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Leveraging Conversational User Interfaces and Digital Humans to Provide an Accessible and Supportive User Experience on an Ophthalmology Service

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Designing E-Health services that are accessible, engaging, and provide valuable information to patients is an endeavor that requires research and validation with potential users. The information needs to be perceived as trustworthy and reliable, in order to promote people’s ability to make informed decisions about their health. This Master’s thesis work focused on understanding the potential of conversational user interfaces (CUIs) featuring digital humans (DHs) as communication agents to provide healthcare-related information to users. The case study underlying the research was proposed by Roche: the company wanted to create an informational ophthalmology website featuring a digital human to substitute the traditional text-based website.

The main goal of this work was to understand whether CUIs and DHs can provide a higher level of accessibility and engagement for users, with a special focus on people starting to live with low vision (potential ophthalmology patients). Managing to address these aspects would allow providing a better user experience for people visiting the website. Since digital humans are not yet extensively adopted in the healthcare domain, few design guidelines are available. The work employed a human-centered design approach, to gather requirements and feedback from users, and led to defining six guidelines and an extensive set of observations about user experience and accessibility. These guidelines are: ensure that the digital human is as realistic as possible; create a clear and easy to follow conversation; present options simply and allow flexibility in choice methods; provide a text version of the content; ensure that easy and self-explanatory navigation; ensure compatibility with assistive technologies and provide flexibility, personalization and integration.

The user research was divided into two phases. First, an exploratory research session was conducted, where ten participants were recruited to investigate the needs and expectations of people living with eye conditions towards an
informative service and their first impressions of DHs. This session employed the semi-structured interview methodology, and the results informed the further development of the service. When the first proof of concept prototype version of the website was built, an evaluative research phase with eighteen participants was conducted. This session was conducted using the participant observation methodology paired with semi-structured elicitation interviews. Afterwards focus group sessions were organized to have the participants further discuss their experience. The user-based research was paired with expert evaluation using the cognitive walkthrough methodology and a simplified WCAG 2.1 accessibility assessment. Combining the two approaches gave a good overview of the merits and issues of the approach. The results of the research allowed building a good understanding of the positive and negative aspects of using a digital human as an agent in a conversational user interface. Users generally appreciated the concept: they found it engaging, trustworthy and easy to use. However, there are some aspects that could not be addressed during this research, and which need further understanding. The primary areas that need to be addressed are guidance, navigation, and error management. Nonetheless, the positive feedback gathered from the participants of the evaluation sessions proves that it is worth investing in the research and development of this relatively new kind of service. In fact, the results of the work show that having a digital human as agent for a conversation-based informative service in healthcare has strong potential, in terms of both accessibility and engagement.

Keywords:
Digital humans; e-Health; human-centered design; user experience; conversational user interfaces; accessibility

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1 Introduction

1.1 Scope

The term E-Health started becoming popular in the late 1990s, and Eysenbach (2001) later defined it as the “health services and information delivered or enhanced through the Internet and related technologies”. For the author, the “e” does not stand for “electronic” only, and he coined the 10 e’s in e-Health to explain all that it stands for. The words that explain e-Health are efficiency; enhancing quality; evidence-based; empowerment; encouragement; education; enabling; extending; ethics; equity. As these terms show, e-Health has the goal of providing fairer and more ethical services, which can enhance the accessibility and availability of health-related information for people who need it. E-Health services also aim at making healthcare more efficient and quality-focused, and to empower patients to make their own informed health decisions, based on scientific evidence.

While digital healthcare services are steadily developing and growing, with more and more people relying on them to manage and monitor their health, they still pose concerns, and they do not always reach their goals. One of the main causes of low adoption rates is the failure to meet patients and healthcare professionals’ needs and expectations, due to a lack of understanding from the designers and developers’ side (Cajander et al., 2016). Other factors that hinder the adoption of e-Health services include usability issues, privacy concerns, culture, and flow disruption (Granja et al., 2018). The involvement of patients in the design of e-Health services allows creating a better user experience and is crucial to achieve acceptability and adoption.

E-Health services come in different forms and with different goals. In their review of articles defining e-Health, Oh et al. (2005) cite the classification that Baur et al. (2001) made of different e-Health services and their goals. The first type of e-Health services that the authors mention are catalogues and health-related databases, which have a referential goal. One example of this type of service is the eHealth Digital Service Infrastructure (eHDSI), developed by the European Union, which allows countries to share medical records in a secure way, enabling for example to get their prescribed medicines in another European country (European Commission, 2022).

Another type of e-Health services is those with the goal of promoting “self-help” or “self-care”. This category includes informative content, support from other peers, and assessments among other options. One example of this type of service is the Omaolo website (Omaolo, 2022), which is a Finnish e-Health service that allows users to assess the symptoms that they might be feeling and to understand more about how they should act according to the results.

Other e-Health services are concerned with organizing and scheduling appointments and consulting results (from exams and other healthcare activities). TreC, the digital health service of the Italian province of Trento is an example of this kind of services (TreC, 2022). It allows users to schedule doctor appointments, to download their prescriptions and to receive the results of their exams and checkups.

Furthermore, the authors identify patient-doctor or caregiver-doctor communication as a common goal for e-Health services, which provide the
channel where the exchange of information can happen, or the support to effectively carry out monitoring activities. The example for this type of services is the Finnish Mehiläinen, which offers a telemedicine service where patients can have remote consultations with doctors (Mehiläinen, 2022).

Finally, the authors identify e-Health services with the goal of selling health products and services, which they ascribe to the term “e-Health commerce”. Online pharmacies have increased in popularity, and one example is LloydsPharmacy, which sells both prescription and non-prescription medicines online and delivers them to the buyers (LloydsPharmacy, 2022).

The focus of this Master Thesis will be “self-help” services, and in more detail on informative e-Health services. These services have the goal of informing the public about health-related topics, and to support them through their journey. In particular, the clinical focus of this thesis will be ophthalmology services. Tham et al. (2021) explain that ophthalmology is one of the medical fields that is most lagging in terms of digitalization and e-Health services. This generally led to the ophthalmology sector not being ready and able to face the COVID-19 situation. The authors believe that there is potential to develop a more digital approach to ophthalmology, and this Master Thesis also aims at contributing to this goal. E-Health services concerned with ophthalmology require a rather high level of attention to accessibility and usability, which will be the main focus of this thesis work.

1.2 Motivation

1.2.1 Scarcity of resources

Already in 2009, Tynkkynen and Lehto noted how the ophthalmology sector in Finland was lacking personnel, especially in the public sector. In fact, the Finnish healthcare system is divided into three different sectors, where one is completely “free” (funded through taxation), and two of them are partly state-funded and partly paid for through insurances or direct payments. Tynkkynen and Lehto (2009) also explain that most Finnish ophthalmologists work in both the public and private sector, which further aggravates the lack of personnel in the public sector. In 2019, the licensed physicians specialized in ophthalmology in Finland were 500 over 15,030 licenses (Finnish Medical Association, 2019). They therefore make up 3.3% of the physicians and 0.009% of the total Finnish population.

Roche noted that in Finland, as well as in other European countries, healthcare services often suffer from scarce human resources, in that healthcare professionals are overwhelmed by the number of people contacting them and needing discussion (Roche, personal communication, December 2021). This results in insufficient discussion time, not because of a lack of interest from the healthcare professionals, but due to a lack of time and resources. For this reason, healthcare professionals tend to try to optimize the patients’ journey and to move them quickly through the healthcare management system. The result of these practices is that patients are often not provided with sufficient information about their condition.

This situation was exacerbated by the Covid-19 emergency, when patients could not visit clinics or hospitals unless they were suffering from a severe condition. This new reality underlines the growing need for reliable and informative digital healthcare services that can support patients in their homes, be it because they
do not wish to or cannot visit a hospital or clinic or because the healthcare professionals cannot cater for the number of requests that they receive.

As previously mentioned, e-Health services aim at extending the scope of healthcare provision (Eysenbach, 2001). They can therefore make healthcare more accessible to everyone, and thus serve the needs of both patients and healthcare professionals and providers. To achieve this, it is crucial to provide information that is reliable and accurate to the patients. In recent years, the trend of patients turning to other patients and to the internet to find health-related information has seen an increase (Briggs et al., 2015). In spite of the benefits that finding comfort and empathy from others in similar situations can bring, it is crucial to ensure that people have access to reliable and scientific information, and that they are redirected to a professional whenever it is needed.

Informative websites that convey knowledge about health conditions can complement the first encounters with healthcare professionals, by providing patients with the desired amount of reliable information about their situation. Adopting this kind of service would benefit both parties and reduce the burden on the healthcare system. However, the services need careful design to make sure that they comply with regulations (privacy, legal, ethical...) and meet the end-users’ expectations.

1.2.2 Consequences of eye conditions
Research performed by Hassel et al. (2006) has shown that suffering from an eye condition puts people at a higher risk of suffering from depression and struggling with mental health. As an example, Taylor et al. (2016) showed that a percentage that fluctuates between 11% and 44% of AMD patients suffer from depression, and this number is up to three times higher than what is seen in healthy individuals of the same age group.

Besides this, eye conditions most commonly result in a loss of independence, which can also affect the quality of life and mental health of people (Hassel et al., 2006). The most common struggle areas include everyday activities and house chores such as cooking, doing the dishes and cleaning, together with leisure activities such as reading and watching television, up to complex activities such as driving. This progressive loss of ability to deal with everyday life activities can affect the emotional state of the patients and consequently their willingness and ability to maintain and build social connections (Hassel et al., 2006). This shows the need to provide a service that can provide emotional support as well as reliable information.

1.3 Thesis aims and Research Questions (RQs)
As previously explained, the broad focus area of this Master Thesis is e-Health services for ophthalmology. In particular, the work focuses on assessing the current state and potential of conversational user interfaces (CUIs) to convey healthcare information and emotional support to patients. CUIs use natural language either in spoken or written form to interact with users (Kocaballi et al., 2020). In this specific case, the CUI will feature a digital human, which is an AI-powered human-looking character, to be the communicational agent that interacts with the user.

This Master Thesis aims at assessing the user experience, accessibility and usability of an e-Health service using a conversational interaction model. The methodological framework is that of human-centered design (HCD), whose goal
is to always keep the user at the center of all design efforts. User experience (UX) includes all the aspects of the interaction between a user and a system, ranging from usability, to emotions, to satisfaction and more. In this case, however, it is more precise to refer to patient experience (PX), rather than to user experience. This different angle allows for the inclusion of more aspects of the experience of users, which are relevant in the healthcare domain. More detail will be provided about the distinction between the two terms. A strong support to positive patient experience is emotional support, which is the ability of a service to convey and trigger positive emotions.

This thesis aims at exploring how to achieve the effective design and implementation of e-Health informative services, particularly for people living with low vision. This resulted in a focus on accessibility and speech-based interaction, with attention being posed on how digital humans and conversational user interfaces can have a positive impact on patient experience. To provide the best possible insights, literature regarding patient experience, e-Health, and patient-computer interaction has been analyzed to gain useful insights to understand how to design a better patient and user experience. Besides this, literature regarding the incorporation of digital humans and conversational user interfaces in the healthcare domain were analyzed and insights were provided on the potential for digital humans to support the experience of informative e-Health services.

**Research Problem:** e-Health services that aim at providing valuable and reliable information to potential patients often fail to be emotionally supportive and informative for people who are starting to explore new conditions.

**RQ1:** Based on empirical research using human-centered design methods, can conversational user interfaces featuring digital humans help make e-Health services more accessible for patients with vision defects, to provide them with the information they need and with emotional support? (case study)

User research will be conducted to understand whether using conversational user interfaces featuring digital humans can provide a more accessible interaction modality. The main user groups involved will be people living with low vision and their caregivers.

**RQ2:** What guidelines can be suggested to foster the improvement of the accessibility and emotional support of e-Health services through conversational interaction?

Based on the user research and the literature analysis, the results will be gathered to create a list of guidelines and best practices that can help designers approach conversational user interfaces featuring digital humans.

### 1.4 Case study

The research was based on a case study, conducted within Roche. Roche was first established in Switzerland in 1896 as F. Hoffmann-La Roche & Co., to industrially produce branded medicines (Roche, 2022 A). The company continued growing and expanding to other countries and to other market sectors such as vitamin and cosmetic production. In 1968, the company entered the sector of diagnostics and research. At this point, the main focus of the
company was biotechnology. From 2007 on, the company committed to achieving personalized healthcare for patients (Roche, 2022 B).

Roche is active in the ophthalmology sector, both through research and development digital health solutions. Low vision and vision impairments is a global health concern: the World Health Organization (2021) reports that over 2.2 billion people are living with a form of visual impairment. According to the WHO, the main causes of these conditions are several, including Age-related Macular Degeneration and Diabetic Retinopathy (two of the main focuses of Roche’s ophthalmic effort), and half of the global cases could have been prevented or still need to be treated. For this reason, raising awareness is a priority to fight against low vision conditions.

The Finnish section of the company has decided to redesign their informative ophthalmology website. The goal of the redesign is to make the content accessible and available to all people, regardless of their visual acuity level. The scope of the website is providing informative material about eye conditions, how to recognize them and how to act accordingly. As explained before, one of the reasons that pushed the team to embark in this activity is that ophthalmology clinics (in Finland especially) are struggling to meet the demand for consultation and general information gathering. Roche Finland therefore wants to provide a service where patients can find information that is reliable, complete and backed by science, to ensure that people can inform themselves.

Since the website needs to inform people about eye conditions, accessibility for people living with low vision was one of the focus areas. In order to reach this goal, the team decided to test an interface using speech interaction and featuring a digital human. Since this is a relatively new approach for informative medical websites, user experience research with the end-users was needed to ensure that the final service would be developed following a User- and Human-Centered approach.

Vision impairment was not the only accessibility theme considered. Other forms of impairments were also investigated, and accessibility was evaluated on general requirements. Closed-captions of what the digital human would say were envisioned to increase accessibility for hard-of-hearing people. Besides this, the possibility to just read the text instead of listening to it was envisioned, and the cognitive load required to interact with the digital human was considered to try and minimize it.
2 Review of related literature

This section aims at reviewing some of the concepts that constitute the theoretical background of this thesis and to present the current state-of-the-art in the domain. The main methodological concepts come from the human-centered design (HCD) approach. Interaction concepts such as conversational user interfaces, virtual agents, affective computing and digital humans will be crucial to understand the nature of the research and work. Finally, some medical-oriented concepts and information will be helpful to focus the research on the particular case study of ophthalmology. In particular, it is important to understand who the users of this type of website could be, in order to focus the scope of the HCD approach.

The articles that constitute the evidence of this section were mostly found in the ACM (N = 8), PubMed (N= 7) and ResearchGate (N = 3) repositories. Additional articles (N = 15) were found on other more specific and less known repositories. In fact, looking for articles to build the literature review section was a challenging endeavor, which required a lot of time and different combinations of keywords, and did not yield a high number of results. It is interesting to note that no result was yielded in any of the repositories with queries such as “digital humans AND ophthalmology”. The term digital human was also swapped for conversational agents and digital avatar, but no relevant article was found. Substituting the term ophthalmology with the term healthcare resulted in a high number of results, but very few were relevant to the thesis work's scope, and therefore chosen to become part of the literature review. The queries that were used to find the relevant articles combined the keywords: digital humans, virtual agents, conversational agents, digital avatars, accessibility, e-health, ophthalmology, healthcare, user experience, patient experience, human-centered design, emotional support, patient empowerment. The difficulty in finding evidence to inform the literature review section shows that the application of conversational interaction in the healthcare domain has not yet been thoroughly explored.

2.1 Patient experience and human-centered design

The concept of “user experience” (UX) has gained increasing interest and recognition in the field of (digital and non-digital) service and product design. The ISO standard 9241-11 (2018) defines user experience as “user's perceptions and responses that result from the use and/or anticipated use of a system, product or service”. In addition to this, Norman and Nielsen (2022) state that it “encompasses all aspects of the end-user's interaction with the company, its services, and its products”. This means that the whole interaction of users with a specific system or service, their feelings, impressions, reactions and frustrations are included under this term.

When the end-user of a product or service is interacting with healthcare systems or services, it is more appropriate to talk about “patient experience”, rather than “user experience”. Patient experience (PX) is defined by the Beryl Institute as “the sum of all interactions shaped by an organization’s culture that influence patient perceptions across the continuum of care” (The Beryl Institute, 2022). This slight term adjustment allows including aspects that are specific to the healthcare domain, such as health literacy. Research has shown that a positive
patient experience is one of the strongest indicators of patient retention and adherence to therapy (Bahja & Lycett, 2016). For this reason, patient experience becomes one of the main measures of the quality of healthcare systems and products.

Human-centered design has become a popular approach to achieve the incorporation of end-users’ needs and expectations into the design of systems, products and services. In fact, the ISO standard 9241-210 (2019) defines human-centered design as an “approach to systems design and development that aims to make interactive systems more usable by focusing on the use of the system and applying human factors/ergonomics and usability knowledge and techniques”. The acceptability and the consequent success of a design strongly depends on its perceived usefulness by the users, and while this is true for any domain, it might be even more crucial for the healthcare sphere (Dabbs, 2009). Although digital healthcare services are increasingly adopted worldwide, they often do not meet their goals because they fail to include the users’ perspective, background and needs in the design process (Cajander et al., 2016). Human-centered design tries to address this issue by iteratively incorporating user’s feedback throughout the whole design process (The Interaction Design Foundation, 2022). This results in designs that are accepted and adopted by the end-users, because they take their needs and expectations into account.

2.2 Conversational user interfaces

The design of a service’s interaction modality plays an important role in the Human-centered design practice: systems can interact with end-users in many ways, and choosing the appropriate modality is an important part of the design process. Since the case study service is intended for people who are starting to experience some form of vision loss, speech interaction using natural language through a conversational agent was considered a good interaction modality.

Conversational agents are interactive systems that use natural language to communicate with users, either through text or voice output (Kocaballi et al., 2020). These systems have benefitted from the constant improvement in the artificial intelligence domain, specifically in speech recognition (Laranjo et al., 2018). Text-based interfaces were first developed in the 1960s, when the goal was to understand whether they could replicate a human conversation as closely as to make the interacting person believe that they were conversing with another human, which indeed proved to be possible (Ciechanowski et al., 2019). However, it has not been until recently that CUIs started to gain recognition and spread to different domains. Some very known examples of CUIs include Apple’s Siri, Amazon’s Alexa, or Google Assistant, together with chatbots (such as the ones that provide real-time help on websites) and other digital characters that can engage in human-like conversations with the user.

Conversational user interfaces (CUI) featuring conversational agents are adopted more and more often in different domains of everyday life, and healthcare management is no exception (Kocielnik et al., 2021). In the last few years, the healthcare domain has proven to be willing to adopt this kind of technology to support patient journeys in an accessible, usable and intuitive way (Kim et al., 2019). However, Laranjo et al. (2018) suggest that conversational agents in the healthcare domain are less developed than the ones
used in different fields, such as booking of services. This might be due to the constraint posed by dealing with sensitive health data.

CUIs have spread and increased in number over the last twenty years, and they proved to deserve a seat at the table in the healthcare sector: Kocaballi et al. (2020) explain that Amazon’s Alexa alone counts over one thousand skills that are related to health. The authors state that even though conversational agents have proven to be beneficial in healthcare services, most of the developed systems lack the ability to analyze and react to natural language that is not constrained to a list of options. This aspect can strongly reduce the feeling of realism of the conversation, and therefore needs further research.

In fact, conversational agents have the potential to create bonds and what is called “therapeutic alliance” with the users, and thus to convey emotionally supportive content (Kim et al., 2019). This is extremely relevant and important in the case of healthcare services, where emotional support is one of the most indicative factors to achieve a positive experience and to increase treatment adherence (Fang et al., 2017). Besides this, ensuring empathy and emotional support from conversational agents is one of the main influences on their credibility (Zeni Montenegro et al., 2019).

For these reasons, CUIs need careful and attentive design to ensure that they can fulfil their potential. If properly designed and implemented, the natural language-based interaction can increase engagement and lead to improved patient experience (Kocielnik, 2021). Furthermore, conversational agents can be successful in lowering the workload that burdens healthcare professionals by providing general or specific information to patients. However, it is important to note that conversational agents can set higher expectations from the users due to their realistic nature, which can also result in higher levels of frustration if these expectations are not met (Ciechanowski, 2019).

Effectively communicating health-related information is crucial to achieve awareness and to empower patients to make informed decisions. Previous research has made it clear that, on a general level, in-person discussions with healthcare professionals is the most effective way to achieve this goal (Bickmore et al., 2010). This implies that conversational agents that can engage in conversations with patients have the potential to be more effective than simple text-based websites. Research has shown that conversational agents can be particularly effective for people with a low level of health literacy (Bickmore et al., 2010; Kocielnik et al., 2021). Kocielnik et al. (2021) argue that providing information through CUIs can make it easier to understand, and that this group of users tends to have a high level of acceptance towards conversational agents.

2.3 Digital humans

Digital humans are one example of conversational agents that can be used to build conversational user interfaces. One crucial aspect to achieve a good patient experience involving interaction with a digital human is that this interaction should feel as if it was a conversation with a real-life person (Kim et al., 2019). To achieve this, storytelling is equally important as the design of the avatar, because it will make the discussion flow naturally. In fact, the users need to feel as if they were talking to a real human, and humans strongly rely on storytelling in their interactions.
The discussion with the digital human should be empowering for the patients and leave them with the feeling that they know more about their health and that they can take action on it. The literature has defined patient empowerment in healthcare as an “essential element of high quality healthcare systems tackling the expanding burden of chronic diseases” (EHP, 2015). Çarçani et al. (2019) noted that, to ensure empowerment, it is important to meaningfully involve the patients and let them interact with the agent, to make sure that their health literacy level is sufficient throughout the interaction and to allow them to manage their own health and make decisions about it. Constantin et al. (2019) investigated the interaction of patients with a digital doctor, and they noted that a good way to achieve the service’s goals is making the interaction scenarios as flexible as possible and allowing the users to provide input freely. For this reason, effective UX writing is crucial.

2.3.1 Digital agent’s personality and emotional support

Another crucial aspect to achieve a positive patient experience with a digital human is the agent’s behavior and its approach to the users. This underlines the importance of investigating with the users the personality that they would expect from the agent. The literature sets a baseline regarding the emotional abilities of the human: Moore et al. (2004) noted that medical interventions are most likely to be successful when the doctors are emotionally supportive and friendly, and when they treat the patient as a peer. Patients value the emotional approachability of doctors, their ability to understand, focus on and cooperate with them, instead of lecturing them from the heights of their knowledge (Donovan, 1995). Shared decision making (SDM) has proved to be the most effective way to reach consensus between patient and doctors in healthcare environments. Previous studies have shown that empathy in digital characters engages and motivates the users, and eventually increases the likelihood of a change in behavior (Lisetti et al., 2013).

All these aspects should be mirrored in a digital human that aims to convey healthcare-related information. Fang et al. (2017) compiled a list of the characteristics that a digital human acting as a carer should embody. They note that an avatar should be attentive, knowledgeable, smart and interactive, motivating and convincing, friendly and supportive, personalized and that it should use simple language. These characteristics lead the patients to be more at ease with the interaction and the advice provided, more confident in their healthcare-related knowledge, more satisfied and more secure. Besides this, it allows establishing a relationship between the digital human and the user, motivating the patient and increasing the user’s understanding of the medical information (and thus their health literacy). Positive emotions elicitation will likely lower the cognitive load for the various activities that users perform on a website (looking for information, answering questions...). This would result in lower stress levels, and thus increase the likeliness of users benefiting from the provided content.

Fang et al. (2017) believe that interacting with a digital human can be beneficial for elderly people, because they often feel isolated and disconnected from the rest of society. Talking to a person instead of looking for information in an aseptic way could improve their engagement and adherence. This is particularly
relevant in this case study, since the main target group for the ophthalmology website is people who suffer from conditions that generally have a late onset.

2.3.2 Human-virtual agent interaction
Building a relationship of trust that can provide real emotional support though a conversational agent should not be taken for granted. When interacting with a computer, people consider it a machine, and apply the corresponding mental model: they expect it to be distant, rational and not empathetic, and this can impact the way users interact with a service (Sundar & Kim, 2019). In fact, Numata et al. (2020) explain that “a person’s belief during human–virtual agent interaction that the agent is a computer program, not a human agent, affects social-cognitive processes.”.

There is another aspect to consider, which is explained by the CASA (Computers As Social Actors) paradigm: users have expectations and apply rules to machines, as they would normally do with humans (Zehnder et al., 2021). This phenomenon is particularly strong in cases where the computer is emulating a human interaction, such as chatbots, avatars and robots. For this reason, there is a need for careful design of the user experience with a digital human, to consider the response that users will have when interacting with it.

Numata et al. (2020) suggested that a virtual agent that adapts to the users’ emotional responses and behaviors builds a better user experience, since the portrayal of human behaviors and emotions can lower the impression of interacting with a machine. On top of that, the authors explain that a good way to provide natural interaction with a digital agent is for it to perform mimicry of behaviors: the human interactors will then feel more comfortable in interacting with the agent, because they will be reassured by its expressions. For this reason, the authors point out that it is crucial to focus on gaze, facial expression, gestures and postures. Achieving a good level of realism in this regard will help make the interaction smoother and more natural, thus enhancing the user experience and the exchange of information. This is defined in the article as building rapport between the user and the digital agent.

2.3.3 Affinity and uncanny valley effect
The relationship between the digital human and the user should be based on trust, to ensure acceptance of the information and ability to act based on them. Trust is achieved when individuals expose themselves to the actions of others, irrespective of their level of control over the situation (Mayer et al., 1995). A good entry point to building trust in the digital human is having affinity between the agent and the user. Affinity with a digital agent is based on the perceived realism of the interaction. Seymour et al. (2021) explain that a project featuring digital human agents must focus on creating an experience that gives the users the impression that they are interacting with a real person. Furthermore, the users should accept the emotional support that the agent provides as if it came from a real human source, and not a computer (Meng & Dai, 2021). A relationship of trust ought to be created between the agent and the human, since the way a partner is perceived can strongly influence the effectiveness of the provided emotional support (Weiss, 1980).

As mentioned before, creating a realistic human avatar providing good user experience is not an easy endeavour. Besides all the concerns already
mentioned, the literature highlights the risks posed by the uncanny valley effect. Mori first proposed the uncanny valley theory in 1970 but did not get much recognition in the first decades from its publication. Thanks to MacDorman and Kageki’s translation in 2012, the theory grew in popularity in the Human-Computer Interaction field. The theory explains that increased realism and anthropomorphism increase the affinity level that a person perceives for a digital agent. However, as can be seen in Figure 1, there is a point (the uncanny valley), where the resemblance to a real human is very high, but not high enough to be pleasant. This causes feelings of eeriness and discomfort in the users, which then leads to unpleasant experiences with the agent. Movement reinforces this effect: moving stimuli cause a much stronger effect than still ones do. This would mean that a less human-like agent would be more trustworthy and pleasant to interact with than a nearly perfect one. Figure 1 shows the curve that Mori created to explain the phenomenon (1970).

Mori’s (1970) recommendation in his seminal article was “that designers [...] take the first peak as their goal, which results in a moderate degree of human likeness and a considerable sense of affinity.” The literature also points out that an increased level of realism can result in the users expecting more from the virtual agents, close to what they would expect if they were interacting with a real human (Zehnder et al., 2021). As a result, the level of disappointment when things do not go the way the users expected can also be higher and result in a worse overall user experience. One way to test whether a digital agent is falling into the uncanny valley is to test the affinity that the users feel towards the agent (Seymour et al., 2021).

![Uncanny Valley Effect from Mori (1970)](image)

It is important to note that almost fifty years have passed since the article was published and ten years since the publication of the translation. Over this time, the technical ability to reproduce a human agent with digital technologies changed and progressed exponentially. For this reason, it is relevant and interesting to evaluate whether this uncanny valley effect exists and whether it applies to the healthcare field as well. In fact, it might be possible that in the
healthcare domain a humanoid figure is appreciated because it gives a sense of closeness that a less realistic image cannot provide.

2.4 Accessibility
As previously mentioned, accessibility was a strong focus for this case study and thesis work. Accessibility is particularly important for the scope of this thesis work, since people interacting with the service might suffer from vision impairments and thus require accessibility arrangements. Accessibility of web services is a broad and complex topic that is regulated by international standards and rules. The main regulatory framework is represented by the Web Content Accessibility Guidelines (WCAG), currently in version 2.1. These guidelines have been specifically designed to support the creation of accessible websites, targeting people with disabilities including low-vision and blind users (WCAG 2.1, 2018).

The framework is based on four Principles: Perceivable, Operable, Understandable and Robust. These four principles are the fundamental characteristics that an accessible website should embody. Each principle then encompasses Guidelines (thirteen in total), which correspond to goals that should be envisioned when building an accessible website. Each guideline is finally further specified through a set of success criteria that are organised on three conformance levels, A, AA and AAA, of increasing accessibility. These success criteria are the framework’s testable elements, and meeting or failing them defines whether a website can be considered accessible. Failing one single criterion is enough to fail compliance with the corresponding conformance level. In many countries, compliance to the AA level is required by legislation to consider a website accessible.

Speech interaction and keyboard or mouse interaction have different requirements, and joining them requires some level of research. Controlling devices through voice interaction is a feature that has been developed and integrated into many devices to improve their accessibility. This feature is particularly helpful for people living with impaired vision. Pradhan et al. (2018) explain that the most common forms of voice interaction are screen readers, which output the on-screen text to speech and dictation software, which allow inputting text and commands using voice. The authors also state that the research community has not yet fully understood how these technologies are being used by people living with disabilities. However, one insight that emerged from their studies is that these accessible speech-interacting devices have the potential to improve the life of people living with vision impairment.

As previously discussed, people with vision impairments tend to suffer from a loss of independence (Hassel et al., 2006). Pradhan et al. reviewed a corpus of online reviews for speech-interactive products and conducted experiments with visually impaired users and concluded that these devices and software help people to regain their independence, by allowing them to perform small daily activities and tasks such as “listening to music, checking the weather, asking for the time or date, reading books, or listening to the news” (2018). The authors went even further and realised that this increased independence level also lowers the caregiver burden associated with visual impairments, which we will discuss in more detail later. Caregiver burden is defined as the additional effort (both physical and mental) that a person experiences when caring for a disabled
or elderly person close to them (Chou, 2000). In the case of speech-interactive
devices, this burden is eased because these technologies can take care of some
needs of the cared person, such as reading, answering questions and other
simple tasks (Pradhan et al., 2018).

2.5 Health literacy
Providing content that is understandable and useful for patients is a strong
priority for services that aim at informing patients on their conditions and the
actions they can take. The main aspects to be considered are the ability of the
users to understand the content and the effectiveness of its presentation. Liu et
al. (2011) explained that the main barriers to communication when it comes to
healthcare information are accuracy of the content, health literacy and language
skills. The authors believe in the ability of collaborative technologies to overcome
these barriers through the reduction of the limits posed by language and health
literacy, and thus improving communication.

Health literacy is defined as “the degree to which individuals have the capacity
to obtain, process, and understand basic health information and services needed
to make appropriate health decisions” (Norman & Skinner, 2006). Since this
information is provided online, the concept of e-Health literacy was introduced.
E-Health literacy is described as “the ability to seek, find, understand, and
appraise health information from electronic sources and apply the knowledge
gained to addressing or solving a health problem” (Norman & Skinner, 2006).

Content concerning e-Health, ranging from interventions available online to
websites providing health-related information requires the ability to read or
understand text, the ability to use information technologies such as digital
devices, the ability to use the provided content to inform decision making
(Norman & Skinner, 2006). e-Health literacy has been defined as the sum of six
core literacies, or abilities: three of them are of analytic type and three of them
are of context specific type. This is called the Lily Model of e-Health literacy, and
it is presented in Table 1, and visually represented in Figure 2, adapting from
Norman and Skinner’s original work.

![Figure 2 Lily model of e-Health Literacy, from Norman & Skinner (2006)]
Analytic type of literacy  | Context-specific type of literacy

**Traditional literacy**: the ability to read text and understand it, and to speak and write a language proficiently.  |  **Computer literacy**: the ability to quickly learn how to use new technologies and software and therefore have access to eHealth resources.

**Information literacy**: the ability to know what possible sources could provide the information regarding a topic, to create a strategy to look for the information appropriate and to filter the information to extract relevant knowledge.  |  **Scientific literacy**: the ability to understand how knowledge is created in a systematic way, its aims, limitations, politics and methods.

**Media literacy**: the ability to analyse the content that is provided through media and to reflect strategically on it.  |  **Health literacy**: the ability to understand health concepts and words and to contextualise them to make appropriate health decisions.

Digital healthcare services have often failed when it came to adoption, because even healthcare professionals using them found that they did not provide the expected effect (Cajander et al., 2016). This is another reason why exploratory research with users is fundamental for these kinds of interventions. The literature shows that people will adopt services that provide information that is easy to find, relevant and credible (Metzger & Flanagin, 2011).
3 Empirical research methodology

The main activity of the thesis work was the research that was conducted to explore and validate the concept of CUIs and digital humans for an informational ophthalmology service. This section explains how the research was organized, conducted and framed in the design process. Information about the employed methodologies and the rationale behind the choice will be provided. The goals of the different research stages will also be reiterated and explained in more detail. The overarching goal of the research sessions was, once again, understanding how potential users would perceive and react to a service that features a digital human as a conversational agent, and whether this concept can work in the context of healthcare-related information.

3.1 Design process

This section aims at explaining how the different research sessions were framed into a clearly defined design process. Although the project had already started when the author took part, the team defined some activities and milestones that should be undertaken in order to have a linear and efficient design process. The design process was organized as shown in Figure 3.

![Diagram of the design process](image)

**Figure 3 Design process for the Master's thesis work**

The previous user research was conducted by another person inside of the company. This research session was exploratory in nature and aimed at understanding how people living with low vision use and approach the Internet,
to gather requirements and preferences. The results were taken into consideration when designing the user research sessions.

The author of this Thesis first conducted a literature analysis, filtering articles to find relevant ones that could inform the design process (as has been described in section 2). Then, an exploratory research session was conducted. These two activities, together with the analysis of the previously conducted research led to the definition of the problem space and the context of use. These insights allowed to build the proof of concept (PoC) version of the service, which was then analyzed by the author both through expert evaluation and a user-based evaluation session. This research phase led to the validation of the PoC.

The user research sessions can be divided into two different approaches:

- **Exploration** of end-users’ needs, requirements, preferences and opinions.

- **Evaluation** of the design, with a focus on usability and accessibility.

The main goal of the user research was to understand whether the digital human solution could be beneficial for users living with visual impairments and how to design the interaction to provide the best possible experience.

### 3.2 User groups

Before introducing the research, it is important to understand who the potential user groups of the case study service are. This section will present and describe the characteristics of these user groups. Courage & Baxters (2005) define three groups of users, based on the impact that the product has on them. The first group, primary users, interacts with the service, and benefits directly from the interaction. Secondary users might not interact with the service themselves, but nonetheless benefit from primary users’ interactions, or they can influence these interactions. Finally, tertiary users are people or organizations who have decision power on whether to start using a service, and thus indirectly benefit from its usage.

*Figure 4* shows the division of the user groups for this specific case. Primary users include people who are starting to experience a decline in their vision, and want to gather information about eye conditions. Together with them, caregivers of people who are starting to experience vision loss are a primary user group. In fact, it often happens that people start noticing their loved ones struggling with their vision, and they therefore decide to look for information. They might also be caring for an older person, who is not able to look the information up on the internet, and therefore they are the ones doing it for them. These situations lead to including them in the primary users group. Another potential user group is people who have not started experiencing vision decline, who nonetheless heard about it and want to understand more. A secondary user group is healthcare professionals, who might benefit from the service because it relieves them from some work burden, as it acts as a first informative encounter. A tertiary user group includes ophthalmology clinics, which will benefit from their healthcare professionals having more quality time to dedicate to patients.
3.2.1 People living with low vision

People who are starting to develop symptoms correlated with vision loss are the main targeted user group of the service. In developed countries, eye conditions are the main cause of blindness and lowered vision, with Age-related Macular Degeneration (AMD) being the number one cause (Taylor et al., 2016). Wong et al. (2014) forecasted the number of people suffering from this disease to reach the staggering number of 288 million in 2040. These numbers advocate for treatment of this and related condition. Besides AMD, another common condition in developed countries is Diabetic Retinopathy (DR). Gregori (2021) explains that people living with diabetes should be monitored closely to avoid this disease to onset and potentially lead to complete vision loss. In fact, both AMD and DR can evolve to a stage where the vessels are leaking into the eye, thereby causing the loss in vision.

The three main conditions considered in the case study service are AMD, DR and Retinal Vein Occlusion (RVO), which occurs when the veins inside the eye cannot supply blood as a result of blockage and therefore not enough oxygen is delivered to the retina (MacDonald, 2013). These three conditions present slightly different symptoms but can all evolve to serious vision loss.

- According to the U.S. Department of Health and Human Services, AMD affects central vision, meaning that usually peripheral vision is not impacted. However, patients progressively lose the ability to see what is in the center of their visual field, or its clarity. This makes daily activities such as reading, watching TV, and driving very difficult (Decarlo et al., 2003).
- DR can have no symptoms in the first phases, and later develop into symptoms such as floating, black or blank spots, blurry vision, lowered dark vision, and blurred colors (Gregori, 2021).
Generally, the loss of vision due to RVO is painless and abrupt, and it includes symptoms such as blurry vision, central vision loss, troubles with both central and peripheral vision or patches in the visual field (MacDonald, 2013).

### 3.2.2 Caregivers

Caregivers are one of the main user groups involved in this research. A caregiver is a person who provides care for another person (most often a family member), who has specific needs due to temporary illness or permanent conditions. This activity results in additional chores to the regular daily ones, and it can escalate and cause the so-called caregiver burden. The World Health Organization (WHO) has defined caregiver burden as “the emotional, physical, financial demands and responsibilities of an individual’s illness that are placed on the family members, friends or other individuals involved with the individual outside the health care system.” (Olowokere, 2019).

Caregiver burden can be divided into two further specifications, subjective and objective burden. Subjective burden refers to the psychological pressure that the caregivers undergo, often resulting in anxiety and higher stress levels, while objective burden is concerned with all the endeavors that caring for someone requires, which take time and energies out of the person’s daily life (Chen et al., 2013). The effects of the subjective burden, especially if the caregiver is caring for a family member, can result in high levels of stress, which can escalate in high mortality rates.

Particular attention should be posed to services that deal with conditions that are likely to result in patients requiring a caregiver (which is often the case for ophthalmic conditions). When designing this type of service, it is crucial to include the caregivers in the design process. In fact, Chen et al. (2013) noted that healthcare digital services can easily worsen the burden of caregivers, by requiring them to take even more action than they normally would. The authors explain that caregivers are often disregarded, and focus is posed only on patients. Since ophthalmic patients often become dependent on other people and therefore require caregiving (Singh et al., 2019), it is crucial to include caregivers as stakeholders and user groups in the design process and to consider their user experience with healthcare-related digital services.

### 3.3 User personas

As a summary of the information gathered about potential users, user personas were designed, trying to cover all the main aspects and differences that characterize the main user groups. The goal of the personas was to align the team on a common perspective whenever trying to understand the users’ point of view during the design process, and to facilitate communication among team members with different backgrounds. The information that was used to construct the personas is presented in Table 2.

<table>
<thead>
<tr>
<th>Eye conditions</th>
<th>Characteristics of the patients</th>
<th>Characteristics of caregivers</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>AMD</td>
<td>Age</td>
<td>Age</td>
<td>Blurry or distorted vision - such as straight lines</td>
</tr>
</tbody>
</table>
Based on these considerations, three personas were created, which reflect the main potential users of the website. The personas were crafted to take into consideration and represent as many of the points that were mentioned before as possible, to ensure their representativeness. The detailed specifications of the personas can be found in section 4.1, and a visual version can be found in the Annex section, as Annex A.

### 3.4 Organization of the research

As previously mentioned, the research was divided over two different moments: the first session was exploratory in nature, while the second one was evaluative. The rationale behind this choice is that the exploratory research would help the design and development team to create the best possible proof of concept version of the service, which needed to include the end-users’ opinions and preferences. On the other hand, the evaluative part would provide feedback on the design and help iterate on it to create a better version of the service, which will be launched as a minimum viable product (MVP).

The two sessions were conducted at different times and using different methodologies. However, both took a qualitative rather than quantitative research approach. The relatively new approach of digital humans and speech interaction justifies this choice, since in-depth insights into the opinions of the
users, their perceptions and the level of usability and accessibility of the service were needed.

The exploratory research was conducted using the semi-structured interview methodology, to explore the context of use and the expectations of potential users. The results helped to understand several topics, including the current approach of potential users towards the first search for information regarding eye conditions; the kind of character and personality people would feel comfortable discussing with; the information they would prioritize receiving and their first impressions of the digital human.

The evaluative part of the research was composed of an expert evaluation session and a user-based session. The expert evaluation focused on usability and accessibility, employing the cognitive walkthrough method and an assessment using WCAG 2.1 guidelines (WCAG 2.1, 2018). Issues were identified and suggestions made to increase the level of both usability and accessibility of the service. The user-based sessions were conducted with a panel of people living with low vision and caregivers. A participant observation methodology was chosen and paired with semi-structured interviews following the exploration of the website by the users. The results helped to understand potential end-users’ perception of the digital human, their level of appreciation of the new interaction style, whether they would like to use it again, the interaction between the digital human website and screen reader, and the emotional responses that the digital human caused.

3.5 Exploratory research

This section presents the goals and methodologies of exploratory user research. Details are provided about the rationale for choosing the methods employed, the participants, the procedure and the way data was collected and analyzed.

3.5.1 Goals and objectives

The goals of the exploratory research included identifying needs, exploring the context of use (some insights about this also came from the previous research that was mentioned before), and specifying requirements. These goals are in line with the Human-Centered Design process, as they result in understanding of the context of use. In order to make sure to elicit valuable insights from the users, the research team adopted a collaboration-oriented approach. The session therefore did not only employ methodologies such as interviews, but used Miro (Miro, 2022) as a collaboration and brainstorming tool.

The research focused on the following aspects:

- **Patient journey and health knowledge:** understanding people’s approach to looking for information about eye conditions, previous experience with online content and ability to understand medical information.
- Familiarity and opinions on digital assistants: understanding whether speech interaction is something that they use and are fond of, to see whether this could actually benefit them.
- **The personality of the service and the digital environment expectations:** understanding the participants’ expectations towards a design persona, meaning a description of what the personality of the digital human (and therefore the service) would be. Besides this, investigating the look and
feel of the human and the environment where it will be placed to help uncover expectations.

- **The uncanny valley effect elicited by the digital human**: since a first version of the digital human was already available, this research session also gathered some feedback and impressions on it, to investigate impressions of eeriness possibly correlated with the uncanny valley effect.

- **The prioritization of the content**: helped understanding what users are most keen on receiving in terms of information and content. It allows exploring expectations and needs for the informative material.

### 3.5.2 Methodology

The methodological approach was qualitative, as previously explained. The sessions were organized as semi-structured interviews, featuring some more collaborative activities, carried out on Miro. Semi-structured interviews are characterized by a loose definition of the interview questions, which can be adapted or expanded during the conversation (Galletta, 2013). This provides great flexibility, and the possibility to go deeper into topics of interest. The sessions started with some questions about the background and previous experiences of the participants, specifically with their condition and with information search. The more collaborative activities included choosing among characters and environments, prioritizing content and observing and giving feedback on some content.

This methodology was chosen over other possibilities such as focus groups and more quantitative approaches such as questionnaires. Both possibilities have their advantages, and great potential. However, the nature and the goals of the session resulted in the opinion that a focus group or a questionnaire would be less informative than single-participant in-depth interviews.

Kitzinger explains that focus groups can help elicit insights that individual interviews will hardly expose (1995). The author specifies that this technique uses interaction among the participants as a tool to foster ideas exchange and exploration. However, this encouragement of discussion and exchange of ideas can sometimes result in people self-censoring and just agreeing with the bigger group. Besides this, during a focus group it is harder to dive deeper into the reasons for a specific participant to hold a specific idea. For these reasons, the single-participant semi-structured interview methodology was preferred over the focus group methodology. Since creative idea generation was not the focus of this research activity, it was traded for the more in-depth insights that people can provide during individual interviews.

Another methodological option was questionnaires. The main advantage of questionnaires is that they allow gathering feedback from a large number of people, without interaction between the participants and the researcher, which makes them quick and efficient to use (Williamson, 2013). They provide quantitative data that can inform and motivate design decisions. Due to the exploratory nature of this session, and the rather difficult-to-target end-user group, this methodology was not well suited. Besides, this methodology does not accommodate the goal of gathering in-depth insights into the expectations, needs and previous experiences of the participants. For these reasons, a qualitative approach was preferred over a quantitative one.
3.5.3 Participants

Participants were recruited through the usertesting.com platform. This platform allows researchers to post their studies and access a vast pool of potential users all around the world (UserTesting, 2022). Since the Finnish Roche team wanted the case study service to be scalable, it did not matter where the participants were from, but on the contrary, representing different locations and backgrounds was positive. However, the fact that no Finnish participant was recruited could be a potential limitation to the study.

The advantages of using the usertesting.com platform are:

- **The ease to reach a wider audience**: participants meeting the pre-requirements for the study are notified by the platform. This significantly lowers the researchers’ effort in recruiting participants, which often requires networks that researchers themselves do not have.
- **The possibility of creating screeners**: the platform allows creating a screener questionnaire to ensure that the recruited participants correspond to the profiles that the researchers are looking for. This process strongly relies on participants’ transparency.
- **The built-in tools**: the platform provides a scheduling tool that automatically connects to Google Calendar and to Zoom. Besides this, the interviews are automatically recorded, and the video is uploaded to the platform for further consultation and analysis.
- **Permissions**: when participants sign up to be testers, they agree to be recorded and that the recordings are stored in the system. This means that there is no need to provide an additional informed consent form to the participants.

Despite all these advantages, which make usertesting.com a valid and useful tool, the platform has some limitations. Limitations include the participants’ distribution of nationality, with the most represented countries being United States, United Kingdom, India, and Canada, with little variation outside of this. Furthermore, although screeners are useful, they rely too heavily on participants’ transparency, and it is not always guaranteed that the recruited participants will prove to be informative for the study. One more limitation is that this platform is not very accessible or used by people living with impairments in their vision, hearing, or more, and that all people that sign up have a quite homogeneous (and high) level of technology competence. This inevitably biases studies towards a more skilled audience and might not be very effective for products that aim at including elderly people, people who have low familiarity with technology and people who live with severe disabilities.

The screener that was used for the recruitment focused on filtering participants based on whether they were living with eye conditions or whether they were caring for someone living with these conditions. To make sure that the participants corresponded to the profile needed, the screener included specific questions such as whether the condition was diagnosed by a professional, whether it significantly affected the participants’ ability to use a computer, or, for caregivers, how often they cared for the person.

Ten participants were involved, four females and six males, aged 22 to 48, with the distribution shown in *Figure 5*, with generally average or advanced web expertise. This means that they were used to engaging with technology either in
their daily life or for work, which for example allows them to operate Zoom without issues.

The age distribution of the participants is different from what one would tend to expect. In fact, eye conditions generally concern older people, while the average age in this panel was 31.6 years. This rather surprising distribution is easily explained by the nature of the usertesting.com platform. In fact, people signing up for such a platform are generally younger, since it requires quite some digital skills.

**Age groups distribution**

![Age groups distribution graph](image)

*Figure 5 Graph for the distribution of age groups in the exploratory research*

The nationality distribution of the participants was the following (Figure 6):

- United States (2)
- United Kingdom (1)
- United Arab Emirates (1)
- Canada (2)
- France (1)
- India (1)
- The Philippines (1)
Five caregivers and five people living with low vision were recruited, and the distribution of the conditions among the participants can be seen in Figure 7 and it was as follows:

- 5 people living with low vision
  - 2 people living with AMD
  - 1 person living with DME
  - 2 people living with other conditions
- 5 caregivers
  - 1 person caring for someone living with AMD
  - 2 people caring for someone living with DME
  - 2 people caring for someone living with another condition
Figure 7 Graph for the distribution of conditions in the participants to the exploratory research

The participants joined the session with a personal computer. The sessions were held on Zoom, with a link provided by usertesting.com. All participants completed all the activities involved in the study.

3.5.4 Procedure

The interview session was organized on four steps:

- An **introductory phase**, which welcomed the participant, broke the ice, and set the scope of the interview.

- An **exploration phase**, which aimed at gathering the participants’ perceptions and opinions. This phase was divided into several subsections.
  
  - The participants’ needs and expectations were explored using a semi-structured interview methodology. Focus was posed on the topics of health journey, initial health literacy, information channels (healthcare professionals, online resources, patient communities), and quality and understandability of the information. The questions aimed at understanding the process of information search that the participants went through, their information sources and their impressions about the process and the understandability of the information.

  - The expectations towards the UI personality, using a cards-based interview approach on Miro. The goal was to identify underlying personality features of the interactive agent that the participants would appreciate. The participants were asked to choose two
characters among a set of options that they would envision themselves talking to and getting information from about eye conditions. They were also asked to explain the reason behind their choices. After this, they were asked to match the three adjectives, friendly, trustworthy and knowledgeable, to the characters. Figure 8 shows the characters cards and the activity that was presented to the participants.

Figure 8 Activity 1 and 2 of the exploratory research on Miro

- The expectation towards the environment, using a cards-based interview with a collaborative approach, to understand what kind of environment would make the participants most comfortable. The participants were asked in which environment they would feel most confident discussing eye conditions, and the reasons behind the choice. Figure 9 shows the environment cards and the activity that was presented to the participants.
An assessment phase, which aimed at gathering first impressions about the current version of the digital human, but also to gauge the possible uncanny valley effect elicited by the avatar. This was done by showing both still pictures and a non-interactive video. This assessment was conducted after the exploration not to influence the initial perceptions from the participants, and it concerned the features of the DH, mostly in terms of look and feel. Figure 10 shows the pictures that the participants were shown to provide their feedback.
Figure 10 Activity 4 of the exploratory research on Miro

- A prioritization phase, which aimed at gaining insights about content and channels. One goal was to inform information architecture design by understanding the content and information the participants would be more interested in learning about. Another goal was exploring the participants’ preferences in terms of channels to receive information.

The complete script used to guide the interviews can be found in Annex B.

### 3.5.5 Data collection and analysis

Data was anonymized (usertesting.com does not provide personal information about users, but usernames only), and collected in three forms:

- *usertesting.com data*: the platform requires users to provide demographic information about their age, location, technological skills, employment status, field of work, devices and social networks used.
- *Miro board activities result*: the interviews were supported through a Miro board. One individual board was created for each participant, so that the traces of their actions could be retained. The data extracted from the boards includes preferences and prioritization of elements.
- *Interview notes*: the researchers took extensive notes during the interviews, especially for the open-ended questions that were not part of the Miro board activities. These notes can be considered a transcript of the answers given by the participants.

The data was analyzed to discover trends and shared opinions regarding the topics of interest. The analysis was qualitative, and although some numerical data will be shown for informational purposes, this should not be considered statistically relevant. The nature of the study was qualitative, and insights were gathered to give a direction to the design and development work. The results were compared and organized in topics, to provide guidelines and
recommendations. The description of the results can be found in the Results section.

3.6 Evaluative research
This section presents the goals and methodologies of evaluative user research. Details are provided about the rationale for choosing the methods employed, the participants, the procedure and the way data was collected and analyzed.

3.6.1 Goals and objectives
The evaluative user research sessions aimed at understanding whether users appreciate the CUI-based interaction with a digital human to receive information about their potential eye conditions. In terms of the case study, the session aimed to validate the proof of concept of the service, and to provide proof that it provides sufficient value to motivate the development of a minimum viable product.

There were several elements that required investigation to gauge the ability of this kind of interface to provide value to its users, and specifically to people living with low vision. First of all, the session aimed at evaluating the usability of the conversational user interface. Usability is defined in the ISO 9241-11 (2018) standard as the “extent to which a system, product or service can be used by specified users to achieve specific goals with effectiveness, efficiency and satisfaction in a specified context of use”. Because of the nature of the system, usability can be tricky to evaluate. In order to focus the scope of the research to evaluate relevant aspects of usability, the ergonomic criteria presented by Bastien and Scapin (1992) were adopted. This user research session especially focused on the following criteria:

- **Guidance**: how the system leads the user to certain actions, how visual items are organized and how the system responds to user actions. This aspect is important to understand whether the CUI manages to provide the users with sufficient guidance, regardless of their familiarity with such systems. Besides this, it is important to understand whether the interface is clear and understandable and whether it provides appropriate feedback to the users’ actions, especially in the form of speech commands.

- **Workload**: reducing the cognitive effort required by the system. To achieve the goal of providing a smooth patient experience, systems must require the lowest cognitive load possible.

- **Explicit control**: the system should respond only to explicit and intentional actions from the user. This aspect is very important with CUIs because of the likelihood to provide unintentional cues to the system through speech. Besides this, some users might not be used to speech interaction: for this reason, it is important to understand whether speech interaction is a valid design choice and whether the alternative input methods can provide sufficient control for users who do not wish to interact through speech.

- **Error management**: the system should prevent users’ errors and help recover from them. A smooth patient experience is defined by the ability of the system to prevent errors in the first place, and to help users recover when they cannot be avoided. This aspect is therefore important to evaluate usability and users’ satisfaction.
• **Consistency**: the design should behave in the same way over similar sections. This is an important aspect to be evaluated both on the visual UI and on the speech-interaction patterns.

In addition to usability, this session also aimed at evaluating the accessibility of the CUI. The main goal of speech interaction through a digital human is to increase the accessibility of informative e-Health services for people living with eye conditions. However, it is important to assess whether the digital human is truly providing a higher accessibility level for visually impaired users. In addition to evaluating usability and accessibility, this research aimed at understanding whether the digital human can enhance the emotional engagement and support of users receiving information about their potential eye conditions. In order to provide a positive experience and a pleasant interaction, the digital human should be perceived as:

• **Empathic**: the users should feel that the digital human understands and is concerned by their pain points.

• **Engaging**: the users should want to engage in a conversation with the digital human and feel comfortable in asking questions and requesting further details.

• **Trustworthy**: the users should trust the digital human and feel confident when interacting with it.

An additional aspect that this research session focused on in more detail than the exploratory session is gauging the impact of the uncanny valley effect on people’s perception of the service. During this session, the participants were able to interact with the digital human, and this allowed for a deeper and more realistic observation of the potential uncanny valley effect elicitation. The sense of eeriness given by this effect would impact the patient experience and elicit negative feelings in the users. The overarching goal was ensuring that the digital human can be a valuable agent to convey health-related information.

Finally, the session aimed at understanding the users’ perceptions of trustworthiness and reliability of the service. This could be impacted by the patient experience with the service and by the possible uncanny valley effect’s consequences. It is crucial to investigate whether patients consider the information provided by the CUI reliable, as the end goal of this kind of service is to educate and support people in their health journey.

*Figure 11* shows how the interface looked like when participants were interacting with it. The digital human is shown in the middle of the screen. On the top left there is an accessibility menu, on the bottom left a backward button and on the right a forward button. The white band in the middle shows visual feedback of the captured words when the user is speaking. Next to the forward button, the options among which the users can choose are displayed. The buttons are in grey for non-available contents and in orange for available ones.
3.6.2 Methodological approach
To achieve the goals and objectives, two research approaches were combined: expert evaluation and user-based testing. Jaspers (2009) explains that researchers conduct expert evaluation by examining the service and checking it against a guide that was previously prepared and that can use different elements such as heuristics, guidelines, questions, or tasks. These methods do not involve end-users, whereas the author describes user-based testing as involving users either directly (for example in usability testing or participant observation) or indirectly (for example in log-files analysis).

The rationale behind this choice is that expert evaluation, conducted before the user testing session, helps the researchers to get a first grasp of what to expect from the user testing, and to therefore focus attention on aspects that are deemed critical. Besides this, expert evaluation is a fast and inexpensive way to find a first batch of usability and accessibility issues that can easily be included in the next iteration of development of a system.

However, expert evaluation alone is not sufficient to provide in-depth insights from a human-centered design approach. For this reason, expert evaluation should be combined with a form of user research (if time, budget and skills allow). It is not unlikely that expert evaluation will uncover issues that users navigate around with no trouble, or the other way around. Besides this, users’ feedback is crucial to ensure that the system reflects and responds to their needs and expectations, which are likely to be very different from those of the researchers.

3.6.3 Expert evaluation
This section will present more details about the expert evaluation session, including goals, methodology, procedure and data collection and analysis.
3.6.3.1 Goals and objectives
The goals of the expert evaluation were to get a first quick and high-level evaluation of the service, before testing with the users. The session also helped the researchers to familiarize with the service and to know which aspects to focus on. Focus was put on accessibility, usability and learnability of the service. The researchers used the personas to empathize and take the perspective of the potential users.

Learnability concerns the ease to understand how to use the service, and it was the main focus of the cognitive walkthrough methodology. In this context, learnability is very relevant because it is likely for users not to be familiar with CUIs. Usability and overall expected user experience were also evaluated through the cognitive walkthrough methodology. To assess accessibility, an evaluation following the WCAG 2.1 (Web content accessibility guidelines, 2018) guidelines was conducted. The guideline level was chosen instead of the success criteria level because of time constraints, to keep the evaluation as quick as possible.

3.6.3.2 Methodology
The two most common and documented methods for expert evaluation are heuristic evaluation and cognitive walkthrough. Jaspers (2009) wrote a thorough comparison of the two methods in her article. She explains that none of the two methods is inherently better: both have their strengths and weaknesses, and the most appropriate one should be chosen depending on each specific situation.

Heuristic evaluation is a methodology based on the ten heuristics presented by Molich and Nielsen (1990) in their seminal article. A heuristic corresponds to a simple way of solving a problem. In this methodology, the evaluator goes through the interface and notes the issues encountered with a reference to the violated heuristic and the severity of the issue (Mack & Nielsen, 1993). Jaspers (2009) explains that heuristic evaluation is efficient and cost-effective, but it can be biased by the evaluators’ inclinations to focus on specific problems and it can also be hindered by the lack of expertise of the evaluators in the specific field of application. Besides this, the author mentions that, compared to other methodologies, heuristic evaluation tends to find the highest number of cosmetic (low-severity) problems, which are often not found in user-based testing. This lack of alignment between the expert-found problems and the user-found problems is especially problematic if the two methodologies are combined, as in the current research.

Mack and Nielsen (1993) described the cognitive walkthrough as another expert evaluation methodology, with a stronger focus on the learnability of the systems. The evaluation is based on explicit user tasks, and the researcher needs to consider the cognitive processes that guide real users through the systems. The authors pose specific focus on first-time users and the way they interact with a system, including the goals they set, the inspection process they make, the action they choose and their assessment of the system’s feedback. Mack and Nielsen list four questions that the evaluators should ask themselves throughout the process:

1. Will the user try to achieve the correct effect?
2. Will the user notice that the correct action is available?
3. Will the user associate the correct action with the desired effect, and, if the user performed the right action?

4. Will the user notice that progress is being made toward accomplishment of his goal?

A negative answer to any of the questions will result in the identification of a usability issue. Jaspers (2009) notes that, for the method to yield valuable results, background about the users and well-defined tasks are necessary. She adds that this methodology is more suited to uncover issues of a higher severity, even if the total number of identified issues is lower than that of other methods.

Based on the characteristics of the case study, the cognitive walkthrough methodology was chosen. Not only the background of the users was already known, but the definition of tasks was also needed for the user-based testing. This significantly lowered the major drawback of the method, which is preparation time. Besides this, Jaspers notes that cognitive walkthrough is suitable for early design stages and incomplete systems, which was the case in this specific evaluation, since the evaluated system was a proof-of-concept version, with only a few features implemented. Since expert evaluation was the first round of assessment of the service, high-severity usability issues needed to be prioritized, to possibly address them before the user-based testing sessions. One final reason that led to choosing the cognitive walkthrough is that this methodology is more focused on learnability than heuristic evaluation (Jaspers, 2009). This is relevant for this case study because, for this service, more first-time users are expected, rather than recurring users. Therefore, it is crucial to understand how people learn to use the service and how they explore and understand it.

To complete the expert evaluation, an accessibility evaluation was performed following WCAG 2.1 guidelines (Web content accessibility guidelines, 2018). Following WCAG is a standard way of gauging the level of accessibility of a website. An accessibility evaluation is conducted by exploring the service while checking guideline by guideline whether it complies with the standards. It is possible to run both manual checks, which include observing the website, testing characteristics such as keyboard interaction and inspecting the HTML code, or automatic checks, using ad-hoc tools. In this specific case, guidelines are more complicated to interpret due to the interaction modality, which is not the standard text-based one. Hence, both manual and automated approaches were combined to double check the accuracy of the evaluation.

**3.6.3.3 Procedure**

The cognitive walkthrough method requires evaluators to clearly define tasks and steps to complete them. In this case, one task will be defined, which comprises several subtasks and steps to complete it. The background of the users was defined through research and documentation and resulted into three personas (section 4.1). The scenario is based on one of the personas and plays out as follows:

“In recent times, you have noticed that the central part of your visual field is getting blurry. You gave yourself a couple of days to see whether this would resolve on its own, but now you decided to look for information on the Internet. You recently heard someone talking about age-related macular degeneration, and you are wondering if that could be your case.”
**Task:** “I want to understand more about how I can know if I have AMD”.

**Action sequence:**

1. Open the website. *(System response: the conversational agent starts speaking)*
2. Allow microphone usage. *(System response: the system starts using microphone and lets the user know about it)*
3. Discover eye conditions, either by clicking the button or by saying it. *(System response: the conversational agent continues to that content and restates the location) and chooses “age-related macular degeneration - AMD”. *(System response: the conversational agent continues to that content and restates the location)*
4. Explore the content. *(System response: the conversational agent continues to that content and restates the location)*
5. Go through the slideshow. *(System response: the conversational agent progressively goes through each “slide”)*

**Interface:** the service is tried on a computer screen.

This expert evaluation session was performed following Mack and Nielsen’s procedure: the researcher used the service to complete all of the sub steps, and asked the four questions at each step to identify possible usability issues (1993). This approach allowed visualizing how users would navigate the service. Particular focus was put on whether first time users would be able to interact with the service.

Sometimes it can be hard to motivate why a specific element or process was considered to be problematic. In this sense, the heuristic evaluation is more precise, and a blend of the two methods could have been useful. Instead of doing that, some criteria were used to comment on the findings. This was done to ensure that issues were identified and explained thoroughly. The ergonomic criteria by Bastien and Scapin (1992) were used, since they provided a good fit with the use case. The criteria are the following:

1. **Guidance:** includes prompting (1.1), grouping and distinction of items (1.2), immediate feedback (1.3) and legibility (1.4).
2. **Workload:** includes brevity (2.1), concision (2.2), minimal actions (2.3) and information density (2.4).
3. **Explicit Control:** includes explicit user action (3.1) and user control (3.2).
4. **Adaptability:** includes flexibility (4.1) and user expertise (4.2).
5. **Error Management:** includes error protection (5.1), quality of error messages (5.2) and error correction (5.3).
6. **Consistency.**
7. **Significance of codes.**
8. **Compatibility.**

These criteria were also useful to define issues that are incidental to the completion of the task, but that yet pose usability concerns. Besides this, a severity score was assigned to the issues encountered, thus providing prioritization for the development team. Nielsen’s severity scale (1994) was adopted. This scale features four levels of severity: cosmetic problem, minor usability problem, major usability problem, usability catastrophe.
For the accessibility evaluation, the thirteen guidelines that compose WCAG 2.1 were checked while interacting with the service. For each guideline, the service was inspected to understand whether it complied with accessibility requirements. First, the researcher performed a manual check, meaning that the researcher read the guidelines and the related success criteria, inspected the service or the HTML code and checked whether the service was compliant. Secondly, the researcher used Microsoft’s Accessibility Insights service to run an automated check, to confirm the evaluation that was made and to potentially find issues that had been overlooked (Microsoft, 2022). The results of the expert evaluation will be presented in the Results section.

3.6.3.4 Data collection and analysis
The data was collected in the form of notes, for both the cognitive walkthrough assessment and the WCAG-based assessment. For the walkthrough, the notes were taken in the form of answers to the four questions and general notes explaining the failure or success story. The notes also comprised the criteria that the issues were related to and their severity on the Nielsen scale. These notes were then used to provide an overview of the aspect that the service performed well on, and the ones that needed adjustments. To analyze the text data, the content analysis methodology was chosen. This methodology involves the detailed analysis of text data, and it can be both quantitative and qualitative, by focusing on occurrences or meaning (Hsieh & Shannon, 2005). For this thesis, a qualitative approach was preferred, aiming to find trends and insightful aspects of the participants’ contributions.

For the accessibility evaluation, notes explaining whether the service conformed or not to the guidelines were taken. The notes were organized based on WCAG’s principles and guidelines. While performing the evaluation, success criteria were considered, but not in a precise and rigorous way, as a WCAG examination would require. In the notes, aspects that are suggested by success criteria are noted, but no specific “pass/fail” evaluation was made.

3.6.4 User-based evaluation
This section presents more details about the user evaluation session, including goals, methodology, procedure, participants, and data collection and analysis.

3.6.4.1 Goals and objectives
The goal of this evaluative session with users was to gather opinions and insights on potential end-users’ perception of the service. Specifically, the session focused on acceptance of the interaction modality and achievement of trustworthiness and support. Since using a digital human to convey medical information is a relatively new approach, validation of this channel was needed. In fact, there is scarce evidence about people’s perception of information coming from a digital character. The exploratory research showed that people did not clearly know what to expect from the digital human.

While usability and accessibility can partially be investigated through expert evaluation, the perception of the service as a whole and the acceptability of the concept need to involve the final users in order to be reliable. For this reason, the evaluation was not strictly focused on usability or accessibility, even though these two themes came up during all the interviews. The session aimed at understanding people’s perceptions of this interaction style, and whether they
liked it or whether they would prefer to keep using more traditional text-based websites.

### 3.6.4.2 Methodology

For this user evaluation session, a participant observation methodology, paired with follow-up semi-structured interviews was chosen. Participant observation is a qualitative methodology that originated in anthropology, and it aims at gaining in-depth insights into a user group by observing them in their environment (Allen, 2017). This methodology is well-suited for the use case because it allows observing how users would naturally interact with the system the first time they access it. In a participant observation session, the researchers observe the users interacting with a system, and pose questions in non-critical moments to explore in deeper detail the reasons why users performed specific actions and their thinking processes.

The participant observation methodology was chosen over the more traditional usability testing methodology because of the nature of the service. Usability testing is a qualitative methodology that aims at evaluating a service by asking users to complete tasks, and observing their behavior (Nielsen, 1993). Usually, the usability testing methodology is paired with the think aloud protocol, which requires the participants to explain what they are doing while they are doing it. This helps the researcher to gain deeper insights into the thought processes of the participants.

Usability testing requires the researchers to administer well defined and realistic tasks to the participants. For example, on an event booking website a task could be “try to book a ticket for [name of the event] for the [date]”. This is very useful for researchers because it allows them to observe specific behaviors and to focus attention on what is most relevant to test. However, usability testing might not be the best suited method to test CUIs that rely strongly on speech interaction. In fact, it is not possible to ask the participants to think aloud, because doing so would interfere with the actual interaction with the service. Besides this, a conversational interface tends to be more complex and flexible than a traditional graphic interface. This means that describing tasks is more difficult and potentially less useful than in other contexts.

The follow-up semi-structured interviews were conducted in a way that is inspired by Vermesch’s work (2007) on the explicitation interview. This methodology involves presenting the actions people took to them and asking them to reflect upon those actions and their reasons. However, the approach of this research is much less methodical and organized than the one described by Vermesch. Taking inspiration from this methodology was chosen because the participants would use speech to interact with the system, which would have made it impossible to ask them to think aloud while performing the tasks.

After the one-on-one interviews, two sessions were organized to have participants discuss among themselves about the concept and their experiences. These sessions were run as focus groups, where the conversation was mostly led by the participants, and the moderator only intervened to give direction to the conversation and not to lose track of the focus. The focus group methodology was chosen to elicit discussion and potential new viewpoints from the participants. Acocella (2011) argues that the confrontation and discussion initiated by focus groups is its most recognized advantage. The author explains
that having discussions with others can encourage people to share more honest opinions than when interviewed alone, and to explore topics that might have not been thought of otherwise. However, this positive effect can hide dangers: the discussion or the opinions of the participants can get polarized and become more homogeneous than they really are. To reduce this effect, it is important to ensure that everyone feels safe to share their opinion, and that everyone is given the possibility to do so.

### 3.6.4.3 Participants

A total of eighteen participants were recruited. Fourteen of them were recruited through Roche’s Patient Advisory board, and ten of them took part in one-on-one interviews. Four more participants were recruited for the one-on-one interviews among the usertesting.com panel that participated in the exploratory research phase. In terms of distribution, twelve of the recruited people were people living with low vision, and six of them were caregivers or people involved in prevention and advocacy for low vision conditions. Among the participants, six people were not visually impaired, six were mildly impaired and six were severely impaired, meaning that they were able to see very little, and three of them used screen readers. Seven females and eleven males were recruited.

The participants’ nationalities were very varied, especially since Roche’s Patient Advisory board includes people who can represent different countries. It was distributed as follows (*Figure 1*):

- United Arab Emirates: 1
- United States: 1
- Philippines: 1
- Canada: 2
- Switzerland: 3
- Sweden: 2
- Germany: 2
- France: 1
- Australia: 1
- New Zealand: 1
- Spain: 1
- Italy: 1
- Finland: 1
A strong difference from the exploratory research panel was the age of the participants. As Figure 13 shows, the majority (67%) of the participants were older than 50 years of age. This distribution is more representative of the potential target group for an ophthalmology informative service. However, most of the participants, and especially the ones recruited through the Patient Advisory board were quite knowledgeable about eye conditions, which is something that is not expected from the potential users of the service. Besides this, the target group of this service would generally not be highly visually impaired, because it is most of all people who are discovering about eye conditions and looking for more information about them. Nonetheless, the participants who are part of the Patient Advisory board are used to taking other patients’ perspectives and to reflect about things considering all of the stages of the conditions. For this reason, they were very helpful and provided valuable insights.
3.6.4.4 Procedure

The interview session comprised two phases:

- An **introduction phase** welcomed the participant, broke the ice, set the scope of the interview, and gathered basic background information from the participant for profiling purposes.

- An **evaluation phase**, where the participants used and explored the service. The participants had never used the service before, which means that it was possible to investigate the discoverability and learnability of the service. Besides this, it meant that participants had a homogeneous level of familiarity with the service, which makes the results more consistent.

Since the chosen methodology is participant observation, no explicit tasks were presented to the participants. However, sequential and complementary tasks were defined for the researchers to guide the evaluation. This was done to ensure that all of the relevant aspects were addressed, and to facilitate note taking for the researchers.

Since AMD is the only condition that was available in the current prototype, participants would be guided back to AMD if they attempted to reach different content. Complementary tasks could be run at any time, following the natural flow of actions from the participant. If the sequential tasks were completed by the participants without having involved the complementary tasks, then the missing complementary tasks were explicitly prompted by the interviewer.

*Table 3* shows the sequential and complementary tasks as defined by the researcher to guide the session.

![Distribution of age groups](image-url)
<table>
<thead>
<tr>
<th>Task</th>
<th>Goals</th>
<th>Helping prompt</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sequential Task 1</strong> - Introduction and microphone</td>
<td>Testing the introduction sequence. Testing the microphone permission sequence. Testing the first impression about the DH.</td>
<td>Please select AMD and then more options will be available. You should now choose [“AMD explanation” or “AMD Diagnosis”]</td>
</tr>
<tr>
<td><strong>Sequential Task 2</strong> - AMD explanation</td>
<td>Testing the AMD explanation sequence. Testing whether the DH’s speech is informative. Testing the presentation of images.</td>
<td>Please select “AMD explanation”</td>
</tr>
<tr>
<td><strong>Sequential Task 3</strong> - AMD Diagnosis</td>
<td>Testing the AMD diagnosis options sequence. Testing a flow with a lot of spoken content. Testing how people explore the service.</td>
<td>Please select “AMD diagnosis”</td>
</tr>
<tr>
<td><strong>Complementary Task 4</strong> - Accessibility options</td>
<td>Testing the accessibility options.</td>
<td>Imagine that you are not able to read very well, so you would like to increase the font size of the content. Try to see if you can do that.</td>
</tr>
</tbody>
</table>

*Table 3: Tasks defined for the evaluative research*

The complete set of questions, with the complete script used to guide the interviews can be found in Annex D. The results of this research are provided in the Results section, and the transcripts of the interviews are provided in Annex E.
3.6.4.5 Data collection and analysis
The data was collected in the form of notes of the participants' opinions and comments. In general, the notes follow the script of the interview, but the questions were not always posed in the same order, since they accounted for the directions that the conversation was taking. The notes were first gathered in a Google Sheets file, during the interviews. Then, transcripts were created from the recordings of the sessions, which were helpful to revisit the content and to focus on aspects that might have been missed during the discussion. When all the interviews had been conducted, the insights were aggregated to identify trends and common opinions. This gave a clearer overview of positive aspects in the experience and issues that needed to be addressed. The aggregated results were then translated into recommendations and observations.
4 Results
This section presents the results of the work, and especially of the research sessions, both the exploratory and evaluative one. Transcripts and notes for the user-based sessions can be found in the Annex section.

4.1 Personas
This subchapter presents the personas that were created to ensure that the whole team could have a clear representation of the characteristics of the potential main users. The personas try to reflect different levels of digital skills, different backgrounds, and different goals. The three personas are divided into:

- **Kalle Kaipio**: a person who does not have much knowledge about eye conditions and is starting to experience symptoms.
- **Karoliina Kerava**: a person who has some background knowledge about eye disease and wants to understand more about treatment.
- **Roosa Ruohola**: a person who has noticed a relative starting to lose their vision and being in denial, which motivated the person to look for information.

4.1.1 Persona 1 – Person living with AMD

4.1.1.1 Personal information
- Name: Kalle Kaipio
- Age: 69
- Location: Tampere
- Education: Bachelor degree
- Occupation: retired, formerly teacher
- Digital devices: iPhone 6 and Windows PC

4.1.1.2 Background
Kalle is a father of two and recently became a grandfather of one. He lives in Tampere, while both of his children moved to Helsinki for work and now live there. He has been living alone for the past five years, since his wife Aino passed away. He used to work as a teacher and is now retired. Kalle's favorite activities include gardening and watching movies. He recently subscribed to Netflix, so he can have a great selection of different movies. He also uses the Internet for other activities including reading the newspaper, checking his social media accounts (he mostly uses Twitter and Facebook), and calling his children, who taught him how to use Zoom. He also sometimes uses YouTube to watch videos about gardening or to listen to music. Kalle also often books appointments online, for example with the bank or the doctor.

4.1.1.3 Digital services used
Facebook, Twitter, Netflix, Zoom, YouTube, Yle website, Bank website, Healthcare appointment booking service

4.1.1.4 Health journey
In recent times, Kalle has noticed that the movies that he used to enjoy look duller in colour and blurrier. At first, he thought that it was a problem with his computer, but in the last week, he realised that the central part of his visual field is getting blurrier than the rest. He gave himself a couple of days to see whether this would resolve on its own, but finally decided to look for
information. He does not want to worry his children and he believes that it is best not to go to the hospital yet because of the Covid situation and because he is not sure of the severity of his condition. Therefore, he starts looking for information about his symptoms on the Internet. He does not have any background knowledge in eye diseases, and therefore starts by typing his own symptoms.

4.1.1.5 Symptoms
- Blurry central vision
- Dull colors

4.1.1.6 Goals
Kalle wants to find out what his symptoms can mean. He is also looking for reassurance that it is nothing severe that he would need to worry too much about.

Kalle has the following questions in his mind:
- What do my symptoms mean?
- Should I see a doctor?
- Is it something temporary or am I developing a disease?
- Should I be worried that I might lose my vision?

4.1.2 Persona 2 – Person living with DME
4.1.2.1 Personal information
- Name: Karoliina Kerava
- Age: 77
- Location: Espoo
- Education: High school diploma
- Occupation: retired, formerly saleswoman
- Digital devices: Android phone and tablet

4.1.2.2 Background
Karoliina is a mother of three and a grandmother of four. She lives in Espoo with her husband, two of their children live in Helsinki and one lives in Oulu. Karoliina used to work in a clothing store in Helsinki, and has now been retired for almost ten years. She enjoys cooking and DIY activities such as crochet. Karoliina sometimes uses YouTube on her tablet to watch recipes videos and instructions videos about crochet projects and she recently learned that she could play checkers online, which she enjoys a lot. She does not use social media and prefers to book all of her appointments by phone calls rather than online, because she is not very sure about how it is done.

4.1.2.3 Digital services used
YouTube, online checkers game

4.1.2.4 Health journey
Karoliina was diagnosed with type 2 diabetes over fifteen years ago. She therefore undergoes regular check-ups every 3 years. Over the last year, she started to notice her vision becoming blurrier, and she knows that diabetes puts her at risk of eye diseases. In recent times, she started seeing floating dark spots in her visual field, which started interfering with her favourite activities. She showed up to her check-up and mentioned this to her doctor and she was
immediately diagnosed with Diabetic Macular Edema. The ophthalmologist prescribed injections as part of her treatment plan and Karoliina was worried about it, but the doctor did not have time to discuss it with her. While she was leaving the clinic, a nurse gave her the link to a website where she said she could find more information about the treatment.

4.1.2.5 Symptoms
- Blurry vision
- Floating dark spots in the visual field

4.1.2.6 Goals
Karoliina wants to understand more about the injections she was prescribed. She wants to know whether they will hurt, what will happen afterwards and how likely they are to work. She is looking for reassurance and more information.

Karoliina has the following questions in her mind:
- Will the injections hurt?
- What consequences will the injections have?
- Are there things I cannot do after the injections?
- Are the injections effective?

4.1.3 Persona 3 – Caregiver

4.1.3.1 Personal information
- Name: Roosa Ruohola
- Age: 49
- Location: Helsinki
- Education: Master’s degree
- Occupation: Business consultant
- Digital devices: iPhone 11, MacBook, iPad

4.1.3.2 Background
Roosa is the daughter of Johanna, and she is a mother of two children in school age. She works full time at a business consulting company and is the school representative at her children’s school. She is also an active member of her local volunteering group. Roosa and her ex-husband divorced five years ago, and he recently accepted a new position in Brussels, so she is currently living with her two children alone most of the time. She relies on her mother to help her with the kids, so she sees her at least three times per week. Johanna is 74 years old; she is living on her own and she is not very familiar with digital technologies. Roosa, on the other hand, does almost everything online, from booking appointments to contacting friends and more. She uses social media and reads the news. She also uses many different digital services for work.

4.1.3.3 Digital services used
YouTube, Netflix, Zoom, Teams, Facebook, Instagram, Twitter, online banking, Yle website, healthcare appointments services...

4.1.3.4 Health journey
Roosa recently started to notice that her mother does not see very well. She started to worry when she asked her to pass her the orange bottle and her mother could not tell which one it was between an orange and a red one. Besides
this, she noticed that her mother tends to look at things sideways, for example, when she reads, she moves the page towards the side of her head. She tried to talk to Johanna, but she quickly changed the subject. Roosa decided to look up on the Internet what could be happening to her mother, to understand whether she should try convincing her to go see a doctor.

4.1.3.5 Symptoms
- Blurry vision
- Duller colors

4.1.3.6 Goals
Roosa wants to understand whether her mother is experiencing vision decline and whether there are some actions that they should be taking to prevent this.

Roosa has the following questions in her mind:
- What do Johanna’s symptoms mean?
- Is Johanna suffering from an eye disease?
- Should they see a doctor?

4.2 Exploratory research
This paragraph presents the aggregated results of the exploratory research sessions conducted to explore the context of use of people starting to experience low vision symptoms. The focus was posed on expectations towards and first impressions of the digital human concept. The collected data, mostly in text form, was insightful and the analysis provided good guidance to proceed in refining the service prototype. On a general level, participants revealed that self-led information search is common and highly important for people approaching eye conditions. There was also consensus on the characteristics that are deemed important in an agent.

4.2.1 Findings
4.2.1.1 Exploration phase
This section will explore the results gathered about the background of the participants (health journey; initial health literacy; information channels; and quality and understandability of the information), and about the expectations towards the character of the conversational agent and the environment.

4.2.1.1.1 Background
Firstly, the health journey of the participants was explored. Six out of ten participants reported that they grew worried when they first started to experience symptoms or to see them in their loved ones. The diagnosis of an eye condition was a shock that they struggled facing, and they often reported that their mental health was impacted. This result is in line with what the literature reports.

One surprising result was that eight out of ten participants reported that they did not have much or any previous knowledge about eye disease, and that therefore they did not understand what was happening at first. Even the participants that are living with diabetes reported that they did not know about DME. This was surprising because diabetic people should be informed by their doctors about the possible impacts on their vision.
Nine out of ten participants reported that they looked for information about eye conditions on the Internet. This speaks to the need to have reliable sources of information for people to turn to. Almost all participants reported that ultimately, they trust the word of doctors more than online information. One participant mentioned that it is always hard to find the right information on the Internet, and that oftentimes, the information is more scary than useful. Another participant reported starting to look for information, but stopping at some point to avoid reading conflicting information to what the doctor would have explained during the visit. Most of the participants looked on the Internet for explanations of their experience, either before their appointments with the doctor when they were worried about the eyesight becoming worse, or after the appointment to get further information.

Some participants would look for information on YouTube, or even professional PowerPoint presentations. Only one participant felt that these videos or presentations were difficult to understand. Nine participants out of ten reported that they were able to understand the content they found online. They reported only needing to look up some specific terms, such as “edema”. Participants said that the information provided by their doctors (general practitioners and ophthalmologists) was comprehensive and understandable.

Three participants only reported turning to patient communities, and when they did, it was usually to receive emotional support. Very few people tried to contact other patients directly and remained “passive observers” instead. The main reason that motivated reaching out to patient communities was to understand how to cope with the condition, to find treatments, or tips to improve and adapt their daily life. For example, one participant said that he would only connect with patients’ communities if his eyesight was to get any worse, to understand how to cope with it in daily life. In the ophthalmology domain, patient communities do not seem to offer much more knowledge to patients, beyond the medical information that is already provided by the health-care professionals. However, it must be noted that eye condition patients may be older on average. This may reduce the average level of engagement in the virtual community, due to lack of trust or digital literacy.

As far as digital assistants are concerned, five participants reported using services such as Google Assistant, Amazon Alexa etc. When they do, it is not connected to the visual impairment, but to complete small daily tasks like asking for the weather or playing music. The participants said that speaking with a human-like entity is sometimes pleasant, although the limitations of a robot are often perceived, including automatic answers or the inability to understand specific accents.

4.2.1.1.2 Expectations towards the character
The exploration of the expected character was conducted on Miro. This allowed displaying the pictures of the 11 chosen characters (Figure 14) all together on a board, and letting the participant observe them and choose their favorite. The results were aggregated in Table 4, which shows the preference trends and the association that participants made of characters and the three adjectives, friendly, trustworthy and knowledgeable.
Following here, some of the general insights provided by the participants.

- Smiling is one of the features that fosters engagement the most. A smiling character appears as pleasant, engaged and listening. Only a few participants selected a character who is not smiling. These participants reported that eye conditions are a serious and concerning topic, and therefore they appreciate seriousness.
- Participants preferred human characters over robot ones, as humans allow building a deeper connection. Participants generally considered robots uncomfortable to discuss with, despite recognizing that they can have great knowledge. One participant reported that robots are often more honest than humans.
- Two participants reported that they would have liked the age of the character to match theirs, because this helps building a connection.
- Clothes appeared to be important for some participants, in that they can convey trustworthiness. The stethoscope might be too much, especially for a service dedicated to ophthalmology.

<table>
<thead>
<tr>
<th>Character description</th>
<th>Preference</th>
<th>Friendly</th>
<th>Trustworthy</th>
<th>Knowledgeable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Young male researcher</td>
<td>2,00</td>
<td>0,20</td>
<td>1,20</td>
<td>2,75</td>
</tr>
<tr>
<td>Older smiling female doctor</td>
<td>4,50</td>
<td>2,70</td>
<td>4,20</td>
<td>1,75</td>
</tr>
<tr>
<td>Young smiling female nurse</td>
<td>3,50</td>
<td>3,53</td>
<td>1,70</td>
<td>1,50</td>
</tr>
<tr>
<td>Serious robot</td>
<td>0,00</td>
<td>0,00</td>
<td>0,00</td>
<td>1,00</td>
</tr>
<tr>
<td>Elmo</td>
<td>0,00</td>
<td>0,53</td>
<td>0,50</td>
<td>0,25</td>
</tr>
</tbody>
</table>
Table 4 Preferences and opinions about the characters during the exploratory research

<table>
<thead>
<tr>
<th>Character</th>
<th>Preference</th>
<th>Friendly</th>
<th>Trustworthy</th>
<th>Knowledgeable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Customer service employee</td>
<td>0.50</td>
<td>0.50</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Young smiling male nurse</td>
<td>1.00</td>
<td>1.53</td>
<td>0.20</td>
<td>0.17</td>
</tr>
<tr>
<td>American older TV presenter</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Cuter robot with big eyes</td>
<td>2.00</td>
<td>1.00</td>
<td>2.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Serious female doctor</td>
<td>0.50</td>
<td>0.00</td>
<td>0.20</td>
<td>0.17</td>
</tr>
<tr>
<td>Einstein</td>
<td>1.00</td>
<td>0.00</td>
<td>0.00</td>
<td>1.42</td>
</tr>
</tbody>
</table>

To create Table 4, each participant’s first preference weighted 1 point, while their second preference weighted 0.5 points. For the three adjectives, 1 point would be assigned for each word for each participant. The participants were allowed to assign the same adjective to more than one character. For this reason, in the case where the same word was assigned to multiple characters the 1 point would be divided equally among the choices. This was done to avoid specific participants’ opinions to outweigh others.

The two characters with the highest rating were the “older smiling female doctor” and the “young smiling female nurse”. The scores of these characters were quite higher compared to those of the other characters. The “older smiling female doctor” scored high in all four categories, and can hence be considered the favorite one. The participants have reported that:

- She looks professional and knowledgeable. This impression is sometimes enhanced by the doctor’s clothes.
- She looks reliable and trustworthy.
- She looks calm and confident, like she would not get too worried. The participants reported that this is good for someone who is talking about health.
- She looks reassuring, which is valuable for some participants. One participant said that she looks like a “motherly figure”, and that he appreciates that.

The high preference that this character received may be explained by the clothes, which symbolize her profession, and by her older age, which could convey a sense of higher experience. The results seem to indicate that the most suitable personality for the conversational agent would require a good balance of friendliness, trustworthiness and knowledge, which all appear as important factors that impact the perception of the digital agent.
4.2.1.1.3 Expectations towards the environment

As shown in Table 5, participants mostly chose the cozy, wooden environments, but some participants noted that the environment should not be too dark. They explained that they look more intimate and comfortable to have a private, friendly conversation.

<table>
<thead>
<tr>
<th>Environment</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Luxury office</td>
<td>1</td>
</tr>
<tr>
<td>Cozy cafe</td>
<td>0</td>
</tr>
<tr>
<td>Hospital hall</td>
<td>1</td>
</tr>
<tr>
<td>Nordic minimalist living room</td>
<td>2</td>
</tr>
<tr>
<td>Clinic modern hallway</td>
<td>1</td>
</tr>
<tr>
<td>Modern minimalist white office/clinic studio</td>
<td>0</td>
</tr>
<tr>
<td>Cozy office with window on nature</td>
<td>3</td>
</tr>
<tr>
<td>Cozy office with library and armchair</td>
<td>2</td>
</tr>
</tbody>
</table>

*Table 5 Preferences for the environment in the exploratory research*

In fact, they reported a preference for peaceful environments, where they could engage in a private and intimate conversation with a trustworthy person. Only one participant chose a hospital setting. They explained that it felt professional and comforting, meaning that help can be found there. This same person acknowledged that few people are likely to prefer this kind of environment: a more cozy environment, such as a home office, would suit better people who want to feel like they are talking to someone they trust and like. Other participants reported that large spaces are too impersonal and that white, sterile, hospital-like places are too cold and dehumanized. However, cleanliness, luminosity and a professional look were valued by the participants.

Windows towards nature were quoted by two participants as an attractive feature of the environment, conveying calmness and peacefulness, and therefore able to limit the emotional impact of the participants’ conditions. Some participants explained that they liked seeing a bookshelf in the environment because it conveys the notion of knowledge, which is reassuring and makes the character look more trustworthy.

4.2.1.2 Assessment phase

Seven out of ten participants said that they liked the version of the digital human that they were presented with, both from the pictures and the short non-interactive video. They perceived the digital human as nice, trustworthy, willing to help, knowledgeable and professional. However, there was no consensus regarding her friendliness. One participant stressed that she did not look very friendly but added that this did not bother them too much, since she still looked willing to help. On the other hand, one participant said that she looked as if she was not really willing to talk. In summary, the first impression about the digital human was that she was professional and straightforward, but not always very engaging.
Four participants specifically said that they appreciated that the digital human’s voice was clear and calm, and they found this aspect important. However, two participants reported problems with lip-syncing: they said that her mouth may look like she’s wearing braces, and her movements sometimes appear too slow or robotic. In fact, the lack of synchronicity between her speech and her movements is the main aspect that triggered some level of the uncanny valley effect. These participants reported that this was weird and that it ruined the experience in some way. Besides this, one participant said that they hated the way she spoke. This impression of lower realism, which triggers the sense of eeriness that is typical of the uncanny valley, is enhanced by the fact that the avatar is moving (Mori, 1970). In fact, participants were generally more positive when they were looking at still pictures, and mostly reported negative feelings after watching the video. Two participants gave negative feedback to the video because they felt like it was artificial, and they did not like that. One of them said that the voice was warm and that it felt like it should make people feel at ease, but that they personally did not feel that way.

This is a clear example of a character that resembles a human closely, but fails on one aspect, which then triggers uncanny valley-related feelings. This shows that in order to create a digital human that does not convey feelings of eeriness, particular attention should be paid to the movement of the agent, which could be even more important than the details of its looks. In fact, only a couple of participants commented on the level of detail of the skin or hair of the avatar, while most of them commented on its movements.

### 4.2.1.3 Prioritization phase

This phase aimed at understanding which information the participants considered the most important to receive when searching online and which channels they preferred for communication of that information. The options participants were asked to choose the three most important pieces of information among a set of options. Table X shows the results of this activity. Each vote weighted 1 point and therefore each participant’s adds up to 3 points.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cause</td>
<td>5,00</td>
</tr>
<tr>
<td>Symptoms</td>
<td>3,00</td>
</tr>
<tr>
<td>Treatment</td>
<td>6,50</td>
</tr>
<tr>
<td>Treatment Side Effects</td>
<td>1,50</td>
</tr>
<tr>
<td>Tips</td>
<td>6,00</td>
</tr>
<tr>
<td>Doctor conversation</td>
<td>3,00</td>
</tr>
<tr>
<td>Patient Conversation</td>
<td>3,00</td>
</tr>
<tr>
<td>Vision test</td>
<td>1,00</td>
</tr>
<tr>
<td>Other</td>
<td>2,00</td>
</tr>
<tr>
<td>Other (detail)</td>
<td></td>
</tr>
<tr>
<td>Medical breakthroughs</td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td></td>
</tr>
<tr>
<td>Progress of the disease</td>
<td></td>
</tr>
</tbody>
</table>

*Table 6 Prioritization of the content during the exploratory research*
Table 6 shows that participants prioritized information about treatments and tips, followed by the explanations about the cause.

- Causes: understanding the cause of the disease, when unclear, is important to the patients or their caregivers. Many participants reported this as one of the main topics that they would like to know about, mostly because at first it might be a way to cope with the news.
- Tips: one participant said “you can never run out of tips”. It seems that people with a later-stage disease (themselves, caregivers not as much) are the most interested in the tips.
- Symptoms: many participants said that they would be interested in hearing about the symptoms to compare them with what they are experiencing and to try and categorize the disease.
- Suggestions: one participant added that they would like to hear about trial programs and experimental treatments, because that could be paired with treatment options and also give hope when few treatment options are available. Another participant reported that they would like to hear about the progression of the disease, to know what to expect.

The preferred channel to receive information is videos: most participants explained that videos are clearer, easier to understand and yet able to reach a good level of detail. Some said that videos can add a human touch to the explanation. Some participants also mentioned scientific articles, because they find them thorough and reliable.

4.2.2 Further analysis

The results of the exploration session highlighted some potential issues with and possible directions for the development of informational e-Health websites featuring a conversational agent, specifically a digital human. First, the study showed that most people do look for information online, and often doubt the reliability of this information. This advocates for creating more reliable resources, where people can find content that they know they can trust. Furthermore, many people lack the understanding of ophthalmic conditions, and therefore do not really know what to look for or to expect, or how to take action to prevent the decline of their vision. For this reason, information e-Health services could not only foster information availability, but also prevention.

The research highlighted that people have quite homogeneous and defined preferences in terms of the agent they would like to be talking to. In order to be appreciated and successful, the digital human must embody the qualities of friendliness, trustworthiness and knowledge. All these qualities are important to ensure a positive patient experience with the service.

The research also highlighted that some people struggle with digital humans, as they do not perceive them in a very positive way. Any uncommon feature or behavior is recognized straight away, and it can strongly impact the user experience in a negative way. The interviews showed that even people who are open or used to digital humans and are invested in technological developments experience the consequences of the uncanny valley effect. To improve and enhance the patient experience with the digital human, it is crucial to avoid triggering the eeriness sensation caused by the uncanny valley effect as much
as possible (Mori, 1970). To achieve this goal, the research hinted that particular attention should be paid to the realism of the digital human’s movements, even more than to its look. The face mimicry, and especially the synchronization of the mouth and speech is extremely important to ensure a positive and more natural experience.

4.3 Expert evaluation
This section presents the results of the expert evaluation, combining the cognitive walkthrough methodology and the WCAG-based accessibility assessment. The methods were applied to the proof-of-concept prototype of the service.

4.3.1 Cognitive walkthrough findings
The cognitive walkthrough methodology was employed to elicit the main issues that the users might encounter. This methodology allows the expert evaluators to step in the shoes of real users and to analyze the service from their perspective. The researchers found several issues of variable severity. Some issues are quite severe, and would result in a negative patient experience with the service.

4.3.1.1 Task 1 - Start the interaction
System response: the conversational agent starts speaking.

**Failure** story: the interface does not switch to Finnish when the language is switched, which poses some serious usability issues, which can be linked to the criteria 4.2 User Expertise. In fact, the system does not adapt to the users’ skills, because it can only be used by people who understand English. Besides this, some visual elements could be presented in a way that is more consistent to standards. This low-severity issue can be traced back to the criteria 1.2 Grouping/Distinction of items. In fact, the visual organization of items that convey information should be optimized to make it as easy as possible for the users. An additional problem is that, if the language is switched after starting to interact with the agent, only the buttons’ labels change language, but the speech and interface remain in English. This is a major usability issue that needs to be addressed. Again, this concerns the criteria 4.2 User Expertise, because the interface does currently not support people who do not understand English. It also concerns the criteria 4.1 Flexibility, because it does not allow to “customize” the interface.

*Table 7* shows the answers to Mack and Nielsen’s (1993) four questions for Task 1.

<table>
<thead>
<tr>
<th>Prompt</th>
<th>Outcome</th>
<th>Why</th>
<th>Suggestions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will the user try to achieve the correct effect?</td>
<td>Yes</td>
<td>If inserting the password is necessary, it is nothing unusual. If not, it is even more conformed to users’ normal behavior with websites.</td>
<td></td>
</tr>
<tr>
<td>Prompt</td>
<td>Outcome</td>
<td>Why</td>
<td>Suggestions</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------</td>
<td>---------</td>
<td>----------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Will the user notice that the correct action is available?</td>
<td>No</td>
<td>The language option might not be evident since it is placed underneath the “Start” button, and users might click the button before seeing it. It might also be helpful to include a clearer identification of the language. The toggle button might also not be the best choice in the language choice case. (Criteria 1 - Guidance - 1.2 Distinction of items, cosmetic problem) If the language is changed to Finnish, the interface remains in English. This could exclude people that do not understand English. (Criteria 4 - Adaptability - 4.2 User expertise, major usability problem)</td>
<td>- Place the language toggle above the continue button and spell out the complete name of the language, in its native version (for Finnish: “Suomi”). Change the toggle button to a more standard way to display language options. <em>(low priority)</em> - Make sure that if the language is switched, the interface language is switched as well. <em>(high priority)</em></td>
</tr>
<tr>
<td>Will the user associate the correct action with the desired effect?</td>
<td>Yes</td>
<td>Inserting the correct password triggers the start of the interaction with the service, which is the standard behavior.</td>
<td></td>
</tr>
<tr>
<td>If the user performed the right action, will the user notice that progress is being made toward accomplishment of his goal?</td>
<td>Yes</td>
<td>The visual and audio feedback tells the users that they accomplished the goal.</td>
<td></td>
</tr>
</tbody>
</table>

*Table 7 Answers to Mack and Nielsen’s questions for Task 1*
4.3.1.2 Task 2 - Allow microphone usage

System response: the system starts using the microphone and lets the user know about it.

Success story: the overall accomplishment of the task is possible and easy. However, the visual feedback for the spoken words should be investigated to ensure that it is not too heavy for users.

Table 8 shows the answers to Mack and Nielsen’s (1993) four questions for Task 2.

<table>
<thead>
<tr>
<th>Prompt</th>
<th>Outcome</th>
<th>Why</th>
<th>Suggestions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will the user try to achieve the correct effect?</td>
<td>Yes</td>
<td>The buttons appear on the screen, are clear and contrasted, and allow the users to choose the option that they prefer.</td>
<td></td>
</tr>
<tr>
<td>Will the user notice that the correct action is available?</td>
<td>Yes</td>
<td>The buttons are visible, and the text is understandable. They might at first speak out a response, but since permission has not been given, this will not work.</td>
<td></td>
</tr>
<tr>
<td>Will the user associate the correct action with the desired effect?</td>
<td>Yes</td>
<td>The label of the button clearly states the effect that it triggers.</td>
<td></td>
</tr>
<tr>
<td>If the user performed the right action, will the user notice that progress is being made toward accomplishment of his goal?</td>
<td>Yes</td>
<td>Feedback is shown when users accept microphone usage and when they speak. However, it needs to be understood whether showing all the words that are processed by the system is good or if it overwhelms the users. Besides this, the text is not contrasted enough. (Criteria 1.2 Distinction of items, minor usability problem)</td>
<td>- Make sure that visual feedback of the spoken words is needed and if so, increase the contrast of the text. (medium priority)</td>
</tr>
</tbody>
</table>

Table 8 Answers to Mack and Nielsen’s questions for Task 2

4.3.1.3 Task 3 - Discover eye conditions
This can be done either by clicking the button or by saying it.
System response: the conversational agent continues to that content and chooses “age-related macular degeneration - AMD”. The conversational agent then continues to that content and restates the location.

**Failure** story: if the users choose one option by mistake and want to go back and choose something else, they cannot do it. The system does not let the users go back to more than one block of speech. This means that the user is stuck in their decision. This is especially bad for error recovery and is a severe usability issue. This is linked to the criteria 5.3 Error correction. The system does not allow for error correction, and making an error is extremely costly, because it requires the users to restart the flow completely. This is a **usability catastrophe** in terms of severity because it traps the users in their choices, and it is extremely costly in case of errors.

*Table 9* shows the answers to Mack and Nielsen’s (1993) four questions for Task 3.

<table>
<thead>
<tr>
<th>Prompt</th>
<th>Outcome</th>
<th>Why</th>
<th>Suggestions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will the user try to achieve the correct effect?</td>
<td>Yes</td>
<td>The agent says that there are three conditions that it can explain, and it mentions AMD. This helps the user to know what to choose.</td>
<td></td>
</tr>
<tr>
<td>Will the user notice that the correct action is available?</td>
<td>Yes</td>
<td>Buttons are visible and speaking gives feedback (even if not contrasted enough, see above).</td>
<td></td>
</tr>
<tr>
<td>Will the user associate the correct action with the desired effect?</td>
<td>Yes</td>
<td>The buttons have understandable labels, and both speaking and clicking work.</td>
<td></td>
</tr>
<tr>
<td>If the user performed the right action, will the user notice that progress is being made toward accomplishment of his goal?</td>
<td>No</td>
<td>The digital avatar restates the word “conditions” at the beginning of the next interaction, which confirms to the users that they made progress and arrived where they wanted to. However, if the user chooses an option and then changes their mind, they cannot go back and change the decision. (Criteria 5.3 Error correction - <strong>usability catastrophe</strong>)</td>
<td>• Allow going back in the flow and choosing options again.</td>
</tr>
</tbody>
</table>

*Table 9 Answers to Mack and Nielsen’s questions for Task 3*
4.3.1.4 Task 4 - Explore the content

System response: the conversational agent continues to that content and restates the location.

**Failure** story: everything is clear and easily achievable if the issues encountered so far are fixed. However, the conversational agent is speaking for a long time, and there is no possibility to interrupt or pause the conversation. This could be a major issue and a great source of frustration for the users. They could be interrupted, not being able to listen to what the agent is saying, and then they would need to restart the conversation block. It is crucial to provide controls similar to a “media player”, with play and pause, stop, rewind and fast forward. Pausing and playing is especially missing in this service, while forwards and backwards buttons were provided. This issue concerns the criteria 4.1 Flexibility, because it does not allow the user to “customize” the interface, and it also mainly concerns the criteria 3.2 User Control, as it does not allow users to be fully in control of the interface. This is a major usability problem and therefore needs to be addressed, because it could lead to frustration and possibly dropout.

*Table 10* shows the answers to Mack and Nielsen’s (1993) four questions for Task 4.

<table>
<thead>
<tr>
<th>Prompt</th>
<th>Outcome</th>
<th>Why</th>
<th>Suggestions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will the user try to achieve the correct effect?</td>
<td>Yes/No</td>
<td>The options are clear, and the interaction method is standard. The</td>
<td>Provide controls similar to a “media player” to allow users to pause and</td>
</tr>
<tr>
<td></td>
<td></td>
<td>users are not provided with a “pause” button and therefore cannot</td>
<td>play and play the discussion flow, go forward and back and stop it.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>achieve the goal of stopping the talk. (Criteria 3.2 User Control</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>and criteria 4.1 Flexibility, major usability problem)</td>
<td></td>
</tr>
<tr>
<td>Will the user notice that the correct action is</td>
<td>Yes</td>
<td>The buttons are visible and understandable and speaking is available.</td>
<td></td>
</tr>
<tr>
<td>available?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Will the user associate the correct action with</td>
<td>Yes</td>
<td>The buttons have meaningful labels.</td>
<td></td>
</tr>
<tr>
<td>the desired effect?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If the user performed the right action, will the</td>
<td>Yes</td>
<td>The conversational agent starts speaking again and repeats the word</td>
<td></td>
</tr>
<tr>
<td>user notice that progress</td>
<td></td>
<td>“diagnose”.</td>
<td></td>
</tr>
</tbody>
</table>
### Table 10 Answers to Mack and Nielsen’s questions for Task 4

<table>
<thead>
<tr>
<th>Prompt</th>
<th>Outcome</th>
<th>Why</th>
<th>Suggestions</th>
</tr>
</thead>
<tbody>
<tr>
<td>is being made toward accomplishment of his goal?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4.3.1.5 Task 5 - Go through the slideshow

System response: the conversational agent progressively goes through each “slide”.

**Failure** story: the system does not explain that the user should manage the slideshow through explicit action. Since the agent has always been moving through the content on its own, it is not self-evident that the users should say “next” or click on the right arrow. This issue concerns the criteria 1.1 Prompting, because in this case the system does not lead the users to take the right action. Besides this, it concerns criteria 6. Consistency, because the interface behaves differently than in any other context, which can be confusing for the users. This is a *minor usability problem*, because it could result in some level of frustration from the users.

*Table 11* shows the answers to Mack and Nielsen’s (1993) four questions for Task 5.

<table>
<thead>
<tr>
<th>Prompt</th>
<th>Outcome</th>
<th>Why</th>
<th>Suggestions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will the user try to achieve the correct effect?</td>
<td>No</td>
<td>It is never stated that the user should make the slideshow progress by either saying “next” or clicking on the right arrow. This behavior is not consistent with the rest of the website, and might be difficult to understand for the users. (Criteria 1.1 Prompting and 6. Consistency, <em>minor usability problem</em>)</td>
<td>The agent could either present the “slideshow mode” at first, and tell the users that they should navigate through it. It could otherwise ask if the user wants to go to the next slide after some idle time. <em>(low priority)</em></td>
</tr>
<tr>
<td>Will the user notice that the correct action is available?</td>
<td>No</td>
<td>The users might not understand what they should click on the right arrow or say “next”, and only do it because they click on the first thing that makes sense.</td>
<td>Improve the understanding of the process, either through speech or visually.</td>
</tr>
<tr>
<td>Prompt</td>
<td>Outcome</td>
<td>Why</td>
<td>Suggestions</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>---------</td>
<td>---------------------------------------------------------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>Will the user associate the correct action with the desired effect?</td>
<td>Yes</td>
<td>Clicking on the right arrow or saying “next” makes sense, even though it is not visible.</td>
<td></td>
</tr>
<tr>
<td>If the user performed the right action, will the user notice that progress is being made toward accomplishment of his goal?</td>
<td>Yes</td>
<td>The agent starts speaking again and the slideshow image changes, which provides feedback that the correct action was taken.</td>
<td></td>
</tr>
</tbody>
</table>

Table 1 Answers to Mack and Nielsen’s questions for Task 5

4.3.2 Accessibility assessment insights
In addition to the cognitive walkthrough methodology, the researcher conducted an accessibility assessment following WCAG 2.1. The assessment focused on the guideline level rather than the success criteria one: although this might result in a lower accuracy of the assessment, it has the benefits of being rather fast and efficient. This section presents the outcomes of the assessment, carried out manually in the first place, and then using Microsoft’s Accessibility Insights automatic checker.

4.3.2.1 Principle 1. Perceivable
Information and user interface components must be presentable to users in ways they can perceive.

4.3.2.1.1 Guideline 1.1 Text Alternatives (fail)
Provide text alternatives for any non-text content so that it can be changed into other forms people need, such as large print, braille, speech, symbols or simpler language.

The labels for the non-text content on screen are often not appropriate because they are not informative enough (see guideline 4.1 for more detail). There is no non-text content that is pure decoration.

4.3.2.1.2 Guideline 1.2 Time-based Media (fail)
Provide alternatives for time-based media.

In the current prototyping phase, the service does not provide captions for the spoken content that the Digital Human provides. However, this was due to time constraints, and it will be included in the following iteration. Audio description might not be needed in this case, since the DH does not engage in actions that need to be explained, and since the images that it provides are only a support to its speech, which describes them in detail. Sign language interpretation is not provided (nor envisioned at the moment) for the information that the DH is giving, which means that even when captions will be added, the service will not reach AAA level of conformance. However, the main target group are people who
experience visual impairment, and therefore would not benefit too much from
visual information such as sign language.

4.3.2.1.3 Guideline 1.3 Adaptable (fail)
Create content that can be presented in different ways (for example simpler
layout) without losing information or structure.

There currently is no written content because the DH is speaking it all. There is
no clear way to understand the structure of the content and the user's location
within it. This might be complicated to judge since the content is not text-based
but speech-based. However, even if the content is speech-based, it should have
some type of structure (sections, sub-sections) and the users should be able to
navigate through them.

The content on screen is presented in a meaningful sequence. The option menu
is on the top left, the forward button is on the bottom right and the back button
on the bottom left. Besides this, the options buttons to navigate through the
content are presented in the order that the DH presents, starting from top to
bottom. The instructions are not based on sensory characteristics.

In the current version, only the desktop view is supported, so orientation is not
flexible. However, the design work was conducted with a mobile-first approach,
to ensure that all the elements on the screen would properly fit on a portrait
mode, which will be included in the next iteration.

The only input field necessary in the service is the password text field. This field
is not properly labelled and therefore is not easy to determine programmatically.
The screen reader might read the placeholder text, which is “password” when
the field is focused, but this does not follow best practices. The same goes for
the buttons (see guideline 4.1 for more detail).

4.3.2.1.4 Guideline 1.4 Distinguishable (fail)
Make it easier for users to see and hear content including separating foreground
from background.

Color is not used as a means to convey information, so there is no issue on that
front. There is no background audio or images of text. The contrast ratio is fine
both for the colored buttons (it is 8.21:1, so it conforms to AA and AAA levels),
for the system buttons, which are white with black text, and for the unavailable
content buttons (it is 10.98).

One major accessibility issue is that the speech of the DH cannot be stopped.
This is extremely frustrating and very user-unfriendly. Besides this, there is no
possibility to adjust the level of the audio independently from the main system
audio level, which could pose problems to screen readers users.

The interface does not respond well to resizing the text using the built-in
zooming option. The content and functionalities are only retained when zooming
up to 125%. This could however change depending on screen size. The service
has the option to increase text size, which can get the font to 28.8px. However,
when increasing the text size and resizing the window, the text overflows the
buttons and some of it can be lost. When zooming up to 400% the text does
seem to reflow. However, scrolling is not possible, hence the loss of most of the
available content.
4.3.2.2 Principle 2. Operable
User interface components and navigation must be operable.

4.3.2.2.1 Guideline 2.1 Keyboard Accessible (pass)
Make all functionality available from a keyboard.

There are no keyboard traps, and everything is accessible through keyboard interaction. Buttons are operable both through pressing the enter key or the spacebar. Dropdown menus are operable both through the spacebar and the enter key, navigation within them is done through up and down arrows and closing the dropdown can be done either through tab or esc.

4.3.2.2.2 Guideline 2.2 Enough Time (fail)
Provide users enough time to read and use content.

Currently, a time limit for idleness is set, and no warning is given before the page is refreshed. This is due to prototyping requirements: the system does not support more than two concurrent users, which is why the developing team set a timer to ensure that users would not just keep the service tab open without using it, and hence blocking anyone else from accessing the DH. However, it is important to ensure that the system provides a warning to the user, and the possibility to extend the timer. In the current version, whenever the timer is over, re-authentication is required, and the system does not save the previous user’s location within the content, meaning that they need to start the interaction all over again.

The DH starts talking without any action performed by the user. This is fine and builds on the realism of natural interaction. Sometimes the DH is also presenting images on the screen, which means that different channels are targeted in parallel. However, there is no option to pause the DH’s speech. This requires users to listen to entire blocks of text in the spoken version in order not to miss any content. This is extremely frustrating, and also brings about severe accessibility issues, which result in the page failing even level A of conformity.

4.3.2.2.3 Guideline 2.3 Seizures and Physical Reactions (pass)
Do not design content in a way that is known to cause seizures or physical reactions.

There are no flashes or animations from interactions on this page. This means that the service fully conforms to guideline 2.3.

4.3.2.2.4 Guideline 2.4 Navigable (pass)
Provide ways to help users navigate, find content, and determine where they are.

There are no blocks of content on the page, since there is no fixed menu but only three possible buttons to click and there is only one page, where the content changes during the interaction. This also means that the title of the page is always the same. For now, the title is “Roche Virtual Assistant”, which should probably be changed to something that includes the word “ophthalmology” or “eyes”. Having a single web page means that there is no need to locate the webpage within a set of webpages. This also means that there would
strictly be no need to provide the users with the information regarding their location within a set of web pages. However, no information is provided to users regarding their location within the content. Since the complete version of the service would include a lot of content and many different options, it might be beneficial to provide users with a way to locate themselves within that content.

The sequence in which elements receive focus when interacting through the keyboard seems to make sense, although it might not be apparent to sighted users: it first goes to the option buttons, then to the “back” button, then to the “next” button and finally to the options menu. This logically makes sense, although it’s a different order than shown on the screen, where they are organized with the back button to the bottom left, the skip button to the bottom right, the menu button on the top left and the options buttons between the back and skip, aligned to the bottom of the screen. When interacting with the keyboard, focus is visible as an accentuation of the focused element.

4.3.2.2.5 Guideline 2.5 Input Modalities (pass)
Make it easier for users to operate functionality through various inputs beyond keyboard.

The service does not use gestures to operate, as it supports speech interaction. If not interacting through speech, no pointer gesture is required, as all functionalities can be operated by clicking. In the same way, no functionality is activated through motion. The targets are all larger than 44x44 pixels, which ensures that they are large enough to be reached.

4.3.2.3 Principle 3. Understandable
Information and the operation of user interface must be understandable.

4.3.2.3.1 Guideline 3.1 Readable (fail)
Make text content readable and understandable.

The language of the page is determined through the <html lang="en"> tag. This is the default language of the page. However, it does not seem that when the chosen language is Finnish, the language of the parts of the service that use Finnish text are marked as such. This might result in screen readers pronouncing the words using English phonetic rules, which would be extremely damaging, since Finnish has very different pronouncing rules than English. The text might not even be understandable.

The English that the DH speaks is plain and does not use idioms and jargon. Medical terms are only used when they indicate a specific procedure or condition. Abbreviations are presented in full extent before being used. No specific mechanism is in place to know more about specific words.

4.3.2.3.2 Guideline 3.2 Predictable (pass)
Make Web pages appear and operate in predictable ways.

No element triggers a change of context automatically when receiving focus. All elements required further interaction to start an action. The interface components that allow changing the settings do not automatically trigger a change of context but require an explicit action to do so. Navigation through the service and identification of elements are both consistent.
4.3.2.3 Guideline 3.3 Input Assistance (fail)
Help users avoid and correct mistakes.

There is no error identification mechanism. Even when inputting the password, if it is incorrect, the only indication that this is the case is that the borders of the text field become red. This is not enough to guide users. As well, the password text field is not well marked and labelled. Another problem that concerns error prevention and error correction is that, when one option is chosen within the content, it is not possible to go back and choose something different. This means that the users are stuck in their decisions. There is no sensitive data inputted on the page, but still this behavior can cause frustration and dissatisfaction.

4.3.2.4 Principle 4. Robust
Content must be robust enough that it can be interpreted by a wide variety of user agents, including assistive technologies.

4.3.2.4.1 Guideline 4.1 Compatible (fail)
Maximize compatibility with current and future user agents, including assistive technologies.

The names, roles and values of the user interface elements are not always programmatically determinable. The interface needs adjustment because it fails to provide significant labels for on-screen elements. For example, the text boxes and combo boxes on the landing page do not have appropriate labelling, which makes it impossible for screen reader users to understand what they are. As Figure 15 shows, the language drop-down menu is labelled “EN”, which is the text that it contains, but which is not understandable as is.

<table>
<thead>
<tr>
<th>Styles</th>
<th>Computed</th>
<th>Layout</th>
<th>Event Listeners</th>
<th>DOM Breakpoints</th>
<th>Properties</th>
<th>Accessibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼ ARIA Attributes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>role: button</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>aria-expanded: false</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>aria-haspopup: listbox</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| ▼ Computed Properties |
| ▼ Name: "EN" |
| aria-labelledby: Not specified |
| aria-label: Not specified |
| Contents: "EN" |
| title: Not specified |
| Role: combobox |
| Focusable: true |
| hasPopup: listbox |
| Expanded: false |

Figure 15 Accessibility inspection for the language combobox

Once the service starts, the buttons on screen have appropriate labelling, but once the accessibility menu is opened, there are additional labelling problems. Once more, the language options button is not properly labelled. Besides this, the button that allows closing the menu (an X-looking button) is not labelled at
all, see Figure 16 so the screen readers read “button 6”. This traps screen reader users into the menu and is therefore an extremely severe accessibility problem.

![ARIA Attributes](image)

**ARIA Attributes**

<table>
<thead>
<tr>
<th>Name</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>aria-labelledby</td>
<td>Not specified</td>
</tr>
<tr>
<td>aria-label</td>
<td>Not specified</td>
</tr>
<tr>
<td>Contents</td>
<td>Not specified</td>
</tr>
<tr>
<td>title</td>
<td>Not specified</td>
</tr>
</tbody>
</table>

**Computed Properties**

<table>
<thead>
<tr>
<th>Name</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Role</td>
<td>button</td>
</tr>
<tr>
<td>Invalid user entry</td>
<td>false</td>
</tr>
<tr>
<td>Focusable</td>
<td>true</td>
</tr>
</tbody>
</table>

*Figure 16 Accessibility inspection for the close button of the accessibility menu*

### 4.3.3 Further analysis

Overall, the system performed well on the following ergonomic criteria (Bastien & Scapin, 1992):

- **2. Workload**: the interface seems to achieve brevity and concision. The system only requires minimal actions from the users and the information density seems to be appropriate. This seems to increase the efficiency of the interface in building a dialogue with the user.

- **7. Significance of codes**: the elements on the screen appear clear in their meaning, with a good semantic relationship between the icons and the buttons presented and the corresponding actions.

- **8. Compatibility**: the users’ and tasks’ characteristics seem to be matched. This aspect needs to be confirmed with the end users, since the age of the researcher and that of the envisioned end-users is very different and might impact the perceptions a lot.

On the other hand, at the current stage the system shows quite severe problems on the following criteria:

- **1. Guidance**: users may have some troubles in understanding how to interact with the interface, which can be mostly traced back to an issue with prompting, because the system might not be inviting the users to perform the right actions. Besides this, if the users pronounce a word that the digital human does not understand, there is no feedback that the users should repeat what they said.

- **3. Explicit Control**: the issues are mostly related to user control, rather than explicit user action. In fact, it seems like the service does only respond to actions initiated by users. However, the users do not have the possibility to interrupt, pause and continue the interaction. This is something that definitely needs to be fixed.

- **4. Adaptability**: the main problem in this case is with user expertise. The interface does not well support the change of language, and this could exclude people that do not speak English. Besides this, it is important to check that the intended end users have the expertise necessary to
interact with the interface. On the other hand, the interface allows a fairly good level of flexibility through the accessibility options.

- **5. Error Management**: the current version of the system has severe issues on error management. The main problem is that whenever users take a decision within the available content, they can never go back and change their decision, unless they restart the whole flow. This means that both error protection and error correction are not well managed. There is one positive aspect, concerning the quality of error messages. Whenever an unavailable piece of content is chosen, the digital human explains that it is not available and offers to talk about something else.

- **6. Consistency**: the main issue is that the presentation of the two available sections is different. In one, the users do not need to take action for the digital human to proceed through the content. However, in another section the users need to click a “next” button or say “next” for the digital human to continue with the content. This might lead to confusion.

Overall, the service is clear and seems to convey information in an appropriate way. However, usability and accessibility concerns need to be addressed. Two main accessibility issues were identified both through the WCAG assessment and the cognitive walkthrough. These issues are concerned with explicit control and error management: it is not possible to stop the speech of the DH, it is not possible to navigate back to a previous node, and error messages are lacking in the current version of the service. These issues are particularly severe and need to be addressed as soon as possible. Furthermore, issues concerning the labelling of elements currently fail to ensure compatibility with screen readers, although keyboard navigation seems to work fine.

Many of the current issues are mostly due to the fact that the current version of the service is a prototype, which means that many of these issues are already planned to be solved in the next iteration of the development. Examples of these include captions for the DH’s speech, flexibility in the orientation (mobile or desktop). These and minor accessibility issues should be easy to fix and already planned for.

In general, the current version of the website does not reach compliance to the A level of accessibility. If the main issues described are addressed, the website should manage to reach the AA level of compliance. Apart from the labelling of the UI element and the presentation of the options, the service currently seems to be quite accessible for people living with low vision. Following the expert evaluation, some of the easily fixable issues were addressed by the development team, such as the placement of some elements and the response to the change of language. More severe issues required longer development times and therefore could not be addressed at this point.

### 4.4 User-based evaluation

This section presents the results of the user-based evaluation sessions. The results presented in this report come from the combination of the fourteen one-on-one calls evaluating the prototype with the potential users and the focus groups organized after that. The one-on-one calls panel featured ten Patient Advisory board members and four people recruited through usertesting.com. The four usertesting.com participants did not join the focus groups, but four more Patient Board members were involved in this phase. This means that a
total of fourteen participants were recruited for both the sessions. The focus
groups were organized in two rounds: six participants took part in the first focus
group and eight participants in the second.

No participants had tried the service prior to the one-on-one calls. This allowed
the opportunity to explore their initial reactions. The four participants that took
part in the previous round of exploratory research had been introduced to the
digital human concept and were able to provide feedback on how their
perceptions changed from their first impressions of the non-interactive media
to the actual interaction with the service.

The sessions produced around sixty items (individual observations and
comments), both negative and positive, which make up a good overview of the
perceptions of the participants panel.

4.4.1 Findings
4.4.1.1 Quality of the user experience
These insights cover the impressions of the participants regarding the service.
Attention was focused on the user experience, evaluated on:

- **Usability and guidance**: overall appreciation level of the functionalities
  of the service and its ability to instruct the users on how to navigate it.
- **Accessibility**: with a focus on low-vision participants.
- **Perception of trustworthiness**: people’s level of trust for the information
  coming from a digital agent. This aspect is particularly important given
  the nature of the information provided.
- **Emotional engagement**: people’s feeling of investment in the digital
  human’s speech, and their perception of emotional support.
- **Perception of realism**: people’s perception of realism of the interaction.

This is linked to the Uncanny Valley effect, which might hinder a positive
experience with the digital human.

4.4.1.2 Usability and guidance
None of the users felt utterly lost throughout the exploration: they were able to
navigate through the service at almost all times and they did not ask for support
from the researchers. Three participants had to ask once which option to choose.
It is important to note that the participants were given a clear scenario and that
the unavailable content was marked. Two participants reported that the current
guidance provided may not be sufficient for people who are not looking for a
specific condition. This means that someone who has not yet been diagnosed
and does not know much about the different eye conditions that are available
on the website might struggle with knowing where to navigate to. For this reason,
several participants encouraged having the option to start the exploration of the
website from the symptoms, which is not available at the moment.

The available options and the DH’s speech sometimes create dissonance. For
example, in the introduction sequence the DH presents the three conditions by
name (it says “at the moment, I am able to tell you about AMD, DME and RVO”),
but does not allow the users to select any of them and forces them to go through
an option named “eye conditions” first. This is highly confusing and makes the
users lose time listening to (currently) irrelevant information. This element was
specifically problematic for visually impaired participants, who cannot see the
button labels, and therefore suppose that they can choose one of the conditions.
Another issue that was remarked by three participants was that it is not easy to follow the DH’s presentation of options. In fact, the list of options available is sometimes very long. For example, in one part of the conversation the DH presents five options (More about AMD, AMD symptoms, AMD risk factors, AMD diagnosis, AMD treatment). The number of options presented, and their quite complex names make it hard to remember which one to choose and all the labels. It is therefore important to make the spoken text as short as possible when presenting options. Besides this, especially for visually impaired participants, but not only, it would be important to have the option to select by number or synchronously with the speech. This means that, when the options are presented, the DH should respond to commands such as “this one” or “the first option”. This would benefit greatly visually impaired users, but it would also make the interaction more natural for sighted users. It is also important to ensure that the DH can restate the options using a simple command.

Almost all participants agreed that the DH’s pace is right, not too fast, nor too slow. There was one screen reader user that reported that the pace was too slow for their taste, because the screen reader speed is usually increased exponentially in order to get the most information in the shortest amount of time possible. On the other hand, another participant (whose native language is different from English) said that the pace was a bit too fast for them. Both of these issues could be addressed through the accessibility option of the voice speed. In fact, all participants reported that they considered the voice playback speed option very important and relevant.

About 20% of the participants questioned whether the user group of people older than seventy years would be able to use the service, meaning whether they would be able to operate the website and to know how to interact with the DH. This user group could make up a big portion of the intended users, since many eye conditions onset in late life stages. More research would be needed to explore this topic, involving less educated and technically skilled participants.

4.4.1.3 Accessibility
Many of the accessibility issues that were found came from people who were using screen readers, or who struggled to see the screen in any other way. The first issue that was encountered was that the elements on the screen did not have appropriate labelling. In fact, the screen reader was often reading “Button number X”, instead of communicating meaningful information. It was the case for almost all of the content of the first page (the password one) and for the accessibility menu. This needs to be fixed as soon as possible.

Screen reader users were also the ones that struggled the most with the presentation of options, as discussed in the previous section. However, the combination of the DH’s speech and the screen reader listing the options and different buttons available on screen seemed to work fine. Screen reader users need the assistive technology and appreciate it, which means that it is definitely not advisable to disable them on the page or to force the users not to use them. One participant said: “I like my screen reader because I’m now used to the way it speaks. At the beginning I was sceptical about this service for this reason. But after trying it, I have to say I really enjoyed it and I would prefer it over the screen reader”. Despite this very positive feedback, there was no clear consensus across participants about the added value of the DH over screen readers. Some
participants said that they would most likely still prefer to get information from a plain text website using their screen reader because it might be more efficient.

One major accessibility problem that emerged was the lack of a possibility to pause the conversation. Some participants reported that they might want to take notes, or to talk to someone else, but at the current state they can’t do it because otherwise they would miss some content. Besides this, some participants reported that they would like to have the possibility to enable and disable the microphone recognition. This would allow them to talk to other people without worrying that the DH would pick up what they are saying. Together with this, they also noted that the feedback of the recognized words from their speech is good to have, but it needs to be bigger and able to host more than a couple of words at a time, otherwise it looks very distracting.

The fact that it was possible to interact with the DH in different ways (speech or selecting the options) was appreciated by the participants. Three participants reported that it is crucial to provide users with as many options as possible, to cater for different preferences and needs. The accessibility options were appreciated by the participants, who consider them appropriate and important. They mentioned that the speech speed option is good for people whose native language is not English, and that captions are essential to ensure that the service is accessible to all. It is interesting to note that no sighted participant, but one answered correctly (“accessibility options”) when asked what they would expect from the menu button for the accessibility menu (which shows the standard accessibility icon). This suggests that it is not an icon that people are used to, and it might be worth investigating which icon to substitute it with, to ensure that people know what to expect from it. Alternatively, displaying both the icon and text explaining it could be a good solution.

4.4.1.4 Content, trustworthiness, and reliability

In general, the digital human seemed to inspire the impressions and feelings that the team envisioned. Participants perceived the DH as trustworthy, knowledgeable, invested, and friendly. This was a positive result because it suggested that people are likely to build a positive relationship with the DH, and that they would trust it. In fact, the participants reported that they consider the information reliable and that they can trust it. This is extremely important in this context, since one of the goals of the service is to provide people with scientific information that they can use to inform themselves about the conditions that they might have been diagnosed with or develop.

Over 75% of the participants were highly educated in the field of eye conditions. For this reason, they reported that the level of depth of the content would not be very suitable for them, but that it would have been perfect for someone who is just starting to approach eye conditions for the first time. Nonetheless, almost all participants reported that they thought that the service should provide the possibility to go into more or less detail, in order to cater for users with different knowledge levels. For example, one thing that they said they wished was developed was the aspects of eye conditions that are not strictly medical, but that include daily life concerns and how to cope with the conditions.

4.4.1.5 Emotional support and engagement

About 70% of the participants reported that they found the conversation engaging. One participant said that, had there been more content, they “would
have liked to explore more”. This was not the only positive content in this sense, with another person saying that they were “kind of hooked into it”.

However, in terms of emotional support, the two focus groups gave very different and potentially contrasting results. On the one hand, the participants of one of the focus groups said that the DH can’t really provide emotional support, and that they would rather just receive factual information from it and leave the emotional component to the real humans. The participants in the other focus group seemed more open to the potential for emotional support that the DH might have.

During the one-on-one calls, one participant said that people would resonate the most with the symptoms, and with content that speaks to them, rather than with the DH itself. Besides this, another participant mentioned that it would be beneficial to have testimonials from other patients, but that this cannot be provided by the DH, which needs to “step aside” and leave space for videos of real people to convey this kind of information. The general trend seems to be that the DH can provide a generic form of emotional support, in a better way than plain text, but that the core of the emotional support work should be left to real humans. About 20% of the participants explicitly reported that the DH version of an informative service would be “less impersonal” than plain written text. Related to this, two participants specifically mentioned that they felt like the DH was “there for them”, and that this made them feel more secure and heard. Some participants mentioned that it looked like the DH was invested and interested in what they were saying and what they wanted to hear.

4.4.1.6 Perception of realism (Uncanny Valley effect)
All participants reported that they liked the voice, which sounds very pleasant and is easy to listen to. One participant said that they knew the voice already, as “it is a common artificial voice”. This suggests that as well it could be a neutral voice, that should not pose too many problems to people. Most participants (about 90%) considered the voice realistic enough to be both engaging and informative. Sighted participants reported that the DH looked realistic, up to the point that one participant said that the DH “made her feel like she was real”. One participant who took part in the exploratory research, and therefore had seen still pictures of the DH and a non-interactive video of it speaking before, said that they did not like it the last time, but that this time it was much better than they expected. One participant only reported that they were distracted by the lack of syncing of the speech and the lips movements.

Two participants said that they did not really like the DH experience, but there seemed to be no evidence of a strong uncanny valley effect among the participants. In fact, none of them mentioned feelings of eeriness given by the DH, which did instead happen during the exploratory research. If possible, improving even more the lip synching would improve the experience of sighted users. Besides this, some participants did not like some of the movements that the DH was performing, especially while waiting (such as looking at an imaginary watch), because they felt like they were not very respectful.

4.4.2 Further analysis
Generally speaking, the user testing sessions provided positive feedback. The results suggest that the concept of receiving ophthalmic information from a digital human is accepted by users and it can be a new supportive way of
guiding people throughout their journey to or after diagnosis. The prototype seemed to achieve the goals of engaging the users and providing them with factual information that they can trust and rely on.

Following are the recommendations that resulted from the user evaluation sessions. They were merged and analyzed based on both the frequency with which they were found and the importance and relevance that they had for the participants.

Usability and guidance:

- Allow the evaluation of symptoms, instead of choosing a specific condition.
- Do not present the names of the available conditions unless the digital human is able to navigate to the corresponding content. Hearing the names of the conditions makes users want to select one of the conditions, but the DH doesn’t allow that at the moment.
- Shorten the option presentation spoken parts as much as possible.
- Ensure that it is possible to select options synchronously with the speech (“this one!”) or by their cardinal number of appearance (“the first option”).
- Allow requesting a restatement of the options in an easy way (“can you tell me the options again?”), without needing to listen to the whole description again. Divide the text between the explanations and the options presentation, so that it is possible to listen just to the options.
- Investigate whether the service is usable for non-technical skilled and elderly users.

Accessibility:

- Give on-screen elements appropriate labelling, so that screen readers can programmatically determine what their functions are.
- Ensure that the combination of screen readers and DH works smoothly (for now, it looks fine), but try to minimize the need for speech output of the on-screen content.
- Add controls similar to a “media player” such as play, pause, stop, forward and back.
- Improve the feedback bar for the recognized words.
- Add a label to the accessibility option icon to make sure that users know what to expect.

Realism:

- Improve the lip synching
- Avoid accidental disrespectfulness in the DH’s movements

One of the main insights that emerged from the sessions is that this option of interacting with a character on screen might not be for everyone, meaning that not everyone will like it. However, participants agreed on saying that it is important to provide the highest number of options possible, and that some people might really benefit from this type of interaction. They also reported that using this different approach is what makes the service different from anything
else that is currently on the market, and that this would be beneficial for potential users.

During the discussion sparked by the focus groups, participants mentioned that they value integration. It would be great to have this service integrated to the ones that they know, and to create a repository of information that is complete and reliable. Another important point is that the information needs to be easily accessible for anyone that is looking for it. For this reason, it is important to reflect upon the distribution channels that this website would go through. The participants mentioned that word-of-mouth could be a precious ally to get people to know the service, but that ultimately a good channel would be healthcare professionals directing people to it.

The results of the user research are encouraging to keep investigating the potential of digital humans and speech interaction to provide information about ophthalmic conditions. However, more work needs to be done to provide a completely accessible service that any user would be comfortable to use. The main accomplishment of the service is that people seem to consider it a reliable source of information that they would trust and listen to. This is a great achievement that contributes to moving towards the goal of informing people and fostering prevention.
5 Discussion
This section provides answers to the research questions, an overview of the limitations of the work, an evaluation of the study and an explanation of possible future research. Finally, some conclusions are provided, to sum up the results of the work.

5.1 Answers to research questions
RQ1: Based on empirical research using human-centered design methods, can conversational user interfaces and digital humans make e-Health services more accessible for patients with vision defects, to provide them with the information they need and with emotional support? (case study)

The research conducted during this case study suggests that people tend to react positively to a digital human conveying information about eye conditions. DHs seem to have the potential to provide a more personalized explanation of conditions, which results in a deeper connection with the user. Users reported feeling “as if someone was there with them”. The concept was generally well accepted, despite the idea that this kind of interaction might not be for everyone.

People with high visual impairment generally appreciated being talked to rather than going through a static webpage. Caregivers also reported that it might have been beneficial for them to have this kind of service when their loved ones first started to experience symptoms. In this sense, it seems that a CUI embodied by a DH can provide a human touch, which people appreciate. Although not everyone might be utterly enthusiastic about this type of interaction, it is a good step towards accessibility and personalization of services to provide content in a different form than plain text.

CUIs can be effective in providing a better user experience and higher emotional engagement to people living with low vision. For people who live with a low-severity condition, it is good to avoid the fatigue that comes from reading content on a screen. People living with a high-severity condition find it pleasant to hear a human-like voice instead of the more robotic screen reader’s voice (albeit much faster and possibly more efficient). Furthermore, providing content that has been optimized for listening and not for reading is an advantage because written content follows a generally more complex structure than the spoken one.

Using conversational interaction to provide reliable medical healthcare information seems to be mostly helpful and relevant for people who do not have a clear understanding of which specific content they are looking for. Exploring a website this way seems to benefit people who do not have much knowledge about eye conditions, and who are not looking for a specific piece of information. Having all the content available for exploration, while being guided by a digital human can also foster the perception of supportiveness of the service. On the other hand, it requires careful design and testing of how navigation can be performed and supported.

In conclusion, conversational user interfaces using digital humans as agents of communication seem to have a great potential in providing users (especially low-vision users) with healthcare-related information. This information is perceived
as factual and trustworthy, and the additional support that a conversational agent can provide is appreciated and can contribute to providing a better user experience.

**RQ2: What guidelines can be suggested to foster the improvement of the accessibility and emotional support of e-Health services through conversational interaction?**

There are several things that need to be taken into consideration for such a service to be successful. First, the digital human’s appearance needs to be well thought and delivered. In order not to fall into Mori’s Uncanny Valley effect (1970), it is crucial not only to pay attention to the realism of the look (for example, hair, skin or mouth), but also to the movements. Technological advance has allowed creating very realistic models of the human figure, but they risk falling short of the movements’ realism. Not only in terms of fluidity, which is utterly important, but also of plausibility. One practical example from the case study is that at some point, when the DH was waiting on the user to make a choice, she would scratch her head or look at her watch. This is something that no real human would ever do because it can easily be perceived as rude or inappropriate.

As previously explained, the natural interaction that a CUI can provide is one of its greatest benefits. However, it is important to ensure that the content is optimized for such an interaction form. In fact, the way written and spoken content is organized is very different. For this reason, it is important to focus efforts on User Experience writing, to provide a conversational flow that feels natural to the listener, is easy to understand and provides all the necessary information. During the user research sessions of the case study, participants reported that they appreciated the simplicity and the logic of the conversation. If the information is already available to the design team in written format, it is necessary to go through a phase of re-writing to adapt it to being spoken out.

One factor that seems to play a major role in the perception of CUI is how options are presented and selected. In fact, figuring out how to present options in a written format is easier than presenting them only through speech, which requires additional work and an iterative validation process. Choosing among options entails a high cognitive load for the receiver, who needs to remember all the options and then go through the decision process. In spoken interaction, it is easy to lose track of the different options and to forget about them. For this reason, a successful CUI needs to present options in the simplest form, and the time needed to present them should be as short as possible. Besides this, it is necessary to allow hearing the options again, without needing to go through any other content. Finally, it is extremely important to provide flexibility in the way options can be chosen. The CUI should be trained to recognize synonyms, cardinal indications, partial answers, and answers synched to the speech. This allows for a much more natural interaction, and thus a better user experience.

To provide an accessible service that can cater to the needs of as many users as possible, it is important to provide a written version of the content as well as the spoken one. This can be beneficial to users who are living with hearing impairment, to users that do not appreciate CUIs, and to users who are in a hurry or who already know what content they want to look for (for example, they only want to know about the treatment options for Diabetic Macular Edema).
Providing a text-based version of the content would greatly enhance the user-friendliness of the website.

One area of concern that needs to be addressed is the navigation of the service, especially when a lot of content organized on different topics is added to the information structure. It is worth considering whether it would be beneficial to have a menu, using standard navigation within the CUI. Otherwise, navigation possibilities should be provided in another form, for example by requesting the DH to navigate to a different section. The ability to go backwards and skip forwards in the speech of the DH is fundamental to provide a positive user experience, because it allows flexibility. Speech commands should be intuitive and easy to trigger.

The user research sessions showed that users who rely on screen readers do not want this technology to be taken away while they interact with the CUI. For this reason, compatibility among the CUI and assistive technologies should be the goal, instead of complete substitution. However, the need for assistive technologies should be reduced as much as possible, by providing self-explanatory ways to navigate and interact with the interface. The digital human’s speech and the screen reader output should not be antagonizing one another but working synergically to provide the best user experience possible. This requires testing with users who regularly utilize screen readers to navigate digital services.

The main guidelines that emerged from this Master Thesis work, summarized and categorized are shown in Table 12.

<table>
<thead>
<tr>
<th>Code</th>
<th>Guideline</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>G1</td>
<td>Ensure that the digital human is as realistic as possible, not only in its looks, but also in its movements.</td>
<td>Realism</td>
</tr>
<tr>
<td>G2</td>
<td>Create a conversation flow that is clear and easy to follow. Do not use long sentences and reduce the language complexity as much as possible. Focus on UX writing.</td>
<td>Cognitive load</td>
</tr>
<tr>
<td>G3</td>
<td>When presenting options, do it in the simplest and most rapid way possible, and allow users to listen to the options as many times as they want. Allow flexibility on how the options can be chosen.</td>
<td>Flexibility</td>
</tr>
<tr>
<td>G4</td>
<td>Ensure that a text version of the content is also available.</td>
<td>Flexibility</td>
</tr>
<tr>
<td>G5</td>
<td>Ensure that navigation is easy and as self-explanatory as possible.</td>
<td>Navigation</td>
</tr>
<tr>
<td>G6</td>
<td>Ensure compatibility with assistive technologies and provide flexibility, personalization and integration.</td>
<td>Compatibility</td>
</tr>
</tbody>
</table>

*Table 12 Guidelines resulting from the research*
5.2 Limitations of the work

The thesis work has some limitations that need to be acknowledged, and that can inform the planning of future research. This section will provide an overview of the limitations of all the phases of the research. In summary, the main methodological limitations are:

- The small number of participants in the user-based sessions;
- Their rather homogeneous demographics and background;
- The little availability of testable content, which impacts the ability to test how people would navigate the content and whether the information architecture could support meaningful exploration;
- The inability to run complete and thorough tests with a consistent group of primary users with lower technological skills, lower or no knowledge about eye conditions and starting to experience vision loss.

5.2.1 Personas

Cooper (2007) explains that, in order to be representative and informative, personas require extensive user research and a huge quantity of data to back them up. Personas require ethnographic and in-depth research, which results in a large amount of background information, that provides detailed information about the background, goals and needs of potential users, and can then be aggregated into meaningful persona. The project discussed in this thesis did not allow to conduct such extensive ethnographic research that would provide statistical data to be leveraged to create perfectly representative personas. However, personas have several advantages, the main one being the easier communication that it allows between design and development team. Personas are a great way to model the users, to encourage all team members to think about them and possibly to re-use them over different stages of the work, and to make consistent choices.

Cooper (2007) explains that when rigorous user personas, meaning personas that are backed up by a big amount of data, are not possible, provisional personas can be built. This is exactly what the personas described in this thesis are: following Cooper, provisional personas are “useful rhetorical tools to clearly communicate assumptions about who the important users are and what they need, and to enforce rigorous thinking about serving specific user needs”. The data that allowed building these three personas came from Roche’s knowledge about ophthalmology services users, and from related literature. Cooper explains that it is usually more beneficial to have roughly drafted personas, than no user model at all.

In conclusion, these user personas are strongly limited by the lack of in-depth ethnographic research, which results in them not being accurate enough to be truly representative of the potential end-users. However, they are a great tool to facilitate conversations within the team, and to provide a shared point of view to look at both development and design.

5.2.2 Exploratory research

The main limitation of the exploratory research was the characteristics of the users panel. First of all, ten participants is a quite small number for a research session. Although user experience research is strongly qualitative in nature, having such a small sample of people means that it would be very hard to generalize the results to other services using a digital human. This number of
participants would be more suitable for an evaluation session, while for exploratory research it would have been advisable to have a larger number of participants. Furthermore, the study would have benefitted from having more participants for each category of end-users, meaning recruiting a more balanced number of caregivers and of patients.

Another limitation to this study is that the pool of recruited participants was probably not completely representative of the real end users’ population. In fact, the participants were generally quite young, and eye conditions most often appear in an elder population. Five participants (50%) were exactly part of the envisioned target audience, despite being younger than 50 years. However, the other participants would probably not be a direct potential user of the service. This imperfection in the recruitment of participants was largely due to the difficulty in targeting such a specific audience on the usertesting.com platform. Despite using a screener, filtering the pool of users was very hard. Besides this, the platform also feeds on the bias towards a younger population, since it requires some digital and technological skills that older people might not have, and it might not be so easy to discover.

Both the number of involved participants and their age result in the inability to generalize the results as much as it would be advisable to. The results were helpful to guide the further design of the service and the experience, but they might not be very informative on a general level.

5.2.3 Expert evaluation

In general, the main limitation of expert evaluation is that it can only provide the point of view of the evaluator, who can be biased or accentuate problems that users might not find relevant. Therefore, expert evaluation needs to be paired with user evaluation as well. Specifically for this case, and in particular for the cognitive walkthrough, the main limitation was the lack of confrontation with another evaluator. The method would require at least two people merging their results and discussing them to come to conclusions. In this case, it was not possible to do so, which means that the conclusions are only based on the author’s evaluation. This limits the depth of the conclusions because some aspects might have been missed, and some might have been given too much weight.

The main limitation of the accessibility evaluation is that it was conducted in a non-rigorous way, meaning that it did not consider success criteria by success criteria, but only guidelines. Success criteria were taken into consideration to guide the assessment, but not followed in detail. The granularity of the assessment is therefore lower than it should be when performing a WCAG evaluation. One strategy to mitigate this effect was the combination of the manual check and the automatic check. This allowed cross-checking the interpretation of the accessibility issue and ensuring that aspects were not overlooked. However, a large part of WCAG cannot be evaluated automatically, which calls for the need of a manual check as well. Another limitation of the accessibility evaluation lies in the nature of the interaction. In fact, WCAG 2.1 is mostly concerned with text-based websites, and therefore some guidelines are hard to interpret for a website that mostly uses speech-interaction.
5.2.4 User-based evaluation

The main limitation to this user research session is the composition of the panel. Even though the number of participants was higher than in the exploratory research and that it was more representative in terms of people living with low vision, the targeting was not flawless. In fact, it would have been beneficial to interview a less homogeneous group of participants, and to hear more opinions from people who are starting to develop an eye condition, rather than people who are living with a severe one. Nonetheless, as previously mentioned, the participants that came from the Patient Advisory board are used to taking the perspective of people who are in a different stage of their health journey than them. This made them valuable contributors not only for their own personal opinions, but also for their knowledge of others and their ability to empathise with them.

It would have probably been more informative to build a panel with the same number of people in each of the three user groups considered:

- People starting to experience changes in their vision, or people who just recently learned about eye conditions. This user group would be helpful in understanding how people might genuinely react to the concept and to the way information is provided when they are not knowledgeable about eye conditions. This is the primary user group for the service, and therefore it should be more represented in an evaluation research session.
- People caring for others who are living with eye conditions, and possibly who have been doing so for a relatively short amount of time. This is the other main group of target users. It was possible to interview a few of them, which was very helpful, but it would be better to have access to a higher number of such people, to make sure that their needs are heard and addressed.
- People who are living with severe eye conditions. This was the most numerous group in this research, albeit not being the main target group for the service. These people were on average quite knowledgeable about eye conditions, which would most likely not be the case for real users. However, it was incredibly helpful to hear their comments and to observe how they experienced the website while using a screen reader. This category of users is most helpful to understand accessibility and to ensure that the service is inclusive. For this reason, including them in the research is beneficial, but it might be worth it to balance out the number.

Creating a more balanced and less polarized user panel would have ensured that all points of view would be equally represented. It would also have been beneficial to organize the discussion groups by having an equal representation of the different user groups. This might have sparked interesting conversations and discussions, which would possibly allow understanding whether there are opinion trends among the user groups.

Another limitation of this user research session was the scarce level of depth of the content to be tested. It was not possible to allow users to freely explore the service, and this hindered the ability to gauge how users would approach navigation and whether the service would be able to support their exploration.
In this case, users had to be guided almost step by step through a scenario, and therefore they were very limited in their exploration. It would have also been interesting to understand what type of content they are most interested in by allowing them to choose whatever they preferred. This would be worth doing in a later stage of the development process, to ensure that the content is actually suitable for the users and provides value for them.

Adding on to the last point, it was not possible to test the ability of the CUI to respond to spontaneous prompts from the participants. Two participants to the evaluation sessions specifically mentioned that one main characteristic that would lead them to use or not the service is the digital human’s ability to answer to questions that they would pose. This might be one of the missing elements to create a great user experience with CUIs. Due to the limited time available, it was not possible to either develop the full content nor all the functionalities that were envisioned. This is a limitation from one side, but it is also encouraging from another point of view. In fact, participants reacted positively to a service that was only in the first prototyping phases, and this speaks to the potential of this kind of solution.

5.3 Evaluation of the study
A qualitative study like the one performed in this thesis work relies on a small amount of in-depth data coming from individuals rather than a big sample of quantitative data. Qualitative research is harder to evaluate than quantitative research, where statistical analysis can be leveraged, and clear criteria can be used to gauge the relevance and value of the results. However, it is important to try and assess the quality of the work presented in this thesis. In order to do so, the criteria defined by Cohen and Crabtree were employed (2008).

Cohen and Crabtree carried out extensive research, which led to the definition of seven evaluative criteria that can be used to evaluate qualitative research, especially in the domain of healthcare (2008). The following paragraph aims at evaluating the presented work against these criteria.

- **Carrying out ethical research**: the user research was carried out following ethical criteria, informing the participants about the nature of the research, providing them with all the information that they needed and allowing them to drop out of the study if they would ever wish to do so. Furthermore, effort was put to ensure that people living with low vision felt respected during the whole duration of the studies, and that every participant felt at ease and comfortable with the questions that were posed.

- **Importance of the research**: this research was specifically important for Roche to understand how to provide an enhanced user experience to patients visiting their informational websites. Besides this, the research adds insights to a field (that of CUIs for healthcare) that is yet to be fully understood and developed. Common guidelines on how to design services featuring a digital human are scarce, and the results of this thesis work can provide a valid addition.

- **Clarity and coherence of the research report**: the research report is organized in a way that provides all the methodological and theoretical background that the reader needs to understand the results of the research. Furthermore, the research design approach is explained in
detail, so that the reader can understand what steps were taken to get to said results.

- **Use of appropriate and rigorous methods**: the methods were chosen according to the research goals, and the rationale behind every choice is explained in the report. The methodologies employed are common in qualitative research and were applied by following clear planning and structure.

- **Importance of reflexivity or attending to researcher bias**: the researcher bias was mitigated by two factors. The first one was that the author had no previous experience with the evaluation of digital humans, and therefore had no expectations towards the way people would react to it. The other factor was the possibility to discuss with another UX expert about the research and findings. This helped recognizing potential bias and trying to stir away from it.

- **Importance of establishing validity or credibility**: Cohen and Crabtree explain that, in qualitative research, important aspects to ensure validity are plausibility and accuracy, and accounting for the complexity of the studies phenomenon. In this work, several research sessions were set up to ensure that as many voices were heard as possible, with the available time and human resources. This speaks towards the accuracy of the results. The results provide a plausible explanation of how people might perceive CUIs and digital humans, since the insights came directly from participants. However, the study does not deny that perceptions are very complex and variable, which is why further research is needed.

- **Importance of verification or reliability**: reliability requires that the studies conducted are optimized for error reduction. In qualitative research it is not such a straightforward endeavor as in quantitative research. One aspect of the research conducted that improved the reliability of the study was the combination of one-on-one interviews to hear the individuals’ viewpoints and focus groups to bring the participants back together. This allowed ensuring that the general trends observed in the interviews were relevant and remained consistent when people were asked to reflect again on their experience.

Generalizability is one aspect where the study conducted in the scope of this Master Thesis may fall short of, and it stems from its strong focalization on the case study. In fact, it would be risky to generalize the results to all kinds of conversational user interfaces adopting a digital human as an agent. Even in the healthcare field, it is not possible to be sure that all domains would be equally acceptant and positive about the concept. Generalizing the results might therefore be too bold of a step at this point. Further research needs to be conducted to provide results that can be generalized and thus inform the design of other systems that provide healthcare information. However, the work achieved showing that there is potential for this kind of solution: providing new and diverse channels for healthcare-related knowledge might build a more inclusive environment, and foster prevention among all age groups.

### 5.4 Future research

Future research should be conducted to ensure that the concept of receiving healthcare-related information is well accepted by people who are not very skilled with digital services. In fact, conversational user interfaces might have
the potential to make websites more accessible for people who generally struggle with technology and the Internet, but this needs to be checked systematically, to provide a generalizable result. Besides this, conducting more quantitative research might be valuable to ensure that the appreciation of the interaction with digital humans can be proved through statistical evidence as well.

Testing whether different cultural backgrounds or different age groups show different opinions about the experience could also provide valuable insights. This naturally requires some sort of unmoderated user research, or a very high number of resources. This information would be valuable to understand which users it is beneficial to target. Such results could show that it is worth adopting CUIs in one sector of healthcare (for example, allergology), but not in another (for example, rheumatology). In this sense, it might be worth conducting a more explorative and ethnography-oriented research, to understand the general perceptions of people towards healthcare-related information first, and then focus in on the channels that it can be provided through, and specifically CUIs. In this thesis work, it was not possible to do so due to time and resources constraints.

Future research is also needed to gauge the limits of the potential of CUIs and digital humans. In fact, one participant to the one-on-one interviews argued that the digital human could never effectively share testimonials of other people living with a healthcare condition, because it would not feel right, and it would not lead the people to empathize with it. It is important to clearly determine the kind of content that the DH can effectively provide and the one that is best left to interaction with real people or to more non-interactive means such as recordings. Having a clear overview of the areas where the digital human cannot provide a strongly positive user and patient experience is important for the development of similar services.

One more area where further research is needed is navigation and guidance. The thesis work could not gauge whether people would feel at ease in navigating a service with a lot of content and many different options to choose from. Understanding how to provide the needed guidance through a conversational interaction without making it heavy and boring to listen to is a challenge that will need to be addressed. Chances are that, if the content was organized logically, there would be no troubles in navigating the service. However, this needs to be thoroughly tested, because struggling to understand how to use the service or how to navigate through the content might cause dropouts for many users.

In general, more research is needed to be able to confidently affirm that CUIs using a digital human as a conversational agent are a good tool to provide healthcare-related information. Nonetheless, the preliminary results that have been presented in this thesis work are encouraging and show the potential of such solutions.
6 Conclusions

This Master Thesis work focused on the case study suggested by Roche of re-imagining an ophthalmology patient’s website to leverage a conversational user interface approach. The work aimed at evaluating whether using a digital human as a conversational agent would provide a better user experience and higher emotional support to users looking for information about eye conditions. The case study allowed for a broader discussion about the potential that digital humans have in offering healthcare-related information. One main goal was understanding whether people would consider the information coming from such an agent to be trustworthy and reliable.

The Thesis answered the two research questions by showing that conversational user interfaces and digital humans have the potential to positively impact the user experience of informational websites providing healthcare-related information. From the empirical research it was possible to collect some general guidelines to inform the design of similar services. These guidelines give some directions for designers and developers but will need to be complemented with other guidelines emerging from further research.

As previously explained, more research is needed to ensure the generalizability of the results, but the current outlook is positive and speaks to the potential of CUIs in the healthcare domain. In fact, despite the limitations discussed before, the results of the research conducted with the users showed that the current level of technological ability to reproduce a human generally manages to provide a positive experience for users interacting with the agent. Besides this, people find the information trustworthy and reliable, which is crucial when conveying healthcare-related information.
7 References


Literature. *Journal of medical Internet research*, 20(5), e10235. https://doi.org/10.2196/10235


8 Acknowledgements

This Master’s thesis concludes the two years I spent in the EIT Digital program. It is absolutely crazy to realize how fast time flies by. These two years have not always been easy, but they allowed me to meet some amazing people and to fall in love with the two countries that hosted me: Finland and Spain. I will cherish forever my time in Helsinki and Madrid. Since it is to close this chapter of my life, I want to take time and space to thank the people that have accompanied me on this journey.

I want to thank Loïc and Johanna for their support during the writing process of this thesis: it is always amazing to work with such helpful professors. I also want to thank Hanna and all of the Roche team for making this possible. A special thanks goes to Damien, who has made work much more enjoyable with his knowledge and his kindness.

I want to thank all of the friends that I have made during this journey. I cannot name you all, but thanks for sharing moments with me and making this Master’s a really fun experience. I want to give a special mention to Nacho, Luca, Nathan, Ana, Simone and Alex, as representatives of the amazing people that I had the joy of meeting.

I also want to thank Ana, Ruben, Jups and Mariika for making moving to a new country a little less scary. Gracias and kiitos.

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Grazie Jacopo, per tutto l’amore che c’è stato, c’è e ci sarà. Sarà un’avventura incredibile la nostra.

Grazie alla mia famiglia, a mio fratello Luca, a mia nonna Maria, e soprattutto ai miei genitori, Andrea e Lucia, che mi hanno aiutata più di chiunque altro a superare i momenti difficili di questo percorso. Poter sempre contare sul vostro appoggio è il regalo più inestimabile che ci sia.
9 Annexes
This section gathers all of the materials that could not fit in the main body of the thesis. This includes a visual version of the user personas and complete notes from the user research sessions (both exploratory and evaluative). The reports of the user interviews are not full transcripts, because only the most important information was annotated, leaving out conversational elements that had no value for the research scope.

9.1 Annex A: User personas
These versions of the user personas were created to facilitate discussions and to have a visual representation to be shown during meetings. They are less dense in details, but they serve the purpose of getting a quick and visual overview of the personas.

Figure 17 Persona 1

Kalle Kaipio
Age: 69
Education: Bachelor’s
Profession: teacher (retired)

Background
Kalle is a father of two and a grandfather of one. He lives alone in Tampere, while both of his children moved to Helsinki. Kalle’s favourite activities include gardening and watching movies. He is quite skilled at using technology and is not scared of it.

Devices:
iPhone 6 and Windows PC

Digital services:

Goal:
Kalle wants to find out what his symptoms can mean. He is also looking for reassurance that it is nothing severe that he would need to worry too much about.

Symptoms:
- Blurry central vision
- Dull colours

Questions:
- What do my symptoms mean?
- Should I see a doctor?
- Is it something temporary or am I developing a disease?
- Should I be worried that I might lose my vision?
Karoliina Kevara

Age: 77  
Education: Diploma  
Profession: saleswoman (retired)

Background
Karoliina is a mother of 3 and a grandmother of 4. She lives with her husband. She enjoys cooking and DIY activities. She was diagnosed with type 2 diabetes over 15 years ago. She has regular checkups every 3 years and was now diagnosed with DME. She was prescribed injections but the doctor did not have time to discuss her concerns with her.

Devices:
Android phone and tablet

Digital services:

Goal:
Karoliina wants to understand more about the injections, the pain, the effectiveness and the consequences. She is looking for reassurance and more information.

Symptoms:  
- Blurry vision  
- Floating dark spots in the visual field

Questions:  
- Will the injections hurt?  
- What consequences there be?  
- Are there things she cannot do?  
- Are the injections effective?  
- Should she see a doctor?

Figure 18 Persona 2
9.2 Annex B: Exploratory research interview script
Following here, the script that was followed to perform the exploratory research with participants recruited through usertesting.com. It comprises all of the questions that were asked and the activities that were proposed to the participants.

9.2.1 Introduction
Hi, and welcome. We are currently collecting the experiences and opinions of people living with eye conditions. This will help us to craft better solutions for people living with low vision. We want to thank you again for collaborating with us: you are helping us greatly.

What we are going to do today is have a chat about your personal experiences and needs when you began to experience a decrease in vision. This will help us in knowing how we can support people living with low vision through a digital service. Remember that there are no right or wrong answers, and that you are the expert in this field. If at any point, you will feel uncomfortable or you will not wish to answer a question, just let us know.
As you know, this session will be recorded, just for us to be able to listen to what you said again and to be able to get the most insights that we can. These recordings will not be shared with anybody outside of the team and your data will be anonymized when presented, meaning that it will not be retraceable back to you. Do you have any questions before we start?

9.2.2 Profile, needs and expectations exploration

**Person living with low vision:** The screener questions that you answered informed us that you have been diagnosed with [].

**Caregiver:** The screener questions that you answered informed us that you are caring for a person who has been diagnosed with [].

**Person living with low vision & caregiver:**

- Do you remember how you first experienced that something in the vision was changing?
- Could you explain to me how much you knew about eye conditions then?

**Person living with low vision:**

- Could you tell me what are the aspects of your life that have changed the most since coping with eye conditions?
  - Is there anyone that is helping you? Is this person helping you find information?
- When you started to feel like something was changing in your vision, did you look for further information? Do you remember how you approached this?
  - Did you connect to other people living with low vision to get more information or would you have liked to do that? Why?
- And after this initial research, do you remember what was the most important information that you looked for, or that you received?
- Were you able to understand the information that you were provided regarding your health condition?

**Caregiver:**

- Could you tell me what are the aspects of your life and your cared person’s life that changed the most since they are coping with eye conditions?
- When the person you care for started to feel like something was changing in their vision, did you help them look for further information? Do you remember how you approached this?
  - Did you connect to other people living with low vision to get more information or would you have liked to do that? Why?
- And after this initial research, do you remember what was the most important information that you looked for, or that you received?
- Were you able to understand the information that you were provided regarding their health condition?

**Person living with low vision and caregiver:**

- Do you use any form of voice assistants solutions? (Alexa, Google home, or screen readers?)
o What are the things that you appreciate the most about this kind of solution?
o What are the things that you dislike the most about this kind of solution?

9.2.3 UI personality and environment exploration

Thank you very much for sharing all this experience with me. This information is going to help us because we are creating a new service that would provide all the needed information about eye conditions.

So, let’s imagine that you would not interact with a website or a web application, but that you would meet someone that could give you information about eye conditions, and advice to cope with it for your daily activities.

[Figure 20 Activity 1 and 2 of the exploratory research on Miro]

(Activity 01) I’m going to present you with several pictures. Just pick the one picture that you prefer, to represent that person you would feel comfortable discussing with about

- **Person living with low vision**: your eye conditions and your daily life.
- **Caregiver**: the eye condition of the person you care for and their and your daily life.

If none of these pictures make sense to you, you can just imagine someone else.

Alright, could you explain to me why you chose that particular picture? And would you have any second choice?
Activity 02: Now, I’m going to present three different words: friendly, trustworthy and knowledgeable. For each of these words, select the one picture that best matches this word. Remember that it is possible to select the same picture several times. Could you explain to me why you made that choice?

Activity 03: Now, let’s imagine that you are having this conversation about eye conditions with [the favorite character]. Here are some photos of the environment where this is happening [in the case of someone with severe vision impairment, the researchers will describe the pictures in detail]. Which one of these would you feel the most comfortable finding yourself in for this conversation? Could you explain to me why you made that choice?

![Activity 03 - Where would you like to chat?](image)

**Figure 21 Activity 3 of the exploratory research on Miro**

### 9.2.4 Digital human assessment & Uncanny valley effect assessment
Thank you very much! In fact, we are planning to create a digital doctor appointment experience. This will involve a digital human, whose name is Anne, and who will be able to answer the questions of people living with low vision about eye conditions.
[Activity 4.01] I will now show you some still pictures of Anne. What are your first impressions?

[Activity 4.02] Now, I’m going to show you a short video on how Anne would behave. The link to the video is the following:

https://drive.google.com/file/d/1P-iPrlJeyDTcxzeK0wX_X_HcFMoOZjSE/view?usp=sharing.

- Could you tell me what you thought of this video?
- How did you feel about Anne?
- Do you think you would feel confident about the information that Anne provides?
- Did you expect Anne to behave differently?

9.2.5 Content assessment
Thank you so much! So, of course, this character would have to provide some relevant information for you...
Figure 23 Activity 5.1 of the exploratory research on Miro

[Activity 5.01] Among these different information, what are the three ones that you would like to know more about:

- Reason for the onset of the condition
- Symptoms of a condition
- Possible future evolution of the condition
- Possible treatment solutions
- Potential side effects of a treatment
- Testing my vision
- Tips and advice to help with daily activities
- Conversations with a doctor
- Conversation with other peers

[Activity 5.02] And which presentation mode would you prefer?

- To get some information about some condition or a treatment?
  - Watching a video
  - Reading a written document, sometimes with images
  - Listening for explanations
- And to discuss with a doctor or some other peers?
  - Calling with video
  - Calling with audio only
  - Texting through a chat
Writing messages (not in real time)
9.2.6 Wrapping Up
This concludes our interview session! I want to thank you so much once again for your help. Your insights are extremely valuable for us to be able to create something meaningful for people living with low vision. Thank you so much again, we really appreciated your help.

9.3 Annex C: Exploratory research transcripts
This section presents the notes resulting from the exploratory research sessions with the usertesting.com panel. All of the results are anonymised. The notes for one participant are missing because they were taken on paper, and after aggregating the results, these papers were lost.

9.3.1 Participant 01
9.3.1.1 Part 1 - General information

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<tr>
<td>Age</td>
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</tr>
<tr>
<td>Diseases</td>
<td>Patient has AMD</td>
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</tbody>
</table>
9.3.1.2 Part 2 - Profile, needs and expectations exploration
Their father has AMD and a brain tumor, which is the second time he gets. He can't see much or almost nothing. The first sign that he was losing his vision was that he couldn’t see objects. Their father can’t go anywhere and do anything anymore.

None of them knew much about eye conditions. They mostly relied on doctors and didn’t look too much on the Internet.

They didn’t connect to anyone, the only forum they can think of is Quora.

The doctor explained everything and they were able to understand, even though the first time their father went through chemo and treatment not everything was clear.

They use Google Assistant and find it user friendly. Their father doesn’t use any.

9.3.1.3 Part 3 - UI personality and environment exploration
**First choice:** Image 2 - Older smiling female doctor

This character looks like a doctor, which they liked. They think that they can get information from her. They find her reliable and comfortable to talk to.

**Second choice:** Image 3 - Young smiling female nurse

They like that she is a doctor. They like the smile and the professional look.

Environment choice: Image 1 - Luxury office

It looks like a nice place where they would feel comfortable.

9.3.1.4 Part 4 - Uncanny valley effect assessment
Anne looks like a doctor or nurse. She looks friendly but also knowledgeable.

They liked the video. She would have preferred if the hands moved more and if she made more eye contact.

9.3.1.5 Part 5 - Content assessment
They would like to hear about causes because they want to understand why the disease can start. Then they would like to hear about symptoms because they help identify the disease. Finally, they would like to be able to have a conversation with a doctor, because they know about the diseases and they are more reliable than anything else.

Watching a video is more impactful and understandable. Video calls have more interaction. Can do more things and can do everything else that is listed.

9.3.2 Participant 02

9.3.2.1 Part 1 - General information

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<tr>
<td>Diseases</td>
<td>Diabetic Retinopathy</td>
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</tbody>
</table>

9.3.2.2 Part 2 - Profile, needs and expectations exploration

They have known they have diabetes for 11 years. Started experiencing vision symptoms 2 years ago. One morning they woke up with swollen eyes and
blurred vision. They thought at first that it was just something that could go away by washing their face. When they experienced these symptoms, they had almost no knowledge about DR, they had been given a quick briefing by their doctor when they got the diabetes diagnosis, but the doctor made it sound very remote, they did not think it would come that early. They scheduled an eye appointment the same day but could only get it for 3 or 4 days later. These days were very scary because they experienced the symptoms constantly. They stopped driving, started wearing glasses to protect their eyes, made serious diet and medication changes, cut down on the number of hours spent using devices, bought an additional screen shield to reduce brightness of the screen, and changed glasses.

When they experienced the symptoms, they did some research on their own, but he didn’t want to find conflicting information with what the doctor was going to tell them. They watched videos, read articles and medical blogs, and visited forums where people shared tips and experience. In terms of connection to the community, they responded to messages and asked questions on the forums but never exchanged contacts. The most important information that they found while looking was something that they already knew, but that needed to be stressed again, which is controlling their sugar levels. It was obvious that it was important, but they needed to hear that again. They needed the tips on what to do, how to test the blood sugar levels and how often, what exercises to do, how to manage stress. While they were looking for information, some words were complicated, but they just did some research to understand them and that was enough. They were able to understand the information found.

They had an Echo device but gave it away. They don’t use any assistants because they think they are still functional enough. They understand that they might be helpful though.

9.3.2.3 Part 3 - UI personality and environment exploration

First choice: Image 2 - Older smiling female doctor

She looks reassuring, which was the main reason for choosing her. She also looks knowledgeable (mentions the stethoscope), and this makes her trustworthy.

Second choice: Image 1 - Young male researcher

He looks very knowledgeable. They would have chosen this one if it wasn’t for the smile of the other, which made them feel good.

Environment choice: Image 6 - Modern minimalist white office/clinic studio

It looks tidy and nice and minimalistic. They really liked that and made them feel very comfortable.

9.3.2.4 Part 4 - Uncanny valley effect assessment

She looks like a typical nurse. She looks professional. Her face doesn’t look friendly, but she does look knowledgeable. She is not here to be your friend, but she is definitely there to help. They stress that she doesn’t look friendly.

The graphics are good, even if she still looks a bit robotic in her movements. They like her approach, and find her voice very clear. They say this is important because they would be relying on voice clarity a lot in this case.
9.3.2.5 Part 5 - Content assessment
They know about symptoms, so they are not too interested in that. They are more interested in knowing whether there are other causes that can cause the condition. The thing they are most interested in is the tips. They say that you can never run out of tips that can help you in your daily life. They added that they would like to know about trial programs or experimental treatments that might be available. They looked for this information when they were starting to experience the symptoms.

In terms of communication, they prefer video and then reading articles to find information about the conditions.

For connection to the community, they would choose a real time text chat and for communicating with a doctor they would choose audio calls.

9.3.3 Participant 03
9.3.3.1 Part 1 - General information

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<td>Diseases</td>
<td>RVO</td>
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9.3.3.2 Part 2 - Profile, needs and expectations exploration
They started to realize that something was wrong because they weren’t able to see the blackboard in school. They experienced a drastic change in vision, which was shocking. They were already a bit familiar with eye diseases. They had a problem with their retina, which required surgery. It was difficult for them to understand, they were very young. The change in their vision resulted in the others treating them differently. They were mocked. They tried to familiarize with the disease and got involved in different activities.

They searched a lot about the disease and the surgery, mostly through articles and blog posts. They were interested in the experience of others. However, they did not connect to anyone.

Knowing about the surgery was helpful. 90% of the information that they found was clearly presented and understandable.

They sometimes use Google Assistant on the phone.

9.3.3.3 Part 3 - UI personality and environment exploration
Most important thing is the expression and the clarity.

**First choice:** Image 3 - Young smiling female nurse

A smiling doctor brings relaxation, this is nice to see. She is comfortable to talk to and she is confident, she brings a sense of familiarity and makes it easy to talk to her. The character should be professional and peaceful, and this one is.

**Second choice:** Image 2 - Older smiling female doctor

It conveys relaxation. She is calm and composed, and looks like she doesn’t get worried too much, which is good. She looks more confident and knowledgeable.
**Environment choice**: Image 3 - Hospital hall & Image 4 - Nordic minimalist living room

Image 2 looks like a hospital, which gives them relaxation. They do not mind hospitals, because they find them comforting. They would choose image 6 for people who don’t like hospitals, and who want to feel more like they are talking to a friend scenario.

**9.3.3.4 Part 4 - Uncanny valley effect assessment**
The last picture is not very welcoming. In the others, it looks like she is having a good experience and that you could rely on her and trust the knowledge she gives. They liked the nodding because it makes you understand that she is listening.

**9.3.3.5 Part 5 - Content assessment**
Conversation with people in the same situation is helpful.

**9.3.4 Participant 04**

**9.3.4.1 Part 1 - General information**

<table>
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<th>Status</th>
<th>Caregiver</th>
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<tbody>
<tr>
<td>Age</td>
<td>33</td>
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<tr>
<td>Diseases</td>
<td>Patient has Diabetic Macular Edema</td>
</tr>
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</table>

**9.3.4.2 Part 2 - Profile, needs and expectations exploration**
Their mother is 64 years old and she was diagnosed last year with DME. They mostly help with doctor appointments. She doesn’t like going to the doctor. She also first hid the first signs that she saw from the family, he says that she was in denial. They went to see a doctor, who sent them to ophthalmology. At first, they noticed that she started to not see objects even though they were obvious, but now escaped her vision. Or sometimes she would complain that the room was dark or that the weather was cloudy when in fact it was sunny. The tipping point was when she was driving and she couldn’t read the road signs, she used to see them perfectly. The loss of vision was a process, but the way it turned very serious was relatively sudden, and the denial made it worse for the caregiver.

They knew very little about eye disease, they didn’t know anyone else who had these kinds of conditions. They didn’t even know what DME was. Their mum also knew very little. She knew she was diabetic; she could take care of it herself and she was doing the same things as usual.

She gets eye shots regularly. They don’t allow her to drive anymore and drive her around. Apart from this, not much changed. They spend more time together mostly because of the driving, and she stays more at home.

They did try to look for information, they looked for signs of vision loss and what it could mean. There’s lots of information available and it’s not like they can diagnose anyone. So, they found some possibilities of what it could be and they showed it to her. They decided to rely on professional opinion because they were getting worried. When they were looking for information, they did see that it could be connected to diabetes. They felt a little overwhelmed: they could
understand the information but it’s not easy to come to a conclusion based on it because it is hard to understand whether it applies.

She did not connect to other people. She is independent and doesn’t like to share weakness. She has her own way of doing and coping with things.

They don’t use these services because they are a bit backward with technology. He feels like it sounds weird to ask questions to a machine. Computers should not talk back. He sees that this kind of interaction has possibilities, but he has reservations towards it.

9.3.4.3 Part 3 - UI personality and environment exploration
First choice: Image 2 - Older smiling female doctor
She has experience. She is smiling. Motherly figure.
Second choice: Image 1 - Young male researcher
Laboratory is a nice touch. Has experience and has tools to help him.
Environment choice: Image 7 - Cozy office with window on nature or Image 8 - Cozy office with library and armchair
Talking one on one, not a crowded waiting area. It is just for you. Mostly for privacy and having a one-on-one conversation.

9.3.4.4 Part 4 - Uncanny valley effect assessment
She looks formal and friendly. Gives out a good impression. She is a nurse there to help you.
They didn’t like the video that much, but it is hard to explain why. They don’t like things that look totally artificial. They felt like it had machine coldness. The voice was warm, and the animation should make you feel at ease, but they don’t feel at ease. It feels like it is designed to make you feel comfortable but sometimes it’s like it’s trying to impose it on you, which makes him suspicious.

9.3.4.5 Part 5 - Content assessment
Symptoms are useful to understand and compare to what they are experiencing. Treatment is helpful to know what they can expect from the future. Testing the vision and the symptoms is good to check if it goes with the symptoms. This confirms the disease.

Video adds human touch and gives more direct information. And can go in detail clearly. They don’t like video chat. Prefers chatting.

9.3.5 Participant 05
9.3.5.1 Part 1 - General information

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<tr>
<td>Diseases</td>
<td>AMD</td>
</tr>
</tbody>
</table>
9.3.5.2 Part 2 - Profile, needs and expectations exploration
Their eyesight changed suddenly from one day to the next. The severity escalation was very fast. They first experienced that with low lights in a restaurant they couldn't read the menu.

They knew nothing about eye conditions, also because they had perfect eyesight. It was completely sudden, they were experiencing massive headaches, but the vision loss was very sudden. This experience was quite worrying, but they haven't panicked yet. They are worried because he works online and needs to see the screen. They now have to zoom in on the phone all the time, which they never did before.

They didn't look for anything on the internet because they trusted the doctor. Since it literally happened overnight, they got worried and went straight to the hospital. They think that there is too much information on the internet. The information that they got from the doctors was understandable and clear, mostly because it is common.

They didn't connect to any other patient for now, but they said that if it gets worse, they will connect to other people to understand how to cope with it.

They use Google assistant and Alexa in the car. They like the speech interaction.

9.3.5.3 Part 3 - UI personality and environment exploration
A lot of bright colors together look too bright and make it hard to understand pictures. Black and white looks clearer.

First choice: Image 11 - Einstein
This one is the clearest. They like someone that is knowledgeable, old-school, and experienced. He would like a traditional, reliable figure.

Second choice: Image 2 - Older smiling female doctor
She looks traditional and more experienced. The most important thing for them is that the character would be knowledgeable.

Environment choice: Image 8 - Cozy office with library and armchair
It looks comfortable and relaxed. The others are very modern and some of them look too clinical and anonymous. They want something more relaxed and that has personality.

9.3.5.4 Part 4 - Uncanny valley effect assessment
The picture on the left looks like she is interested in you, and it’s the one they like the best. The ones in the middle, look like they have no personality, and are extremely digital. The one to the right looks like she is trying too hard. She looks like a generic person, a normal nurse. The color is alright, and he likes that there are not too many different colors. Lip syncing is off, and it distracts them because it draws a lot of attention.

She looks friendly. They like the music in the background. They have hearing problems and the music helps because background noise helps to focus on the voice better. The volumes were correct. Her accent was good. The graphics were fine, and he likes the space allocation. She wasn't distracting. Lip syncing is a problem.
Wants it to be about them and not about everyone. Best way to make it stand out is being easy. Keep it standard and simple.

**9.3.5.5 Part 5 - Content assessment**
They say that the answer to this question highly depends on where you are coming from: it would be really different if they didn’t have the diagnosis yet. Suggests adding how the disease can progress.

They say that they use YouTube a lot. They also use the NHS website webMD, where they read articles. They think that reading an article gives more control. With a video, you just need to follow, while with an article you can skim and see what you’re most interested in. They would first off trust what they are told in the hospital. Then they would trust articles, and they say he would never listen to something.

Audio call best and quickest and easier and more comfortable.

**9.3.6 Participant 06**

**9.3.6.1 Part 1 - General information**

<table>
<thead>
<tr>
<th>Status</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>33</td>
</tr>
<tr>
<td>Diseases</td>
<td>DME</td>
</tr>
</tbody>
</table>

**9.3.6.2 Part 2 - Profile, needs and expectations exploration**
In 2015 (26 y.o.) the first issues occurred while they were driving a motorbike in Thailand. They could not see in the center of the vision. They had blurry signs (was it because of the computer?). They thought they were sitting too long in front of the screen, the muscles tired and looking for exercises. The peripheral vision changed. The phone bothers their eyes. Driving is not an issue, because of the large visual scope. They have problems with focus on the center of the vision.

Did not know much about eye diseases. Went to the ophthalmologist, 2.5 years later, and got diagnosed with an intermediate stage of dry AMD, and got prescribed vitamins and minerals. They then found their different brands on their own. They turned to alternative medicine, eastern medicine, but nothing was found in this case. Drugs are good for pharma companies, but they were looking for other solutions. The information was easy to understand, but they were skeptical.

They tried to find a community because they wanted to talk with people. However, they haven’t found a satisfactory group yet. They found several, but not the one they resonate with. There are older adults in these communities - people there accept things, they are not motivated. Young people like them are much more motivated.

They use Siri on the phone, trying to be minimalistic. It is very useful, but they sometimes get frustrated by the wrong directions. They don’t like the fact that she’s listening all the time.

**9.3.6.3 Part 3 - UI personality and environment exploration**

**First choice:** Image 9 - Cuter robot with big eyes
It is impersonal. It would be more honest to discuss with a robot. Medical characters are like a turn off to them.

**Environment choice:** Image 4 - Nordic minimalist living room


**9.3.6.4 Part 4 - Uncanny valley effect assessment**

Doesn't like scrubs. Blue is not the best color. Some multi colors would feel more relaxed. Seems too serious, like a hospital. Face is engaging, features of the face are nice. The voice does not seem to match the look. The voice seems older than the girl, who looks 23-24. They liked the voice, could be deeper, half step a note. Besides, it is not well synced. She looks friendly, trustworthy, because of her cheeks, reminds me of someone I know.

**9.3.7 Participant 07**

**9.3.7.1 Part 1 - General information**

<table>
<thead>
<tr>
<th>Status</th>
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</tr>
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<tbody>
<tr>
<td>Age</td>
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</tr>
<tr>
<td>Diseases</td>
<td>Vision impairment</td>
</tr>
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**9.3.7.2 Part 2 - Profile, needs and expectations exploration**

The disease was genetic, so they mostly got information from the family. They use audio searching tools, such as Google search and Google Home. Sometimes it is difficult to be understood and it provides the wrong information if pronounced incorrectly.

**9.3.7.3 Part 3 - UI personality and environment exploration**

**First choice:** Image 7 - Young smiling male nurse

They would prefer peer to peer conversations, so the character should be the same age as them. Robots are not trusted and not wanted.

**Environment choice:** Image 7 - Cozy office with window on nature

They don't like the office style, and would change the table and chair, which are unnecessary. Having books would be better, to look for information. It would make them feel like the person would be a bookworm, which would make it trustable, since they are a reader.

**9.3.7.4 Part 4 - Uncanny valley effect assessment**

She’s a nurse, she looks sad and doesn’t want to talk to you. The mouth when she’s searching is like “what am I doing now??”, which they didn’t like.

They hate the way she speaks; it is weird. The animation is not perfect: they like to watch movies, but this one looks lagging, looks slow. She doesn’t smile enough, eyes are too small, she looks too shy. Her energy is too low, she looks exhausted. She looks like she’s wearing braces, and there are problems with her teeth - she looks like a rabbit.
9.3.8 Participant 08

9.3.8.1 Part 1 - General information

<table>
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<tr>
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</thead>
<tbody>
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<td>Age</td>
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</tr>
<tr>
<td>Diseases</td>
<td>Retinitis Pigmentosa</td>
</tr>
</tbody>
</table>

9.3.8.2 Part 2 - Profile, needs and expectations exploration

The person they care for was diagnosed at the age of 5. He can’t walk without a stick and needs help to use public transport. He doesn’t see almost anything, only blurry shadows for people.

They were curious to know more about the disease. YouTube wasn’t very helpful, not clear and hard to understand. They saw some PowerPoint from ophthalmologists, but it wasn’t very clear because they were talking about other patients, and the disease varies a lot among different people.

They don’t know whether he uses a Voice Assistant, but they don’t and don’t think he does.

9.3.8.3 Part 3 - UI personality and environment exploration

**First choice:** Image 1 - Young male researcher

He looks knowledgeable.

**Second choice:** Image 10 - Serious female doctor

She looks knowledgeable and professional.

**Environment choice:** Image 5 - Clinic modern hallway

Looks clean and professional.

9.3.8.4 Part 4 - Uncanny valley effect assessment

In the picture on the top left, she looks friendly because she is smiling. The graphics look good, it’s realistic, she has a badge and an iPad to take notes, she looks professional. The video is also nice and realistic, it is pleasant because she looks serious, and this is a serious topic.

9.3.8.5 Part 5 - Content assessment

If they were a patient, they would prefer text information, and how information is formulated is very important. To talk to a doctor, they prefer an audio call.

9.3.9 Participant 09

9.3.9.1 Part 1 - General information

<table>
<thead>
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<th>Status</th>
<th>Patient</th>
</tr>
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<tbody>
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<td>Age</td>
<td>23</td>
</tr>
<tr>
<td>Diseases</td>
<td>Diabetic Macular Edema</td>
</tr>
</tbody>
</table>

9.3.9.2 Part 2 - Profile, needs and expectations exploration

The first symptoms were a blind spot and blurriness in the eye at age 19. The fact that it was linked to diabetes was a shock. They couldn’t drive anymore.
They looked for communities online, but it didn’t work very well. They mostly looked for information about how people cope with the condition, if there are exercises that they can do to slow down the worsening, and how to adapt nutrition. They looked for YouTube videos. They got some hope, but then it was not sustained, and they became depressed.

They use a screen reader when the eyes are tired. They use Alexa for example to play music. What they like about it is that it is like a real person, that it gives detailed answers and allows getting sources for the information too. The thing that they don’t like is that sometimes it doesn’t understand well that it sometimes gives these pre-recorded answers that are annoying and the way that it phrases the questions.

9.3.9.3 Part 3 - UI personality and environment exploration

First choice: Image 9 - Cuter robot with big eyes

It looks like NED, it makes them feel comfortable.

Second choice: Image 3 - Young smiling female nurse

She looks like she would give honest answers. She makes them feel at ease.

Environment choice: Image 7 - Cozy office with window on nature

You can see outside; nature gives a calming effect. It makes you want to talk. The other spaces are too big and make you feel empty.

9.3.9.4 Part 4 - Uncanny valley effect assessment

She feels a bit impersonal; she lacks facial expressions. However, in the video she looks engaging and reassuring. They like that she nods when she is listening. They like the video.

9.3.9.5 Part 5 - Content assessment

They would like to hear about whatever can be done to slow down the disease. Besides this, symptoms, treatment, and tips are the most important.

9.4 Annex D: Evaluative research interview script

Following here, the interview script that was followed to lead the evaluative research sessions. The participants were asked to explore the service autonomously and the questions were asked after they completed the exploration.

9.4.1 Introduction

Hi, and welcome. First and foremost, we want to thank you again for collaborating with us: you are helping us greatly.

We are currently building a service that should provide information and advice concerning eye conditions. Today, we want to evaluate the current version of the service, which is a prototype for now. This means that everything is still being developed at the moment, and you will see that the available functionalities are quite limited. Everything that you see today will be updated and the quality will be enhanced. Especially in terms of content, only a couple of subbranches are currently working, and we will guide you towards them.

Still, even if this version is not final, we would be really glad to hear your opinion about this concept. Please remember that we are evaluating the service and not
your performance with it. This means that there are no right or wrong actions or responses that you might have to the service.

We would like to record this session, just for us to be able to listen to what you said again and to be able to get the most insights that we can. These recordings will not be shared with anybody outside of the team and your data will be anonymized when presented, meaning that it will not be retraceable back to you. Do you give us permission to record the session?

Thank you very much for that, it will help us a lot. Do you have any questions before we start?

9.4.2 Evaluation

We will now start the evaluation part of this session. The way it will work is the following: I will ask you to imagine as if you would find yourself in a situation, which I will describe for you. Then, I will give you some tasks to complete, imagining that you would be in the scenario that I mentioned. Whenever you think you reached the goal that I will give you, please let me know. Once again, I want to remind you that there is no right or wrong way to do things, and you might not even be able to complete everything that I ask you to do. Also, I want to remind you that this is not a feature-complete version of the service, which means that many options are currently not available.

I will now provide you with a scenario: this is what you should try to think about during the completion of the tasks. Try to complete them as if you were the person described in this scenario.

For people living with low vision:

Recently, you started to notice that your vision is changing: wherever you look, you see a black spot in the middle of your visual field. At first, you thought that it could only be the stress of the moment and that it would go away soon. Now, it has been two days, and nothing has changed. So, you decide to look on the Internet for some explanations of what is going on with your eyes. This website comes up and you decide to take a look at it. You specifically want to know more about what AMD is, a general description of it, and the diagnosis options that are offered for AMD.

For caregivers:

Recently, you started to notice that your mother is struggling with her vision: she is having trouble distinguishing colors such as orange and red from one another and she often moves things to the side to read or look at them. You asked her if everything was alright and she replied that everything was fine, and even looked a bit bothered by your question. However, this has now been happening for some time, and it looks to you like it is getting worse. So you decide to look on the Internet for some explanations of what is going on with your mother’s eyes. This website comes up and you decide to take a look at it.

Great, now that you have completed the exploration of the website, we would like to ask you some questions. We will show you screenshots of the different sections of the website to make sure that we are talking about the same things, but please try to reflect on your experience.
9.4.3 Follow-up questions
Thanks for all your patience! We would now like to ask you a couple more questions about your experience with the service.

- What was your first impression about Anne?
- Did you feel comfortable in all of the actions that you took?
- What did you think of the images and media that Anne showed? Did they help to understand the content?
- Were the explanations clear?
- Did you feel like Anne was conveying important information?
- In the accessibility menu, did you find the options helpful?
- How would you describe Anne to a friend if they asked you about your experience with her?
- Would you be able to tell me the thing you liked the most about this experience and the one you liked the least?
- What is your impression of the available content? Was it too long, too short, too difficult to understand, too boring?
- How easy or hard did you feel it was to use the service?
- How would you describe your feeling interacting with this character?
- What interaction type did you prefer, speaking or reading the chat?
- When this service is released with full content, would you like to use it?
- Having in mind that full content will be available, do you think you would rather prefer to use Anne, or a regular website?
- And what about a website with a little window in a corner (like a chatbot assistant) to discuss with Anne?
- Do you think you would recommend this service to other people?

9.4.4 Wrapping Up
This concludes our interview session! I want to thank you so much once again for your help. Your insights are extremely valuable for us to be able to create something meaningful for people living with low vision. Thank you so much again, we really appreciated your help.

9.5 Annex E: Evaluative research transcripts
This section presents the notes taken during the evaluative research sessions. All of the results are anonymized. These are not complete transcripts, because the conversational elements that did not serve the purpose of the research were left out.

9.5.1 Participant 01
9.5.1.1 General information and notes
The participant is fully blind, and uses the Jaws screen reader to access the internet. The computer could not connect to the service, maybe the screen reader was blocking it. In the end, the researcher shared the screen and let the participant talk to the Digital Human. Whenever the speech was not recognised, the researcher would repeat what the participant said. This also meant that no screen reader was working during the session, which did not allow for testing whether the two modalities are compatible.

9.5.1.2 Evaluation
P1: When she asked to use the microphone, we heard something and you had to click confirm, so I guess you clicked on something that I couldn’t see, which
maybe explained that the microphone would be used this time only. If I didn’t
hear that, I would be reluctant to allow the microphone usage. It should explain
what I am agreeing to.

This distracts the participant from the question that the DH posed, which makes
him confused about what the options are.

P1: Tell me about AMD, that would be my question.

The researcher needs to explain the options again, to make sure that the
participant knows what the options are.

Anne presents the options.

P1: The first one.

This doesn’t work because the exact option should be spelled out.

P1: She gave us three options right, and I will likely remember the option that I
would choose, but probably not the text that is in that option. So I would like to
be able to say ‘the first option’ or ‘the second one’. Because I don’t even
remember for example what the others are. I think it would be much easier for
me, being blind, to be able to say numbers because it’s hard to remember the
text.

DH: Would you like to listen to more information about AMD?

P1: Yes

DH [disregarding what the participant said]: Or would you like to talk about
another condition?

P1: When she says “would you like to continue with this”, I would like to say
“yes, please”, which is a natural answer. But then she continues with “or would
you like to continue with that”. Then I need to remember what she said or ask
her to repeat the options. Again, I would like to have the possibility to say “the
first option”. And then to know what to say, that could be explained at the start
of the session, so that she says “you can say option 1, option 2 eccetera”, so she
explains what can actually be said. Having options explained well in speech is
good not only for completely blind people, but also for people whose eyesight
is getting worse. When I arrived at a point where I had to strain a lot to be able to
read, I would have still preferred to have something reading out the text instead
of needing to read it, which is very tiring at that point. The avatar has a nice
voice and it’s easy to understand her even if I’m not a native speaker.

R: So how clear did you think the explanation was?

P1: Very clear, the only problem was choosing the options, anything else was
clear.

R: And did you think that she was conveying important information? Or would
you have cut something out for example?

P1: I thought it was good, but it depends on where you’re coming from and how
much you know. For me, a lot of information was repeating, but that’s also good.
A beginner might have understood too.

R: How would you describe Anne to a friend if they asked you about your
experience with her?
P1: I would probably say trustworthy, easy to listen to, understandable. It sounded like she knew what she was talking about.

R: Would you be able to tell me the thing you liked the most about this experience and the one you liked the least?

The least is the easiest, is the way that options are handled. I really like that she had a voice that was easy to listen to and I could easily understand it even though I'm not a native speaker.

R: What is your impression of the available content? Was it too long, too short, too difficult to understand, too boring?

P1: I think that it’s good that you give an overview picture first, and then for example you can ask for more detail. I guess that you could go even in deeper detail in specific content. There probably should be different levels of depth of the explanations.

R: How would you describe your feeling interacting with this character?

P1: I'm not sure about emotions, but she sounded reliable. I trusted her, she had a trustworthy voice. I was mostly calm.

R: If we fixed the options issue, When this service is released with full content, would you like to use it?

P1: I would like to explore and I would recommend it.

R: Do you think you would rather prefer to use Anne, or a regular website with the screen reader?

P1: Starting the session I thought I wouldn't like it, because I'm very used to the screen reader and I have never used this kind of thing before. But it was actually very simple and if the options issue was solved, I would probably go for this speech interaction, even though I'm very keen on using my screen reader, it felt fairly simple in fact. I would definitely give it a try using my voice, but before today I would have probably said no, so that's a good sign. Because I'm a white old man who never changes his option, according to what people say [chuckling], but I did change my opinion.

R: And what about a website with a little window in a corner to discuss with Anne, such as the assistants that sometimes are available on websites? Which one do you think is the best?

P1: I know that you have websites where you can make them talk. I never use that because I don't know how that website will talk, whereas I know how my screen reader talks, so I must be convinced that the technology is better than my screen reader. You should probably have both, but I think it was really good that she started talking right away because if she didn’t and waited for me, I wouldn't know what to do and I would start using my screen reader. I didn't have to go through the website with the reader because she was talking to me, which made it really easy. I usually have to explore the whole page and this is why I'm usually not much on the Internet, because it takes such a long time to explore each page. But in this case I didn't have to do it, and that was brilliant. I was hooked right away, so that was good.
9.5.2 Participant 02

9.5.2.1 General information and notes
The participant lives with RP, is living with low vision, but uses their mouse. The participant uses the mouse and clicks on the buttons instead of using speech interaction. He asks the DH to repeat some content. He tries clicking on non-available buttons.

9.5.2.2 Evaluation
P2: I miss the opportunity to repeat something.

R: At some point if you don’t understand you would like her to repeat right?

P2: Yes, I would like her to repeat.

R: How would you describe Anne to a friend if they asked you about your experience with her?

P2: If you’d ask me if I would recommend it I would say no at the moment. Maybe because I’m used to talking to people, instead of talking to a digital human, or reading a leaflet, and I wonder about the target group. It’s nice but I’m not sure about the benefits at the moment.

R: What would be your expectations in terms of benefits?

I don’t know how intelligent the system is. If you could ask direct questions, and it is really intelligent and asks real questions, that could be helpful.

R: At the moment the DH is not able to answer questions. Would you say that this is the line that needs to be crossed?

For example, it would be good to be able to ask direct questions instead of having to go through the whole content.

R: You said you had to go through the steps. Do you think it was too long or too superficial?

P2: It depends, if you’re not deep into the topic, it might be helpful, but maybe it should be possible to be able to learn more and more and more, to be able to find more details.

R: How would you describe your feeling interacting with this character?

P2: Well, I’ve never talked to an avatar, but I guess you get used to it. I’m not sure if I changed my mind, I was curious what would happen. I guess with more time then it becomes easier and you get used to it.

R: Would you be able to tell me the thing you liked the most about this experience and the one you liked the least?

P2: There are only a few options, but it’s nice that it’s working. Making it able to reply to questions would improve it a lot.

R: When this service is released with full content, would you like to use it even though it wouldn’t be more intelligent?

P2: I’m not sure whether the target would actually accept this avatar, if it is only describing text in other forms. The benefit would be if it’s able to answer my questions.
R: Having in mind that full content will be available, do you think you would rather prefer to use Anne, or a regular website?

P2: I guess older people use websites already, and they might prefer what they already know and use. So I’m not sure this would be very engaging.

R: Did you have any difficulties at the beginning?

P2: I wasn’t sure whether it would be still available if I didn’t open my microphone, and whether it is essential for use. Maybe you should inform people in advance that the microphone is optional.

R: Did you think that the content was informative?

P2: Some content was missing in my opinion, for example the macula, and not only the retina.

R: What about the images?

P2: The images were not clear to me, I wasn’t able to see them properly because of my impairment. For caregivers, I’m sure it would be useful.

R: Was the vocal content enough to understand?

P2: Yes, the first impression was alright.

9.5.3 Participant 03

9.5.3.1 General information and notes
The participant is strongly visually impaired, and uses screen reader technology. They have troubles with screen sharing, so the researcher shares their screen instead. This means that the experience is not completely natural, because the researcher needs to speak in the place of the participant.

9.5.3.2 Evaluation
R: What do you think about it?

P2: It’s very positive that she doesn’t say that AMD leads to blindness. It’s very smart and it’s nice to look at her, although I only see part of it because of my condition. The voice is there and the information comes from it, but then why the pictures? I guess for people that see better... But I think this type of presentation is very interesting. What I find a bit strange and irritating is how she presents some of the content because it can be a bit scary since it is only in images. Maybe there is a better way to present those. But in general it is a good idea. In the first moments it made me think of Star Trek [laughing]. But it is entertaining.

R: What would you say we should do to do better?

P2: You said some features are not available at the moment... I think the options that you provide like chat could be good especially for family members that want to read and get information fast. It’s good that you also have written text.

R: Did you feel like Anne was conveying important information and that they were enough?

P2: Yes. It depends on what people are looking for. For people that are looking for information before diagnosis, I think it’s good. I also liked that she asks if
you want to go deeper in some parts. I think actually for this kind of presentation, the information was quite good. I was a little surprised by her name...

R: Do you think we should choose another name for the English speaking community?

P2: I don't know, but it might be unimportant. The case with me was that I struggled to understand her first sentence and didn't manage to catch her name. And I think she says something about a hospital... so the first surprise effect is like “oh, she’s talking to me! What is her name? Eh?”. I felt like I didn't get the information [laughing]. It's not of any importance what her name is, but I think it should be better pronounced. It might be a lot of information when she introduces the service first. Because after that all of the information was ok, and it was also much more important. To me, she looks like in a movie, but maybe for you sighted people it looks normal. To me it looks like a cartoon figure. She is very realistic. I think I was looking whether I could make out if she was a cartoon or a film or a real woman. And then I was thinking, is she looking like a woman or like a man. Because I was wondering if you chose an androgyn figure. And then I realized she was a woman, and then I began to listen. Maybe that’s what happened. And in these seconds where I was distracted there was all of the important information.

R: So, what do you think of this character?

P2: A woman is always a good choice. She’s very sympathetic, beautiful and her voice is very nice. Her clothes are very neutral and she looks very trustworthy and serious, like she knows what she is talking about, although she is not like a teacher or a doctor. It’s good.

R: If you had to choose this interaction or a traditional website, which would you choose?

P2: Good question. I'm used to my text-to-speech. So I get the text read out to me. But people that have these features are usually people that are already well informed. So I would think that it is always a relief not to read if you have an eye condition, and it is also an entertaining effect of course. As you know, there is only limited information but you can always go back and listen again. What I found good was the presentation of the diagnosis options.

R: And what about a website with a little window in a corner to discuss with Anne, so combining the two things?

P3: Yes, because maybe people want to go back and read. Especially, as I said, for people like family members. But I think it’s very entertaining to look at her. But how many times would people go back to look at her? I think it’s a good idea, but I also have the text.

R: Do you think you would recommend this service to other people?

P3: Yes. People coming to me as a peer counsellor, they don’t look for information for me, but for support. I would refer them to this for more questions they might have when they go home and have no one to ask them to.
9.5.4 Participant 04

9.5.4.1 General information and notes
The participant is a sighted caregiver. They went through all of the options by clicking on the buttons instead of speaking. They tried clicking on content that was not available. Sometimes they don’t wait for the DH to finish speaking before choosing the option they wanted.

9.5.4.2 Evaluation
R: What would you expect from the button on the right top side of the screen?
P4: Maybe find the whole content or links to more things to take me further on.
R: Can you try clicking on it?
Participant takes a look at the options.
R: Do you think this is useful, clear?
P4: I think it’s good that you can choose these things. I think the most important thing is the voice speed, especially if you’re non-native speaker.
R: Was it easy to go through the microphone permission procedure?
P4: Yeah, it was really easy.
R: Do you remember what was your first impression of Anne?
P4: I kept thinking that she made me feel that she was real in a way. She talked calmly and friendly in a way. I didn’t really think this was a robot, but a person that talked to me.
R: Did you feel comfortable in all of the actions that you took?
P4: Yeah, I felt very confident and it was clean and easy to understand how to operate. At first, I opened something that wasn’t available, but she explained it to me. I think simplicity is key.
R: May I ask you if there is a reason why you decided to click on the buttons instead of speaking?
P4: Maybe because I’m a bit shy and didn’t want to speak English, it was easier to click than to talk. And maybe because I’m sighted, because I think if I didn’t see, maybe it would be easier to speak.
R: Was the explanation clear?
P4: I thought she had a simplicity there also, and even if i didn’t know any of this before, i think i would have understood it anyway thanks to the clear and simple language.
R: What did you think of the images and media that Anne showed? Did they help to understand the content?
P4: They were helpful, it’s always helpful to have several ways of learning, listening and seeing.
R: Did you feel like Anne was conveying important information?
P4: I thought it was short and informative, I didn’t feel like I would have needed more, like something I expected and wasn’t there. But also, i don’t know much about AMD so maybe someone with more knowledge might have needed more.
R: What did you think of the way the different options were presented in the diagnosis part? Was it easy to follow Anne’s speech there?

P4: As I said, it was still simple, so it was easy to go along with it. It was simple enough for someone who doesn’t have background information. I didn’t really find anything bad and I found it really nice. I thought that if this was around when our son got his diagnosis it would have been a happy moment for me to know more, so I think it’s just fantastic.

R: How would you describe Anne to a friend if they asked you about your experience with her?

P4: I would say she is friendly and that she is interested in me, in what I think and what I want and what I would like to hear.

R: Would you be able to tell me the thing you liked the most about this experience and the one you liked the least?

P4: The thing I liked the most was that I felt very secure interacting with her and I liked how she showed me these pictures. I don’t think that I really have anything I didn’t like.

R: You already told me it was quite easy to use the service, but do you think it would be easy for anyone?

P4: Yeah, I think that now it wasn’t fully functioning, and she gave the feedback that it wasn’t. I think that keeping feedback is good. So, giving it when there is something where you could go wrong. She might say “I see you said this, but maybe you are looking for this”. Because she was very helpful to me. Maybe if you don’t find the right content or function, she could help.

R: How would you describe your feeling interacting with this character?

P4: felt very secure, compassionate, interested, helping, like she was there for me. She looked like someone I would have liked to listen to more if she had more to tell me. She has a very nice tone of voice.

R: We are planning to have the possibility to have a chat mode. Do you think this could be useful?

P4: I think I could prefer both things. If you have a chatbot or something like that, the most important thing is that you allow asking for questions that she can really answer because it’s the most annoying thing when you ask things and you get in a loop of “I don’t know” or “I can’t answer”. That is important to think through. This would destroy the good things.

R: When this service is released with full content, would you like to use it?

P4: Yeah, I would certainly like to use it and recommend it.

R: Having in mind that full content will be available, do you think you would rather prefer to use Anne, or a regular website?

P4: No, I would use this format of interaction because it becomes an interaction with someone, even if she is... but she really looked human, that’s what I liked. But I would have certainly chosen her, maybe also because it is something that can attract the younger population, because it’s like a gaming situation. And that is the future, instead of plain text.
R: And what about a website with a little window in a corner to discuss with Anne, such as the assistants that sometimes are available on websites? Which one do you think is the best?

P4: Just starting to talk to her is better. I liked it very much.

9.5.5 Participant 05

9.5.5.1 General information and notes

The participant is strongly visually impaired and needs a screen reader to navigate their computer. They struggle with inserting the password because the fields are not labelled, and they struggle to find the right position. The participant navigates the screen with their keyboard, and they can read all of the buttons apart from the accessibility menu. Once the participant starts navigating the page with the keyboard, it looks like the DH is not listening to them anymore. They try speaking but the system doesn't respond. It might be a settings issue as well. They keep navigating with the keyboard, which suggests that the screen reader is reading the buttons aloud. They combine reading the buttons through the screen reader with speaking their responses. This is quite effective.

9.5.5.2 Evaluation

R: Would you like to try the upper left corner button?

P5: What is it?

R: It's probably not labelled correctly... is it possible to use it?

The participant tries to tab through, reads aloud some of the content of the menu and the DH starts speaking again, and the participant looks confused. The accessibility menu doesn't seem to be usable through keyboard interaction.

R: What did you think about this experience?

P5: It's nice. Just when the assistant is speaking, you can't do anything I think, or at least I wasn't able to. The voice is nice, I like it. The content is good.

R: Could you tell me a bit more about the technical environment you're using?

P5: I can't see you, which means that I use Jaws access for workstations. This is the most common screen reader in Switzerland. I don't use a mouse or screen, just the keyboard.

R: With your equipment, did you have any difficulties navigating or selecting the options?

P5: No, easy. You just tab through.

R: And the screen reader reads the labels of the buttons?

P5: Yes.

R: And what did you think about the character?

P5: I'd say she's a nice person. She calls herself a nurse, and I believe that.

R: How would you describe your feeling interacting with this character?

P5: I was wondering how she's doing it, what she is explaining. The tempo of her speech is good, not fast or too slow. Usually, most people listen to content at a bit faster speed than normal, and they keep more content in mind. This is
interesting. When she is changing from one bullet point to the next there is a break and sometimes, I thought that she was done, but then she started speaking again. The break might be too long and left me wondering sometimes.

R: What is your impression of the available content? Was it too long, too short, too difficult to understand, too boring?

P5: No, I think it’s ok. The point is that it doesn’t have to be too long, otherwise you lose people, but there is always the possibility to have more. For myself, I wouldn’t like that, but for most people I think that this is great, so you don’t have to listen to everything, but you can skip and go ahead. So, for example, when you’re done with the diagnosis, you can choose what to hear next. I think that’s great for people.

R: Do you think that when the content is fully available, people would like to use it, maybe also compared to more traditional websites?

P5: I don’t know... this is another way to get information and it is reliable information. I think you would look for that for your own condition, not for other conditions. You just go and search when you are somebody who has this condition.

R: Yes, we are in fact thinking of people who don’t know which conditions they are experiencing...

P5: Oh, so they would go looking for the symptoms and they put together their own diagnosis [laughing]. That’s a bit risky. But I think that with these conditions the risk might not be too big. Sometimes you start having problems, which are not too big yet, and then you would go to “doctor google” and look for information. And if this makes you go to the ophthalmologist, that’s ok. And there you explain the symptoms and get checked. If these are the consequences, it is ok.

R: Yes, this is what she was saying at some point.

P5: Yeah, she was saying like “if this is the case, you should go to the ophthalmologist”. I think this should be a bit more direct. Not “if you want to be sure”, but “if you notice some symptoms, then ask your eye doctor”. You probably should include guidelines about how often you should get a check-up with eye doctors after a specific age.

R: Do you have any other comments?

P5: It was easy to listen and to handle, I liked it.

9.5.6 Participant 06

9.5.6.1 General information and notes
The participant is eye sighted, lives with type 1 diabetes and is an advocate for low vision prevention. They interacted with the service both using voice and clicking the buttons. The buttons were used mostly when the DH didn’t pick up what they said straight away. The participant at some point felt like the DH didn’t pick up what she said because of their accent.

9.5.6.2 Evaluation
R: What do you think the button on the left top corner does?
P6: I would think that maybe it is a help button, but I’m not really sure. If I open it, everything is easy enough to do. The options seem nice, they are probably the right things to have. It wasn’t clear when she said that we could restart, that this restart button was the way. It was not clear to me at the beginning how to do that, and I wouldn’t have known unless I clicked there I guess.

R: What was your first impression about Anne?

P6: It looks super simple, clean, it doesn’t have any clutter so that’s useful. I don’t have low vision, so it wasn’t in any way hard for me to look at her. Her instructions are very clear apart from the restart. The only thing is that depending on a person’s low vision level, I’m not sure how much they would be able to pick up the initial starter, the part about the microphone permission. It wasn’t a problem for me, since I can see, but I’m wondering whether people with low vision would actually be able to manage. Once you’re in it makes much more sense, but it might be difficult to get there.

R: Did you feel comfortable in all of the actions that you took?

P6: Yeah, I found it fine. I wasn’t completely clear on whether it is possible to go through it only using voice... if that’s the case it is fine.

R: Was the explanation clear?

P6: Yes, they were very clear, and I felt like it was pasted very well. She was speaking short sentences and it gave time to absorb what she was saying and the points that were being made. I have to say that I was following her mouth while she was talking and it looked like you know when the audio and visual are not synchronized... and I found that quite annoying. It looked like she was not saying the same words as the ones spoken, and I found that a bit distracting.

R: What did you think of the images and media that Anne showed? Did they help to understand the content?

P6: So, the images were fine. I was wondering if the image of the eye in the AMD explanation had too small detail to be perceivable for people with low vision. However, it was being explained very clearly, so it felt like it was an add-on. I also appreciated the pictures for the diagnosis options. That was very clear and quite good.

R: Did you feel like Anne was conveying important information?

P6: No I did feel like it was important, but it’s high level information. It gave a good overview without going into too much detail, which is probably a good thing. I guess there could always be an option to get more detail. But in terms of an introduction to what AMD is I felt like it had just the right amount of information and it was very clear.

R: In the diagnosis part, what did you think of the way the different options were presented? Meaning the fact that it was on you to move forward?

P6: I’m not sure why that did not work automatically and I had to click on the next button. I guess I should have been silent and then I would have heard her telling me if I wanted to continue, but people don’t really like silence and they might feel a bit weird.
R: I wanted to know a bit more about what you thought of Anne. How would you describe Anne to a friend if they asked you about your experience with her?

P6: I would say quite neutral. She felt quite factual and warm and I felt like she was constantly sort of checking in. Because part of it is self-directed, it felt quite consultative.

R: Would you be able to tell me the thing you liked the most about this experience and the one you liked the least?

P6: I felt that I really liked the simplicity and clarity of it, and the cleanliness of how it looked. The thing that probably annoyed me was the audio and video not being synched.

R: What is your impression of the available content overall, considering that there would be more? Was it too long, too short, too difficult to understand, too boring?

P6: I wouldn’t have it any longer, but I felt that it is quite high level information. I liked that it wasn’t repetitive, which is often the case for medical information, where things are repeated half a dozen times and that is really frustrating. I liked that this was not the case. It gives a really good snapshot and a good overview, if you want to know more there should be directives to do that but just for that high level it’s a good length.

R: How easy or hard did you feel it was to use the service?

It wasn’t hard at all, it was very straightforward and very easy. The only thing I would say is that I didn’t know how to restart when she said it, and I would put it at the beginning. Without it being explained I didn’t know that I could change the text size. So maybe highlight that there are these options at the start.

R: How would you describe your feeling interacting with this character?

P6: It felt like a very neutral experience. Which I think it’s a good thing. For me a bad thing would be walking away feeling like it was really doom and gloom, and there would be nowhere else where I could go. But I felt like it was an experience where I could get what I was looking for.

R: We are planning to have a chat mode, similar to a chatbot, where you can read the conversation as if it were a live chat. First of all, do you think it would be useful and what interaction type would you prefer, speaking or reading the chat?

P6: I think some people might prefer that and since it is voice activated it might not need a person. But I would say that having both is better because some people might respond better to seeing her, while some might prefer the SMS-like interaction.

R: When this service is released with full content, would you like to use it?

P6: Yes, absolutely. And I think it would be something really useful to people as a starting point. If you are looking for information for the first time, this could be a good start and a good way to know where to go next. I’m assuming that there will be explanations on how to find more information, because usually people like to do a bit more of their own learning before going to talk to a doctor.
R: Having in mind that full content will be available, do you think you would rather prefer to use Anne, or a regular website?

P6: I would prefer just a normal website. But I do understand that a lot of people love the idea of it feeling like a conversation. So I think that it is very much of a personal choice, but I always like it when there are options that people can choose from, so that they can use what works best for them.

R: And what about a website with a little window in a corner to discuss with Anne?

P6: I would prefer that, and I would probably not use it though. But I guess it always comes down to how would people with low vision be able to navigate through what they are presented and to find that. So it should be very prominent if there is an option. The thing that I like about it is that at the beginning it says “here are the topics” and so I didn’t go for the first one, but for the one that I wanted. It is nice to choose your adventure for how you would like to actually see the information. I think that it is quite appealing and it also means that somebody might not want to go through the full explanation, but just a part of it to understand whether they wanted to explore more.

9.5.7 Participant 07
9.5.7.1 General information and notes
The participant evaluated the Finnish version of the service. They required live translation from Finnish to English to discuss with the researcher. They are visually impaired but can see the screen. At some point, the participant asks what she should select. They first try by voice a command that is not available and then use the mouse to click on the available option. They mostly interact with the mouse.

9.5.7.2 Evaluation
R: Could you hear what Anne was saying when you opened the website?

P7: Yes, but now she looks like she is thinking about something. Should I do something, there are alternatives.

R: It would be great if you could open your microphone for this session.

R: What did you think about this experience?

P7: Absolutely fantastic. It was really good, informative, and I was left thinking that perhaps regarding the terminology of the eye diseases, someone who has been healthy until now and hasn’t heard about eye diseases, could be challenged by it. But of course, you have to use the right names. But maybe someone seeing this for the first time, could benefit by a clearer explanation of the terminology. At least, I personally remember that at the beginning it was hard to understand the terminology, and even now I’m not able to understand everything. Maybe with the audio there was a little bit of disturbance, but otherwise I thought that the digital human was absolutely wonderful and the information, for people, timely will make them think whether they could have AMD, and then go through matters related to that. And I would give thumbs up for that.

R: Do you have any suggestions on how to invite new people to get access to the right content?
P7: Do you mean how this digital nurse shares information to people or invites new people?

R: Since you were saying that people might not understand terminology at first, how can we guide them?

P7: That’s a good question when we think about AMD, which comes from an English word, so what is the Finnish name? So maybe opening and explaining what macular degeneration means in Finnish.

R: What about the interactions? I noticed that you mostly used the mouse. And only sometimes talking. What is your preference?

P7: That depends on the user of course and the visual acuity of the person. If you have low vision, you might need the voice control to navigate the options and ask questions by voice. You should have the option to use the voice or mouse to make choices. Because the intention here is to provide information to people and I’m sure that you want to produce more content for disease that maybe leads to people not having vision, and then they could discuss by voice.

R: How would you describe Anne to a friend?

P7: I think that this virtual human is just like an animated character but I felt very comfortable with her. Her appearance was very pleasant and human-like.

R: And in terms of emotions and emotional traits?

P7: I think that you made very good choices. Emotionally she was easily approachable and not like a doll. She was very pleasant and her tone of voice too. You fine tune it if need be but it was good.

R: Do you think you would use it when more content is available.

P7: For sure. And because when a person ages you have to understand that your wellbeing is in your hands and taking care of yourself is on you, if such an assessment for care is available, you can do it yourself and this would be really great. And when you go through this content and the information, you can test your eyes. And if there are problems you need to understand that you have to visit the doctor.

R: Do you think the content was too long or too short or difficult to understand?

P7: I think it was good and I’m sure once it’s finalized, when you have more options and you can navigate them, then it is perfect.

R: And did you find the navigation difficult?

P7: It was very easy for me. But once again, it depends on how well you use a computer, like elderly people. But then you have to think where it would be published. Is it an application or where will it be available, then people can ask for help if they can’t use a computer. But you have to build awareness that such a service is available and people need to know about it. May I ask if you have thoughts about how to share this and make it available?

R: Some partial knowledge. It is expected to be presented as a website and referenced as such. Do you think that comparing this to a regular website, which one would you choose?
P7: This interactive one would be my choice, it would be more pleasant. I’m thinking maybe 10 or 20 years on, for ageing people this is much more pleasant to use than a regular website where you just read the content.

R: What would you think about a traditional website with the opportunity to switch to this conversation?

P7: Yes I think that would be the perfect option actually, because people can make their choice. That would be the best solution.

R: Would you recommend this solution?

P7: Yes absolutely. For my friends I would recommend this and I would be using it because due to my back conditions I can’t work anymore but I have worked in healthcare for 35 years and I know the sector quite thoroughly. For me personally such a webpage has its own address and for example ophthalmology offices and often they look at people’s eye conditions. These professionals should have this information available, so that they could test and get good information. In Finland we have lots of private consultancies and ophthalmologists, and it’s quite an extensive network where this service could be important to have and to offer to the patients. I think that this would be the easiest channel to spread this.

R: It seems that you enjoy this experience. Would you be able to tell me the three most enjoyable aspects and the three that you would like to see improved?

P7: As an experience, I think that the informativeness is very good. Gaining factual information is very good. Then the pleasant nature, accessibility and ease of use and the clarity of the information and easy going use of this was very good. Audio quality can be improved, there were buzzing noises. But otherwise it’s difficult to find improvements to make. I really liked it and I liked the character. She was very pleasant, her behavior, her movements, she was very human-like in how she acted.

9.5.8 Participant 08

9.5.8.1 General information and notes

The participant has severe vision loss due to RP. They use a screen reader to access their computer, and have been using it for a while, so they are expert about it. They went through the explanation section only, but twice: the first time, they decided not to allow microphone usage, and the second time they did interact through speech.

9.5.8.2 Evaluation

P8: I wanted to say that for someone who is using speech output technology, this text takes far too much time. In this case, I would go for the printed text. When you first go into low vision people would use the text and not listen. Because you know “bla bla bla”, it goes very long. Then you have to listen to the whole thing twice or three times because you didn’t get where she wanted you to go. I couldn’t reach the button she wanted and I had to go through it with my assistive technology, but if I would only depend on her, it would be very boring… or you would give up immediately. She is very good, the sound is excellent. You have an artificial voice here, but do you also have a male voice?

R: No, at the moment we don’t.
P8: You know, when you get elderly you have auditory loss and the first thing is you get trouble hearing female voices because they are at a pitch that is impaired first. Elderly people might better understand a male voice. So I’m wondering whether you have the choice to choose a male voice.

When choosing among the three conditions (three options on screen).

P8: How you present this... because if I’m only depending on the voice, she is saying that these are the conditions, but I have no information at all. It would be nice to say “please click the button”. Personally, I know that there might be a button or a link, but if you think about those who are relying on the voice, you should tell them that there are buttons. If I would choose not to use the microphone, because it’s quicker, then the text should contain “please click the button”. Or then have the sentence “you can ask me”.

P8: So now she is asking “are you interested in any of these today?”. Then I would continue “then press the button A, B, C or D”. Because when you answer you have to be precise on what the text is and that’s something that people might forget or say differently, and then it would be difficult to get a response. It would be good to have a phrase like the one in the retina explanation for the buttons each time.

The participant opens the accessibility options menu and feels confused.

P8: I opened “options”. I have first a button that is not marked. Then the language one. Then “button 6” [the text size button] and the restart button. It’s important that the buttons are marked.

R: The first one is to close, the other one is to increase the text size.

P8: Oh, a really important one.

The participant got lost while tabbing and opened the link again.

P8: Oh, I have to restart... There is no possibility to go directly to one of these points later?

R: No, not for the moment.

P8: Ok, this thing that just happened to me to get lost in the tabs and it happens often to visually impaired people. Because you can’t see what you’re looking for, you try with the escape key and you’re out. And if you have to restart from zero... most people won’t do it.

P8: I have a question: is there a possibility to read the text?

R: We’re planning to have a chat mode.

P8: I think that’s very important. If people are not native speakers, they will take the text and translate. And it’s so easy today with Google Translate. So they will just take it and translate it. And people who are hearing impaired might prefer to read rather than listen. That helps the understanding. Because the text is very good, nicely written and easy to understand. So it would be good to have the text. If you have the written text some people might prefer to take their magnification tool and to read it that way. You also have the menu to magnify. For many people it is easier to read than to listen. Elderly people have cognitive problems.

R: For yourself, would you prefer to use a traditional text-based website?
P8: Personally yes, but it's just my personal opinion. The public you are addressing is mostly 70+ and they have these different problems: vision impairment, hearing impairment and they are not used to listening. They are more used to learning by hearing. That's why if you had both possibilities to read and listen and ask questions, that would be nice.

R: So in your opinion it would be better to have double options?

P8: Yes.

R: Let's go back to your experience. Do you remember your first impressions about Anne?

P8: I know her very well, I am used to her. This is a common artificial voice. You have her on the iPhone and more. I knew her and I'm used to her. I understand her very well and it's good. Many people choose this voice.

R: Not all of the actions were clear right?

P8: Yes. So like saying “do you want to know more?” is not enough, people who don’t see need to be told that they need to press a button.

R: In terms of the explanations, were they clear?

P8: Yes.

R: Was anything missing, was it too much, too little?

P8: For that, I have to read carefully. I was too concentrated on how to handle it and find out how it works. I thought at the beginning it's ok, not too much, but for the details I would need to go through it again.

R: Was it important information?

P8: The information that I could see was very basic, a beginner’s story.

R: And is that negative?

P8: It depends who’s reading. For someone looking for the first time it is perfect, for someone who already knows it might be too basic.

R: If you had to describe your experience to a friend, what would you say?

P8: Interesting experience. And something new, I haven’t seen this so far.

R: Would you be able to tell me what you liked the most and least.

P8: That has to do with the fact that I’m used to using the voice, and I'm using it at a very fast speed [the screen reader], so when I listen to humans giving information I get very impatient. Because it’s not quick enough. But it’s because I’m used to speech output and to use it differently. You know, I would accelerate it to 150, 180, so things are going quicker. So if it’s slower you go “please come to an end”. But again, for somebody who is new, this is ok.

R: In general, how easy or hard was it to use the service?

P8: It’s pretty easy. When you find out how it works it’s pretty easy.

R: Do you think it would be beneficial to have an introduction to how to use it?

P8: Perhaps as an option. So that you don’t have to go there but you can find help. But when you listen you really have to know how to continue.
R: What was the main feeling that you had?
P8: I found it interesting. But it was an exploratory way to look at it.

R: If you were to find this website on your own time...
P8: Oh, I would have gotten frustrated the first moment when I didn’t know how to continue. And when you have yes and no, you need the button back, which goes to the page before. When you go into a question, you would need to be able to go back to the previous menu.

R: Do you think you would recommend it to others?
P8: Yes, I would. I think it’s easy and that makes it good. It has good content. If you work on it properly I would recommend it.

The participant then decides to try it again with the mic on. The participant gets stuck at the part where “Explore the symptoms”, “Eye conditions” and “Useful tips” are presented as options. They try to select “AMD”, which is not recognized.
P8: I’m just trying to get her to work!

The researcher explains that this problem was encountered before and how to move forward.

The participant nods and approves when Anne understands her commands. They then try to go for a content that is not available and approves the feedback message.
P8: But now you see I don’t remember what content was available and what I could do. So you could say “please tell me or press the corresponding buttons”. Because it worked.

R: Is there any additional comment that you have?
P8: I think it works well but it needs to define the terms that you can have. There is a difficulty because the options are presented in a long sentence and then you don’t remember. Like this “Risk factors”. And it should go there even if it only gets part of the sentence. And give more guidance that the buttons are there. And there you avoid frustration.

R: And once she didn’t understand what you were saying and she didn’t do anything.
P8: Yeah, she was just quiet… so you don’t know, did she get it or not?

9.5.9 Participant 09
9.5.9.1 General information and notes
The participant is sighted, a relative has been diagnosed with RP. The participant decides not to allow microphone usage and navigates the service using a mouse.

9.5.9.2 Evaluation
R: What did you think of this experience?
P9: I appreciate it and I think that the information is good and should be understandable at least to most people. One thing I missed was an option to read it or subtitles maybe, because for some people hearing might also be an issue, or just some of the words are difficult for people who don’t know about
these conditions. It can also just be bullet points, but it might be helpful. I didn’t try the skipping option, and I don’t know how that would look. Because nowadays people want information very quickly. So maybe something like a menu where you can pick and choose or skip might be helpful.

R: What would you expect from the button on the top left corner?

P9: That to me is an accessibility feature.

R: Could you please open it and tell me what you think about the options?

P9: To me they are understandable and very clear.

R: We were thinking of having captions and a chat mode where you could see the messages coming, similar to a chatbot. Would that be something similar to what you were talking about before?

P9: Maybe additionally. I would probably just have a menu where you can have all of the topics and you can choose from the submenus.

R: Do you think that whether you opened one of the options, would it be better to access written content or go back to her speaking that content?

P9: I would probably have both on one screen. I would just do the bullet points and not the full written text and it would all fit on one screen.

R: Do you remember your first impression of Anne?

P9: I liked that there is somebody talking to you instead of an impersonal experience of a normal website. They always look kind of funny when they speak, just because they are not human. I think people are used to it and don’t really mind that. I quite liked it.

R: Was there any emotional response from yourself?

P9: Not necessarily, just because I think that most people have symptoms and might look them up instead of the disease in general. In that way I think you’d connect more: by talking about the symptoms instead of about the disease. I did relate a lot to the scenario that you presented me, because that happened to me as well with my father. I have experienced that, and I think that it is the symptoms that make people worry and push them to google and understand what is happening, rather than the explanation of what is going on physiologically.

R: So you’re saying that it is the content more than how she is interacting that triggers emotional response in people.

P9: Yes, I would say that. Of course the tone of voice is important, but I think people connect more through the content than the way of talking.

R: Did all of the actions that you had to take feel clear, or was there anything that was not so clear?

P9: No, it was clear to me.

R: And was the explanation clear?

P9: Yes, but I also know a lot about AMD, so I may be the wrong person to ask.

R: Did you feel like something was missing? Was it too long or too short?
P9: I liked the graphic of the eye. I liked the thickness of the lines and the contrast. I also liked that you provided information about the tests that ophthalmologists use, because oftentimes you can’t find it or it’s very complicated.

R: What did you think of the fact that in the diagnosis section you had to navigate through the content?

P9: On the one hand, you have to take one action to go on, but it also gives you time to think about the information and you don’t just get this long explanation of all the different types of tests. The terms are also quite complicated so it might be better to have to click next.

R: Would you also have it in the explanation section?

P9: I don’t think so.

R: Would you be able to tell me what you liked the most and the least?

P9: What I liked the least... As I said, I would like to have a menu so that if I already know something, I would be able to skip stuff by choosing in a menu what I want to hear about. What I liked the most... I did like that you have sort of this personal assistant that is explaining things to you, i like this idea because it seems more personal than this very neutral text about a disease that affects you very personally, so I really liked that. However, I do think that nowadays you want to provide as many options as possible so that everyone can find what they prefer. Some people might choose the personal assistant and some just text.

R: Do you think it would be better to have the assistant on one corner, and you can open it. So maybe you land on a traditional website and you can open this option, or the other way around.

P9: if you did, i would probably start with the assistant and have the option to go to the text, just because i think that is what makes you different from the other information you can find. And you also want to talk to visually impaired people and text might be difficult to read for them. You could also do a website with videos integrated, but I think I would still prefer the virtual assistant just opening and having the option to read text or bullet points.

R: How hard or easy did you feel it was to interact with Anne?

P9: I think it was easy. Maybe one thing for accessibility, I might not put the buttons next to each but underneath one another so that they start at the same place.

R: Do you think that if this service was upgraded to full content you would use it or recommend it to someone else?

P9: Yeah sure. There is a ton of information out there, but I think that it would be good for many people to have this option where someone is explaining it to you rather than reading. Because a lot of people don’t do anything until they already have quite severe symptoms and often struggle with reading. So it is a great option to have someone explain it through actual speech.

R: And would you- personally prefer this kind of interaction or a traditional website?
P9: It depends. If I were new to all of this and wanted all the information, I would like it this way. If I wanted a refresher or specific information I would probably prefer written text. But I have no difficulties reading anything.

R: Do you have anything to add?

P9: You talked about a chatbot. I personally don’t like those and especially hate when they just pop out. Maybe with something like this it would be different. I would rather google my question rather than using a chatbot. But I think they are not for everybody.

9.5.10  Participant 10

9.5.10.1  General information and notes

The participant doesn't use a screen reader, but the size of the items on the screen is increased. Asks for information about whether they should click or talk. The participant navigates the system using the mouse and doesn't speak.

9.5.10.2  Evaluation

R: What do you think about the accessibility menu?

P10: I think it is critical to give people some options, especially about text size. These are two options. I'm intrigued by the closed captions. And especially if the users are in a busy waiting room, closed-captions could be a good option.

R: What did you think about this experience?

P10: I think people would appreciate it and have interest in it.

R: How would you describe it to a friend?

P10: Almost everything that is available on the web is written or static videos that you can’t click on when you’re ready, and I think having that and the way it is set up, people might be interested in its use. So if i was trying to describe it’s an animated icon that is navigating you through your early learning experience with your diagnosis as you try to learn about your disease, and it is interactive, whereas much of the other resources that you see are not, which allows you to travel at your own pace.

R: What would be the three things that you enjoyed the most and the three that you enjoyed the least?

P10: I'll go to the negative first. The voice activation was clearly translating what i was saying but was i supposed to click on that box? It didn’t seem to activate it or respond to me. So I think that would need better clarity, so I didn't use it but continued clicking instead. I think having a dialog around what it means to live with would be great. It was clear, the content. The initial heading is what people would be looking for.

R: What did you think about the content? Was it too superficial or right?

P10: There are some questions for future development. It constantly refers you back to an ophthalmologist, so I think it has to be country-specific, and explaining the rules of the three O would be good because people don’t know which professional to go to. There is a lot of interest in trying to understand the warning signs and give them comfort and reinforce what they need to do. So getting your eye exams. This is an early stage and could be pre-appointment, to help them understand which questions to ask to the doctor. I think that’s
something that is always helpful, so they can maximize their time with the doctor. Another thing that is very helpful when people are navigating the system is finding resources after they have their appointment, or peer-support groups, or resources for caregivers. I do think this has potential for people because it is more friendly and it goes at their own pace, because it allows them to go back and listen to it again.

R: And do you think that this digital human would be a good way to provide all of this information compared to the ways that are on the internet today, conventional websites?

P10: I would encourage thinking about having testimonials. The animated character is not the authority to deliver what other people have been feeling. I think having them as part of the presentation would be good and that is the limit of the animated character.

R: It would be possible to provide videos.

P10: When you showed the tests, you did provide media. I didn’t know when I was supposed to click the next button, so I don’t know if there’s a way to explain that. But absolutely there is no reason why those graphics couldn’t be the first-person video about the experience. In that case, I think it shouldn’t be an animated character that doesn’t smile.

R: What did you think about the images?

P10: I had no reaction to it. I did have some loading issues from my system, but other than that it was fine.

R: What about the first moments when you started to interact with it?

P10: I think you want people to get into it, or else they’ll just walk away if the intro part is too long. It wasn’t too long for me, and it wasn’t too short either, the balance was fine. Other than the fact that she doesn’t smile... smiling plays a big role on how people react.

R: What would you say about her personality?

P10: She was professional, had a serious look because she wasn’t constantly smiling. I noticed you had her scratch her hair when there was a time delay. I’m not sure that’s respectful, it’s kinda funny that reaction... But I thought the character was good. Are you gonna be able to make it more reflective of the country or is it going to be static?

R: For now, it can’t be changed.

P10: I think that diversity is very important. Also, the experience videos give that opportunity. It’s a big issue also in the States and it is very relevant.

R: You were also talking about the movements. There is no real environment now, but it would be possible to have it...

P10: The simpler you make it the better. Most of these people won’t see it before they come to the clinic, so they’re going to be 70/80 for sure. You have to be conscient of an elderly population and their abilities. So, I think the more you make the background complex, the harder it would be to get it. Maybe a bit more friendly, but not more complex, it will make it harder to see. The colors right now look good. The text size is also critical.
R: Would you recommend this kind of solution in full content?
P10: Oh yeah, absolutely. You have to go through the right delivery channel.
R: Do you think this kind of interaction adds value compared to a traditional website with written text?
P10: I think people would appreciate having the options to stop and start instead of reading. Having the audio is very important.
R: And what about a mixed version where you would have some written corner but also a way to get access to this discussion?
P10: I think you want to walk them through the animated experience, because if they want to read, they can go to another website. But having a document that they can download that summarizes the content, that would be very friendly to people. People have different learning styles.

9.5.11 Participant 11
9.5.11.1 General information and notes
The participant doesn’t use a screen reader, but their left eye is strongly impaired and only sees blur. The participant almost exclusively used voice commands.

9.5.11.2 Evaluation
R: So, I wanted to ask you what you would expect from this button on the top left corner of the screen.
P11: I think that’s an option to change the appearance of the digital human, maybe to change the figure or something.
R: What do you think about these options?
P11: The language option is really good because someone who is not comfortable with English or more comfortable with another language can choose. So the language option is really amazing for someone who wants to speak with the digital human in their own comfort language. And the text size... I usually prefer larger text sizes, so if another person has a worse one than mine, they might also want a little bit bigger font. So, the option for choosing the font size is really amazing, I have to say, because we could choose according to our comfort zone. I think the caption is that I can have the written text, similar to the text next to the microphone symbol. I have to say that that caption is like a very small box, it would be more comfortable to me if it would be a longer one. As you can see here, I could not even read the words completely, only some portions of the words. Having an option to increase and decrease the voice speed is also a really good option.
R: What did you think about the experience?
P11: I have to say that this one is really amazing. When I was diagnosed with my condition, I had to search the Internet for the proper solution, I had to go through different websites, most of which are not user friendly to me. But when I see this one, I feel like I have someone to share my condition with, like I have a friend. She is like a nurse, so I can feel that she is a real person who knows more about my condition and is also very friendly to me. It comforts me, that’s the main thing, the comfort zone. I feel comfortable using this one, and there are so many options to choose what we want to know. There is an option to
share my conditions with her right... No, that’s not available now, but that option is also really amazing so that I can share my symptoms with her. I think she may give some suggestions according to my symptoms, so that would be really amazing. The only problem that I see is that there is a white background. I’m not comfortable in white or brighter background, I usually prefer a darker background. When she’s speaking to me, I could not see her face perfectly because of the lighter background for me, which is blurring her face. If I look at a lighter background for a longer time my eyes may get watery. If there was an option to adjust the contracts that would be really amazing.

R: So, you already told me a little bit about it, but I wanted to ask you in a bit more detail what your first impression about Anne was.

P11: My impression about the character is that I like her, so she’s almost the same age as me, so she can understand me. So, I think she’s like a friend. She’s like a nurse, so I feel like she’s professional and I think she knows more about eye conditions. We prefer a doctor or nurse because they are more informative. It feels like she’s very intelligent in the medical field. I feel very comfortable with this digital human, it feels like a real human to me.

R: Did you feel comfortable in all of the actions that you took?

P11: Yeah, I’m comfortable with that. I like that you can choose a condition, what are the symptoms, what are the diagnosis and more. Almost all points are listed there, we could choose what we wanted to hear, and that is really amazing. Maybe someone already knows about the symptoms, and they only want to know about how to diagnose the condition, and they could directly go to that section, they don’t need to hear all of that stuff. The communication between me and the digital humans was really amazing, as if we are communicating with a real person, I don’t feel any kind of complexity or difficulty in communicating with that person. Because the options are really good.

R: Did you feel that what she was saying, so the actual pieces of information that you were saying were clear?

P11: Yeah, that was clear to me. There is no complexity in the words she’s using, so that every person can easily understand. She didn’t use any tough words or any words that I do not understand. She explained the conditions and all the information in very simple English, so that everyone can easily understand and be comfortable with.

R: What did you think about the images that she showed?

P11: That was really helpful. If she was just speaking, it would not be as easy to understand. I think that is really helpful. By looking at that picture we can understand and get a quick idea about what it is.

R: And did you feel that the information that she gave was relevant and important?

P11: The information is relevant and feels like genuine information to me.

R: I wanted to ask you if you would be able to tell me what you like the most and what you like the least about the experience.

P11: The most likeable thing is the appearance of the digital human and the fact that I feel comfortable in her appearance and the way she speaks. The
information she provides is also really good. I do love everything about the experience, like the option to change the font size option and to select the language. Communicating with a person that lets me select an option is also really good. The only issue is the background issue... sometimes if I look at a bright light my eyes become watery very quickly, so I try to avoid brighter light and lighter background, so if there is an option to adjust the contrast of the background that would be more comfortable. To me that’s the only issue that I felt during this experience.

R: How would you describe a name to a friend if they asked you about your experience with her.

P11: I will tell my friend that this is a great experience for everyone who is looking to understand more about their own conditions and it’s a friendly website. It’s a friendly digital human, so we can share all about our condition, and she will be there for us and give some tips and give some recommendations. That would be very comfortable to us: very informative and very friendly, so we feel like we have someone to stand with us during our condition.

R: What was your impression of the content in terms of was it too long, was it too short, did you feel like something was missing, was it boring?

P11: No, nothing was boring, I really loved to hear all the information. If there was more information, I would definitely explore that one also, because I just want to know more about everything. I would definitely explore my own condition so that I will share my condition with her, so I feel like everything is perfect for me.

R: How easy or hard did you feel it was to use the service?

P11: The platform is very simple: there are only three buttons. So, there is no complexity in communicating with the digital human, the language that she speaks is also very simple, so everyone can easily understand. The communication is really perfect. By clicking itself, we could understand everything. There is no complex image or complex words in it, it is a nice experience.

R: Would you be able to tell me what kinds of feelings you had during your interaction?

P11: I felt comfortable, she was friendly, I felt like there is someone who is with me during my condition, and I can share my condition with her like with a friend, not only a professional nurse or a professional doctor. I felt like she was a very experienced and informative person who stood with me to share my condition with her, and her opinion would be really helpful for me. I felt like I was talking with a doctor who is friendly to me.

R: So, do you think that if this service had the whole content and the whole functionalities, you would prefer to use this kind of service or a regular website where you just read the information?

P11: I will definitely use this kind of website because I can directly ask her what I want to hear. When it comes to a regular website, you have to go through each and every section, and that is time consuming. Sometimes it’s boring, and there are so many issues to find what we want. On this platform there is someone to
help us, this one is very easy to use, and I feel comfortable with it, more than with something I have to read and find it myself.

R: We were wondering whether it would be better to have something like the chatbots where you have the icon somewhere and then you can start to interact with it. Do you think that would be better or starting straight away with the DH is best?

P11: The interactive website is the best thing, so that we don’t need to use the entire website, but we can get only the information that we need. When it comes to a regular website, we have to go through everything to get what we need, so this kind of website is really better, I think.

R: So, would you recommend this service to other people?

P11: Definitely, I will definitely recommend this to others.

9.5.12 Participant 12
9.5.12.1 General information and notes
The participant is sighted. At the beginning they tried to talk to the DH, but the command was wrong, so the DH did not respond. The participant tried insisting for 3 times, but then gave up and started to interact mostly through the mouse. Sometimes, they try speaking again and it works.

9.5.12.2 Evaluation
R: My first question would be if you could tell me what you would expect from the button on the top left corner of the screen.

P12: I suppose that would be like a menu for what part of the human body you want to ask the virtual assistant about. I mean that’s what I’d expect because you have to choose what you want to learn

R: Can you please try to click on it and tell me what you think about that menu.

P12: The language of course it’s important if you’re not a native speaker. Text size, I guess it’s for people who have hearing impairments, so they can only read what the assistant is telling them.

R: What did you think about the experience in general?

P12: Well, I think it was pretty useful, I mean a bit better than I expected. The voice is pleasant enough and it explains what it can and tells you what it can show, so I think it would be pretty useful.

R: And do you remember what your first impression was about Anne?

P12: Yes, my first impression weeks ago was that I didn’t like her all that much. Now I find it’s a suitable character for what is required. I mean when you’re looking for information it’s pretty good.

R: How would you describe Anne to a friend if they asked you about your experience with her?

P12: Well, I’d say it’s a user friendly and knowledgeable AI virtual assistant. So, I think I’d say it’s one of the first places to look for finding out more information about the human body. It’s better, a bit more personal than just text telling you.
R: Would you be able to tell me what kind of feelings this interaction made you feel?

P12: I'd say it's more like a bit of a personal feeling. I don't know, it's more personal than just looking for 10 medical texts or diagrams on the Internet. So, I'd say it's a better feeling because it's almost like you're talking to someone and it's like someone that's just there for you.

R: Would you be able to tell me the thing that you like the most and the one that you like the least about this experience?

P12: I did like the way it was presented. It tells you everything she can tell you about: first the different conditions, and then the different symptoms etc. What I disliked most was that most options didn't work, I mean, I couldn't check them out. Otherwise, I didn't dislike anything. It was there, providing the information. I just have to listen, it's easy to use.

R: What was your impression of the content? Did you feel like it was too long or too short, difficult to understand or boring?

P12: No, I find it was pretty much the right length that tells you what you need to know about it, and then it tells you the truth about what the doctor can do to determine so it's I found it pretty, to the point. And if you want to go a bit faster, there is the next button. So, it's good.

R: What did you think about the images that she showed?

P12: I think they were necessary to better understand what she was saying. Images are often worth more than words, so I think the images were great. They really helped in understanding what she was talking about.

R: Was it clear what she was saying?

P12: No, no, I think it's pretty clear. It was all clear and easy to understand.

R: What about the relevance of the information she was providing?

P12: I think the information was important to know. She wasn't droning on and on about useless things that should be superfluous information. You just get the information pretty much that you're looking for. I don't really see how it could be shorter, or better. She has to tell you enough information so that you can actually get an idea, so I found it just about the right length and.

R: What do you think about the fact that in the diagnosis part you had to click next to proceed through the content?

P12: I didn't mind. I found it, I found it okay. The button appears when she's about done and that helps to know when she's done with a certain option.

R: If the website was released to full content do you think you would use it.

P12: Yes, yes, I think so because, like I said, it's more personal than just medical texts. It's mixing a human appearance talking or with images. I find it's clearer than just text. So, if I needed to find something I would use it.

R: Would you say that you would prefer this approach or a regular website where the content is just listed, and you read it in text.

P12: I think I'd prefer that to this website, because just texts can be confusing and this one was kind of simplified. She tells you the options and guesses with
some symptoms. If you don't know what you're looking for there could be lots of options. I find it could be useful to find what you're looking for more quickly.

R: We were also thinking about the possibility of having this embedded into a traditional website, and then you can open this new window to talk to her and interact with her or just continue on you know, like the assistance that you have sometimes on the websites.

P12: Well yeah, I guess that would be fine I mean I some people would rather have a text version. It’s always better to have more options because not everybody’s the same.

R: And in that case, which one would you prioritize?

P12: Well, I think I like the way it is; it is now better.

R: So, my last question would be whether you think you would recommend this website to other people.

P12: I think so, yes. It’s sometimes hard enough to find information, and I think this one would be a good means. I don’t see why I wouldn’t recommend it.

9.5.13 Participant 13

9.5.13.1 General information and notes

The participant is sighted. The researcher needed to share their screen because the service was not loading on the participant's machine. For this reason, the participant gave instructions to the researcher on what to choose, and the interaction was only through clicking.

9.5.13.2 Evaluation

P13: The facial expression of this girl hasn't really improved for me. I already said that the expression is very serious, it’s not really friendly.

R: The first thing that I wanted to ask you is what would you expect from this button here on the top left.

P13: Okay, so I would expect that there’s another AI person to choose from. The other time, I suggested that the character should be close to the user’s age. I expect when I click that one, I can choose any avatar.

R: Can you tell me what you think about the menu?

P13: It's not the right icon for it. I guessed it was a person and I could choose a different one. It would be great to have subtitles. And also, it would be good that this person can speak any language. And also, it’s good that we can also resize the text. Also, there’s a voice speed option. They are very recommendable and important options.

R: In general, what did you think about it?

P13: It’s not really colorful. I would prefer a background like a hospital or office where you can feel at home, where there’s books at the back. And the face of that AI for me it’s not very friendly, it is very serious. Maybe she can smile a little. Also, she talks really fast for me. It’s very intelligent so I’m going to tell her “Please go back, I forgot the process” and she will do that. Also some of the people are really worried about the information, meaning how can we assure that this intelligent person is saying the right thing. If the company could provide an assurance paper that she is talking accurately 100%, we would really
believe this. If she did that, I would be amazed, because I'd know it’s good Information.

R: Could you tell me a bit more about which one was your first impression?

P13: She is really serious for me. The total impact of and it’s very good but she talks too fast. And sometimes it is glitchy and lagging a little bit. Also, she didn’t really move. There’s a lot of space and it’s nice that she is moving a little to the side, but for me it’s not moving too much, and it would be better to have more natural movements. I guess that’s the facial expression again that’s the problem for me. It’s very strict. It might be so that people know that she’s getting my information and would really believe that she’s giving correct and accurate information... but it would be great to have more of a peer-to-peer approach. The current approach is very okay for adults.

R: Did you feel like whatever she was explaining was clear?

P13: I would like to have labels on the pictures, and maybe even on the content. For example, in the explanations, when she’s showing pictures of the eye, it wasn’t always clear what was changing.

R: Did you feel like the information was relevant and important?

P13: Yes, it’s very important, it’s relevant for me. But again, I hope that the company itself is going to show some kind of certifications to tell us that it is talking 100% accurate and it is relevant information. This is because some people are hesitant when it comes to online information.

R: Would you be able to tell me the thing that you like the most and the one that you like the least about this experience?

P13: The thing that I like the most is the process. It’s very easy. And I liked that you could have captions and also slow the pace down. The thing that I don’t really like about it is, it wasn’t clear what it would do. The other one that I didn’t like about it is that there’s no label on all the information that she’s giving.

R: Was your impression of the available content? Was it easy or difficult to understand, was it too long to short, was it boring?

P13: For me it’s the right length. We should, of course, tell the correct and accurate information. The length is alright.

R: How easy or hard did you feel like it was to use the service?

P13: It’s easy for me, very easy. You can also go back to the last part that she’s talking about.

R: Would you be able to describe for me the feelings that you were having while interacting with Anne?

P13: I guess it’s knowledgeable like. I know I am hesitant and worried if it is correct and precise information, but I thought she is very knowledgeable, and it makes me more assured.

R: So, if the service was released with full content and full functionality, do you think you would prefer to use this kind of service or a regular text based website?
P13: I know all the information that she is giving us is already provided in Google, but it might be fun to learn this way, so that you're not going to read but there's someone reading the information for you. You're going to relax and listen and you don't have to search, so it is also organized already. So, I prefer this kind of thing, because I don't really trust Google a lot, but I hope I'm going to use this intelligent AI I would feel at ease. I would prefer using the AI.

R: So, in terms of the interaction style, if the content was the same, which one would you choose?

P13: I will choose AI again. It's very fun, because there's a person who is talking, who is smiling (I hope it's going to smile) and I would then feel at ease. If I'm the one reading the information, I might get worried. But when I'm talking to that AI, I feel less stressed.

R: Would you recommend this service to others?

P13: I would recommend it; it is really accurate. So, if my friend or my colleagues would be worried and they would be going to search on Google, I would tell them to use this link.

9.5.14 Participant 14

9.5.14.1 General information and notes
The participant is living with low vision, mostly blurry, but they are still able to see the screen. The participant interacted using the mouse.

9.5.14.2 Evaluation
P14: Oh hi! Now she's smiling! Okay, so I see that as I'm speaking, she's actually listening in from the microphone, which is on. I think it wasn't clear that this was going to be the case, like once my microphone is turned on that means whatever I say she's going to be listening in and I don't know how she's going to process all of this. I think it wasn't really clear that that was going to be the case.

P14: I would want to have a pause button. To be able to pause what she's saying and maybe take notes or go talk to someone or just do something and then come back and pick up where I left off. And also, I think when it's up and running fully I would like to be able to turn off the microphone just by clicking on the icon.

P14: Before I continue, I want to say that so far this is really good. I like what I'm seeing. I'm getting a lot of value here cause right now I'm putting myself in that scenario where I'm just here to find out and I don't have that much knowledge. So, I'm thinking of the first time I heard about this and how I would feel just seeing all of this information, and this is really good.

P14: Okay, this might be a bit too much, maybe for the website, but I'm thinking: the images are really okay, but I'm thinking if we could have short videos, so it's like motion pictures. While she's talking and explaining you just have this motion picture going on, I think that would make it really come to life. It will make the user feel like this is an experience but otherwise this is also okay.

R: The first question is, what would you expect from the button on the top left of the screen?
P14: It looks like a person, so it looks like I'll be able to pull up my medical profile from here in my personal profile, like a personal account from yourself.

R: Okay, could you try to open it and let me know what you think about it?

P14: Oh alright... I see language, text size, closed captions, voice speed. This is not what I was expecting. But I think it's okay to have it here, it would help users to catch up with what's being said, and for people from different languages. And the text size, I can increase it depending on how comfortable it is for my eyes or have closed captions to read what she's saying. But this is not what I expected because of the icon.

R: What was your first impression of Anne?

P14: yeah, I think I do, I said she didn't smile a lot she seemed too serious, but now I think she's a bit more friendly. And, also, I had a comment about the graphics, and I said it wasn't really lifelike but now I think it's more lifelike and her movements are more fluid. So, it's better. Her speech is also almost lifelike. I almost couldn't distinguish that you know wasn't a real person talking.

R: And did you feel comfortable in all of the actions that you had to take?

P14: Yes, yes, I mean I wanted to keep going.

R: My next question would be whether the information that she provided was clear for you?

P14: Yes, it was very clear. I like that she used a lot of everyday English, not a lot of strong medical terms that would leave me confused, it was really simple to understand.

R: And did you feel like the information was also important and relevant?

P14: Yes, very useful. Viewing this from the perspective of someone who's not seen this information or doesn't know about this and it's just trying to find out for the first time, it's super helpful, I mean I could see myself; you know with a pen and paper taking notes.

R: Do you have any other comments about the images or the media in general?

P14: I think if you're going to use still images, then they should kind of blend into the background. The background was gray, and then to have multi-colored images, it was a stark contrast, and it didn't make the page beautiful. Maybe you can take out that gray background and kind of put a hospital background or like an office or nurse's station, something that just makes it look more realistic. And in that way, if you put still photographs, I think it would still be okay. But videos will still be better for me.

R: And so, did you notice that the presentation of the explanation and of the diagnosis part was a little bit different? Do you have any thoughts on that?

P14: No, I think I have a question. When it's fully operational, would I be able to say I want to select something and will she be able to pick that up and continue from there, or do I still have to manually click?

R: No, no, she would have been able to do this at this point too.

P14: Oh, right okay well that's super cool then. I really like that.

R: So, you think it was useful to have the next button?
P14: Super useful.

R: How would you describe Anne to a friend if they asked you about this experience?

P14: I’d say a digital nurse that has a lot of knowledge.

R: And would you be able to tell me what kind of feelings you had during the interaction?

P14: The first was a wow feeling like wow this is real like it is so knowledgeable. But generally, I felt good. I didn't feel off in any way.

R: Would you be able to tell me the thing that you like the most and the one that you like the least?

P14: I think I liked that it was a very close to life experience, because there were diverse things she was talking about, from general knowledge to specific things. It was just a very good feeling. The one you like the least was not being able to pause.

R: What is your impression of the content? Is it too long or too short, is it easy or difficult to understand, is it boring?

P14: I think I think it’s interesting, I think the time is adequate cause you would go into a hospital, and you really cannot tell how long you’re going to spend. At that point you’re not even worried about the time, you’re just worried about understanding what’s going on in your body at that time. And I think she did a good job in explaining that and letting me know what is going on and why I’m feeling the way I’m feeling and what steps I could take next so everything was adequate.

R: How easy or hard did you feel it was to use the service?

P14: It was very easy.

R: Is there a specific reason why you always clicked?

P14: That’s because I didn’t honestly I didn’t know if that was going to work. I wasn’t patient enough, but I think if I was using a real website I would wait and see what would happen if I tried out a couple of things.

R: Let’s say that the content would be available to its full extent. Do you think you would prefer to use this kind of interactive website or a regular text based website?

P14: I think this is better, this is closer to a real life feeling, and I want to get what’s closer to real life even so i’ll go with this.

R: And what about a website with a little window in a corner to discuss with Anne?

P14: I think starting to talk to her is better. But I would also expect I won’t be thrown off if I saw a form to fill in, just put in some details about me. So you have to form, where you put your name and a couple of details about you and so that, when she’s talking to you, she can address me directly, use my name, for example. Stuff like that would make it really feel like a real life situation because that’s how a nurse in real life is.

R: Do you think you would also recommend it to other people?
P14: Oh yes, definitely most definitely.

R: Do you have any other comments for us?

P14: Yeah, that will be the icon I was mistaken for my profile. I think it should be changed, maybe for a chat icon?

R: We were also thinking of having the option to open a chat mode, let’s say so that you wouldn’t see her speaking or interacting with you anymore, but you would see a more standard chatbot. Do you think that would be useful, or is it not really needed?

P14: I’m trying to think in the broader scheme of things. For example, for those who have a deficiency in hearing, I think it will be helpful to be able to chat, so I think that’s useful.

R: And also, maybe the option could be that you know she still is on the screen, but on half of the screen you see the chat.

P14: Oh yes, that would be a lot better.

9.5.15 Group session 1
9.5.15.1 General information
Number of participants: 6

Number of participants that took part to the one-on-one interviews: 5

9.5.15.2 Notes
One of the things that is most valued by the people in their organization is getting the support from other peers.

P1 suggests checking whether different channels are perceived as more or less trustworthy. The example is with a video of an ophthalmologist.

P2 says that it should be addressed as an informational character, not an emotional supportive one. Suggests that they should be able to choose between a female and male voice because people losing hearing struggle with female voices.

P3 agrees to have peer support. They think that it could be the thing that differentiates the service from others out there. Some people do prefer to engage with “robots” because they had a bad experience with doctors, or because they would make them feel less heard. The detachment from a bot might be really good for some people. Especially people with diabetes might feel judged by the healthcare professionals. The people with diabetes might be the most interested in this “detachment”. It won’t be for everybody, but some people will love that they will walk away more informed but not judged.

P4 agrees with P1 and P3. P4 thinks that this could be very helpful because often HPs don’t have enough time to spend with patients. Providing factual information easily is very important. For people who have been recently diagnosed, this could be a great tool. It’s valuable to have a lot of information coming from different channels.

P5 thinks it would be a good tool both on the way to the doctor and on your way back from the doctor. It allows you to get precise information in a smart and nice way. Wonders whether the target group would take advantage of the opportunity and be open to the interaction. Sometimes it’s the grandchildren or
children who tell them how to find the information. Hearing the information many times would help to absorb it.

P1 thinks that they wouldn’t feel like they got what they wanted from an AI. It didn’t really resonate with it. The human touch and the fact that people can talk from experience is much better than getting from a robot. Has seen videos of AIs online, and there is potential to be a bit more human. They are not sure how much difference it would make. Could be useful to ask questions you gather before going to the eye specialist, to know what to ask in the clinic. Think that whatever engagement you have with the robot you will want to spend some time with a human and discuss with a human.

P4 disagrees. When they see the regular eye doctor, they talk from a position of authority, using medical terms that they don’t understand. So having information available in clear understandable language is very helpful. Regarding emotional support, it is important how a specific person copes to the illness. In that sense everyone is different. And covering all of the scope is impossible. The character is good, can be fine-tuned, it is not a real person, and it can’t replace one, but she can tell things that we chose to hear. It is a digital character, and the point is not to replace a real person.

P1 thinks that if you’re using screen readers, there should be clues that you can use the buttons and where they are.

P6 thinks that the image chosen was a human, but maybe it would be better to have a figure that is not human at all, but something like a cartoon.

P2 thinks that emotional support should be defined. One way is to think that it is caring for the user, and that can’t be done. But giving information in a factual way, that would be good. The character is not taking care of emotions. The character shouldn’t be too talkative, the sentences should be short. The different stages bring different problems.

P5 would not expect emotional support from the DH, which might be more on the peer-to-peer side. Oftentimes, the HCPs don’t have enough time to give information but also to give emotional support.

P1 wasn’t engaging with the emotional support idea because the first thing he thought was that it’s not real, which might invalidate what it is saying. If the voice would be more human-like, warmer, it would make a difference in terms of engagement.

P3 thought that Anne was quite warm. Some people might get very annoyed by talking to a robot, it can turn off a lot of people. It was probably one of the best AI they have seen, and they are not a big fan of being spoken to by robots. It was quite good from a technological point of view. Sometimes it could be very nice to be passive and just listen to the information. They think some people might really really love this.

P5 thinks that real-life HCPs also don’t always act as warm as you would like them to be. They like the voice of the DH.

P2 thinks that the informational support should be prioritized. Getting information pulled up automatically. It should react to the people’s needs more than to their emotions.
P4 does not really appreciate the DH being able to recognize human emotions using the camera. The robot shouldn’t get too intimate, so it should prioritize giving information in the right way.

P1 agrees and wouldn’t let it recognize the faces. It would be good that it recognizes the words used to for example adjust the depth of the content. Like if someone says “oh yeah” it could recognize that they already know that.

P3 thinks that when you are surrounded by good HCPs you might not need to look for information elsewhere, but this is not the case for everyone. In general, it is mostly a personal preference.

P1 thinks that the feedback for the input speech might be complicated to see and use. It might be seen as a distraction. Having captions would be vital.

In general, participants aren’t too favorable to the DH providing emotional support, but more looking for factual information.

9.5.16 Group session 2
9.5.16.1 General information

Number of participants: 9

Number of participants who participated to the one-on-one interviews: 5

9.5.16.2 Notes

P2 thinks very well of it. The distance from doctors is increasing so this could be a very good interface, so the user can be accepted and find information.

P6 thought no one would like it. It was good work. They are concerned that the target group (older) would not be able to use it.

P3 was very skeptical but ended up being almost addicted to it and would have really liked to use it. It was very easy to use and to get around. They were convinced almost straight away. Word of mouth might be the best way to convince skeptical people. It might be very useful to many people.

P2 is really positive about it. They want to suggest that people of older age struggle with interaction on websites. These people often get support from other people. For everyone else it works really well.

P9 agrees with everything that has been said. It’s a good initiative that can help to facilitate information to people that are looking for it. It will have different results depending on the age group and the skills of the people. It’s a great complement to the available information. People are getting used to the dialog form of interaction. Such a platform can really help. It is complicated to make it respond in a non-confused way. There cannot be mistakes. People who might visit the website are full of doubts, and concerns.

P1 is really supportive of the technology. It might be worth embedding it to other websites. The main user group would be the newly diagnosed people. Having a tool like this to have more information would be very friendly and valuable. There might not be the possibility to provide very specific answers to specific questions.

P4 thinks it would be helpful, because it is always available at any time. Having the option to have it as text form would be interesting and useful. It’s a great option for supporters.
P8 thinks that it would be good to provide balance between medical information and how to deal with it in real life.

P2 it is very important to inform the caregivers. There is a lot of suffering and isolation. The doctor has very little time to dedicate to patients, and they do not really check the background of the patients, if they are alone or supported. Important to explain what will happen, reassure the patients, inform the caregivers, explain to the patients the treatments. The patients should be protected from frauds and be protected and sheltered. People are increasingly lonely and isolated, which accelerates the worsening of conditions. This is the role of the services: making people feel like they are not alone.

P6 there needs to be high quality translation. And also consider cultural differences among the countries.

P7 this kind of tool can take many directions: the patients (who could not be linked to technology), so maybe identifying family members that are close to the patients to support and help them. There is a medical desert, and we need a technology expert to be linked to patients. It’s a way to be in touch with people. Families with technological skills are ready to use the service, but patients might not be. It is very important to provide call options. Understand what the channels to be in touch with the patients are.

There is a need to consider different ages. Word of mouth might be very important. HCPs communication might be really important. People might be more aware of technology and interaction. People are growing lonely and it is important to address that.

P8 felt like they were talking to a real person.

P2 says it looks really good and wouldn’t modify it.

P5 liked the voice, the way she speaks, she’s just great. Easy to understand, most of the time it is easy language. Would appreciate the possibility to go further into detail. But for people who don’t know much it is perfectly fine. It is useful information, and I might be happy to find this if I was looking for information. In the long run, people might want more information.

P4 says that the day-to-day experience is missing. For now, the content is a bit impersonal, the little day to day things are missing, the tips. Tips on how to help before going into treatment. It’s good to have the option to hear it both peer to peer and in this impersonal way.

P3 says it’s very engaging and suited for beginners. It would be good to have information in deeper detail.

P1 says it was very medical in the presentation. There are questions related to daily life, which are emotional, and it would be good to address those. Also, it would be good to know which professionals to turn to. Preparing for the appointment would be very helpful. Some people will be willing to receive emotional information from a robot, some won’t. Having a bot might be a safe space where they can start thinking and then being redirected to other resources. The bot allows you to get the elephant in the room questions and then be ready for the HCPs appointment.

P8 thinks it could be useful from a supporter’s perspective and from a parent’s perspective. It would have been nice to have a site like this during their journey.
You might get your answers and open the dialog with the children or with the doctors. It could appeal to the younger generations.

P9 says that it is important not to limit it to medical information. It can be a first step to have more confidence in the information, not only on the medical perspective, but also the emotional side. The psychological support is lacking and is important. People really need this to accompany its journey through the information. It can be a good instrument to support, initiate and guide. In the first steps it can really guide the person looking for information and needing the support.

P5 thinks that there are very important questions about how independent their life will be. This might be a good place to ask these questions. People tell stories and the best response is other stories. People resonate with personal stories. This can be a good way to express empathy.

P7 thinks that perfection is the enemy of good. There are different stages of response to a diagnosis. It is important to be involved in all the possible options to involve the patients. It is important not to try to be perfect straight away.

P2 also agrees that we shouldn’t try to be perfect in the first stages. It is during use that we will understand how to make it better. Over time it is possible to enlarge the scope. Every country has different cultures and limits. Not being abandoned and not having an unknown interlocutor (as on social media) is good. The system is high quality and reliable.

P3 agrees that aiming for perfection straight away is not doable. It is not easy to answer all of the questions.

P9 thinks that the problem is really serious and can influence the whole life of many people. It is all dependent on the development of the AI and its ability to actually react to the emotional content that comes from the user.

P2 thinks that the emotional side is extremely important. It is important to guide the person straight away from the start. Once the condition is understood, it is important to understand which condition. They believe in standardization, and people need to be grouped automatically. Many demographic information needs to be understood. There is a lot of complex information that needs to be understood in order to guide and support patients.