the research.

6.8 CO-CREATION WITH PARTICIPANTS REPLACED THE VIDEO/AUDIO RECORDING

The role of the designer as a facilitator became more obvious and significant at this stage when participants were not comfortable enough with the data collection method. The new method that was proposed and tested for remote data collection and some of its details were developed over time was engaging the participants in cocreation sessions with the designer on the phone or in zoom. The designer facilitated the cocreation session to give space to the participants to share their stories and give feedback on proposed solutions.

Participants with visual needs preferred this method since it was less confusing for them in terms of what should be covered in the journey. Also, it was more time efficient to have direct access to the interviews when they were sharing their experiences so that they could answer any questions that would come up regarding their journey.

After the second interview, they also were asked to give feedback on the journey maps created based on their daily routines in a cocreation session. Then, the journey maps were revised based on the participants’ feedback to make them as close as possible to the real situation and decrease the unreal assumptions about participants’ experiences.

6.9 SECOND INTERVIEWS

As mentioned above, the second interviews that replaced the video ethnography were aiming at having the participants share their daily routines and their challenges of the interaction with the products and services.
6.9.1 Questions for the second interview

Not matter what the level of vision loss was, some participants preferred a phone call, and some preferred a zoom meeting. However, it was mostly based on their access to technology. Not having access to a laptop, 2 interviewees preferred individual phone calls and the rest happened in individual zoom meetings.

The participants received a list of daily routines via email before the interview.

### Questions

- Getting dressed (or any relevant task)
- Access to Doctors/ Healthcare Tasks
- Budget management
- Managing the Mailbox
- Cooking
- Doing exercise
- A career/ study related task
- Using transportation/ Commuting
- Anything else you want to add to the list

The participant was asked to determine the level of difficulty of each task while talking about them. As the data collection tools and techniques were developed in the research process by testing and getting feedback, the step of ordering the tasks from easy to difficult was only conducted for one phone interview and 2 zoom interviews, then it was removed for the next interviewees.

6.9.1.1 Phone interview

After a quick brainstorming on how the ordering can be performed easier, the participant was asked to assign a number to each task depending on the level of difficulty:
Participants usually did not have any preference in starting with a specific task, so the designer took the lead in making this decision to make the process less overwhelming for the participant. Notes were made during the conversation and the participants were asked if they would allow to record the session so it could be used in case any detail was missing in the notes.

Figure 24: Notes from the phone interview.

6.9.1.2 Zoom interview

Participants were asked if they have access to google doc or word document so that the list of tasks could be shared with them, and they could work on them together in the meeting.

- A google doc including the tasks was shared with the participant.
- They were asked if they prefer to write in the document or want the researcher to do it.
- They wanted to take the lead in this part, so they started working on the document after being asked to assign the level of difficulty to each task.
- Each participant used their preferred vocabulary and put it near each task such as: easiest, medium, not too hard, a bit more difficult, super easy, medium-hard.
- Then, they started talking about each task. In this stage participants preferred different ways of performing the activity. One of the participants experiencing tunnel vision preferred to work on the document on her own in a couple of days.

6.10 FORMS OF THE JOURNEY MAPS IN THIS PROJECT

1. **Narratives**- The whole primary research started with the storytelling during the interviews and the narratives communicated by the participants. Accordingly, the visual and non-visual journey maps were created to illustrate the participants’ lived experiences including their feelings and interactions.

2. **Visual**- They were made in Miro as a collaborative platform to make it possible for the researcher and the participants to work on the journey maps collaboratively in cocreation sessions.

3. **Non-visual**- It was used for participants with no vision or those who did not have access to a large screen like a computer to open the visual journey map and give feedback on it.

Although the process of creating the journey maps including before, during and after the activity can be performed differently for different participants based on their vision condition and technology accessibility, here are the steps that were taken in this project in addition to considerations to make the journey maps more adjustable and inclusive.

6.10.1 **Narratives extracted from the interviews**

Considering the various vision and living conditions, they all shared many different experiences and strategies they have used to address a challenge. The following stories have been extracted from the interviews:

- “My biggest challenge is recognizing people. Also, technology wise, my challenge is dealing with the little icons. Any app usually has little icons at the bottom that tell you
what this is, but they are all visual and I have to memorize where each icon is, and that makes me probably lose interest.” *Quote from a participant who is legally blind and has functional vision to get around.*

- “I had a stroke in my left eye. After a couple of months, it happened to my right eye. Everything is foggy. I’m losing my vision gradually. When it happens to you, you don’t know what you need. There is a period of confusion and adaptation. Also, pandemic has made the training process slow and difficult. The face-to-face training is not happening now, and an online training is not efficient.” *Quote from a participant who is legally blind and screen reader is the only assistant technology he uses so far.*

- “I would identify my visual condition as legally blind. I have a tunnel vision, and I wear glasses. That is why people assume that I can see everything. The nurse came into the patient room and asked me to sit on the chair. I said, could you show me where the chair is? It gets frustrating when I need to explain my visual condition to everyone because they make assumptions.” *Quote from a participant Retinitis Pigmentosa (RP).*

- “We used to have older blind caseload and a caseload for homemakers. For adults who were not trying to go to work, and just trying to manage the household, we can no longer serve them with free orientation and mobility (O&M) training, teaching braille and so on. There is no place for them to get that training unless they go to some other centers and pay for the training. So, people who need the cane training, do not always get it.” *Quote from a teacher with vision loss working at a center giving services to individuals with visual needs.*

- “They think the cane is the most visible symbol of blindness. And they think that if they use the cane, then people will see them as an easy target to rob them, and they will never be able to identify me. I tell people, you look less like a victim, when you use that cane. I said if you're shuffling along the sidewalk, and your head is looking down at the ground you can't see other people coming up around you or pay attention to anything else. And that is an easy target. If you have got a cane, and you're walking with confidence down the sidewalk like you can see, they don't know that that's necessarily a cane for people who are blind. And you look like you're aware, you look like you're seeing everything. And you look like you got a weapon. You look less like a victim, and a target, when you can walk confidently.” *Quote from a sighted orientation and mobility trainer.*
6.10.2 How to create a visual journey map?

Miro as a visual collaborative platform was used to create the journey maps for the participants with vision loss who were comfortable enough playing with visuals although their level of interaction could be different. Miro was selected as an appropriate collaborative platform to be able to get real time feedback from the participants and change the shapers, text, colors, and composition if needed. Miro is a digital whiteboard used for different tasks such as brainstorming and creating user journeys in a live session. All the information will be saved there and accessible for all collaborators to work on that anytime they want to. Here are some suggestions for creating the journey map in Miro based on what has been tested in this research:

<table>
<thead>
<tr>
<th>Stages of Creating the Visual Journey Map</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Questions</strong></td>
</tr>
<tr>
<td>The author thought about the following questions before creating the journey maps:</td>
</tr>
<tr>
<td>- What is your key question and what do you want to get from this journey map?</td>
</tr>
<tr>
<td>- Who do you want to test via the cocreation session with the participant?</td>
</tr>
<tr>
<td>- What do you expect the participant to do during the session? (e.g., sharing the experience of doing a daily task)</td>
</tr>
</tbody>
</table>

6.10.2.1 Steps and suggestions for co-creation in Miro

1. The following items were considered in creating the journey map (they can be adapted to the specific needs of other users with visual needs). They have been adopted from the factors that are considered in different maps such as empathy map which helps to understand the users’ needs. According to Campese et al. (2019), data collected from the users can be categorized to what they see in their environment, what they hear, think, say, and do, what are their difficulties and achievements:
- Say, think, do: quotes and key words from the participant, what are their needs and desires, what actions have taken place, what strategies they have used to handle the situation.

- Touchpoints: usual contact medium, images, etc.

- People: whom the participants had interactions with

- Senses: that the participants rely on most in a specific situation

- Feelings: they experienced during their journey

- Insights (for designers): a good thing that was observed or heard during the research

- Opportunities (for designers): what can be done better, not a solution but an observation or a thought

2. For each task that the participant shared in the previous meeting, one journey map was created in Miro. The existing journey map frameworks can be used as an inspiration to find what is more suitable to what the author needs.

3. If the participant is going to interact with the map visually, the most important feature of any tool that is going to be used to create the journey map is the possibility of zooming in/out.

4. The journey map of the most challenging task was created first to help figure out the details of the next journey maps easier and faster. The task was mapped out from the beginning to the end based on the last interview with the participant with low or no vision. It was shared with the participant in a cocreation session in Miro or word document to get their feedback. Then, the journey maps of other tasks were created based on the participant’s feedback in the cocreation session. They were shared with the participant after the meeting to get their feedback. The participants gave their feedback on the Miro board for the author or if they preferred in another zoom or phone meeting.

5. In this project, the participant was invited to the Miro board by an invitation link. They opened the link, received an invitation from Miro, created an account, and got into the Miro board.

6. The following instructions were shared with the participant in the beginning of the session before going through the map:
- How the Miro works including screen setting bar, how to pin/unpin the map and find their location on the map.

- Details of the journey map including the senses icon, the emojis, how to add and move a text box, and zoom in and out.

- The goal of the emotions (their feelings during an activity) and the senses (the senses they have used during an activity) icons to prevent any confusion.

7. The author and the participant went through the journey map of using transportation and got participant’s feedback on it.
8. The features of the map were adapted to the participant’s vision condition based on the first interview or previous information that has been received about their vision condition.
9. Different colors and shapes were included for the icons so that the participant could choose among them in the meeting. If possible, different colors should be tested in the collaborative tool (Miro in this project) during the session to see which color and shape is easier to distinguish for the participant. They may eventually pick a color and shapes that were not even considered by the author.
10. To make sure that everything was easy to read and distinguishable, the participant was asked to give feedback on the colors, shapes, the composition of the journey map, and any other part of the map with which they had direct interactions.
11. The author realized that the size and color of the text and shapes would be more significant to be considered in the map:

- Size: Please let me know if the icons/shapes are clear enough. Is the text/shape too small?
- Color: This one is blue (since the participant might be color blind, it is better to mention the color). Do you like it, or would you prefer trying a different color?

12. The author opened the color palette and started trying different colors while they were telling the participant what color they were.
- Let us try yellow, how about light/dark green? I am trying different colors, let me know which one looks better.

The participant said the yellow had more contrast with the text in black, so they preferred the yellow for the text box.

13. The participant was asked to go through other tasks later and answer the author’s questions that was marked by a question mark icon. The participant would answer the questions and could put her questions/comments on the map.

14. The participants who were going to give feedback on other journey maps on their own were asked to do the following tasks:

- Please comment on any part of the map that needs any changes.

- Please add any new emotions in a blank oval that have not been mentioned in the map guide.

- Please add any questions or comments on the map.

15. The participant was asked in the beginning how they want the author to be engaged in the cocreation session. They were asked to let the author know whenever they wanted them to jump in or if there is any part that needs more clarification by the author.

16. Sometimes it is just the matter of going with the flow and paying more attention while the participant is working on the map to notice where you need to jump in and help the participant without making any distraction instead of asking them repeatedly if they need any help. Move to regular text.

**Participant's Feedback**

The participant was asked for any feedback or suggestions which would be considered in creating the journey maps of all other tasks. Here is the feedback from a participant with low vision and color blindness which was applied in or after the meeting. However, it should be...
noted that these may only work for this person because each participant could have different needs and preferences:

- Since the map is usually zoomed in on a specific part while the participant is working on it, there should be multiple movable map guides on different spots of the journey map so that the participant has access to it easily and does not have to zoom out and go back to the guide map every time they need it. This will help to speed up the process and make the interaction easier.

- For the sense’s icons, the filled in black ones are easier to see and distinguish than the white ones.

- The emojis are sometimes confusing. “I don’t mind if it’s an emoji or a text to show the feelings”, participant said.

- “For text boxes, the black text on yellow is good”. Participant with low vision and color blindness although everyone should be asked what they would prefer.

- “The contrast is important for me”.

- “It was easier to write things instead of asking you to do it”.

- “Maybe I could write, and you (the designer) put emotions and senses”.

- “It makes sense to follow map. I could see the flow”.
6.10.2.2 Next steps

At the end of the meeting, the participant received the following instructions for the next steps:

- The rest of the maps will be shared with you when they are ready, and you can work on them on your own or in a meeting.

- You can put your questions and comments there and let the author know if you have any questions while working on the maps.

Participants were asked to pay attention to the following items while working on the map:

- If possible, please record you screen while doing this activity for at least one task.

- Use the character icon in the map and change it to the name of the specific person whom you had an interaction with during the journey such as a bus driver.

- Use the object icon to show the touchpoints in different steps of the journey if applicable.

- Use the senses icons when you want to include sense(s) that you were mostly rely on in the situation.

- Use the blank comment box when there are any new senses, emotions, or objects that were not mentioned in the map, and add the box to the relevant spot.
6.10.2.3 Getting feedback on a visual journey map in Miro

Figure 25: Cocreation and getting feedback on a journey map in Miro with a participant with low vision and color blindness, the participant is testing different colors for the text and the box to find an appropriate contrast.
Figure 26: Cocreation and getting feedback on a journey map in Miro with a participant with Retinitis Pigmentosa (RP)- Tunnel Vision, the participant is going to work on the map in Miro on her own, but she is giving feedback on the design and the components of the map in the meeting.
6.10.2.4 Example of the visual journey map created in Miro

From left to right, the journey map shows the process of doing a task including the details which is using transportation in the example. Also, from top to bottom, different aspects of a task can be presented so by moving to the next line, a different component of the task can be discussed.

Figure 27: the function of horizontal and vertical directions of the journey maps.
a. Before Participant’s Feedback

The following diagram is the first Miro journey map of using transportation by a participant that was created based on the participant’s experiences that were shared with the author.

![Diagram of Transportation Journey Map]

*Figure 28: First version of the journey map of using transportation.*
b. After Participant’s Feedback

After getting feedback from the participant on the first journey map, the author applied all necessary changes which resulted in the following map as the final version.

![Figure 29: Final version of the journey map of using transportation.](image-url)
Figure 30: Stage 1 of the using transportation journey map, Before.
Figure 31: Stage 2 of the using transportation journey map, During.
Figure 32: Stage 3 of the using transportation journey map, After.
6.10.3 How to create a non-visual journey map?

For participants with no vision or participants with low vision who use screen reader (text to speech) or speech to text, a non-visual journey map was created for their daily routines.

The following document was first made in Google doc to consider the possibility of working on it together with the participant to get their immediate feedback in a meeting. One table with a couple of rows and columns was made for each task to order the steps and the details of each task.

![Figure 33: The first version of the non-visual journey map shared in Google doc.](image-url)
Figure 34: Co-creation in Zoom with a participant with no vision. The participant is suggesting an accessible format for the nonvisual journey map by using headings.

6.10.3.1 Participant’s Feedback

The participant was asked if the whole document is accessible, and the following is the participant’s feedback on the functionality of the first version of the non-visual journey map which led to the second version using a word document:

- “We cannot work on this collaboratively in google doc because the screen reader does not work well in google doc”.
- “It takes time to understand what is happening in the table while using a screen reader so it would be confusing”.
- “If you make the title real headings, in browse mode I can use shortcuts like ‘H’ for headings or ‘T’ to skip through tables”.
- “I can be in browse mode or in edit mode when reading the document”.

65
There were other challenges for giving feedback on the non-visual journey maps by the other participants:

- A participant with no vision: “I don’t have access to laptop now so I can’t check the file”.
- A participant with low vision: “I worked on it on the phone and my eyes got tired. I’m sure I have missed some details in the document although my phone screen makes the document accessible by increasing the contrast between the text and the background color”.

**6.11 SUMMARY OF THE EXPERIMENT INSIGHTS**

In the whole data collection process, the welfare of the participants was the most significant factor. This helped a lot to build trust between the author and the participant. There were participants who stopped answering the emails or messages after a while, and those individuals were not pursued further.

Not getting any response for the video ethnography proved that the video/audio recording was not efficient and practical. Therefore, it was replaced by a more feasible and realistic method to collect more authentic data. It may happen in any design project that the designer needs to find a more practical method to collect data. The nature of a human centered approach is flexibility, learning from failure and paying more attention to the participants’ needs which were considered in this experiment phase of this project resulted in creating three different forms of journeys including narrative, visual and non-visual journey maps. This approach provided the possibility of addressing a wider range of needs.

Although the level of difficulty of the tasks was supposed to be determined by a number during the interview, ordering them from easy to difficult was not much helpful and this step was removed from the next interviews because of a couple of reasons:

- The participant’s assumption of the level of difficulty was different from what it really was when they started talking about the task. This was a good observation about the level of difficulty and how much the user’s assumption can be different from the reality.
- Since each task can include different subtasks, it is not easy to assign one number to all of
  them. For example, getting dressed and clothes related tasks was assigned number 1 in
  one of the interviews but when the conversation continued, it was revealed that the level
  of difficulty for other related tasks is different. The participant mentioned that an assistant
  is needed to figure out the size and color when he intends to buy clothes in a store.
- the online shopping would be different because some websites are accessible, and people
  can figure out the details of an item by using a screen reader.

Although it was assumed that it would be difficult for the participants with no vision to
share a document in the meeting and give live feedback, it was a wrong assumption. The
researcher should be cautious about the methods they use to ensure that they are adapted to the
participant’s comfort zone, but they should not underestimate the participant abilities when they
do not have enough information. The best way is that they always ask direct or indirect questions
to prevent unbiased assumptions. Contrary to what was assumed in the first interview, a
participant who was born blind was totally comfortable with using different technologies and
sharing ideas and experiences and giving live feedback. It was an observation that was made in
the last meeting when the participant suggested to share her screen to show how she works on
word documents. She was using two headphones simultaneously, one for the zoom meeting and
one for the screen reader.

Even though there are individuals with visual needs who need to have access to necessary
training to get used to their new living condition, they do not have easy or free access to it.
Providing faster and easier access to required training for people who have recently lost their
vision would improve their mental health as well as physical health.
CHAPTER 7: INSIGHTS FROM EXPERIMENTS

7.1 INTERVIEW INSIGHTS

Here are the following insights concluded from the interviews.

1. In addition to the users with visual needs, their network including family members, O&M trainers, braille teachers, and occupational therapists should be interviewed.
2. To create a safe environment, it is suggested that direct questions about the cause of vision loss should not be asked unless participants are willing to talk about it. Also, they should have space to start talking about anything related to their lived experiences.
3. Interview starts with general questions and depending on the participants’ responses, follow up questions can come later.
4. Avoid asking too many questions- Participants decide when to stop or continue the conversation and having too many questions may be discouraging.
5. Alternative methods of data collection should always be considered in case the first one does not work for the participant.
6. Depending on the profession and the length of vision loss experience, the level of confidence in using different assistive technologies may vary.
7. Phone interview- if the participant’s feedback is needed, everything should be read for them in an appropriate pace. They should be repeated if the participant wants to.
8. Zoom interview- documents can be shared with the participants in a google doc or a word doc. If working together on the document, the participant should be observed carefully to understand if they want the designer to take the lead or not.
9. Any activity that is designed for the participant to perform on their own, should be specific enough to avoid any confusion.
10. In a remote observation, video ethnography may not work to collect data from participants with visual needs since usually someone else should accompany them.
11. Recording a video/ audio on their own can be challenging for participants with visual needs because they are not able to see the recording and make sure it is aligned with the need of the project.
12. It should always be considered that the participant’s assumption of a subject can be different from what they really feel so indirect questions should be asked to ensure that the response is close to a real situation.

7.2 JOURNEY MAP INSIGHTS

The co-creation sessions and meetings for getting feedback on the visual and non-visual journey maps from the participants resulted in the following insights.

1. Interview and cocreation mediums should be adjusted to the participant’s preference and their access to technology.
2. Before making any assumption about what the participants prefer to do, they should be asked and provided with the available options and see which one works for them.
3. Size and color of the journey map components should be adjustable to the participant’s needs.
4. A voting tool/sticker for cocreation of visual journey maps would help to choose among different options based on participant’s feedback.
5. Every component of the visual journey map should be adjustable as much as possible to tailor it to the participant’s needs.
6. A moveable map guide for the visual journey map would make the interaction faster and easier for the participant with low vision.
7. A simple Google doc can be used for the non-visual journey map for those who use the NVDA screen reader.

7.3 TOOLKIT INSIGHTS

The following insights were concluded from evaluating the existing toolkits.

1. Shift of mindset- the tool can include information, resources, and guidelines for the whole design process or only some stages to change the mindset in designers who have not been communicating with people with visual needs or have unreal assumptions about the needs of this population.
2. Individual or group- depending on the situation and the participants’ preferences, the toolkit can be used individually by the participants, or in groups of 3 to 4 participants with different kinds of vision loss while the designer facilitates the co-creation session.
3. Remote/ in person- technology accessibility and the possibility of in person interaction between designers and the participants for reasons such as geographical distance, or pandemic may affect this. Each version needs to be accessible and understandable for the user group which can be designers, individuals with visual needs, or both.

7.4 STAKEHOLDER MAP

This map was made according to participants’ stories of daily routines and how they communicate with their surrounding people and environment. This is a dynamic diagram which always can be developed further with more stories.

Figure 35: The network of an individual with visual needs based on the interviews.

All the above insights were analyzed and narrowed down to three main insights which will be discussed in the next chapter.
CHAPTER 8: DESIGN PROCESS

8.1 FINAL INSIGHTS

After categorizing and narrowing down all the insights, three final insights were extracted for the direction of the project including focusing on interactions, shift of mindset and designing accessible tools.

1. The nature of the interaction is very important and should be a mixture of collaborative or individual approaches, which could be remote or in person. In addition, the most important aspect of these communications is how to facilitate them.

2. Shift of mindset is often necessary to include techniques and strategies that would change the designers’ perspective toward the area of visual needs. To meet this goal, introducing more precise forms of vision loss simulation, stories of daily experiences and the strategies that individuals with low or no vision use in challenging situations would be highly beneficial.

3. A variety of tools and resources that is going to be utilized during the interactions between designers and participants with visual needs, should be accessible in a way that participants would be able to review them and give feedback on their functionality. Research tools such as journey maps to help with storytelling and experience sharing, resources and guideline for designers in the design process, and using different senses such as tactile materials to help facilitate the in-person meetings would be some ways of improving the whole design and research process.

8.2 FORMAT

After summarizing all the insights and clustering them multiple times, three broad categories were finalized, based on the format of the proposed solution including physical, digital, or the combination of physical and digital components.
8.2.1 Physical & digital toolkit ideas

This group of ideas focuses on both physical and digital format of the toolkit. Depending on the situation that the toolkit is going to be utilized, a combination of physical and digital components can improve the interaction in in person and online meetings.

The following diagram shows some ideas for the physical and digital toolkit.

![Diagram of physical and digital toolkit ideas]

Figure 36: Physical & digital toolkit ideas.
8.2.2 Physical toolkit ideas

Depending on the participants’ preferences and their level of vision loss, the whole design process and the interactions with the end users may happen in person. In this situation, the whole toolkit components should be presented in a physical format.

The following diagram shows some ideas for the physical toolkit.

Figure 37: Physical toolkit ideas.
8.2.3 Digital toolkit ideas

There are different reasons that the whole primary research for data collection could happen remotely such as geographical distance, or pandemic or participant’s preference. Accordingly, all the toolkit components should be designed for remote communications between designers and participants with visual needs while they are accessible for the participants.

The following diagram shows some ideas for the digital toolkit.

---

Figure 38: Digital toolkit ideas.
8.3 FINAL IDEAS

As a result of the insights and different toolkit ideas, the following ideas were investigated to be components of the possible toolkit solution.

8.3.1 Instructional cards for designers

Designing instructional cards could be beneficial to help designers gain more knowledge in visual needs and be able to involve the participants with visual needs in a more inclusive way. These cards can include the following information:

- Interview questions- including suggested interview structure and questions to make a safe environment for target users with visual needs to share their experiences.
- Dos and Don’ts for before, during and after the interviews
- Resources including centers, organizations, and existing guidelines.

**Figure 39: Instructional Cards.**
8.3.2 Stories

Focusing on the stories collected from the participants with visual needs would provide a vast amount of information about their lived experiences, needs and their interactions with the environment. Therefore, in addition to listening to the stories, the way that these stories are going to be collected and reviewed by the participants to make sure that they do not make unreal assumptions about what the participants have shared.

To this goal, beside sharing the stories, there should be a tool or techniques to help collecting the information and getting feedback on them in an effective way. There are various tools that designers use to collect, categorize and analyze the experiences of the participants such as journey maps and stakeholder maps.

Figure 40: Stories can be collected in an app or on paper using different tools.
Figure 41: Journey map and stakeholder map are two data collection tools that help designers to understand the interactions between the user and people, products, and services, as well as user’s feelings in the process of doing a task or using a product or service.
After identifying these two components including instructional cards and the stories as a part of the toolkit, their effectiveness in terms of providing authentic information of the users’ real needs in the whole design process was investigated based on the primary research. As discussed in chapter 6, the experimental work, the whole research process from the interviews and co-creation sessions led to creating accessible journey maps to have the participants share their stories in a safe environment when they could give feedback on the design of the maps and the information included by designers based on the stories that were shared in interviews. It was concluded that the journey maps could be a great tool to provide this opportunity for both designers and participants to improve the quality of their interactions while they can give live feedback on the prototype and the details of the stories.

Therefore, Journey maps were selected as the focus of the toolkit solution to be utilized by designers to improve their communication with the end users resulting in improving the quality of products and services designed for people with visual needs.

8.4 DESIGNING ACCESSIBLE JOURNEY MAPS AS THE FOCUS OF THE TOOLKIT

Although a data collection tool for designers can include different tools as a toolbox, among all the tools and techniques, journey maps were determined to be the most useful tool for collecting stories to give space to the user to collaborate in creating the journey map that would reflect their real lived experiences.

While this tool should be accessible for people with visual needs to review and give feedback, it can be provided in physical or digital format depending on the type of iteration between designers and the participants as well as the participants’ preferences.
Tom is 45 years old and has lost his vision partially 10 months ago. He still has 50% vision. He lives with his wife and 1 year old son.

![User Journey Diagram](image)

**Figure 42:** An example of a user journey of using transportation for a person with vision loss.
<table>
<thead>
<tr>
<th>Phase of journey</th>
<th>Decide about the location and how to get there</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actions</td>
<td>Find the location</td>
</tr>
<tr>
<td>Touchpoint</td>
<td>Lyft/Uber App</td>
</tr>
<tr>
<td>Customer Thought</td>
<td>Lyft/Uber is expensive</td>
</tr>
<tr>
<td>Customer Feeling</td>
<td>😞 😞</td>
</tr>
<tr>
<td>Process ownership</td>
<td>Who is in the lead on this?</td>
</tr>
<tr>
<td>Opportunities</td>
<td>A service that pick them up wherever they are</td>
</tr>
</tbody>
</table>

*Figure 43: Journey of using transportation, phase 1.*
**Figure 44: Journey of using transportation, phase 2.**
<table>
<thead>
<tr>
<th>Phase of journey</th>
<th>Return</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actions</td>
<td></td>
</tr>
<tr>
<td>What does the customer do?</td>
<td>Call someone, Get Lyft/Uber</td>
</tr>
<tr>
<td>Touchpoint</td>
<td></td>
</tr>
<tr>
<td>What part of the service do they interact with?</td>
<td>Phone, Application</td>
</tr>
<tr>
<td>Customer Thought</td>
<td></td>
</tr>
<tr>
<td>What is the customer thinking?</td>
<td>People may not have time to wait for me, If I'm familiar with the neighborhood, I would take a walk</td>
</tr>
<tr>
<td>Customer Feeling</td>
<td></td>
</tr>
<tr>
<td>What is the customer feeling?</td>
<td>😞</td>
</tr>
<tr>
<td>Process ownership</td>
<td></td>
</tr>
<tr>
<td>Who is in the lead on this?</td>
<td>🔄</td>
</tr>
<tr>
<td>Opportunities</td>
<td></td>
</tr>
<tr>
<td></td>
<td>A free app to pick them up wherever they are</td>
</tr>
</tbody>
</table>

**Figure 45:** Journey of using transportation, phase 3.
Narrowing down the final insights to focusing on the interactions between designers and the participants, the shift of mindset in the design process resulted in three different formats for the toolkit solution. Considering the geographical distance, users’ preferences and their accessibility to technology, the toolkit can be designed in three different formats; physical, digital, or the combination of digital and physical components to suit the design process.

In the next ideation phase, the components of the toolkit were narrowed down to instructional cards and stories. They were investigated based on the insights from the experimental work with the participants with visual needs and what was more beneficial for that stage. Since the journey maps became the focus in the remote primary research of this project, the author chose them as most effective tool in the design process although they needed to be redesigned to be made accessible for the participants considering their vision condition. Also, including some guidelines in the process of creating the journey maps were suggested to give more information to designers about the area of visual needs.

As a result, ‘Design beyond the eyes’ emerged as the prototype of the toolkit solution to facilitate the design process and the communication with the participants when the focus of the project is on including the real needs of the users with visual needs.
‘Design beyond the eyes’ is a web-based toolbox including a set of data collection tools to help designers gain a better understanding of the needs and lived experiences of users with low/no vision to build an effective communication with them and collect authentic data.

Although there are different tools that can be helpful to address this need, creating adjustable user journey maps, is the most effective storytelling tools in the design process, and is the focus of ‘Design Beyond the Eyes’. In the next pages, the characteristics of this web-based tool and the steps to create the journey maps remotely with participants with low/no vision have been introduced. This toolkit solution includes two parts: Webpages and a workbook to print out.

9.1 WEBPAGES

They include the designer’s journey steps, the description of each step in yellow pages, and stories of exclusion.

Designer’s journey- The Hero’s Journey by Joseph Campbell has been used as the storytelling structure of the designers’ journey which focuses on the individual who is transforming in the process of going through different stages of the journey (Campbell, 1949; Lupton, 2017). As the primary user of this toolkit, designer takes the journey of using this web-based toolkit whose knowledge, skills, and abilities improve in this journey.

![Figure 46: Hero’s journey by Joseph Campbell.](image)
Stories of exclusion—stories of exclusion are another component of this web-based tool including the stories of Amy, Tom, Jane and Kevin. Haigler stories have been created based on real experiences of the participants and their strategies to face the situation.

These are the pages of the website that designers can go through to get familiar with the area of visual needs and create the journey maps of their user group using the guidelines of this tool.

Figure 47: Webpage 1.
Figure 48: Webpage 2.

Figure 49: Webpage 3.
Figure 50: Webpage 4.

Design Beyond the Eyes

Join

USERNAME
Shafagh

PASSWORD
*******

Contact

Figure 51: Webpage 5.

A web based toolbox including a set of data collection tools to help designers understand the lived experiences of users with low/no vision leading to building an effective communication with them and collecting authentic data.

Creating remote adjustable journey maps, as one of the most effective storytelling tools in the design process, is the initial focus of Design Beyond the Eyes.
Figure 52: Webpage 6.

Figure 53: Webpage 7.
Need

- The lived experiences of individuals with low vision or no vision are different based on their living condition, vision condition, and the duration of low/no vision experience.
- Designers who are not familiar with this user group should gain a deeper understanding of their lived experiences to address their real needs.
- Generalizing the experiences of the end users can lead to proposing one solution for everyone without considering their differences. Designers need tools/techniques that would help them include everyone's needs.
Institutional Review Board (IRB)

- Any kind of interactions with human subjects to collect information for the research within a university would require an Institutional Review Board (IRB) approval to keep the information confidential.
- Any identifier should be removed from the collected data to keep them anonymous.
- Participants should receive a consent form that would give them information about the research procedure and how their information is going to be used. They may give their consent on paper, digitally or verbally depending on their preferences.
Figure 60: Webpage 14.

Figure 61: Webpage 15.

Vision loss varies from low vision to severe vision loss/no vision. Asking the following questions from the users before getting started would help identify the user group and their needs:

1. How old are you?
2. Do you have any vision experience?
3. If so, when did the vision loss happen/start?
4. Is it partial or complete vision loss?
5. What type of vision loss are you experiencing?
6. Was it sudden or gradual?
Figure 62: Webpage 16.

Figure 63: Webpage 17.
Figure 64: Webpage 18.

Figure 65: Webpage 19.
Figure 66: Webpage 20.

Figure 67: Webpage 21.
Figure 68: Webpage 22.

Figure 69: Webpage 23.
Participants with Visual Needs

Profile
55 years old
Assistant professor
She is legally blind. She has a congenital condition which is gradually gotten worse, but she still has a functional vision to see things and get around.

Figure 70: Webpage 24.

Journey Map of Daily Tasks
Participant 1

Transportation  Doing Exercise  Cooking
Budget Management  Managing Mailbox  Healthcare

Figure 71: Webpage 25.
Figure 72: Webpage 26.

Figure 73: Webpage 27.
Figure 74: Webpage 28.

Figure 75: Webpage 29.
Figure 76: Webpage 30.

Figure 77: Webpage 31.
Figure 78: Webpage 32.

Figure 79: Webpage 33.
The possibility of adding the completed journey maps to this tool (as shown on pages 26 and 31) will provide a bank of journey maps for future users of this tool.

9.2 WORKBOOK PAGES

In the following images, the screen shows what the designer sees on the website. If they hit the download button, the white page layout will be shown so that the designers can record their own work electronically in their website account as PDFs or on paper.

These pages include questions and guidelines for each step of interviews and cocreation of the journey map with the participants with low/no vision.

At the end, by attaching all pages together, the designers are going to have a workbook that would help them through the data collection process of a project focusing on users with visual needs.
Figure 80: Workbook page 1 _ top image, on screen; bottom image, on paper / Pdf.
Figure 81: Workbook page 2.
02. Interview Guidelines

02.1. Before

02.2. During

02.3. After

03. Journey Map Guidelines

3

Before the interview

02.1.1. How old are you?

02.1.2. What is your career?

02.1.3. Do you use asny assistant technology?

02.1.4. What do you prefer for communication? Zoom, phone call, email, survey...?

Figure 82: Workbook page 3.
Figure 83: Workbook page 4.
02. Interview Guidelines

02.1. Before
02.2. During
02.3. After

03. Journey Map Guidelines

After the Interview

Participants should receive this list before the next interview so that they will have time to think about them:

- Getting dressed (or any relevant task)
- Access to Doctors/ Healthcare Tasks
- Budget management
- Managing the Mailbox
- Cooking
- Doing exercise
- A career/ study related task
- Using transportation/ Commuting
- Anything else you want to add to the list

Figure 84: Workbook page 5.
Figure 85: Workbook page 6.
Figure 86: Workbook page 7.
This will be the last page that the designer is going to download to print to complete the Workbook. They will choose their cover template among the provided options and print out the front and back book cover as well as the project description page which goes after the front cover page. In addition to the physical format, the workbook can also be shared as PDF.

Figure 87: Cover page _top image, on screen; middle image, front and back cover page; bottom image, designer’s profile page coming after the front cover page.
Figure 87: Cover page _ top image, on screen; middle image, front and back cover page; bottom image, designer’s profile page coming after the front cover page.

As the last step, the printed pages can come together in order via spiral binding or any other method.

Figure 88: Hard copy of the workbook.
9.3 FORMS OF THE JOURNEY MAPS SUGGESTED IN THIS TOOLKIT

The following forms of journey maps can be created by using this toolkit.

1. **A Visual Journey Map**: Adjustable journey maps

2. **A non-visual Word doc journey Map**: Can be made in a word documents which is accessible via a screen reader (NVDA)

3. **Narrative**: Stories of exclusion

9.3.1 Visual journey map

9.3.1.1 Components

   a. **Participant’s profile**: the participant’s profile which was gradually created based on the information collected in interviews about the participants. They should be kept anonymous while it would still represent the characteristics and real lived experiences of the participants.

   ![Participant’s Profile](image)

   *Figure 89: Participant’s profile.*

   b. **An adaptable Map Guide**: It was designed and used for the use of designers and participants. Based on the participants’ feedback it has been designed to be movable in the map so that they will have access to it any time they need it and they do not need to zoom in and out multiple times to find it.
9.3.1.2 Tested journey maps with participants

- Journey Map of an individual with low vision while using transportation.

Figure 90: Journey map guide.

Figure 91: Tested journey map of using transportation.
If the journey map is going to be sent to the participant to work on it alone, some instructions for them is required to prevent any confusion while they are working on the map.

- A visual journey map template for a participant with low vision: It is a suggested templated which can have different numbers of boxes in different colors depending on the participants’ preferences.
Figure 93: A visual journey map template for a participant with low vision.
Different possible ideas for the non-visual journey maps would be the following:

<table>
<thead>
<tr>
<th>Digital format</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessible PDF</td>
<td>- Everything should be explained in detail including the images.</td>
</tr>
<tr>
<td></td>
<td>- The uses cannot work on the document, and they can just read them.</td>
</tr>
<tr>
<td>Google document including a table for each task</td>
<td>- Google document does not work well with screen reader and is not accessible enough.</td>
</tr>
<tr>
<td></td>
<td>- Use a table to organize the steps of each task: It would be confusing for the user to figure it out.</td>
</tr>
<tr>
<td>Simple word document with headings and subheadings</td>
<td>- It would be easier to use the shortcuts keys.</td>
</tr>
<tr>
<td></td>
<td>- Accessible via NVDA screen reader</td>
</tr>
</tbody>
</table>

*Table 3: Possible formats of a non-visual journey map.*

Although all the above options can work, the simple word document would be the easiest way for the participants who uses a screen reader to go through the document and give their feedback.
9.3.2.1 Accessible word document via NVDA screen reader

Journeys of the participant during a list of daily routines including cooking, using transportation, doing exercise and so on.

What the participant does, says, feels, and changes in the environment, and which senses they rely on most in a specific situation are the focus of these journeys.

Document Guide: If there is any question for the participant to answer, they have been marked with the letter ‘Q’ before the question.

Participant’s Profile

Q. How old are you?

Profession-

Living condition-

Vision Condition-

Q. Do you use social media?

Q. What adaptive/assistive technologies do you use in your daily routines?

1. Cooking’s journey

Overall Questions about the task

1. Has COVID19 had any effects on your cooking process?

2. Have you experienced any unexpected situation related to cooking? If yes, what was your feeling in that situation?

3. Do you want to add anything else to this part that includes challenges and how to address them?

Regular procedure of the cooking experience

Figure 94: Suggested format for an accessible non-visual journey map.
Participant 00- Daily Tasks Journeys

Technology or adaptive equipment

Q. Would you suggest any other equipment than what you already use that could make the cooking experience easier?

Preferences and desires

2. Using Transportation’s Journey

Figure 94: Suggested format for an accessible non-visual journey map.
9.3.3 Narratives

The following personas and their characteristics were created based on the information collected from the primary research. They represent the possible situations that users with visual needs may experience and the strategies they may use to face them.

9.3.3.1 Persona 1- Amy

Amy is 56 years old. She lost partial vision in both eyes 2 years ago. She is legally blind, and due to severe vision loss, she could not continue her job as a carpenter, and she cannot drive anymore.

Figure 95: Amy’s story, page 1.
Figure 96: Amy’s story, page 2.

Figure 97: Amy’s story, page 3.
9.3.3.2 Persona 2- Tom

Tom is 45 years old and has lost his vision partially 10 months ago. He is still in the process of getting used to the new condition and getting the required training which does not happen regularly due to the pandemic.
Tom’s Story

Tom’s wife works outside, and he takes care of their toddler most of the time. It’s 4 o’clock and the time of his medication. Tom opens the bottle to take a pill, but he suddenly drops the bottle and spills all the pills on the ground. His son is crawling on the floor, and he is worried if he would pick up a pill.

What does he do?

Tom starts cleaning the floor with a vacuum cleaner. “I should keep the dustpan close to find it immediately,” Tom says to himself. He finished the cleaning, but he was still not sure if he cleaned off everything. He could not see the floor clearly so there might have been some pills still left on the floor.
Figure 101: Tom’s story, page 3.

Figure 102: Tom’s story, page 4.
9.3.3.3 Persona 3- Jane

Jane is 48 years old who lives with her family. She was born with no vision, but she sees some lights and shadows. She is an artist and an associate professor in theater.
Jane’s Story

Jane likes to stay active by doing regular exercises. She is adventurous and likes to try different things to stay active and motivated. "I try to stay fit. It’s something that’s important to me", Jane says. She used to go to gym regularly, but COVID happened, and she stopped it.

Figure 105: Jane’s story, page 2.
9.3.3.4 Persona 4- Kevin

Kevin is 61 years old and lives alone. He used to work as a clerk for 30 years, but he is retired now. He was born with no vision and identifies himself as totally blind.
Kevin’s Story

“Since I was born with no vision, I don’t have the sense of loss,” Kevin says. He has received different trainings since his childhood such as walking with a cane, and braille reading and writing. Today, due to technological developments, there has been a lot of changes in everyday products and services that he should get used to.

Daily Challenges

1. Many things are touchpad like phones and kitchen appliances.

2. Although, it is possible to find information about many things online, some websites are not accessible for people with low or no vision.
9.4 WHEN DO WE USE VISUAL, NON-VISUAL AND NARRATIVES?

Regarding all the details that have been shared about how to create the journey maps, it is time to compare some of their benefits when they can be utilized.

9.4.1 Visual journey maps

They are helpful for visually oriented designers to map out an experience and play with the details.

They provide an environment for sighted designers to find some specific details on the map quickly by using a specific icon attached to it.

If they are made in a collaborative platform like Miro, designers would be able to get immediate feedback from the participant with low vision who are able to interact with the visual map. Using different components such as shapes, colors, images, and so on would make it
possible to include the participants with different preferences and different kinds of vision loss such as color blindness.

9.4.2 Non-visual journey maps

The non-visual journey maps work best when a designer wants to share it with a participant with low or no vision. They may not be as attractive as the visual journey map for the sighted designers, but they provide a better method of getting feedback from the participants.

To understand how they this type of journey map work and to make sure that the details of the map work well, it is suggested that designers use a screen reader and test the map with it.

Although a non-visual journey map which can be created in a word document let designers and unsighted participants work together, but it is often cumbersome to include a visual journey map which has to be explained in text and has limited possibilities for sharing.

9.4.3 Narratives

Since everyone tells stories or listens to other’s stories in their daily routine, they are naturally familiar with storytelling and use it as a tool for making social connections with people. Narratives increase empathy and the sharing of experiences.

Narratives can be created faster and easier than the visual and non-visual journey maps because they are just made of words and sentences. It takes more time to organize the structure of the journey maps that include more components such as visuals, emojis, map guides, and participants’ profile. However, since narratives communicate information in a couple of lines, it is not suggested to not include too many details in them. On the other hand, given the flexible structure of the journey maps, they can communicate a variety of information in a more focused way.
CHAPTER 10: CONCLUSION AND THOUGHTS FOR THE FUTURE

Given the objective of gaining a deeper understanding of the needs of users with low or no vision, this project addressed this need by exploring the experiences of users with a variety of vision abilities and living conditions. It is important to acknowledge that everyone has different needs which should be addressed in their own way. A single solution often does not work for everyone, and one principle of this project was the importance of determining the individual needs and expectations of people with visual needs.

Although it was planned to mainly focus on the elderly who have lost their vision in adulthood, in the process of subject recruitment and the primary research, the author realized that this approach would significantly limit the perspective and impact of the project. Therefore, the groups of participants were expanded to include any adult who has experienced low or no vision in any level and for any reason to generate more stories not only from them but from their network including their family, trainers, and occupational therapists.

Creating a toolkit that would help designers address the needs of people with low- or no-vision was selected as the focus of this project. The proposed toolkit solution provides guidelines for designers who are new to the area of visual needs and includes components to facilitate that interaction between designers and users.

In the process of creating this toolkit, the author had a great opportunity to hear different personal stories of the participants which reinforced the notion that everyone has their own journey which should not be generalized. Vision loss occurs on a spectrum which leads to very different lived experiences depending on the kind and the length of vision loss, as well as individual’s profession and living condition. The creation of a safe environment to understand and share experience is essential to the success of the collaboration.

Figuring out the best approaches for communicating and collecting data from the participants, the author came up with a lot of great insights that helped to adopt the most useful and feasible tools and methods and adapt them to the needs of the project. The following were two main considerations in this process:
1. As one of the data collection challenges, it was required to find alternatives to tools and techniques that designers typically use to interact with sighted participants. Considering the level of participants’ vision loss, these tools had to be adjusted to their preferences.

2. The interviews and observations usually happen in person in the design process, and the existing tools are appropriate for these kinds of interactions. Since all the interactions occurred remotely in this project due to COVID19, the author needed to find different strategies that would provide as much authentic information as possible.

Since building trust and providing a safe environment for the participants to share their experiences were significant, the author had to be very conscious about the language and the question that were used in the communications. The initial emails and interview questions were shared with experts in visual needs to make any necessary adjustments for the participants.

Zoom and phone interviews were conducted for data collection while the participants were asked in each step of the process, if they felt comfortable with the interview mediums and methods from the initial interviews to creating journey maps in co-creation sessions. All the documents and tools were made accessible and tailored to the participants vision abilities and their accessibility to technology. Also, they were advised to avoid answering any questions or performing any tasks that they did not want to do.

Although this project was supposed to prevent designers from making unreal assumptions, the author realized that thinking too much about what participants may not want to do can lead to underestimating the participants’ desires and abilities. They should always be asked what their preferences are to avoid biased assumptions by designers.

As an alternative to in person observations, the participants were asked to video/ audio record some of their daily tasks. However, it did not happen because participants did not feel comfortable with doing it since they could not see and review their recording. It also required to spend more time and energy than just having a free conversation about them in a meeting. That is why, they preferred to share their thoughts and feelings with the author in a meeting to be able to talk about any details and ask any possible questions that may arise in the process.
As a result of the whole research and design process, this project focused on developing accessible journey maps as a tool for sharing user experiences. The goal is to make people’s lives better by using the journey maps as part of the design process as these are familiar and accessible tools. Using this toolkit, designers receive information about the definitions of different kinds of vision loss, their characteristics and needs. Also, they are provided with interview guidelines and instructions to creating visual, and non-visual journey maps leading to creating their own journey maps based on the direction of their projects and the lived experiences of their participants with vision loss.

There are however many other approaches which can be used and other tools that can be developed to facilitate the collaboration between designers and the users of their work. Much future research and design work could still be done based on this notion of interaction and collaboration. Different design projects will have different specific goals to address, so other tools will be developed to improve design solutions. The principles embodied in the toolkit can help designers to collect authentic information from end users leading to better designs for people. Although this work was specifically orientated towards people with visual needs, similar approaches can be used for other groups. The empathic approach and the development of a safe environment for collaboration are essential.
REFERENCES


136


Snowden, D. J. (2001). Narrative Patterns: the perils and possibilities of using story in organisations ARK: Knowledge Management.


World Health Organization. (2021, February 26). *Blindness and vision impairment.*
https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment

APPENDIX A: IRB DOCUMENTATION

IRB FORMS

There are a couple of forms including protocol form, consent form and additional materials that were submitted for IRB. The whole process took about one month and a half while I was in touch with them to ask questions about the questions of the forms and how to process. The following materials were confirmed after 5 modifications and getting feedback from the IRB staff.

1. Protocol form

2. Waiver of documentation of informed consent

3. Social_behavioral_research_consent_ caregivers or family members

4. Social_behavioral_research_consent_ participants with vision loss

5. Additional materials provided by the designer based on the research

6. Research materials

7. Emails

8. Attached to the protocol form and waiver of documentation of informed consent
Notice of Approval: New Submission

October 20, 2020

Principal Investigator: David Weightman
CC: Shafagh Hadinezhad
Protocol Title: MFA Thesis - Maintaining a healthy lifestyle for people who lose their vision in adulthood
Protocol Number: 21206
Funding Source: Unfunded
Review Type: Expedited 6, 7
Status: Active
Risk Determination: No more than minimal risk
Approval Date: October 20, 2020
Closure Date: October 19, 2025

This letter authorizes the use of human subjects in the above protocol. The University of Illinois at Urbana-Champaign Institutional Review Board (IRB) has reviewed and approved the research study as described.

The Principal Investigator of this study is responsible for:
- Conducting research in a manner consistent with the requirements of the University and federal regulations found at 45 CFR 46.
- Using the approved consent documents, with the footer, from this approved package.
- Requesting approval from the IRB prior to implementing modifications.
- Notifying OPRS of any problems involving human subjects, including unanticipated events, participant complaints, or protocol deviations.
- Notifying OPRS of the completion of the study.

Figure 110: IRB approval, page 1.
Protocol Form

IRB Number: 21206

Guidelines for completing this research protocol:
- Please submit typed applications via email. Handwritten forms and hard copy forms will not be accepted.
- For items and questions that do not apply to the research, indicate as “not applicable.”
- Provide information for all other items clearly and avoid using discipline specific jargon.
- Please only include text in the provided boxes. The text boxes will expand as they are typed in to accommodate large amounts of text.

Before submitting this application, ensure that the following have been completed.
- Protocol Form is complete.
- Relevant CITI modules have been completed for all members of the research team at www.citiprogram.org.
- Informed consent/assent/parental permission document(s) are provided.
- Relevant waivers and appendices are provided.
- Recruitment materials are provided.
- Research materials (e.g. surveys, interview guides, etc.) are provided.
- Any relevant letters of support are provided.

Instructions on the non-exempt review process and guidance to submitting applications, can be found on the OPRS website. You may also contact OPRS by email at irb@illinois.edu or phone at 217-333-2670.

Submit completed applications via email to: irb@illinois.edu.

Figure 111: IRB approval, page 2.
Figure 112: IRB approval, page 3.
Figure 113: IRB approval, page 4.
Protocol Form

6C. Letters of support from outside institutions or entities that are allowing recruitment, research, or record access at their site(s) are attached. □ Yes □ Not Applicable

Section 7. PROCEDURES

7A. Select all research methods and/or data sources that apply.
- Surveys or questionnaires, select all that apply: □ Paper □ Telephone □ Online
- Interviews
- Focus groups
- Field work or ethnography
- Standardized written, oral, or visual tests
- Taste or smell testing
- Intervention or experimental manipulation
- Exercise and muscular strength testing
- Noninvasive procedures to collect biological specimens (e.g., hair and nail clippings, saliva, etc.)
- Noninvasive procedures to collect physiological data (e.g., physical sensors, electrocardiography, etc.)
- Procedures involving radiation
- Recording audio and/or video and/or taking photographs
- Recording other imaging
- Materials that have already been collected or already exist, specify source of data: I am going to collect some of the information and data for my project through the secondary research. I am going to find articles and data sets related to my topic that already exist to provide a background for my research and also find a gap in them.
- HIPAA-protected data
- FERPA-protected data
- GDPR-protected data
- Other, please specify:

7B. List all testing instruments, surveys, interview guides, etc. that will be used in this research.
Online survey/questionnaire, interview with participants online or on the phone. Guidelines about how to record daily routines in a productive way by providing different methods for the participants and they can choose the one that is more comfortable.
Drafts or final copies of all research materials are attached. □ Yes

7C. List approximate study dates. 15 September, 2020-15 March 2021, about 2 or more meetings each month depending on the participant’s availability. The rest of the research will be on participants to self record their activities and send them to the researcher. See the Attached document

7D. What is the duration of participants’ involvement? The research procedure will last about 6 months including about 20 meetings for about 30-60 minutes each, and about 20 audio/video recordings of activities which may last about 10-30 minutes or more depending upon the type of activity.

7E. How many times will participants engage in research activities? 20 meetings, 20 times of doing activities and self recordings.

7F. Narratively describe the research procedures in the order in which they will be conducted.
Section 8. PERFORMANCE SITES TO INCLUDE INTERNATIONAL, SCHOOL, AND COLLABORATIVE STUDIES

8A. List all research sites for the protocol. For non-University of Illinois at Urbana-Champaign sites, describe their status of approval and provide contact information for the site. If the site has an IRB, note whether the IRB has approved the research or plans to defer review to the University of Illinois at Urbana-Champaign.

Performances Sites

#1 There is no research site because participants will be interviewed through a phone call or online meeting. They will be asked to video/audio record some activities during their daily life and send them to the researcher. There is no in-person research.

#2

#3

If there are additional performance sites, include them on an attachment and check here:

8B. Is this a multi-center study in which the Illinois investigator is the lead investigator, or the University of Illinois at Urbana-Champaign is the lead site? Yes No

If yes, answer 8C and 8D. If no, proceed to Section 8E.

8C. Who is the prime recipient of funding, if funded?

8D. What is the management and communication plan for information that might be relevant to the protection of research subjects (e.g. unanticipated problems involving risks to subjects, interim results, and protocol modifications)?

8E. If subjects will be recruited from Illinois public or private elementary or secondary schools, additional deadlines and procedures may apply. Criminal background clearances might be required. Special consideration must be given to the exclusion of protected populations. Please contact the School University Research Relations (researchplacements@education.illinois.edu) for more information. Select one: Illinois schools will be used Illinois schools will not be used

Section 9. SUBJECT ENROLLMENT GOAL & EQUITABLE SELECTION OF SUBJECTS

9A. For each performance site, indicate the estimated total number of participants.

<table>
<thead>
<tr>
<th>Performance Site</th>
<th># Male</th>
<th># Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>20</td>
<td>20</td>
<td>40</td>
</tr>
</tbody>
</table>
Protocol Form

9B. Select all participant populations that will be recruited.

Age:
- Adults (18+ years old)
- Minors (<17 years old)
- Specific age range, please specify:

Gender:
- No targeted gender (both men and women will be recruited/included)
- Targeted gender, please indicate: Men/boys Women/girls Other, please specify:

Race/Ethnicity:
- No targeted race or ethnicity (all races and ethnicities will be recruited/included)
- Targeted race or ethnicity, please specify:

College Students:
- No targeted college population
- UIUC general student body
- Targeted UIUC student population, provide the instructor or course information, name of the departmental subject pool, or other specific characteristics:
- Students at institution(s) other than UIUC, please specify:

Any research with students on UIUC’s campus needs to be registered with the Office of the Dean of Students.

Other:
- Inpatients
- Outpatients
- People who are illiterate or educationally disadvantaged
- People who are low-income or economically disadvantaged
- People with mental or cognitive disabilities or otherwise impaired decision-making capacities
- Adults with legal guardians
- People who are non-English speaking
- People with physical disabilities
- Pregnant or lactating women, human fetuses, and/or neonates
- Prisoners or people with otherwise limited civil freedoms
- Other, please specify:

9C. Describe additional safeguards included in the protocol to protect the rights and welfare of the populations selected above.

See the Attached document

Section 10. INCLUSION/EXCLUSION

Figure 116: IRB approval, page 7.
Protocol Form

10A. List specific criteria for inclusion and exclusion of subjects in the study, including treatment and control groups.

The target group includes individuals who have lost their vision in adulthood, but as long as the participants live with some kind of vision loss who needs some training to adjust themselves to their new condition, they will be potential participants.

10B. Explain how the inclusion/exclusion criteria will be assessed and by whom. If special expertise is required to evaluate screening responses or data, list who will make this evaluation and describe their training and experience.

Although there is a specific target group for this study, the research team decided to include individuals with partial vision loss or those who were born blind as well helping expand the perspective of this study. No special expertise is required.

10C. Drafts or final copies of all screening materials are attached. ☒ Yes ☐ Not Applicable

10D. Describe procedures to assure equitable selection of subjects. Justify the use of the groups marked in Section 9B. Selection criteria that target one sex, race, or ethnic group require a clear scientific rationale.

See the Attached document

Section 11. RECRUITMENT

11A. Select all recruitment procedures that will be used.

☐ Student subject pool, please specify:

☒ Email distribution

☐ MTurk, Qualtrics Panel, or similar online population, please specify:

☐ US Mail

☐ Flyers/brochures

☐ Website ad, online announcement (e.g. eWeek), or other online recruitment, please specify:

☐ Newspaper ad

☐ Verbal announcement

☐ Other, please specify:

☐ Not applicable (secondary data only)

11B. Drafts or final copies of all recruitment materials (including verbal scripts) are attached.

☒ Yes ☐ Not Applicable

11C. For each group of participants, describe the details of the recruitment process.

Potential participants will be reached out by the research team or a third party who can be a DRES staff, the thesis committee and so on. See the attached document.

Section 12. REMUNERATION AND PLAN FOR DISTRIBUTION

Refer to the University Business and Financial Policies and Procedures for further guidance on the compensation process and reporting requirements.

12A. Will subjects receive inducements or rewards before, during, or after participation?
Figure 118: IRB approval, page 9.
<table>
<thead>
<tr>
<th>Question</th>
<th>Response 1</th>
<th>Response 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>13E. Describe the expected benefits of the research to the subjects and/or to society.</td>
<td>Since people who lose their vision in adulthood usually deal with other health issues, it is significant to understand their real needs to be able to address them in an appropriate way.</td>
<td></td>
</tr>
<tr>
<td>13F. Weigh the risks with regard to the benefits. Provide evidence that benefits outweigh risks.</td>
<td>The risks are very low and easy to remove if they are detected. Participants will receive clear explanation about what they will be doing. If there is no one else to video record them or if they are in a sensitive situation, they will not record it live.</td>
<td></td>
</tr>
<tr>
<td>Section 14. INFORMED CONSENT PROCESS TO INCLUDE: WAIVERS, ASSESTS, ALTERATIONS, ETC.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14A. Indicate all that apply for the consent/assent/parental permission process.</td>
<td>☐ Written informed consent (assent) with a document signed by</td>
<td>☐ Waiver of Documentation (signature) of informed Consent (include the relevant Waiver Form)</td>
</tr>
<tr>
<td></td>
<td>☐ adult subjects ☐ parent(s) or guardian(s) ☐ adolescents aged 8–17 years</td>
<td>☐ Waiver of Informed Consent (include the relevant Waiver Form)</td>
</tr>
<tr>
<td></td>
<td>☐ adult subjects ☐ parent(s) or guardian(s) ☐ adolescents aged 8–17 years</td>
<td>☐ Waiver of Informed Consent (include the relevant Waiver Form)</td>
</tr>
<tr>
<td></td>
<td>☐ adult subjects ☐ parent(s) or guardian(s) ☐ adolescents aged 8–17 years</td>
<td>☐ Waiver of Informed Consent (include the relevant Alteration Form)</td>
</tr>
<tr>
<td></td>
<td>☐ Alteration of Informed Consent (include the relevant Alteration Form)</td>
<td></td>
</tr>
<tr>
<td>14B. List all researchers who will obtain consent/assent/parental permission from participants.</td>
<td>Shafagh Hadzinezhad</td>
<td></td>
</tr>
<tr>
<td>14C. Describe the method for obtaining consent/assent/parental permission.</td>
<td>Since most of the participants will be adults with vision loss, they may be more comfortable with just giving the verbal consent instead of signing a document. So, I will be reading the consent form for them and they will let me know whether they agree.</td>
<td></td>
</tr>
<tr>
<td>14D. Describe when consent/assent/parental permission will be obtained.</td>
<td>The consent form will be sent by email and will be obtained in the beginning of the interview after an explanation about it. If it is difficult for the participant to sign the form, the consent will be obtained verbally. See the attached document.</td>
<td></td>
</tr>
<tr>
<td>14E. Will participants receive a copy of the consent form for their records?</td>
<td>☑ Yes ☐ No, if no, explain:</td>
<td></td>
</tr>
<tr>
<td>14F. Indicate factors that may interfere or influence the collection of voluntary informed consent/assent/parental permission.</td>
<td>☐ No known factors</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ Research will involve students enrolled in a course or program taught by a member of the research team</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ Research will involve employees whose supervisor(s) is/are recruiting participants</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ Participants have a close relationship to the research team</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ Other, specify any relationship that exists between the research team and participants:</td>
<td></td>
</tr>
</tbody>
</table>
### Protocol Form

If applicable, describe the procedures to mitigate the above factors. Not applicable.

14G. Copies of the consent form(s) are attached. ☒ Yes ☐ Not applicable

14H. Will this project be registered as a clinical trial? ☐ Yes ☒ No

If yes, effective January 21, 2019, an informed consent form must be posted on the Federal Web site after the clinical trial is closed to recruitment, and no later than 60 days after the last study visit.

#### Section 15. DEVICES & DRUGS

- Equipment [Researchers collecting physiological data, not testing the device]
  - (include Appendix A, the Research Equipment Form)
- Devices [Researchers planning to test devices on human subjects]
  - (include Appendix B, the Device Form)
- Materials of Human Origin
  - (include Appendix C, the Biological Materials Form)
- Drugs and Biologics
  - (include Appendix D, the Drug and Chemical Usage Form)

☐ MRI AT BIC To use the Beckman Institute Biomedical Imaging Center (BIC) in human subject’s research, you must obtain prior approval from the BIC (217.244.0446; ryambert@illinois.edu) and use BIC-approved screening and consent forms. Attach:
  - ☐ BIC approval
  - ☐ BIC screening form
  - ☐ BIC consent form

#### Section 16. CONFIDENTIALITY OF DATA & PRIVACY OF PARTICIPATION

16A. How is participant data, records, or specimens identified when received or collected by researchers? Identifiers include, but are not limited to, name, date of birth, email address, street address, phone number, audio or video recordings, and SSN.

- ☐ No identifiers are collected
- ☒ Direct identifiers are collected
- ☐ Indirect identifiers (e.g. a code or pseudonym used to track participants):
  - ☐ Does the research team have access to the identity key? ☒ Yes ☐ No

16B. Select all methods used to safeguard research records during storage:

- ☐ Written consent, assent, or parental permission forms are stored separately from the data
- ☐ Data is collected or given to research team without identifiers
- ☒ Data is recorded by research team without identifiers
- ☐ Direct identifiers are removed from collected data as soon as possible
- ☐ Direct identifiers are deleted and no identity key exists as soon as possible
- ☐ Participant codes or pseudonyms are used on all data and the existing identity key is stored separately from the data
- ☒ Electronic data is stored in a secure, UIUC-approved location, please specify. Electronic data will be stored in a folder in the U of I box. No one will have access to this folder but me.

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*Figure 120: IRB approval, page 11.*

150
Protocol Form

- Hard-copy data is stored in a secure location on UIUC’s campus, please specify.
- Other, please specify.

16C. How long will identifiable data be kept? 6 months

16D. Describe provisions to protect the privacy interests of subjects. The participants will only interact with the researcher. The audio and video recording will be done by the participant individually or with the help of someone whom they trust. The researcher is the only person who have access to the information.

16E. Describe the training and experience of all persons who will collect or have access to the data.
They have completed relevant CITI modules.

Section 17. DISSEMINATION OF RESULTS

17A. List proposed forms of dissemination (e.g., journal articles, thesis, academic paper, conference presentation, sharing within industry, etc.).

17B. Will any identifiers be published, shared, or otherwise disseminated? ☑ Yes ☐ No
If yes, does the consent form explicitly ask consent for such dissemination, or otherwise inform participants that it is required in order to participate in the study? ☑ Yes

17C. Do you intend to put de-identified data in a data repository? ☑ Yes ☐ No
If yes, explain how data will be de-identified. All information regarding participants' personal identity will be removed while entering the information into the data repository including spreadsheets or word docs.

Section 18. INVESTIGATOR & DEPARTMENTAL ASSURANCES

- I certify that the information provided in this application is complete and correct.
- I certify that I will follow my IRB Approved Protocol.
- I accept ultimate responsibility for the conduct of this study, the ethical performance of the project, and the protection of the rights and welfare of the human subjects who are directly or indirectly involved in this project.
- I will comply with all applicable federal, state and local laws regarding the protection of human subjects in research.
- I will ensure that the personnel performing this study are qualified and adhere to the provisions of this IRB-certified protocol.

The original signature of the PI is required before this application may be processed (electronic signatures are acceptable).
Figure 122: IRB approval, page 13.
Protocol Form
IRB Number: 21206

Protocol Form – 7C. Please provide the guidance/instructions you will be providing to the participants to prepare them for recording their daily routine.

15 September, 2020 - 15 March 2021, about 2 or more meetings each month depending on the participant’s availability. The meeting or phone call will be recorded. The participants will be asked in the beginning of the meeting whether they give permission for the recording. The rest of the research will be on participants to self-record their activities and send them to the researcher. Depending on the level of participation, the research team will describe the research procedure for the participants. The instructions will be provided for them verbally in the first online meeting or phone call, and any questions regarding these instructions will be answered in the meeting. After the meeting, the instructions will be sent to the participants via email. They can reach out to the research team via email with any questions relevant to the procedure.

Here are the instructions:
These are a list of activities that you can video or audio record. Feel free to add an activity to this list if you prefer:
- Getting up
- Preparing breakfast
- Doing exercise
- Getting dressed and leaving the house
- Going to bed
- Other...

After finishing the activity, audio record your feedback on the activity. You can do it right after the activity or whenever you find free time during the day: What did you do during this activity? How was the experience? What did/did not go well? What surprised you? Was it easy or difficult? Did you face any challenges? ...

Questionnaire instead of audio recording the feedback on the activity:
- Explain what you did during this activity?
- How was the experience?
- What did/did not go well?
- What surprised you?
- Was it easy or difficult?
- Did you face any challenges?
- Other ...

The number of doing these activities is up to you, but it is suggested that you record them at least three times a week. You can send the recordings/reflection questionnaire to the research team each time separately or on a weekly basis.

The research procedure will last about 6 months including about 20 meetings for about 30-60 minutes each, and about 20 audio/video recordings of activities which may last about 10-30 minutes or more depending upon the type of activity. You are free to attend the whole procedure or a part of it and you are free to withdraw at any time.
It is indicated that the research team will attempt to obtain consent without obtaining a physical signature. This can be done through a Waiver of Documentation of Informed Consent; please complete the Waiver of Documentation (attached to this email) and return it to me.

**Protocol Form – 9C.** Although all the information from participants is going to be used anonymously, they will not be used or shared with the public without their permission. They will also give permission on whether they want their information to be shared anonymously or not. Participants can freely and without any restriction withdraw from participation at any time and any level without giving an explanation.

Since the meetings with participants will happen online, the consent will be obtained without obtaining a physical signature which is going to be done through a Waiver of Documentation of Informed Consent. Consent forms will be sent to the participants before the meetings via email. In the beginning of the meeting, participants who have already read the consent form will talk about what part of the information about them can or cannot be shared by the research team.

**Protocol Form – 10C.** The research team and those who are going to help with the recruitment procedure have a kind of understanding of partial/ severe or complete vision loss which is enough to find the potential participants for this study since the goal is getting as much information as possible about the challenges that vision loss brings to individuals in adulthood. As described above, if the individuals who have accepted to participate in this study are experiencing severe or increasing vision loss, they are appropriate for this study and there is no need for evaluation because a small difference between what is needed for the study and the actual condition of the participant is not going to hurt anyone or anything. Any participant with some degree of vision loss can somehow help this research.

**Protocol Form – 11C.** Here are the email drafts that will be sent out to potential participants by the research team or the third parties including DRES staff, the thesis committee, Staff at some centers such as Chicago lighthouse, Center for Independent Living in Urbana or someone else who have some connections with people who are blind or with the instructors/family members/caregivers of someone with vision loss. These individuals help the researcher to reach out to more people and find participants for the project. They use these email drafts to send the information about the project to some potential participants and if they agree, they will be provided with the contact information of the research team including the email address and phone number so that they can reach out to the research team if they are interested in participating in this study. When participants reach out to the research team, they will receive a consent form via email to make sure they understand the procedure and what they are expected to do. After reading through the consent form, participants are supposed to reach out to the research team to inform them about their decision and the level of their participation. The research team will start the procedure with the online interviews/ phone calls.

**Protocol Form – 14C.** The consent form will be sent by email and will be obtained in the beginning of the interview after an explanation about it. If it is difficult for the participant to sign the form, the consent will be obtained verbally. Participants with vision loss may use assistive technologies such as screen readers to read the consent form or ask their caregivers to help them with reading the
Documents for them. Since in the beginning of the first meeting, the participants will be asked if they have read and comprehended the documents, if none of the above ways work for them, the research team will read the consent form to the participants and obtain oral consent before asking any questions relevant to the research.

If the caregivers are going to help the participants to comprehend the consent forms, the consent form will be sent to them with the following description:

Attached you can find the consent form. Please read it fully to the participant and make sure they have understood all parts of it. If they have any questions about the consent form, they can ask their questions from the research team in the beginning of the first meeting or if the participants prefer to, the questions can be sent to the research team by participants or caregivers before the first meeting. The research team will read the questions and answer all of them in the beginning of the first meeting.

After all the questions and concerns have been addressed in the beginning of the first meeting, the consent will be obtained verbally. Then, the research team will start asking the questions relevant to the research.
Research Team

For Listing Additional Researchers who are Involved in the Project
All forms must be typewritten and submitted via email to irb@illinois.edu.

When to use this form: If there are collaborating researchers participating in a research study, including those from other institutions, complete this form by listing all collaborating researchers. Include all persons who will be: 1) directly responsible for project oversight and implementation, 2) recruitment, 3) obtaining informed consent, or 4) involved in data collection, analysis of identifiable data, and/or follow-up. Please copy and paste text fields to add additional research team members.
Note:
- Changes made to the Principal Investigator require a revised Protocol Form and an Amendment Form.
- A complete Research Team form with all research team members included needs to be submitted every time the research team is updated.

Section 1. PROTOCOL INFORMATION

1A. Principal Investigator: David Weightman
1B. Protocol Number: 21206
1C. Project Title: Maintaining a healthy lifestyle for people who lose their vision in adulthood

Section 2. ADDITIONAL INVESTIGATORS

<table>
<thead>
<tr>
<th>Full Name</th>
<th>Degree</th>
<th>Dept. or Unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shafagh Hadinezhad</td>
<td>Master of Fine Arts</td>
<td>School of Art and Design</td>
</tr>
</tbody>
</table>

Professional Email: shafagh2@illinois.edu

Campus Affiliation:
- University of Illinois at Urbana-Champaign
- Other, please specify:

Campus Status:
- Faculty
- Academic Professional/Staff
- Graduate Student
- Undergraduate Student
- Visiting Scholar
- Other, please specify:

Training:
- Required CITI Training, Date of Completion (valid within last 3 years): June 2019
- Additional training, Date of Completion:

Role on Research Team (check all that apply):
- Recruiting
- Consenting
- Administering study procedures
- Handling identifiable data
- Other, please specify:
- This researcher should be copied on OPRS and IRB correspondence.
- This researcher is no longer an active research team member.

Date added to research team: Date removed from research team:

Figure 126: IRB approval, page 17.
Email Distribution

These emails are for potential participants for my projects or third parties who are individuals introduced by someone else like a DRES staff, the thesis committee, Staff at some centers such as Chicago lighthouse, Center for Independent Living in Urbana or someone else who have some connections with people who are blind or with the instructors/family members/caregivers of someone with vision loss. These individuals help the researcher to reach out to more people and find participants for the project. They use these email drafts to send the information about the project to some potential participants and if they agree, they will provide an email address or a phone number which will be sent to the researcher by this person. The researcher will reach out to them when their contact information is provided, or they will reach out to the researcher via the email address provided for them.

1. Dear ...,  
I am Shafagh Hadinezhad, a third-year master’s student in industrial design working on my thesis in the last year of my studies. Here is a brief explanation of my thesis project: "Designing the means of maintaining a healthy lifestyle for people with severe vision loss through an adaptive storytelling toolkit in a design thinking process: To design more effective products and services to maintain a healthy lifestyle for people who have lost their vision in adulthood, designers should be able to use a design thinking/storytelling toolkit comprising different data collection methods to help understand the users. This project aims to develop and test a toolkit or a product/service to address the problems explored through the communication with this user group.”  
Looking forward to hearing from you.
Best,
Shafagh

Shafagh Hadinezhad  
MFA Candidate, Industrial Design, School of Art & Design,  
University of Illinois, Urbana-Champaign

2. Dear ....,
Hope you are doing well.
I am planning to start my interviews with participants of my project in about 10 days. I believe I can have your help in finding participants for my project. I am planning to talk with about 40 people including people who have lost their vision in adulthood recently or for a long time, and individuals who have been born blind or lost their vision at the very young age, and their caregivers/family members/instructors if possible.
Also, it would be great if I can have an individual meeting with maybe 2 or 3 more teachers who work with adults with vision impairment.

I would greatly appreciate your help. Please let me know if you need more information, and feel free to share my contact information with them.
Looking forward to hearing from you.
Best,
Shafagh

Shafagh Hadinezhad
MFA Candidate, Industrial Design, School of Art & Design,
University of Illinois, Urbana-Champaign

3. Dear ...,  
Hope you are doing well.
Regarding the communication with the end-users/participants, I am going to first conduct online interviews with them to gain a deeper understanding of how the vision loss affected their life and daily routines. What does a healthy lifestyle mean to them and has vision loss affected it somehow? What are their biggest challenges after losing their vision? In the interview, I am going to ask them if they accept to do some daily journals through video or audio recording while doing some daily routines. They can even audio record their thoughts/insights after doing some activities and send them to me as a self-feedback on those activities. It will help me to find the challenges. Also, after the research process when I start designing a solution to the challenge that I found through the interviews and daily/weekly journals, I am going to ask them to help me with developing the end product to make sure that it is something that addresses their real needs.
Participants may accept to do one of the above activities or all of them. It is totally up to them. Whenever they feel that they do not want to continue their participation, they can withdraw, and I totally understand. Also, any stories or information that I collect through these interviews or journals will be used anonymously. I will ask for participants’ permission if I decide to tell a part of their stories in my project. The whole process of this project may take about six months and I may want to get feedback from the participants on my work every now and then, but this is something that I will have a conversation with them about in the first interview to know what works best for them.
To be honest, even if they decide to participate in just one interview, it would be still very helpful for me because I do not want to risk losing any potential participant by burdening them with a lot of work.
Please let me know if you need any further information, and feel free to share my contact information with them.
Best,
Shafagh
Shafagh Hadinezhad
MFA Candidate, Industrial Design, School of Art & Design,
University of Illinois, Urbana-Champaign

4. Dear ..., 
In my project, I am going to interview with individuals who have lost their vision in adulthood. Also, I am going to conduct online interviews with people who have been working or communicating with them such as caregivers/instructors/family members to get insights about what the challenges might be and what the existing solutions are. Regarding the communication with the end-users/participants, I am going to first conduct online interviews with them to gain a deeper understanding of how the visual impairment affected their life and daily routines. What does a healthy lifestyle mean to them and has the vision loss affected it somehow? What are their biggest challenges after losing their vision? 
Also, in the interview, I am going to ask them if they accept to do some daily journals through video or audio recording themselves while doing some daily routines. They can even audio record their thoughts after doing some activities and send them to me as a self-feedback on some activities they have done in a day. 
Also, after the research process when I am designing a solution to the challenge that I found through the interviews and daily/weekly journals, I am going to ask them to help develop the end product to make sure that it is something that addresses their real needs.
Participants may accept to do one of the above activities or all of them. It is totally up to them. Whenever they feel that they do not want to continue their participation, I totally understand. Also, any stories or information that I collect through the primary research will be used anonymously. Also, I will inform the participants if I am going to use their stories and I will not do it if they do not give me permission to.
Please let me know if you have any further questions, and feel free to share my contact information with them.
Best,
Shafagh

Shafagh Hadinezhad
MFA Candidate, Industrial Design, School of Art & Design,
University of Illinois, Urbana-Champaign

Figure 130: IRB approval, page 21.
Recruitment message which will be sent to the participants of this study via email

I am Shafagh Hadinezhad, a third-year master's student in industrial design working on my thesis in the last year of my studies. Here is a brief explanation of this thesis project: "Designing the means of maintaining a healthy lifestyle for people with severe vision loss through an adaptive storytelling toolkit in a design thinking process: To design more effective products and services to maintain a healthy lifestyle for people who have lost their vision in adulthood, designers should be able to use a design thinking/storytelling toolkit comprising different data collection methods to help understand the users. This project aims to develop and test a toolkit or a product/experience/service to address the problems explored through the communication with this user group." In this study, individuals who have lost their vision in adulthood will be interviewed as the target audience. In addition to the target population, people who have been communicating with them such as caregivers/instructors/family members will be interviewed online to get insights about what their challenges might be and what the existing solutions are. Interviewees will include people who have lost their vision in adulthood recently or long time ago, and individuals who have been born blind or lost their vision at their very young age, and their caregivers/family members/instructors if possible.

Regarding the communication with the end-users/participants, they will first be participating in online interviews to gain a deeper understanding of how the visual impairment affected their life and daily routines. What does a healthy lifestyle mean to them and has the vision loss affected it somehow? What are their biggest challenges after losing their vision?

Also, in the interview, the next step of the study will be introduced to them to see if they want to do it or not. They will be asked to do daily journals through video or audio recording themselves while doing some daily routines. Instead of video/audio record the activity, they can audio record their thoughts/feedback after doing the activities, or even fill out a reflection questionnaire about the activity they have done.

Also, after the research phase, in the process of designing a solution to the challenge that has been found through the interviews and daily/weekly journals, participants will be asked to help develop the end product to make sure that it addresses their real needs.

Participants may accept to do one of the above activities or all of them. If they feel that they do not want to continue their participation, they can withdraw their participation at any time. Also, any stories or information collected through the primary research will be used anonymously. Participants will be informed if their stories are going to be used. It will not happen without their permission.

Please ask them to contact the research team via one of the following ways if they are interested to participate in this research.

Email address: shafagh2@illinois.edu
Phone number: 8103948987
Research Materials

1. Online or phone call interview with the participants with vision impairment

The online interviews will be semi-structured with open ended questions. There will be more questions based on how the interviewees answer the following questions. I will ask them to say more about their experiences and stories in an unstructured manner.

Questions for the users/ subjects

Anytime you feel that you do not want to answer any of the questions, please let me know and we skip the question or we will remove the activity from the list of activities that you will be recording.

Your age, degree of vision impairment, and other health related conditions will be disseminated anonymously in the research.

Name
Age
Career

What is the degree/ kind of your vision impairment?
Do you live alone?
Do you have any assistant to do your daily routines or any other activities in your life?

Which of the following tasks are challenging for you in your daily routine?

- Cooking; Shopping, taking a walk; Personal hygiene; Exercising, etc.; Explain your challenges during doing these activities

Does anything unexpected happen during your daily activities that could endanger your safety or lead to any health issues? (such as drop and shatter something, you can’t find the needle on the floor, )

Which of the following ways would you prefer to record your daily routine?

- Audio recording by yourself
- Video recording by someone else living with you
- Answering daily questionnaire

Tell me more...
2. **Online or phone call interview for getting feedback on the design**

This part will be an open discussion and ask for participants’ feedback on the design which has been sent to them prior to the meeting or will be shared with them in the meeting.

- What do you think about the design?
- Does it address the challenges you face in your daily routines?
- Does it communicate the challenges with the audience well?
- Tell me more...
3. **Survey after doing the activity; the subject**

To collect your feedback on the activity you have done, you can fill out a form including the following questions, or you can record your answers and send the recording to the researcher.

- What was the specific activity you did?
- Where did it happen?
- Did someone help you to do it?
- Did you use any specific device or equipment for doing this activity?
- What were your challenges during the activity?
- How long did it take?
- Tell me more...
4. Survey after doing the activity; the Caregivers/ teachers/instructors/ whoever have worked with participants

To collect your feedback on the activity you have been assisting with, you can fill out a form including the following questions, or you can record your answers and send the recording to the researcher.

- What was the specific activity?
- Where did it happen?
- What was your responsibility?
- Did you use any specific device or equipment?
- What were your challenges during the activity?
- How long did it take?
- Tell me more...
5. Daily Journal

It is up to you how many times you want to do it but not less than 3 times if possible. Recording a daily journal, about the challenges you have faced during the day for maintaining a healthy lifestyle, even though you have not recorded the activity, is going to help the researcher to gain a deeper understanding of daily challenges of the participants.

You can use an audio recorder or fill out a questionnaire.

- What are your daily challenges to maintain a healthy lifestyle?
- How would you deal with it or solve it?
- Tell me more...
6. Interview with the teachers/instructors/ Caregivers/ whoever have worked with participants

Name:
Age:
Occupation:
What is your career?
How long have you been working with people with vision impairment?
How do you communicate?
How often do you communicate?
What are the challenges you both face in your communication?
Tell me more...
Social Behavioral Research Caregiver Consent Form

A design thinking toolkit to improve healthy lifestyle for people who lose vision in adulthood

You are being asked to participate in a voluntary research study. The purpose of this study is to understand the real needs and challenges of people who have lost their vision in adulthood to maintain a healthy lifestyle. Participating in this study will involve online/phone call interviews, self-audio or video recording and your participation will last 6 months. Risks related to this research include getting distracted by the recorder while recording the activity done by the individual with vision loss which is a minimal risk; benefits related to this research include gaining a deeper understanding of the real needs of people who lose their vision in adulthood to be able to address them in an appropriate way. The alternative to participating in this study is to fill out an online survey or just an online meeting.

Principal Investigator Name and Title: David Weightman
Department and Institution: School of Art and Design at the University of Illinois at Urbana-Champaign
Contact Information: diw@illinois.edu

Why am I being asked?
You are being asked to be a participant in a research study about designing a toolkit/product/service experience to improve healthy lifestyle for people who lose vision in adulthood. The purpose of this research is to help designers to understand the real needs of people who lose their vision in adulthood and address challenges that the users of this research face in their life. You have been asked to participate in this research because you have been communication with the end users of this research study. You are the expert as an observer and someone who is somehow involved in their daily routines who can give authentic feedback and information regarding their real needs. Approximately 40 participants will be involved in this research at the University of Illinois at Urbana-Champaign.

Your participation in this research is voluntary. Your decision whether to participate will not affect your current or future dealings with the University of Illinois at Urbana-Champaign. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

What procedures are involved?
The study procedures are online meetings, surveys and self-audio or video recordings.

The meetings will be performed online so there will be no in person meeting or observation. For about 6 months, there will be a couple of online meetings or phone calls and you will be recording the participant’s activities and giving feedback on the activity and sending it to the researcher. Each of the meetings will last about 30-60 minutes or more and the duration of the recording of each activity may last about 10-30 minutes or more depending on the type of activity.

The instructions will be provided for them verbally in the first online meeting or phone call, and any questions regarding these instructions will be answered in the meeting. The meeting or phone call will be recorded. The participants will be asked in the beginning of the meeting whether they give permission for the recording. After the meeting, the instructions will be sent to the participants via email. They can reach out to the research team via email with any questions relevant to the procedure.
Here are the instructions:
You are supposed to video or audio record the activities that the participant will be doing. These activities may include the followings
- Getting up
- Preparing breakfast
- Doing exercise
- Getting dressed and leaving the house
- Going to bed
- other...

After finishing the activity, audio record your feedback on the activity. You can do it right after the activity or whenever you find free time during the day: What did participant do during this activity? how was the experience? What did/did not go well? What surprised you? Was it easy or difficult? Did they face any challenges? Did you have any interaction with the participant during the activity?

Questionnaire instead of audio recording the feedback on the activity:
- What did participant do during this activity?
- How was the experience?
- What did/did not go well?
- What surprised you?
- Was it easy or difficult?
- Did they face any challenges?
- Did you have any interaction with the participant during the activity?

It is up to you that in how many activities, you want to get involved and give feedback on. You can send the recordings/reflection questionnaire to the research team each time separately or on a weekly basis. The research procedure will last about 6 months including about 20 meetings for about 30-60 minutes each, and about 20 audio/video recordings of activities which may last about 10-30 minutes or more depending upon the type of activity. You are free to attend the whole procedure or a part of it and you are free to withdraw at any time.

What are the potential risks and discomforts?
Minimal risk- Losing balance or getting distracted while recording the participant's activities. If you prefer, you can remove this risk by stop recording and just observing the participant. You can give feedback during or after the activity by video/audio recording, doing a survey or writing a journal after or during the activity.

Are there benefits to participating in the research?
Gaining a deeper understanding of people who lose their vision in adulthood and what their challenges are.

What other options are there?
You have the option to not participate in the full study and just fill out a questionnaire instead.

How can I indicate the level of my participation in this study?
In the last question, you can indicate if you are going to participate in the full study, or just the questionnaire.
Will my study-related information be kept confidential?
Faculty, staff, students, and others with permission or authority to see your study information will maintain its confidentiality to the extent permitted and required by laws and university policies. The names or personal identifiers of participants/ caregivers/ family members will not be published or presented.

Can I withdraw or be removed from the study?
If you decide to participate, you are free to withdraw your consent and discontinue participation at any time. The researchers also have the right to stop your participation in this study without your consent if they believe it is in your best interests, you were to object to any future changes that may be made in the study plan.

Will data collected from me be used for any other research?
Your de-identified information could be used for future use including an academic, journal or conference paper related to this research without additional informed consent.

Will I be reimbursed for any expenses or paid for my participation in this research?
You will not be offered payment for being in this study.

Who should I contact if I have questions?
Contact the researcher of this study, Shafagh Hadinezhad, at +18103948987 or shafagh2@illinois.edu if you have any questions about this study or your part in it, or if you have concerns or complaints about the research.

What are my rights as a research subject?
If you have any questions about your rights as a participant in this study, please contact the University of Illinois at Urbana-Champaign Office for the Protection of Research Subjects at 217-333-2670 or irb@illinois.edu.

Please indicate if you want to participate in the full study or just a part of it.
- [ ] Full study including helping participant with the self-video/audio recordings (as many recordings as you are willing to) and feedback sessions on the design (solution to the challenge found based on the recording journals)
- [ ] Questionnaire about your routines and challenges instead of the self-recordings
- [ ] Feedback sessions on the design

I have read the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

_____________________________     ______________________________
Signature                                        Date

_____________________________
Printed Name

Figure 140: IRB approval, page 31.
Figure 141: IRB approval, page 32.
Social Behavioral Research Participant Consent Form

A design thinking toolkit to improve healthy lifestyle for people who lose vision in adulthood

You are being asked to participate in a voluntary research study. The purpose of this study is to understand the real needs and challenges of people who have lost their vision in adulthood to maintain a healthy lifestyle. Participating in this study will involve online/phone call interviews, self-audio or video recording and your participation will last 6 months. Risks related to this research include getting distracted by the recorder if you will be holding it in your hand while you will be doing the activity which is a minimal risk; benefits related to this research include gaining a deeper understanding of the real needs of people who lose their vision in adulthood to be able to address them in an appropriate way. The alternative to participating in this study is to fill out an online survey or just an online meeting.

Principal Investigator Name and Title: David Weightman
Department and Institution: School of Art and Design at the University of Illinois at Urbana-Champaign
Contact Information: dw@illinois.edu

Why am I being asked?
You are being asked to be a participant in a research study about designing a toolkit/product/service/experience to improve healthy lifestyle for people who lose vision in adulthood. The purpose of this research is to help designers to understand the real needs of people who lose their vision in adulthood and address challenges that the users of this research face in their life. You have been asked to participate in this research because as the end user of this research study, you are the expert who can give authentic feedback and information regarding your real needs. Approximately 40 participants will be involved in this research at the University of Illinois at Urbana-Champaign.

Your participation in this research is voluntary. Your decision whether to participate will not affect your current or future dealings with the University of Illinois at Urbana-Champaign. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

What procedures are involved?
The study procedures are online meetings, surveys and self-audio or video recordings.

The meetings will be performed online so there will be no in person meeting or observation. For about 5 months, there will be a couple of online meetings or phone calls and you will be recording your activities and giving feedback on your activity and sending it to the researcher. Each meeting will last about 30-60 minutes or more and the duration of the recording of each activity may last about 10-30 minutes or more depending on the type of activity.

The instructions will be provided for them verbally in the first online meeting or phone call, and any questions regarding these instructions will be answered in the meeting. The meeting or phone call will be recorded. The participants will be asked in the beginning of the meeting whether they give permission for the recording. After the meeting, the instructions will be sent to the participants via email. They can reach out to the research team via email with any questions relevant to the procedure. Here are the instructions:

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IRB #: 21266
These are a list of activities that you can video or audio record. Feel free to add an activity to this list if you prefer:
- Getting up
- Preparing breakfast
- Doing exercise
- Getting dressed and leaving the house
- Going to bed
- Other...

After finishing the activity, audio record your feedback on the activity. You can do it right after the activity or whenever you find free time during the day: What did you do during this activity? How was the experience? What did/did not go well? What surprised you? Was it easy or difficult? Did you face any challenges? ...

Questionnaire instead of audio recording the feedback on the activity:
- Explain what you did during this activity?
- How was the experience?
- What did/did not go well?
- What surprised you?
- Was it easy or difficult?
- Did you face any challenges?
- Other ...

The number of doing these activities is up to you, but it is suggested that you record them at least three times a week. You can send the recordings/reflection questionnaire to the research team each time separately or on a weekly basis.

The research procedure will last about 8 months including about 20 meetings for about 30-60 minutes each, and about 20 audio/video recordings of activities which may last about 10-30 minutes or more depending upon the type of activity. You are free to attend the whole procedure or a part of it and you are free to withdraw at any time.

What are the potential risks and discomforts?
Minimal risk: Losing balance or getting distracted while recording which can be removed by asking someone else for help, place the recorder somewhere instead of holding it in your hand or do not record it live.

Are there benefits to participating in the research?
Gaining a deeper understanding of people who lose their vision in adulthood

What other options are there?
You have the option to not participate in the full study and just fill out a questionnaire instead.

How can I indicate the level of my participation in this study?
In the last question, you can indicate if you are going to participate in the full study, or just the questionnaire.

Will my study-related information be kept confidential?

University of Illinois at Urbana-Champaign
Institutional Review Board

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IRB # 21206

Figure 143: IRB approval, page 34.
Faculty, staff, students, and others with permission or authority to see your study information will maintain its confidentiality to the extent permitted and required by laws and university policies. The names or personal identifiers of participants will not be published or presented.

Can I withdraw or be removed from the study?
If you decide to participate, you are free to withdraw your consent and discontinue participation at any time. The researchers also have the right to stop your participation in this study without your consent if they believe it is in your best interests, you were to object to any future changes that may be made in the study plan.

Will data collected from me be used for any other research?
Your de-identified information could be used for future use including an academic, journal or conference paper related to this research without additional informed consent.

Will I be reimbursed for any expenses or paid for my participation in this research?
You will not be offered payment for being in this study.

Who should I contact if I have questions?
Contact the researcher of this study, Shafagh Hadinnejad, at +18103948987 or shafagh@illinois.edu if you have any questions about this study or your part in it, or if you have concerns or complaints about the research.

What are my rights as a research subject?
If you have any questions about your rights as a participant in this study, please contact the University of Illinois at Urbana-Champaign Office for the Protection of Research Subjects at 217-333-2670 or irb@illinois.edu.

Please indicate if you want to participate in the full study or just a part of it.
- [ ] Full study including self video/audio recordings (as many recordings as you are willing to) and feedback sessions
- [ ] on the design (solution to the challenge found based on the recording journals)
- [ ] Questionnaire about your routines and challenges instead of the self recordings
- [ ] Feedback sessions on the design

I have read the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

_________________________________________  __________________________
Signature                                                                 Date

_________________________________________
Printed Name

_________________________________________  __________________________
Signature of Person Obtaining Consent  Date (must be same as subject’s)

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Figure 144: IRB approval, page 35.
Figure 145: IRB approval, page 36.
Waiver of Documentation of Informed Consent

For Requesting a Waiver of the Documentation of Informed Consent
All forms must be typewritten and submitted via email to irb@illinois.edu.

Section 1. PROTOCOL INFORMATION
1A. Primary Investigator: David Weightman
1B. Protocol Number: 21206
1C. Project Title: MFA Thesis- Maintaining a healthy lifestyle for people who lose their vision in adulthood
1D. Is this research regulated by the US Food and Drug Administration? ☒ Yes ☐ No

Section 2. REQUEST FOR WAIVER OF DOCUMENTATION
A consent procedure which does not document obtained consent through a physical signature may be approved by the IRB under certain conditions. To request IRB approval of a consent procedure which does not document consent through a physical signature, provide a response to only one of the following. Note that the IRB may require the investigator to provide subjects with a written statement regarding the research, even though the documentation requirement may be waived.
2A. The only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Each subject will be asked whether the subject wants documentation linking the subject with the research, and the subject’s wishes will govern. (Note: A waiver of documentation of informed consent is not permissible under this category if the research is subject to FDA regulations.)
2B. The research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside the consent. The participant will freely decide about what information they want to share with the research team during the online interviews and video/audio recording or what is going to be shared with public by the research team. See the attached document.
2C. The subjects or legally authorized representatives are members of a distinct cultural group or community in which signing forms is not the norm, the research presents no more than minimal risk of harm to subjects, and there is an appropriate alternative mechanism for documenting that informed consent was obtained.

Figure 146: IRB approval, page 37.
Waiver of Documentation of informed Consent  
IRB Number: 21206  

Waiver of Documentation Form – 28. The participant will freely decide about what information they want to share with the research team during the online interviews and video/audio recording or what is going to be shared with public by the research team. They may take a survey or will be just interviewed if they prefer it to the audio/video recording. Although all the information from participants is going to be used anonymously, they will not be used or shared with the public without their permission. They will also give permission on whether they want their information to be shared anonymously or not. Participants can freely and without any restriction withdraw from participation at any time and any level without giving an explanation. Since the meetings with participants will happen online, the consent will be obtained without obtaining a physical signature which is going to be done through a Waiver of Documentation of Informed Consent. Consent forms will be sent to the participants before the meetings via email. In the beginning of the meeting, participants who have already read the consent form will talk about what part of the information about them can or cannot be shared by the research team.