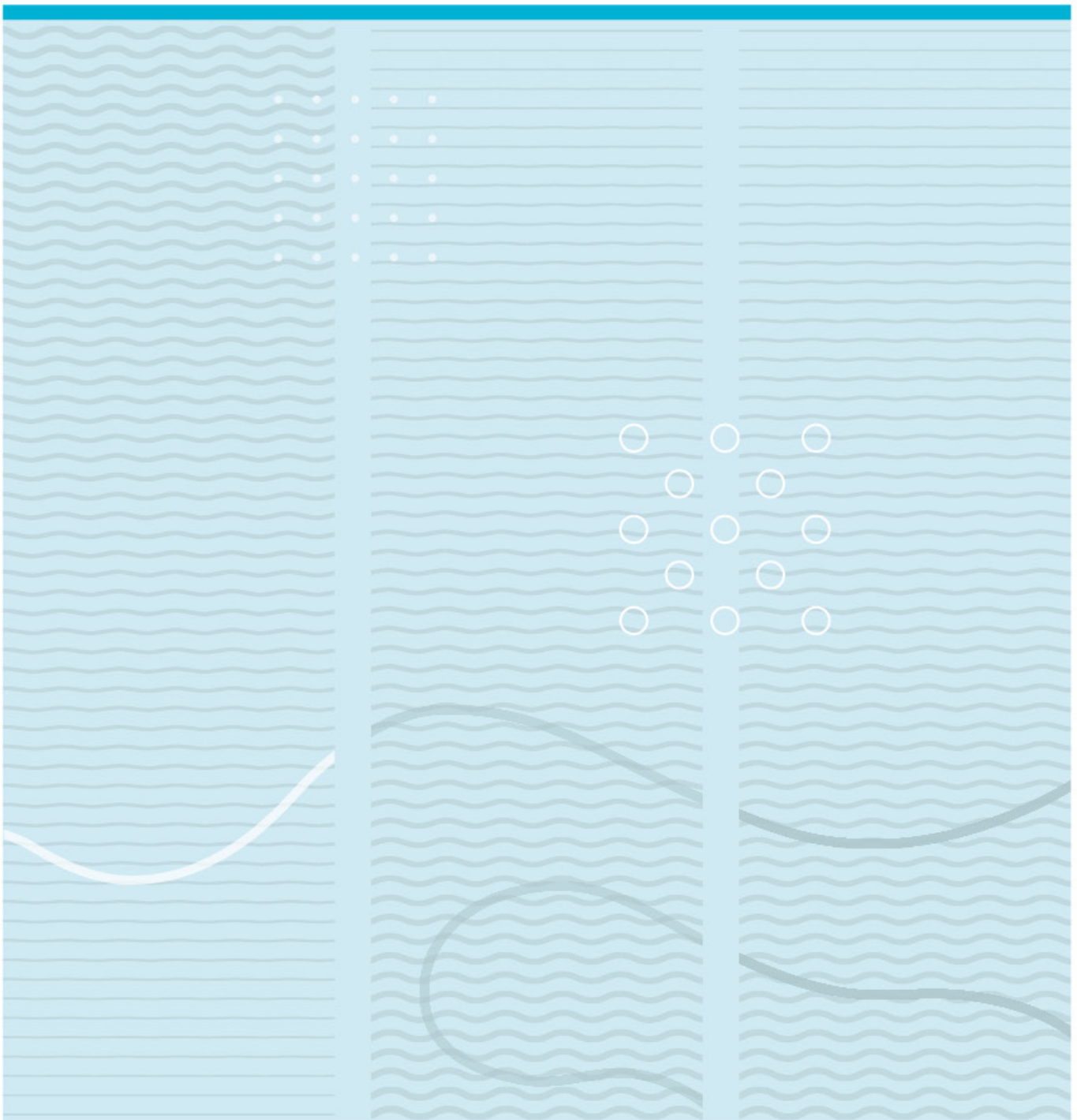


Sindre Gården Paulsen

# RetiPlus and Retinitis Pigmentosa

A qualitative study looking at experiences of persons with RP using an advanced AR device.





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Denne avhandlingen representerer 30 studiepoeng

## Abstract

**Background:** Retinitis Pigmentosa is an umbrella of progressive inherited eye-diseases that affect a person's night vision, peripheral visual field, light sensitivity, and ability of light adaptation. RP usually affect a person after they have settled their life with normal vision. It assumes psychosocial challenges as tasks in their daily life become more challenging and it affects their participation in society. Related to the progression of RP, they tend to need technical aids for orientation and mobility. RetiPlus is a pair of video glasses using Augmented Reality to add digital information to the real world. As new devices using AR gets accessible, new technical aids for orientation and mobility will emerge. The purpose of this study was to explore how the use of RetiPlus for orientation and mobility is experienced by persons with RP, and to explore their reflections on how AR can contribute to orientation and mobility for persons with RP.

**Method:** Semi structured interviews were conducted with 4 informants two times. The interviews were recorded, and the recordings were subsequently transcribed to readable text. Through a Qualitative Content Analysis, the texts were read to get a sense of the whole, then divided into meaning units that were condensed, of which codes, sub-themes and themes were defined.

**Results:** Through the analysis, two themes with three sub-themes each emerged; Descriptions of the usefulness of RetiPlus, and Factors that affect motivation to use RetiPlus. The sub-themes were 1) RetiPlus is useful as it is, Situations where RetiPlus was useful, and The user experience is not good enough, and 2) Motivational approach, Motivating to use RetiPlus, and Negatively affects motivation to use RetiPlus. The usefulness of RetiPlus was closely related to the visual functioning of the informants. Some experienced increased vision, while others did not. It is most useful in relative darkness, for example in the evening, and in combination with other technical aids. RetiPlus eased orientation and mobility since it simplifies the visual scene. Judging distance was hard due to the one camera sitting on one side, and the capacity of the battery could be better and not be affected by cool temperatures so much. There is a threshold of using it in public.

**Conclusion:** RetiPlus is a useful technical aid for persons with RP related to orientation and mobility. It can be more useful for more persons by implementing improvements to its physical design among other things. It is important to lower the threshold for using RetiPlus so the rehabilitation process of persons with RP won't be hindered.

**Keywords:** Retinitis Pigmentosa, experiences and reflections, technical aids, AR.

# Sammendrag

**Bakgrunn:** Retinitis pigmentosa er en paraply av progressive arvelige øyesykdommer som påvirker en persons nattesyn, perifert synsfelt, lysfølsomhet og evne til lysadaptasjon. RP påvirker vanligvis en person etter at de har satt livet med normalt syn. Det forutsetter psykososiale utfordringer ved at oppgaver i hverdagen blir mer utfordrende og det påvirker deres deltakelse i samfunnet. Relatert til utviklingen av RP, har de en tendens til å trenge tekniske hjelpemidler for orientering og mobilitet. RetiPlus er et par videobriller som bruker Augmented Reality for å legge til digital informasjon til den virkelige verden. Etter hvert som nye enheter som bruker AR blir tilgjengelige, vil nye tekniske hjelpemidler for orientering og mobilitet dukke opp. Hensikten med denne studien var å undersøke hvordan bruk av RetiPlus til orientering og mobilitet oppleves av personer med RP, og å utforske deres refleksjoner om hvordan AR kan bidra til orientering og mobilitet for personer med RP.

**Metode:** Semistrukturerte intervju ble gjennomført med 4 informanter to ganger. Intervjuene ble tatt opp, og opptakene ble deretter transkribert til lesbar tekst. Gjennom en kvalitativ innholdsanalyse ble tekstene lest for å få en følelse av helheten, og deretter delt inn i meningsenheter som siden ble kondensert, hvorav koder, undertemaer og temaer ble definert.

**Resultat:** Gjennom analysen fremkom to temaer med tre undertemaer hver; Beskrivelser av nytten av RetiPlus, og Faktorer som påvirker motivasjonen for å bruke RetiPlus. Undertemaene var 1) RetiPlus er nyttig som det er, Situasjoner hvor RetiPlus var nyttig, og Brukeropplevelsen er ikke god nok, og 2) Motiverende tilnærming, Motiverende til å bruke RetiPlus og Påvirker motivasjonen til å bruke RetiPlus negativt. Nyttien av RetiPlus var nært knyttet til informantenes synsfunksjon. Noen opplevde økt syn, mens andre ikke gjorde det. Det er mest nyttig i relativt mørke, for eksempel om kvelden, og i kombinasjon med andre tekniske hjelpemidler. RetiPlus lettet orientering og mobilitet siden det forenkler den visuelle scenen. Avstandsbedømming var vanskelig på grunn av det ene kameraet som sitter på den ene siden, og batterikapasiteten kunne være bedre og ikke påvirkes av kjølige temperaturer så mye. Det er en terskel for å bruke RetiPlus offentlig.

**Konklusjon:** RetiPlus er et nyttig teknisk hjelpemiddel for personer med RP relatert til orientering og mobilitet. Det kan være mer nyttig for flere personer ved å implementere forbedringer rundt den fysiske utformingen blant annet. Det er viktig å senke terskelen for å bruke RetiPlus slik at rehabiliteringsprosessen av personer med RP ikke blir hindret.

**Stikkord:** Retinitis Pigmentosa, erfaringer og refleksjoner, tekniske hjelpemidler, AR.

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## Preface

I must give my appreciations to persons and organisations for helping me make this thesis a reality.

My supervisor Ellen Svarverud at USN helped me with the whole process from the initial research protocol in autumn 2021 and till this thesis was uploaded. Also thank you for many interesting and engaging sparring sessions.

This thesis is based on experiences by certain persons who participated in this study as informants. Their contribution has been essential.

Including providing units of RetiPlus for the informants to use and borrow, the research project by Eikholt National Resource centre for the Deafblind and Hurdal Vision and Coping centre provided facilities, boarding and lodging for the informants and myself.

My employer Adaptor AS give me the flexibility I needed to finish this master's program and final thesis, and my colleges supported me throughout.

I need to thank my Wife, friends, and family for supporting me throughout this master's program, and especially thanks to my Wife and Grandfather for helping me tidy up this thesis.

Eidsvoll, 23.04.2023

Sindre Gården Paulsen



# 1 Introduction

Persons with visual impairment tend to need technical aids to compensate for loss of visual functioning. We tend to settle our lives according to our situation, and if we have normal vision, it affects this settlement. There are progressive diagnoses like Retinitis Pigmentosa, abbreviated RP, where the person starts out with normal vision, and vision slowly degrades over time. Usually, RP stays underneath a person's radar as they settle their early lives as teenagers and afterwards as adults who works and may have established a family. Suddenly things such as tasks within their work and daily life become more tiring and stressful. The person is then in need of rehabilitation programs for persons with visual impairment. Rehabilitation involves learning to use different technical aids one might need. As technology in general evolves at an increasingly faster rate, new advanced technical aids become available. The use of technical aids is required when a person with visual impairment tries to stay in or come back to the workforce. Working life constitutes a huge part of a person's economy and social life, factors attributed to a person's quality of life. In Norway, the authorities are by Law required to provide appropriate technical aids for persons with visual impairment. Since technical aids tend to be relatively expensive, it is important to know how motivated persons with visual impairment are in general to use new technical aids.

## 1.1 Background

During 2022 and 2023 a research project arranged by Eikholt National Resource centre for the Deafblind [Eikholt] and Hurdal Vision and Coping centre [Hurdal] looked at different programs to improve visual functioning of persons with RP. One of these programs was introduction to and training in the use of RetiPlus, a pair of video-glasses using Augmented Reality. Both Eikholt and Hurdal are central actors within rehabilitation for persons with visual impairment. One of the different programs the project looked at was the use of RetiPlus. The research project was divided into two separate weeks at Eikholt, one in October 2022, and the second in January 2023. During the first week, the informants got introduced to RetiPlus and its functions. Each one got to borrow their own set of RetiPlus, and the systems were set up with the tablet computer according to the informants expressed visual functioning.



*Picture 1: RetiPlus with the hardware in front of a tablet computer with the software.*

RetiPlus is a software developed by the Spanish company PLUSINDES SL based in Madrid, Spain (PLUSINDES SL, 2019b). The software is put on a pair of video glasses called EPSON MOVERIO. For simplicity the system, software and hardware combined is referred to as RetiPlus. It takes advantage of AR and has different functions to simplify the visual scene. RetiPlus was developed to improve visual functioning of persons with RP related to orientation and mobility (PLUSINDES SL, 2019a). The glasses have two small translucent screens placed vertically in the middle of the glass on both sides. There is a darker screen that can be put in front of the glasses to improve the user's ability to see the screens, and it can be flicked up out of the way if necessary.



*Picture 2: RetiPlus worn by a person with the filter screen flicked up.*

On the righthand side of the frame the camera sits, and from the left-hand side a cable goes down and connects to the control box where the software is installed and where the battery sits. The functions of RetiPlus take the visual scene and makes modifications accordingly. Sorted by how advance they are, the functions are as follows:

- Adjustable level of zoom
- Adjustable level of brightness
- Adjustable level of contrast sensitivity

- Highlight function that can be turned on or off.

For the highlight function RetiPlus uses artificial intelligence to detect edges and apply digital lines marking the edges. The functions listed above can be manually adjusted by the user through the control box. As needed, the user can adjust the level of zoom, brightness, and contrast sensitivity, and turn the highlight function on or off. A certified RetiPlus specialist can set other functions through a tablet computer, see Picture 1: RetiPlus with the hardware in front of a tablet computer with the . RP affects the visual field different from person to person. The size of one's residual visual field varies greatly from user to user, and the position varies as well. Through the tablet computer, the specialist can adjust the size of the image on the screen. The image can be maxed out filling the whole screen, or partially fill the screen. When the image is not maximized, the position of it can be moved. The specialist can also set standard profiles the user can manually flick through. For these profiles, the functions as listed above can be pre-set making it easier for the user to quickly adjust the image. For example, the specialist can set three profiles where one is a baseline which has a standard unchanged image, the second can have its level of zoom increased two times, and the third can have the highlight function on. The user can choose the baseline for maximum field of view, quickly turn the highlight function on to detect objects of interest, and then quickly zoom in to verify.

## **2 Theory and terminology**

### **2.1 Participating in society**

For persons to join and stay in the workforce after finishing school is very important to many as it has a huge influence over one's quality of life. There are more factors that affect a person's quality of life, most of which involves participating in and contribute to society. To contribute to society can be described as a fundamental factor for the quality of all persons. This contribution can be achieved through different means, such as participation in the workforce. Research has suggested that motivation for working is related to more than outside motivation such as money and status. There is a psychosocial aspect where persons see work as worthy because of inner motivation based on cultural values and basic human needs (Stjerne & Øverbye, 2012, pp. 48–50). Persons with visual impairment have in general the same needs for participating in and feel that they contribute to society, just like everybody else. In their study, Andersen & Skarholt (2014) point out that the basis for their study is that there are health benefits, both physical and psychological, for persons with visual impairment to participate in the workforce (p. 82). Work constitutes a relatively large part of a person's social life after school age. In Norway, high school is normally finished in a person's 18<sup>th</sup> year (Andersen & Skarholt, 2014; Stjerne & Øverbye, 2012).

### **2.2 Vision and Retinitis Pigmentosa**

Vision is by nature our main sense we use to move around and navigate the world. When we read and observe details, we use our visual acuity, and we use our peripheral visual field to gather information of our immediate surroundings in front of us. Our peripheral visual field gathers a lot of information at once without moving our point of fixation, the point where we focus our visual acuity. When the visual fields of both eyes overlap, a normal visual field has a horizontal plane of about 180° from right to left, and about 120° vertically from top to bottom, though not in an oval shape (Høvding, 2016, pp. 342–343; Whittaker et al., 2016, pp. 62–64). The world, including us humans, consists of variation in many ways, amongst which is our peripheral field. The information from our peripheral visual field can warn us about obstacles in our pathway we'd like to avoid. We all want to travel safely. When our peripheral visual field is restricted, avoidance can become a challenge in relation to orientation and mobility (Geruchat & Smith, 2010; Høvding, 2016; Whittaker et al., 2016).

Retinitis Pigmentosa (RP) is the most common inherited form of visual impairment worldwide (Verbakel et al., 2018, p. 1). It is estimated to affect 1 in every 3500 to 4000 people in North America and Europe (National Library of Medicine, 2020). With the same ratio used on the

population of Norway about 5.489 million (Statistisk Sentralbyrå (SSB), 2022), there may be between 1300 and 1500 persons with RP. It is an umbrella term for many different diagnoses that all affect the retina in somewhat the same way, causing many similar symptoms, such as decreased ability to see in relative darkness otherwise known as night blindness, restricted peripheral visual fields, increased time for vision to adjust to new levels of light called light adaptation, and increased sensitivity to certain frequencies of light leading to a tendency for light sources to temporarily blind a person through glare from and halos around the sources (Høvding, 2016, p. 304-306). Of the two types of sensing cells, the rods are affected first. They are more sensitive to light and thus require less light to function. Night blindness therefore tend to be the first symptom of RP. A person usually experiences visual impairment as one's peripheral visual field decreases, decreasing the number of details one can view at once without moving one's eyes. RP tends to debut at the end of school-age and beginning of adulthood, though RP can debut at any point during a lifetime. A common thread is that persons already have settled themselves for a life with normal vision (Høvding, 2016; Whittaker et al., 2016; Verbakel et al., 2018).

Andersen & Skarholt (2014) conducted a study on what promotes and what prevents persons with visual impairment's participation in the workforce in Norway. 45% of the participants with visual impairment reported to have a progressive diagnosis, and most of these had their diagnosis set before or during school-age, and a few during working life (Andersen & Skarholt, 2014). According to Chaumet-Riffaud et al (2017), RP also entails challenges at an inner level. They conducted a quantitative study of 148 persons with RP in France where they found that 36,5% of the respondents reported challenges with anxiety, and 15,5% reported depression. These psychosocial challenges are quite common among persons with visual impairment in general (Chaumet-Riffaud et al., 2017; Whittaker et al., 2016, pp. 79–93; Welsh, 2010).

Optical lenses can do one of two things, either magnify or minify the visual scene. A magnifying lens is convex, making the image zoomed in. All details in the image are bigger, though the number of details is fewer. A minifying lens is concave, zooming out and thus expanding the field of view. The number of details in the image is increased, though all details are smaller (Whittaker et al., 2016, p. 68). Magnification and minification are the two sides of the same coin. The two terms are the same for digital presentations of visual scenes.

## **2.3 Orientation & Mobility**

Persons with visual impairment tend to need technical aids for daily life activities, such as making food to oneself and others, shop for groceries, get around independently or through transportation systems. These persons have many different diagnoses, where the biggest inherited reason for visual

impairment among persons within working age is RP. This tends to affect persons late in their teens to middle adulthood, meaning most have settled their lives as having normal vision. When RP causes visual impairment to a certain extent, persons have the need for rehabilitation, which includes the introduction and training of different appropriate technical aids. Orientation and mobility, abbreviated O&M, is the field within vision rehabilitation that focuses on how persons with visual impairment orient themselves and move around:

*“Orientation refers to knowledge of one’s distance and direction relative to things observed or remembered in the surroundings and keeping track of these spatial relationships as they change during locomotion; mobility is the term used to describe the act of moving through space in a safe and efficient manner.”* (Wiener et al., 2010a, p. 15)

We use our senses to observe our position relative to everything else in the world, and to do this vision is the most influential. There is a lot of information when we move around. When a person lives with visual impairment, travelling becomes more challenging as observing our surroundings gets harder to do. Normally our senses work together providing our brain with as much information as possible. Vision is the dominant of these as it has the most effect on all the other senses. As one’s visual functioning decreases, the other senses tend to take over responsibility since the brain wants as much information as possible despite how the senses function. The brain’s highest priority is to survive, and how it does so is less important. Especially hearing and kinetic feeling gets more dominant related to orientation and mobility. Our kinetic feeling involves the tactile system, haptic awareness, and vestibular system. The person pays more attention to audible clues that hint towards physical properties of our surroundings and clues of actions we’d like to be aware of. An example of this is a car moving towards us. Kinetically we can differentiate between for example hard pavement, pointy growl, or soft grass by how we feel through our feet. As we move, proprioceptive information about the parts of our body lets us determine many things such as our speed and position relative to the ground etc. In other words, we do not need our vision to move around and orient ourselves, though vision makes this easier and less tiring (Geruchat & Smith, 2010; Lawson & Wiener, 2010; Rosen, 2010).

### 2.3.1 Technical aids

As technology evolves, more technical aids for orientation and mobility will be available. They are physical objects that a person uses to compensate for visual impairment among other things, and all have their strengths and weaknesses. It is advised to use multiple technical aids in combination to face complex tasks like for example getting to their mailbox, going shopping, getting to their workplace. The more advanced a technical aid is to use the more important it is for programs that

teaches the use of it to be good and efficient (Jacobson, 2013; Smith & Penrod, 2010). A technical aid is not just an object used by the user; it is a part of the user. Thinking of different life worlds of persons with visual impairment, it is found that they talk about psychosocial aspects of using technical aids. Persons can experience stigmatisation from the reactions of others in the world who can view the user as abnormal. Because of this, persons tend to not be wanting to use for example a mobility cane. Feeling abnormal hinder a person's rehabilitation. We know that technical aids tend to assume increased independence and quality of life for persons with visual impairment when eventually the aid becomes an integral part of the body, extending the reach of our senses (Berndtsson, 2018, 2005). The physical environment is not accessible enough for persons with visual impairment. There are regulations in place that states how constructed outdoor areas and indoor facilities are to be made, but these may not be too known by planners. Because of this, it is most probable that persons with visual impairment will use technical aids for the foreseeable future (Barlow et al., 2010; Jacobson, 2013; Berndtsson, 2005).

### 3 Prior research

Augmented Reality (AR) is an increasingly used technology in many aspects of society where digital information is added to the visual information about the real world (Lee et al., 2021, p. 1; Azuma, 1997, pp. 2–3). This differs from Virtual Reality (VR) where one can't see the real world, only digital information creating a virtual reality. Devices using AR are becoming increasingly more powerful, and so does the technology's ability to detect increased details in our immediate surroundings. AR presents the real world and adds digital information augmenting it.

There is little research on how technical aids using AR affect experiences of persons with visual impairment in general. Htike et al (2020) conducted a systematic review of literature about Head-Mounted Display Technology in relation to Rehabilitation for people with visual impairment in general, published up until November 2018. They looked at 28 publications. The technology used in the studies are divided into “*video see-through displays (VSTs) and optical see-through displays (OSTs)*” (p. 5). VST refers to VR, and OST to AR. The devices using AR have the benefit of see-through displays, which lets the devices be used when the system is off. Devices using VR are unusable when the system is off since their screens are non-see-through. Devices using AR are therefore better as a type of technical device that can be used by persons for orientation and mobility. All the devices they found were headsets that had to be always connected to a computer through a cable. This restricted how far the user could move from the computer, affecting the devices use in relation to orientation and mobility. As they point out, if the devices can use a battery, they can become more viable as technical aids for persons with visual impairment in relation to orientation and mobility. This is problematic when battery-technology is taken into consideration as batteries have a defined amount of time before they need to be charged again. They are also affected by temperature (Htike et al., 2020). None of the studies they looked at provided qualitative data on how the users of these devices experienced the devices or the technology of these. They point out that such data are important, as pointed out by others (Berndtsson, 2018). Htike et al (2021) presented a qualitative study where they interviewed 18 persons with different visual impairments. The persons got introduced to program using Augmented Reality with different functions on a head-mounted device and then got to try it out. As the participants tried the device, they were asked questions related to how they experienced the different functions (Htike et al., 2021).



### **3.1 Study Aim**

The aim of this study is to explore how the use of RetiPlus for orientation and mobility is experienced by persons with Retinitis Pigmentosa, and to explore reflections on how AR technology can contribute to orientation and mobility for persons with restricted peripheral visual fields. Questions to address the aim are: How can the usefulness of RetiPlus be described? What thoughts do the informants have about the future of AR? What affects motivation to use RetiPlus?

Parts of this thesis has been presented in the project protocol, as the final exam in MMET4001 Research methods and Ethics (Paulsen, 2021) at USN (unpublished).

## 4 Method

### 4.1 Study Design

This is a qualitative study that uses semi structured research interviews to address the aim and research questions for the study. Qualitative studies have a cyclic model that implies a flexibility between the phases of the study design. We usually start researching literature and evolve terms related to something we'd like to take a closer look at. We then form aim and research questions. This marks the beginning part of the model. During the data collection, we evolve data with the informants who we cooperate with by for example research interviews. From the data collection, results are made by analysing the raw data from the interviews. The term cyclic refer to movement between these phases rather than the linear model quantitative studies take. The researcher may come back to earlier phases, for example going back from the analysis to the study aim to either confirm that the aim is good or to edit the aim according to new information found during the analysis. The presentation of the results mark the end of the model (Thagaard, 2018, pp. 11–31). There are challenges associated with qualitative studies. All research, both quantitative and qualitative, should be credible, dependable, and transferable for the research to be worth it. The number of participants to recruit for qualitative studies is impossible to say since it depends on the scope of each study. It is important to recruit participants who can shed light on what the study looks at, and the participants should represent a spectrum of light. Another challenge is how data are collected. Semi structured research interviews were used for this study. Who the interviewer is has a huge effect on which questions are asked. The raw data is the answers of the interviewee, and how the interviewer conducts the interview therefore affect the evolved data. This study uses a Qualitative Content Analysis, where meaning units are picked from the text. These meaning units are the basis for the method and thus very influential from a methodological perspective. It is important to clarify how decisions for choosing meaning units were made (Thagaard, 2018, pp. 181–198; Graneheim et al., 2017, p. 33; Engelsrud, 2005).

#### 4.1.1 A Hermeneutical Phenomenological approach

This qualitative study takes a Hermeneutical Phenomenological approach, which is a philosophical tradition that describes the world through phenomena as experienced by the person through their consciousness. In addition to RetiPlus having physical properties defining what it is, RetiPlus is a technical aid that is supposed to be used and thus experienced by the user to whom RetiPlus has a meaning. A student of Edmund Husserl, the man said to be the father of phenomenology, disagreed with Husserl on the separation of world and experience. His name was Martin Heidegger (1889 -

1976), and to him the world is something that exists in the meeting between a person's experiences and the physical world the person is in. Every phenomena exists within a historical context, thus every description of phenomena must take in to account the context the phenomena is in (Lindseth & Norberg, 2022, 2004; Giorgi, 2012; Engelsrud, 2005).

Phenomenology does not on its own give a framework to analyse the descriptions et seeks. For this we add Hermeneutics, the interpretation of texts. Central here is the Hermeneutical Circle, an abstract movement from the context to the text, and back to the context again, presented by Heidegger in 1927, see Figure 1: The Hermeneutical Circle by Martin Heidegger (from Ness Labs, 2022). From having an initial understanding of the context, through reading the text a new understanding is created, and then a new context is constructed. As a circle, it has no certain beginning nor end, it can be repeated infinitely.

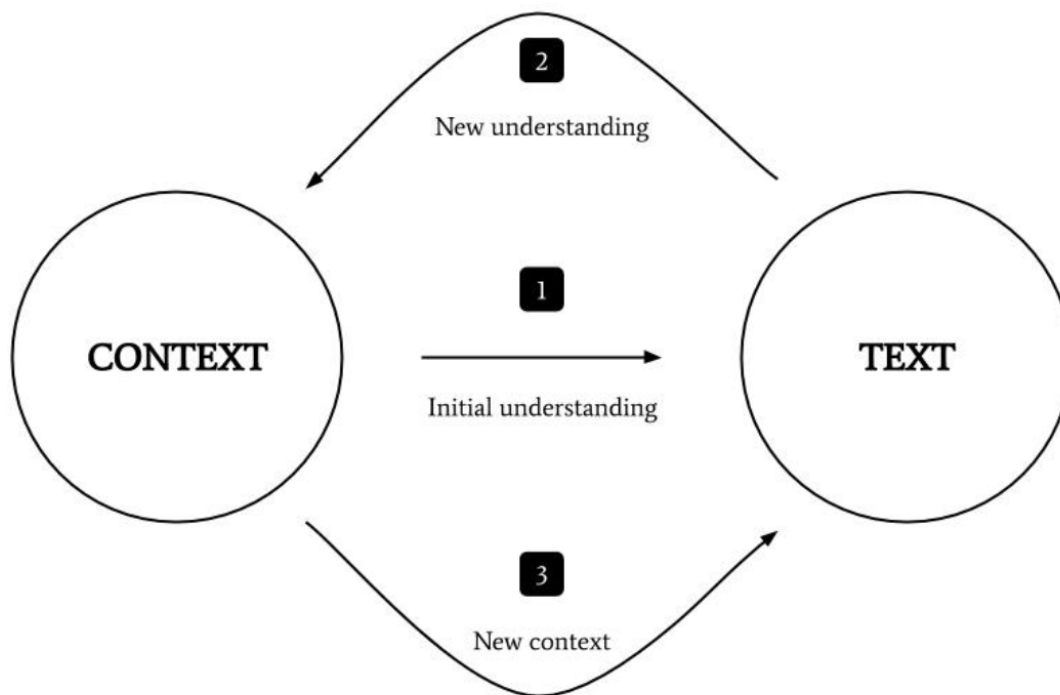


Figure 1: The Hermeneutical Circle by Martin Heidegger (from Ness Labs, 2022)

Paul Ricœur (1913-2005) introduced the notion of distanciation related to interpretation of a text so that one can minimize preunderstanding in the beginning, and through an analysis-process the researcher will evolve their preunderstanding with a new context. Our interpretation is coloured by preunderstanding, and for preunderstanding to evolve, we need to let new understandings evolve themselves before adding them to our preunderstanding. For Hermeneutics to work, a text must be provided for example through transcriptions of records from interviews. When the researcher has a text to read, the researcher must use three stages of analysis: naive reading, structural analysis, and

critical analysis. Through naive reading, the researcher gets a sense of the whole. It requires the researcher to approach the text with an open mind. The whole text is then broken down and structurally analysed before the researcher critically analyses the results again. This qualitative study cannot ignore the nature for human interpretation but must at the same time achieve trustworthiness. To balance this out, hermeneutics are added to create a phenomenological hermeneutical perspective (Lindseth & Norberg, 2022, 2004; Thagaard, 2018; Dreyer & Pedersen, 2009; Ness Labs, 2022).

## **4.2 Recruitment**

The recruitment of informants for this study was done through the research project arranged by Eikholt National Resource center for the Deafblind and Hurdal Vision and Coping center, abbreviated Eikholt and Hurdal. For the research project, possible informants were selected from the overview of persons with RP known by Eikholt and Hurdal. The candidates were then contacted, informed of the research project and the different programs it involved, and asked if they would like to participate in the project. In addition, information about the research project, question of participation and how to show interest to participate was sent to all members of The Norwegian RP Association and The Norwegian Association of the Blind and Visually Impaired. The candidates were given a choice of which program to participate in. To participate in the bigger research project by Eikholt and Hurdal, each informant had to go through tests with certified personal at Eikholt to get updated information of their visual functioning as it was important information to participate in the project. Eikholt has both the instruments and certified competence required to conduct tests of visual acuity, peripheral visual field, and light adaptation.

### **4.2.1 The inclusion-criteria of this study**

The inclusion criteria for participating in this study was that the informants 1) had the diagnosis Retinitis Pigmentosa where the current symptoms create the need for technical aids for orientation and mobility and are using such technical aids to safely navigate the world. 2) It was preferred that the informants were of different ages, were at different progressions of RP, and that the group represented both genders. 3) It was also a criterion to have residual visual function so that the use of RetiPlus could be useful.

### **4.2.2 The informants**

The four informants were from different places in south-eastern Norway. There were three males and one female, and the informants were between approximately 45-62 years of age. All had different states of RP and its symptoms as the informants told themselves and as shown through tests of

refraction and of visual fields. All informants had active daily lives e.g., family, hobbies, and positions of trust. All used to work and lost their job because of RP's progression.

### 4.3 Data collection

The data in this study are the experiences of the informants and their thoughts. To bring these to the outside world, semi structured individual interviews with each informant two times were conducted. During first day at Eikholt in September 2022, the informants attending the program got a common and individual introduction to what RetiPlus is and its functions. Part of the introduction to RetiPlus was for each informant to get their systems adjusted to their visual functioning. This was done individually like the interviews. The interviewer who adjusted the systems used a tablet computer where three profiles were set, 1) standard picture, 2) picture zoomed in, and 3) standard picture with the highlight function on. The informants were then taught how to adjust the parameters. They each got to borrow the adjusted system to use during the first week. Later the same week, an interview with each informant was conducted. At the end of the week, each informant got their system revised by the interviewer thorough the tablet computer. From the first week, the informants got to borrow RetiPlus to take and use at home during daily life until the seminar in January 2023. This seminar consisted of a couple of days where the second interviews with each informant were conducted. This thesis is in English, and the interviews were conducted in Norwegian. The transcriptions and analysis were also done in Norwegian, and the text was later translated into English. A saying from Latin illustrates a challenge of translation in a good way, *traduttori traditore*, meaning *translators are traitors* (Kvale & Brinkmann, 2019, p. 205). It is therefore important for the researcher to be aware and conscious of risks related to translation.

#### 4.3.1 The interviews

In preparation for the interviews an interview guide was devised to get a structure for the coming interviews, making them semi structured. The guide stated open-ended questions and follow-up-questions to get as much information from the informants as possible. Each interview was recorded with a digital sound recorder, and they lasted between 25 and 40 minutes. The role of the interviewer is to get the interviewee to keep talking. The interviewer can achieve this through asking open-ended questions and follow-up questions (Kvale & Brinkmann, 2019, pp. 156–171; Thagaard, 2018, pp. 181–198; Englander, 2012). This type of interview is very resource intensive. When necessary, the interview guide should suggest some possible follow-up questions. The interview is a social setting where unpredictable situations can arise. The interviewee interprets the questions and gives an answer

related to this interpretation. At certain spontaneous moments during and at the end of the interview, the interviewer summarised and afterward asked if the informant wished to add anything.

### 4.3.2 Transcription

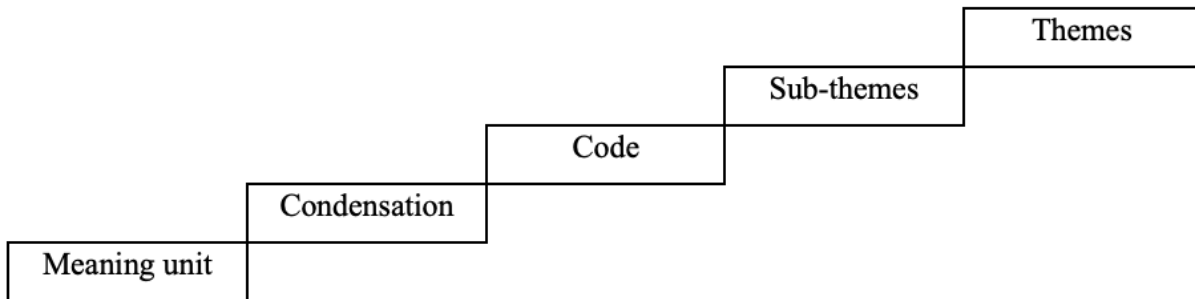
The sound-recordings from all the interviews were kept in a folder within USN Safe, except for the one digital interview which were kept in a regulated channel in Microsoft Teams. NVivo was used for playback during the transcription process, and Microsoft Word was used for the transcribing. The text-files (.docx) were saved and accessed through the channel in Microsoft Teams. Transcriptions are translations of speech into readable texts. This implies different aspects that affect the quality of the texts that are to be analysed. If the interviewer also transcribes, the transcriptions may benefit from a deeper understanding of what is said in the recordings. It's not discussed a lot, but validity, reliability, and transferability are all three just as important in relation to the process of transcribing (see Kvale & Brinkmann, 2019, pp. 204–214; Thagaard, 2018, pp. 181–198).

## 4.4 Data analysis

To analyse the data collected, Qualitative Content Analysis by Graneheim & Lundman (2004) was chosen. Ricoeur's principle of distanciation was used for the analysis to approach the data. According to him, a text is a relationship between speech and writing, it is a structured work, the text is a projection of the world, and it is a mediating self-understanding. What the text says, has more meaning than what it contains. (Dreyer & Pedersen, 2009, p. 66). The goal of distanciation is to present the text as an object. It stands on its own, free from who wrote it and for whom it was written. The text projects a fictional world where meanings from the text, a context, can give new meaning in the present, a new context.

Distanciation is divided into three phases, naive reading, structural analysis, and critical analysis. The transcribed texts were naively read and re-read three times each so that a familiarity to the text was formed. Since the author of this report interviewed the informants and subsequently transcribed the recordings, a familiarity to the texts were formed early on. Lindseth & Norberg (2004, p. 149) point out that this approach has a positive effect on how the data are processed, but it also entails a possibility of creating bias as the researcher can overlook or wrongly interpret meanings from the text. This last point is the reason why the texts were re-read as suggested. Structural analysis involves picking meaning units from the texts, condensing these units and from here make codes. Then themes and sub-themes were created. If we look at the structural analysis as a hierarchy illustrated by a staircase, we can see that each stair represents one part of the whole process. Thinking

of a staircase, to reach the top one needs to start at the bottom. In this phase meaning units are the bottom stair, and theme is the top where we've reached a level of abstraction (Dreyer & Pedersen, 2009, pp. 68–70; Graneheim & Lundman, 2004, pp. 106–109; Lindseth & Norberg, 2004, pp. 149–150).



*Figure 2: Hierarchy in Structural analysis.*

In this phase, the text was divided and sorted into its meaning units before each unit were condensed to clarify the core meaning for the unit. Codes were made to see connections between meaning units. Themes were then constructed. The whole text is presented in a holistic view, given a life of its own. When applying structural analysis, the text is broken down into questions: What does the text say? What does the text speak about? Are there any sub-themes and themes in the text? (Dreyer & Pedersen, 2009, pp. 65–70).

## 4.5 Ethical considerations and Privacy protection

To know that their vision is most likely to degrade over time, but not know when and how much it will degrade, could be hard for a person to accept; vision is after all our most important sense. It is an uncertainty where the only thing that's certain, is that their vision is going to degrade. The informants are a part of a vulnerable group compared to the total population. It's also only the candidates themselves who know how they experience the use of RetiPlus. Every relation between persons, such as interviewer and interviewee, is an asymmetric power-balance. In an interview, the interviewer can be said to have more power since he or she chooses which questions to ask the interviewee. At the same time, an asymmetric power-balance may be needed for qualitative research to be considered science since the data is collected through asking questions. The important thing is for the interviewer to be conscious of the asymmetric power-balance and how this can colour the communication in the interview (Kvale & Brinkmann, 2019, pp. 42–113). Information about the study was given to the informants before the interviews. In addition to oral information, the informants were given a written paper with information about the study and a consent form for having got enough information and understanding of what the study implied for the informants, it explained which data were to be gathered, what the data would be used for and how, and how the data would be kept. To participate in the study, the informants were required to sign the declaration of consent. To ensure the informants Right for Privacy and Anonymity, certain measures were put in place. Before the recorder was started, the interviewer explained that personal information about the interviewee, should not be mentioned as this kind of information was unnecessary for the study anyway. As stated in the written information to the informants, any specific information in the recordings that didn't need to be there, such as the name of the informant's hometown, was generalised. For example Hammerfest would become "a town". This ensured that the informants couldn't be traced back to themselves when only based on the text.

An individual's personal data is by Law defined as sensitive data. This needs considerations when working with personal data so that the individual's Right to be anonymous is kept. The data must be kept safe from unnecessary access and distribution. The recordings from the interviews were for example kept on a secure data-server and accessed through a Virtual Private Network abbreviated VPN, to a computer. Through application, this study was approved by NSD, National Agency for Shared Services and in Education and Research (Reference number 171446).



## 5 Results

The transcriptions were read according to naive reading, and they were read three times each. The texts from the first interviews were read as one whole [text] before reading the texts from the second as another whole [text]. After naive reading, the texts were broken down into meaning units that represented the texts according to the focus during naive reading. The meaning units was condensed and then codified. For the structural analysis, an Excel-workbook was used where tables made the analysis easier. Here, each informant got one worksheet each. see

Table 1: Example of meaning units, condensed meaning units and codes.. Another worksheet was used to set up the table for the themes, sub-themes, and corresponding codes, see Table 3: Example of Descriptions of the usefulness of RetiPlus. and Table 4: Example of Factors that affect motivation to use RetiPlus..

*Table 1: Example of meaning units, condensed meaning units and codes.*

<b>Meaning unit:</b>	<b>Condensed Unit:</b>	<b>Code:</b>
I feel that the flashlight focuses on where I want to see and the camera on RetiPlus then lights up the most where the flashlight is aiming. That way I manage to filter out a lot of the visual noise. It is less tiring for me to walk around.	RetiPlus combined with flashlight works very well. They help me get a focus which makes walking around less tiring.	RetiPlus is useful combined with flashlight
If I met technical problems like others have met here this week at Eikholt, then I know where RetiPlus would end up. They'd be kept in the case for a long time.	If technical problems would arise, I'd lose all motivation.	Uncertainty affects motivation to use RetiPlus
I think there is a threshold to use the glasses around acquaintances. It is the only negative aspect about the glasses, that they are so clearly a technical aid. You need to have a strong backbone to use RetiPlus in public.	There is a threshold of using RetiPlus in public since they are to clearly a technical aid.	Threshold to use RetiPlus in public affects motivation to use the technical aid

To get an overview for all codes, condensed units and corresponding meaning units, another worksheet with a table containing a column added to the left of the first column was added as shown in **Feil! Ugyldig selvreferanse for bokmerke..** In this added column, the codes were put, and all

corresponding meaning units and so forth from each informant were put in order by each code. This summarised all codes and informants connected with each code.

*Table 2: Example of table organisation of all codes, meaning units and condensed units.*

Code:	Informant:	Meaning unit:	Condensed unit:
x	1	Blablabla	Bla
	2	Lablablab	Lab
	4	Ablablabl	Abl
y	3	Seasea	Sea
	4	Easeas	Eas

The themes that emerged through the structural analysis were “Factors that affect motivation to use RetiPlus”, and “Descriptions of the usefulness of RetiPlus”. The themes, sub-themes and codes were re-visited through the critical analysis to make sure the interpretation of the data would be as representable as possible. The critical analysis was done in English.

## 5.1 Descriptions of the usefulness of RetiPlus

All informants described different things about the usefulness of RetiPlus. The codes associated with the theme made three sub-themes that we’ll take a closer look at below. Here we see an example of the theme, its sub-themes, and some associated codes.

*Table 3: Example of Descriptions of the usefulness of RetiPlus.*

Theme	Descriptions of the usefulness of RetiPlus		
Sub-themes	RetiPlus is useful as it is	Situations where RetiPlus was useful	The user experience is not good enough
Codes	RetiPlus is useful as a technical aid	Useful In relative darkness	Battery capacity could be better
	RetiPlus is useful combined with flashlight	Useful when around other people	Not too comfortable to use
	RetiPlus is useful combined with a guide dog	Useful when going between light levels	Judging distance is hard

### 5.1.1 RetiPlus is useful as it is:

Some of the informants felt that RetiPlus could aid them in their daily life, and therefore could consider applying for RetiPlus as a technical aid for orientation and mobility.

*“I think they were fine for what they are.”*

Improvements can be made for RetiPlus as for everything else, but with the attributes RetiPlus has now, they're good enough. The informant continued explaining that all technology has its restrictions, and technology will improve over time.

*“With RetiPlus I can see better.”*

Therefore, the informant thought of RetiPlus as a usable technical aid to apply for. With RetiPlus, the informant mentioned seeing things they hadn't done for many years, which was an *“emotionally strong experience”*.

All informants used flashlights as technical aids in their daily life, and some found using RetiPlus in combination with flashlights useful. One informant who explained that getting a guide dog was revolutionary, also found using RetiPlus in combination with the guide made using the mobility-cane for identification obsolete as RetiPlus made identification through vision more viable.

RetiPlus has different functions related to manipulating the video-feed caught by the camera. In short, the highlight function and variable zoom function were the most useful. One informant was able to see a small ball that was thrown underneath a table which without RetiPlus or flashlight the informant was not able to see. The informant observed the same effect when looking through a tunnel for walking under a road. With the highlight function, obstacles and unevenness became easy to identify and locate before entering the tunnel. RetiPlus and other technical aids may have other uses than what they were intended for. One informant found a use for teaching normally sighted family members on how their vision functions.

### 5.1.2 Situations where RetiPlus was useful:

All the informants found RetiPlus useful in the evening and so on where there's less ambient light, also called dusk or twilight. One informant explained that the camera of RetiPlus probably was generally more sensitive to light than what the informant's eyes were, and therefore RetiPlus worked

very well in the evening, especially where no other artificial light source could be found such as in the woods. There is usually some ambient light around that can be sensed by eyes and cameras that are sensitive enough, which made the informant seeing more during the evening. By this, hiking in the woods in the evening was feasible.

RetiPlus is more usable in certain situations, for example where there's other pedestrians moving in different directions and at different speeds. Most informants found RetiPlus useful when around other people.

*“They worked well in situations where there were a lot of people around since RetiPlus increased my field of vision.”*

Another symptom of RP that all informants mentioned as challenging is the vision's ability to adapt to different light levels: the time for vision to adjust to new light levels. One informant said that RetiPlus smoothed out the changing light levels so that light adaptation became less challenging. Another informant mentioned trying RetiPlus when driving to the cabin with the family. When looking out the window to take in the view, RetiPlus made all the changes as the car moved along the road less affecting, *“Usually I must look down as we drive”*. Using RetiPlus made it easier and less stressful to look around and search for information. Looking for objects was better with RetiPlus since it made contrasts clearer and objects more visually defined.

*“Using the highlight function walking in the forest was more like moving in a cartoon.”*

The complex circumstance of moving in the forest with trees and so on in dusk, got simplified by using RetiPlus. Energy used to stay on the path and avoiding tripping over unevenness in the terrain and crashing into objects or other pedestrians on the path was less.

### 5.1.3 The user experience is not good enough:

All informants had suggestions for changes to improve the functions and usability of RetiPlus in relation to the user experience. One informant said that RetiPlus is big and heavy, and it's easy for it to fall off, especially when walking since their head keeps moving. The same informant wished that the frames of RetiPlus had more opportunities for adjustment to different shapes of heads and facial attributes. For another informant, the small lamp indicating battery status was too dim compared to the colour of the control box [which is matt black]. The lamp should be changed for a LED light so that seeing battery status could be easier. For some, the battery capacity was a little too low for

extended use, especially outside in cool weather. As one stated, the battery should be able to last at least for most of a typical workday.

The placement of the camera and how the camera gathered information was by most informants making it somewhat hard to judge distance. One informant said that the picture got shifted so relation to objects got distorted. The same informant also felt that the picture got too grainy when zooming in to study details. For another informant, the challenge of judging distance made certain tasks at home easier and more efficient to do without RetiPlus.

Central for using the software of RetiPlus are arrow buttons. The navigation panel on the front of the control box surrounds a button that freezes the picture until pressed again. For one informant this made using RetiPlus especially hard since it was difficult to feel where the different buttons were, making it easy to press the wrong button or press two buttons at once. This was frustrating as the informant explained.

All informants who reported trying out the glasses over a period, at least about 50 minutes, reported that the control box got relatively hot during use. The months the informants got to try out RetiPlus at home, was from October to beginning of January. Trying to hide the cable and to keep it from dangling, one informant tried to keep the control box in an inner pocket of the thick winter jacket. The control box got uncomfortably hot, and it had to be moved to an outer pocket that in turn made the cable dangle about outside the jacket.

## 5.2 Factors that affect motivation to use RetiPlus

The motivation of the informants to use RetiPlus was affected in ways summarised by three sub-themes, 1) Motivational approach, 2) Motivating to use RetiPlus, and 3) Negatively affects motivation to use RetiPlus. In the table below we see an example of the theme, its sub-themes, and some codes.

Table 4: Example of Factors that affect motivation to use RetiPlus.

Theme	Factors that affect motivation to use RetiPlus		
Sub-theme	Motivational approach	Motivating to use RetiPlus	Negatively affects motivation to use RetiPlus
Codes	Solution orientation	To be perceived as normal	Threshold to use RetiPlus in public affects motivation to use the technical aid
	Having high expectations	I can see better with RetiPlus	Disappointment when learning more about RetiPlus
	Curious to learn more	Eased orientation and mobility	Feeling that RetiPlus is just in the way

### 5.2.1 Motivational approach:

Some informants expressed thoughts on learning to use RetiPlus as to learn other technical aids:

*“It is a matter of getting used to using RetiPlus.”*

To be proficient with using RetiPlus, one informant stated that RetiPlus must be used routinely. In the second interview, the same informant explained that RetiPlus had been used with the assumptions the informant had about the aid.

The informant further said that one suddenly got high expectations for RetiPlus when one first heard and learned about the system. Another informant who initially expressed increased vision by using RetiPlus, talked about how it drove their expectations that in turn drove motivation to use it.

All informants talked about being curious around RetiPlus and enthusiasm to learn. One informant was very eager to learn more and wished the week at Eikholt could be extended so one had more time to for example talk with the other informants and with the experience consultants. All the informants

expressed excitement to see the next version of RetiPlus and the development of AR-devices for orientation and mobility in general.

### 5.2.2 Motivating to use RetiPlus:

All informants talked about different things that had positive effects on their motivation to use RetiPlus. For all the informants, being perceived as normal was important, and all also linked losing their visual functioning to a feeling of being perceived as less normal. Two informants talked about RetiPlus easing orientation and mobility so that one could function more normally. They explained that one could walk faster, more confident, and more natural by using RetiPlus. It made it easier to walk with their back and neck straighter, which in turn increased the feeling for being perceived as normal.

By easing orientation and mobility, some of the informants also talked about how RetiPlus increased their visual functioning towards how it used to be before RP progressed too far. One informant talked about how hiking in the woods used to be relaxing before RP made hiking rather stressful. When using RetiPlus in conjunction with a flashlight, the informant said that hiking became more relaxing again. Another informant talked about how RetiPlus increased their visual functions in general.

Feeling autonomous was something all informants wanted to get back after losing it as RP progressed. For two informants, using RetiPlus did just this. One informant talked of a situation one evening during the first stay at Eikholt when going shopping for groceries with a normally sighted human guide.

*“With RetiPlus, I accompanied my normally sighted companion in the store.”*

After many years of being reliant on other normally sighted persons to accompany the informant, to accompany another whose vision is normal was for the informant a new feeling. This hinted back to when the informant had normal vision and therefore was autonomous,

### 5.2.3 Negatively affects motivation:

Closely related to negative effects on motivation to use RetiPlus, all informants talked about a threshold to use RetiPlus in public. This threshold was linked to how the informants feared being perceived as abnormal by others in their neighborhood and hometown due to RetiPlus so obviously pointing out the informants as visually impaired,

*“They’re not discreet, and you will be seen wearing them.”*

One informant explained that RetiPlus is not something one wears to dress up. Another pointed to how young boys may find RetiPlus looking cool like some action figure, but that would probably be it. Explaining that technical aids can improve a person’s feeling of independence, an informant stated that it’s important to lower the threshold of using RetiPlus so that the feeling of independence can get increased.

Also related to negative effects on motivation was how disappointment was experienced when trying out RetiPlus. This was prominent for two informants. It caused one informant to not wanting to borrow RetiPlus home to try out further. For another it caused losing motivation when trying RetiPlus for practical hobbies at home. RetiPlus was for the informants just in the way. This was closely related to the informant’s experienced visual functioning. One informant whose general goal was to get back a normal visual field said that their visual field was just as good without RetiPlus as with it. All informants explained that compensating strategies had been learned after many years of visual impairment.

Two informants talked about the complexity of RetiPlus and the lack of tactile differentiable buttons. Both compared meeting the complexity and possible technical issues as being a main factor for losing motivation to use RetiPlus. Uncertainty also affected motivation in a negative way. Uncertainty about using RetiPlus outdoors was something all informants talked about in one way or another. One informant said they tried to search for information about the resistance to moisture and dust of RetiPlus through the developer’s web site but couldn’t find any answers. This was the reason why the informant had not tried out RetiPlus as much as they could have. Another informant talked about uncertainty of forcing technical issues from pressing the wrong buttons in RetiPlus as being a de-motivating factor.



## 6 Discussion

RetiPlus was developed to be a technical aid for persons with RP in relation to orientation and mobility. As with every technical aid for persons with visual impairment, RetiPlus is experienced by the user. The results show that different users have different approaches, expectations and needs that determine how RetiPlus may be experienced. The informants were all different persons with different experiences and expectations. A common thread was that all had settled their lives with normal vision related to family life, transportation and working life to name a few. Everyone talked about how they used to work and participate in for example sport, but as RP progressed, its effect in daily life made continuing to work and participation in society more challenging.

### 6.1 Its usefulness

There were differences among the informants in how they considered the usefulness of RetiPlus. Some did not see the value of using it, while others felt like applying NAV for RetiPlus as a technical aid. A person with RP may find that they suddenly can see things they hadn't done for many years. They may suddenly be able to see things in their periphery without having to scan. Since scanning require more resources than not scanning, RetiPlus can ease orientation and mobility. Typical for persons in general is that we settle our daily lives according to our situation, and we strive to be perceived as normal. RP usually affect persons after settling their daily life as a person with normal vision. As night blindness sets in and their visual field get noticeably restricted, different things become more and more difficult in that they require more of the person in form of their time and resources. Certain tasks at their workplace take more energy, for example restricted visual fields make it hard to recognize acquaintances in the hallway. This can create frustrations both for the visually impaired employee and they're colleagues. Also doing tasks that require using a computer get harder as their visual field gets restricted since one may not see the whole screen at the same time. This leads to a need for scanning the screen to get an overview of the information on it. Scanning takes more time and energy than seeing everything at once, and it is related to the residual visual field of the person. Each scanning may take little time on its own, but when adding up how long a normal workday last and how many times a person may need to scan the screen, these small periods of scanning become large periods that affect the daily life of the person. Computers are a central part of most workplaces in our information age and feeling that using a computer gets harder and harder probably leads to many frustrations over a workday. This can in turn lead to a feeling of not being good enough (Andersen & Skarholt, 2014). A part of what is reported being contributing factors to bad psychosocial health among persons with RP are such many small frustrations becoming

overwhelming. This typically leads to persons losing their jobs or making it difficult to get a job. It also affects other aspects of daily life (Chaumet-Riffaud et al., 2017; Andersen & Skarholt, 2014). When one loses visual functioning, orientation and mobility can become challenging. Keeping track of many things simultaneously such as other pedestrians, where the edge of the sidewalk is, quick bicycles that are relatively silent, become harder and requires more energy. This energy must be taken from somewhere. For a person who likes to hike, it is the energy used to relax when hiking (Jacobson, 2013; Wiener et al., 2010a). However, not every person living with visual impairment find the same technical aid useful, and this is the same for RetiPlus. Feeling that they're vision is good enough, can make a person not seeing the usefulness of it. They're peripheral visual field may not improve by using RetiPlus and it can be more tiring to use it. Not all persons with RP uses the same technical aids for the same tasks. Using any technical aid takes up space that could be used for other things. An example is RetiPlus and filter glasses both being glasses that take up the same space, making it impractical to wear both at the same time. To perceive any technical aid as useful is a compromise. Every technical aid is made with some intent to help persons with certain tasks. RetiPlus was developed for persons with RP, improving the user's visual functioning, increasing their visual field, brightening up the surroundings and smoothing out the different light levels in our environments (PLUSINDES SL, 2019a). For some, RetiPlus may increase these things regaining some of their visual functioning, whereas for others visual functioning will not be improved.

## **6.2 Symptoms and related functions of RetiPlus**

RetiPlus has different functions of which some are more useful than others. Which functions that are the most useful is correlated to which circumstances persons prefer to use RetiPlus in. Since RP assumes night blindness making it hard for persons to see, RetiPlus has a positive effect for persons with RP in relative darkness (Høvding, 2016, pp. 304–306; Whittaker et al., 2016, pp. 62–64). Relative darkness affects persons with RP, and the winter half of a year In Norway is relatively dark, making RetiPlus a viable technical aid especially during autumn and winter. It can also make going to restaurants, cinemas, and other typically dark locals less tiring, which makes RetiPlus able to increase social and cultural participation.

Other symptoms of RP are inability to quickly adjust to changing light levels and increased light sensitivity that assumes blinding (Høvding, 2016, pp. 42; 304–306; 442). RetiPlus takes all the light it sees and smooths out changes in light. Shadows may become brighter, making walking along a footpath when the sun shines through the trees less tiring. During December the sun turns, making it the darkest month in Norway. This is also the month with the most artificial light sources in form of Christmas decorations on buildings and torches on the ground. The light level from all the different

light sources can be smoothed out by RetiPlus, lessening the energy someone otherwise would use trying to see despite the many light sources. In turn this will make participating in the town square during Advent where they meet acquaintances and in general enjoys Advent with their family more doable.

Technical aids may have other uses than what they are designed to do. A person living with RP may find that they're family members who have normal vision, in general have difficulty understanding why they so often veers and seems so uncertain. The person can first explain what they see in their visual scene without RetiPlus, and then explain what they see with it on. It is hard for someone else to understand how another person with restricted peripheral visual field sees. Using RetiPlus as a point of reference, persons with RP can get others to understand their vision better, affecting the psychosocial aspect of having visual impairment in a positive way (Welsh, 2010).

### **6.3 Useful combinations**

Persons with RP tend to use flashlights and filter glasses as technical aids. Some may find a mobility cane useful, and others a guide dog. Certain technical aids have certain functions and can't be used for other functions. This makes single technical aids not usable for complex activities, and it is therefore generally advised that one should use a combination of technical aids (Wiener et al., 2010a, 2010b). An example of a complex activity is when a person is moving around in a central bus station in rush traffic trying to find the way to the platform the bus leaves from before it leaves so that one can reach their workplace in time. If a person with RP have worked at the same workplace for some time before RP debuts, they may have learned the layout of the bus station and where their bus leaves from. Such a bus station may during rush traffic get unpredictable to move through. Persons are going in different directions at different speeds. Some stand around waiting for their bus, and others are sprinting to reach theirs. For the person to get their peripheral visual field restricted due to RP, makes this hectic situation more tiring, and crashes among other things may occur more often. This may contribute to persons with RP losing their jobs (Andersen & Skarholt, 2014; Chaumet-Riffaud et al., 2017; Wiener et al., 2010a). Since RetiPlus expands the visual scene by default, persons with RP may stay in work longer by using it.

A guide dog is supposed to be the user's eyes, making travel safer. At the same time, the user is responsible for orientation and giving commands to the guide dog where to lead the user (Franck et al., 2010). The purpose of a mobility cane is to aid orientation and mobility for persons with visual impairment by conveying tactile information of the user's immediate surroundings (Jacobson, 2013, pp. 134–141). If the persons can't use their own vision, its advised use or to keep a mobility cane available when walking with a guide dog. To identify something when the guide dog stops for some

reason, can be visually feasible with RetiPlus. In general, we want to use our vision to the fullest despite visual impairment (Høvding, 2016; Whittaker et al., 2016). This explains why some may prefer to use RetiPlus in combination with a guide dog rather than using a mobility cane. The latter contributes tactilely, whereas the former contributes visually.

Filter glasses and RetiPlus can't be used at the same time due to both having alike physical properties since they are both glasses to be worn resting on the bridge of the nose. Filter glasses are different from user to user in how they filtrate visible light (Andreassen, n.d.). If a person with RP finds using filter glasses very useful, not being able to combine RetiPlus with filter glasses will affect how useful RetiPlus is perceived. They may then make a compromise choosing their filter glasses rather than RetiPlus.

## 6.4 Room for improvements

As with everything else, we know that there are improvements that can be made for RetiPlus too. The control box of RetiPlus contains a battery which could have a better capacity. Having a chargeable battery, RetiPlus is more mobile than other similar headsets using AR meant for orientation and mobility that other studies have looked at. These other headsets were all reliant on being connected to a computer through a cable restricting how far the user could move from the computer and therefore affecting how mobile the headsets were (Htike et al., 2020). We know that batteries tend to lose capacity when exposed to cool temperatures. There are historical examples of smartphones getting quite hot during use. There are also examples of certain models mitigating this issue through implementing technical measures either through heatsinks, chassis design, efficiency of the hardware and software, or a combination of these. During a cool winter day, a person with RP may want to keep the control box in an inner pocket of a thick winter jacket to improve the capacity of the battery. The control box may get too hot to keep inside the jacket, and the person may then have to put it in an outer pocket, exposing it to the cool temperatures. RetiPlus is intended as a technical aid for orientation and mobility, and such activities often happen outside year around. For RetiPlus to be more viable in Norway where half of the year is relatively cold, the battery of RetiPlus should be better insulated among other things. The issue of the control box getting too hot to use negatively affects the usefulness of RetiPlus. This issue has clearly been improved over time for other devices like smartphones, and it is likely the same applies to the future of RetiPlus.

Judging distance through RetiPlus is probably challenging due to the one camera not sitting on the centreline. By sitting on one side RetiPlus may shift everything to that one side. Our vision normally uses both eyes in conjunction to create stereo vision which makes judging distance feasible (Whittaker et al., 2016, pp. 42–43). The shifting of the visual scene requires a person to compensate

as the visual scene is different from what they are used to. On RetiPlus, the camera sits where it does, but a person may learn strategies to compensate for the shift. It is likely that a person will learn compensating strategies to judge distance through RetiPlus. The time such training takes to mitigate the challenge is probably different from person to person and training program to program (Jacobson & Bradley, 2010).

By default, the camera on RetiPlus minifies the picture which increases the user's visual field. This makes all details in the picture smaller, and it may affect a person's ability to study details by zooming in. RetiPlus is a headset, moving with the head's many minute movements. As magnification increases, so does the movement of fixation when the point is moved (Whittaker et al., 2016, p. 68). Digital stabilisation for video took many years to become widely accessible in smartphones, and the same may apply for RetiPlus.

## **6.5 Optimism, expectations, and curiosity**

Having an optimistic approach to technical aids for orientation and mobility is something that affects the motivation to use a technical aid. If the visual functioning of a person with RP gets improved by using RetiPlus, it creates enthusiasm in the person and increases motivation to use it. Over time we learn, and it makes a complex system not so complicated to use. We can divide our approach to a challenge in two ways. We can either focus on the challenge as being a problematic issue or focus on the solution of it. This affects our motivation to approach the challenge either increasing or decreasing our motivation. An example of such a challenge is the use of RetiPlus. The approach focusing on the solution of a problem can be called solution orientation (see Inde, 2003, 2005). Our experiences are affected by our expectations, and these are in turn based on our prior experiences. RP causes experiences of not being able to do the same activities as they did before their visual functioning got severely affected by the diagnosis. This may lower their expectations towards how they will accomplish certain tasks that require the use of vision. If the use of RetiPlus improves their vision, their experience of improved vision will affect their expectations increasing the height of the bar that RP lowered. For example to experience that getting their mail from the mailbox gets too difficult because of RP, and then experience that the use of RetiPlus mitigates this challenge of getting their mail, their expectations towards RetiPlus in other circumstances may improve. Using a technical aid such as RetiPlus might therefore positively affect their psychosocial health since the use of it increases their expectations through positive experiences (Chaumet-Riffaud et al., 2017; Welsh, 2010).

On the other hand, if the person has expectations that conflicts with the functions of a technical aid, their motivation to use it decreases though they may need the technical aid for orientation and

mobility. RetiPlus has many functions and can be used in many circumstances. The same applies for a mobility cane. We know that persons may benefit from using a mobility cane but using it may imply stigmatisation which hinder them from using the mobility cane (Berndtsson, 2005). RetiPlus is a more advanced device than a mobility cane, but the psychosocial aspect likely applies the same.

Curiosity can affect motivation too far. Experiencing that RetiPlus increases their vision may create curiosity on how it functions in general. This curiosity can make them so motivated that they tend to use RetiPlus till they get too tired to keep going. They may find it hard to put RetiPlus down since they want to keep trying it out as much as possible to find out more. Based on this, it can be argued that persons with RP who experience their vision getting better with RetiPlus may get so curious and motivated that their endurance decreases. For this to not affect rehabilitative programs negatively, these programs should be planned and structured to include breaks. Taking a break from a session assuming curiosity from the students probably affects their learning from the next session about the same after the break (Jacobson, 2013; Jacobson & Bradley, 2010). If their wish is to see better again, the motivation to use a new device that does just that increases a lot. This might affect a person's energy profit for other activities within daily life, such as making dinner, tidying up, helping their children with their homework among other things. It is likely that over time using RetiPlus, persons adjust the use according to their energy profit, which in turn will mitigate this issue.

## **6.6 Complexity and uncertainty**

We know that feeling something being just in the way affects motivation to spend time using and trying it out. Feeling that RetiPlus is just in the way is here assumed to be a balance between seeing the value of it against negative aspects one can think off. Whereas some may see the value of RetiPlus since it increases their visual functioning, others may find the opposite. They may wonder why they should stress to use something they don't see the need of. RetiPlus is an advanced system which can crash as computers can in general. RetiPlus can be argued to be a complex system as it has many functions that are activated by different buttons. Some of these buttons have multiple actions that can be performed through number of pushes, amount of time holding the button down, and maybe even a combination of these. They may force technical issues by pushing the wrong combination of buttons freezing the software. To avoid such possible technical issues, their motivation to use RetiPlus may decrease. Through learning a complex system, the system usually tends to seem less daunting, increasing motivation to keep learning complexity (Jacobson & Bradley, 2010). Comparing RetiPlus to smartphones its potential as a technical aid. We can just look at the introduction of the first commercially successful smartphone around 2007 and compare it to the general knowhow of smartphones found in many societies around the world today.

Different things motivate persons to try out and to spend time learning about RetiPlus. A common thread between each informant and each interview, was the importance of feeling normal. A part of this was to feel autonomous when getting around and orienting themselves. As reported, it is normal for persons with RP to feel that they are losing their autonomy as their visual functioning degrades. The use of certain technical aids tends to increase the feeling of being autonomous again. Looking at how persons experience the use of technical aids for orientation and mobility, Berndtsson found that all persons talked about the wish to feel normal again. This was the main theme in how the persons talked about using technical aids. The persons that lost their visual functioning over time, had experience of being autonomous and feeling normal and then losing it. In turn this assumed psychosocial challenges and the wish to feel being perceived as normal and autonomous again (Berndtsson, 2018, 2005; Chaumet-Riffaud et al., 2017; Welsh, 2010).

RetiPlus eases orientation and mobility for persons who feel their visual functioning increasing by using it. It may make it feasible to go hiking in the woods again when they choose despite relative darkness and variable levels of brightness. For others, it can make visiting the town square during Advent less tiring since RetiPlus brightens up the surroundings, smoothing out the different light levels and making other pedestrians, obstacles, and unevenness clearer. To feel that an activity like hiking in the woods or attending social activities during Advent in the town square is so important, and then losing the ability to do the activity since their visual functioning hinder it, may contribute to reported psychosocial challenges of having RP. Also reported by persons with RP as contributing to psychosocial challenges is to know that their vision is going to degrade. It assumes a fear of not being able to see again, for example things that is important to a person like their family members, friends, pictures of loved ones, their hometown where they grew up. This explains why some may express excitement when talking about RetiPlus and how it eases orientation and mobility and in general make seeing easier. Maybe RetiPlus can't fix the complexity of getting back to working life again, but as the results imply, RetiPlus can give hope (Chaumet-Riffaud et al., 2017; Welsh, 2010).



*Picture 3: RetiPlus worn by the researcher illustrating how they look. The use of this picture is approved by the researcher.*

On the other hand, there is a threshold of using RetiPlus in public as talked about by all the informants in each interview. This threshold is mostly related to its appearance and implies a psychosocial aspect that could hinder the use of RetiPlus in certain circumstances. Looking at the picture above, we can see that RetiPlus does not look like normal glasses we wear to correct visual acuity or filter out especially sensitive light frequencies. Berndtsson found the effect of stigmatisation when persons with visual impairment talked about using technical aids. Stigma is created in the meeting between society's reactions on what it perceives as normal and abnormal, and a person's perception of these reactions related to their experiences of themselves. Using a technical aid extends our body's reach, and over time the technical aid becomes a part of the body rather than an object used by the body (Berndtsson, 2018, 2005). It is interesting and understandable how other people can perceive RetiPlus as something not usual in everyday life. As we can see in Picture 3, the frame is wide and narrow. A cable goes down and is connected to the sweater with a clip. On the right side of the frame a camera sits. These make RetiPlus seem bigger than normal glasses one might wear. It is generally important for persons to come back to daily life as soon as possible when for example their visual functioning decreases or their leg gets broken. If this threshold hinder persons with visual impairment to use a technical aid of which they have a need for, then the time for the person to come back to daily life may increase. It is therefore important to lower the threshold of using RetiPlus which implies making changes to how it looks.

## **6.7 Final reflections**

Through this study I have learned a lot and acquired a deeper understanding of what qualitative research implies. I am a social worker by prior educations, and I have for many years worked as a social worker affecting my pre-understanding. The persons I've worked with have had challenges that led to them losing or not yet have gotten the opportunity for a job. All these persons have for the past 7 years had some challenge related to visual impairment, and many have had RP which has given me a deep understanding of the diagnosis. I have for my whole life lived with visual impairment and



felt the psychosocial affects related to the use of technical aids, affecting how I talk with persons living with visual impairment.

My work role has challenged me to acquire the trust of persons who have been in vulnerable situations, assuming the need for respect and empathy. At the same time, I've had to make sure that their rehabilitation process towards their main goal was as efficient as possible and simultaneously stay true to the notion of user participation. The relations between the informants and myself for this study has had challenges as we've spent time looking at RetiPlus among other things before the interviews. I may have acquired their trust in advance making the phase of gaining trust in the beginning of an interview more efficient. I may also have had bias since I may have believed I could guess what the informant would answer and what they meant, affecting for example my ability to ask good questions. This made having planned the interviews and making an interview guide very important.

Having conducted two interviews with each informant, I have had the opportunity to address things from the first interview which I afterward felt needed more addressing. Understanding how questions affect gathering of data through my prior education and subsequent jobs as a social worker and making interview guides for my other assignments and during this study, has taught me the importance of planning and acknowledging that many details in a future social setting cannot be planned for.

Being the first time using Qualitative Content Analysis, I see how important it is for at least two persons to conduct this process in cooperation, as suggested by Graneheim & Lundman (2017). This study process has had its restrictions towards time to spend and resources to use. Transcribing the sound recordings and doing the analysis was time consuming. This affected my motivation during this study, especially related to me commuting to and from work.

## 7 Conclusion and future implications

This study shows that there are many factors that affect how useful RetiPlus is for persons with RP. As with every technical aid for persons with visual impairment, RetiPlus has different meanings for different persons and every person is different. Some may get their visual functioning increased by using RetiPlus, making them see things again they normally can't. RetiPlus lights up the visual scene and it evens out the different levels of light. With the different functions of RetiPlus, studying details and identifying objects of interest may be feasible visually again, and keeping track of many things simultaneously when moving out and about may get easier. At the same time, others may find RetiPlus not increasing their visual functioning and therefore not see the point in using it. RetiPlus consists of a big and heavy frame, a cable that can get in the way, and a control box that needs to be kept in a pocket somewhere. It can therefore seem more complicated to wear RetiPlus compared to other glasses that are relatively light and easy to wear. RetiPlus can also have to compete with for example filter glasses. It is probable that many persons with RP find filter glasses very useful, and RetiPlus may find itself less prioritised.

Technical aids for orientation and mobility are exposed to outdoor environments year around. For RetiPlus to be more viable as a technical aid for orientation and mobility, there must be made changes. The battery in the control box should last longer and be more resistant against the cool weather that affects the capacity of the battery. The control box gets quite hot during use, probably since the software requires much of any hardware. If the hardware RetiPlus is using could be more efficient like some models of smartphones and computers are, the control box may not get so hot during use which improves how comfortable RetiPlus is to use year around. There should be a focus on making RetiPlus as accessible as possible, and the buttons on the control box should be more tactile, especially important buttons that is used for navigation among other things.

There is also a psychosocial aspect of using RetiPlus as with all other technical aids. Also being an object used, RetiPlus can become a part of the user's body. They may find RetiPlus useful as it positively affects their visual functioning, and at the same time it can create stigmatisation through how others in the society perceive RetiPlus. They do not look like something which is normal to be worn like glasses, see Picture 3. As technology moves forward and AR gets more accessible, RetiPlus has good potential to be a more viable technical aid for persons with RP in relation to orientation and mobility.

It is hard to not compare RetiPlus to smartphones and other similar advanced devices used today. RetiPlus could have more functions that probably will increase its usability for orientation and mobility. Persons with RP may find reading text challenging due to restricted peripheral and central visual fields, and maybe reduced visual acuity. For example as we move around in a city or town, we

might want to read street signs from a distance. Such signs tend to hang quite high up, and sometimes they are placed only on one side of the street. Today there are apps for smartphones that uses its camera to view and then read text in its visual scene out loud. Adding other functions to make RetiPlus better, should not negatively affect the battery and control box of it as presented in this study.

This study is just a drop in the sea. Our physical surroundings can be complicated when a person lives with visual impairment. Technical aids also imply a need for more research as others have pointed out, for example Htike et al (2020) and Berndtsson (2018). RetiPlus uses AR which may have huge implications for persons with RP in relation to orientation and mobility as technology evolves. It will be interesting to see how RetiPlus and AR in general evolves providing new devices that can be used for persons with visual impairment.

## **7.1 Limitations and strengths**

As with every study, there are limitations for this one too. The number of informants used in this study was 4, which could be somewhat low. In turn this affects the transferability of the study. However, the informants can be said to represent a broad spectrum in relation to what the study looked at. The four informants all had different visual functioning and had different experiences of using RetiPlus. The number of participants for qualitative studies have no definitive answer, and it depends on the scope of the study. It is suggested that the group of participants are few enough and at the same time represent a spectrum of different experiences etc (Thagaard, 2018; Graneheim et al., 2017; Engelsrud, 2005). It is not certain that the results would be much different by multiplying the number of informants. The number of informants was also restricted by RetiPlus itself. It is expensive and only so many units are available in Norway. If this study is conducted 5 years from now, then this restriction may not be as affecting since the availability of RetiPlus may have increased. The interviewer, transcriber, analyser, and author who discussed the results, are as stated before the same person. Relying on one person makes their prior experience and pre-understanding hugely influential on how the study is conducted and the results presented. Having one researcher conducting and finalizing a study may assume researcher bias towards the data, affecting the credibility, dependability, and transferability of the study. At the same time deeper understanding of the raw data may occur, positively affecting other phases of a qualitative study. The scope of this study had its restrictions related to the timeframe and resources available. Being multiple persons working together may mitigate the possibility of researcher bias towards the data but can assume certain challenges that one lone person may not encounter at all. This study addresses known phenomena related to other more used technical aids, and it can be said that the author has through his interests and experiences a good preunderstanding.

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# 10 Attachments

## 10.1 Attachment 1

### Intervjuguide

«Takk for at du ønsker å delta i studien min. Formålet med studien er «å utforske hvordan bruk av AR-teknologi for mobilitet og orientering oppleves av personer med Retinitis Pigmentosa og å utforske brukeres refleksjoner rundt hvordan denne teknologien kan bidra innen mobilitet og orientering for personer med begrensede perifere synsfelt.». Studien innebærer at du og jeg har to samtaler/intervju hvor første er i dag, og det neste over Jul. Dette og vårt neste intervju tar jeg opp på lyd for å sikre at all data som kan være relevant for studien tas med videre, men jeg har ikke skrudd på opptakeren enda. Har du noen spørsmål relatert til studien eller formålet? (Hvis det ikke er noe mer) Da skur jeg lydopptakeren på.»

#### Intervju fase 1:

- Fortell meg litt om deg selv.
  - Jobber du, og hva innebærer i så fall arbeidet?
  - Er det noe du liker å bruke tid på (fritidssysler) på fritiden? (Formulering tilpasses etter hvordan jeg kjenner kandidaten gjennom samlingen før intervjuet).
- Fortell meg om hvordan du klarer deg i hverdagen?
  - Jobber du, innehar tillitsverv, frivillig arbeid, ev. med hva?
  - Har du en hobby du liker å gjøre på fritiden, og hva er ev. denne?
  - Hvordan kommer du deg rundt når du skal ... (A til B)?
  - Fortell meg mer om ...
- Hvilke hjelpemidler bruker du i dag relatert til mobilitet og orientering?
  - Savner du noen hjelpemidler i hverdagen, og i så fall hvilke og hvorfor?
- Hvordan opplevde du bruk av RetiPlus?
  - Hvordan var det å sette seg inn i funksjonene i RetiPlus?
  - Var det enkelt eller komplisert/vanskelig?
  - Kan du fortelle meg mer om ...?
- Hvis du har, hvilke tanker har du allerede nå om AR-teknologiens plass innen hjelpemidler for personer med nedsatt syn relatert til mobilitet og orientering?
- Er det noe du ønsker å legge til, utdype, spørre om eller lignende før vi avrunder intervjuet, ev. hva?

«Da skrur jeg lydopptakeren av.»

## **Intervju fase 2:**

«Takk for sist. Er det noe du lurer på i forhold til studien? (hvis det ikke er noe mer) Da skrur jeg lydopptakeren på.»

- *Sist fortalte du om [situasjonen din i hverdagen] ..., har det skjedd noen endringer siden sist?*
  - *Fortell meg mer om ...*
- *I vår første «samtale» under samlingen i fjor, fortalte du om .... Kan du fortelle meg mer?*
- *Fortell meg om dine erfaringer med bruk av RetiPlus siden vi møttes i oktober i fjor.*
  - *I hvilke situasjoner har du brukt RetiPlus?*
  - *Hvordan var det å bruke RetiPlus i situasjonene?*
  - *Hva synes du var negativt ved bruk av RetiPlus?*
  - *Hva synes du var positivt ved bruk av RetiPlus?*
  - *Du nevnte ..., fortell meg mer.*
- *I fjor fortalte du meg om diverse hjelpemidler du allerede bruker i hverdagen. Hvilke av disse brukte du i kombinasjon med RetiPlus?*
  - *Kan du fortelle mer om ...*
- *Det er flere funksjoner i RetiPlus som du vet. Eksempler er forstørring, forminskning, invertering av farger, justering av lyset i bildet osv.*
  - *Hvilke funksjoner har du brukt meste, og hvorfor?*
  - *Hvilke funksjoner har du prøvd og funnet ut at ikke var brukbar for deg, og hvorfor?*
- *Hvilke tanker har du nå om AR-teknologiens plass innen hjelpemidler for personer med nedsatt syn relatert til mobilitet og orientering?*
- *Er det noe du ønsker å legge til, utdype, spørre om eller lignende før vi avrunder intervjuet, ev. hva?*

«Da skrur jeg lydopptakeren av.»

## 10.2 Attachment 2

Theme	Factors that affect motivation to use RetiPlus		
Sub-theme	Motivational approach towards using RetiPlus	Motivating to use RetiPlus	Negatively affects motivation to use RetiPlus
<b>Codes</b>	Solution orientation	To be perceived as normal	Threshold to use RetiPlus in public affects motivation to use the technical aid.
	Having high expectations	I can see better with RetiPlus	Disappointment when learning more about RetiPlus
	Curious to learn more	Eased orientation and mobility	Feeling that RetiPlus is just in the way
		Feeling autonomous	Too complicated to want to use
			Uncertainty negatively affects motivation

### 10.3 Attachment 3

Theme	Descriptions of RetiPlus' usefulness		
Sub-themes	RetiPlus is useful as it is	Situations where RetiPlus was useful	The user experience is not good enough
<b>Codes</b>	RetiPlus is useful as a technical aid	Useful In relative darkness	Battery capacity could be better
	RetiPlus is useful combined with flashlight	Useful when around other people	Not too comfortable to use
	RetiPlus is useful combined with a guide-dog	Useful when going between light levels	Jugding distance is hard
	Certain functions were more useful	Useful when searching for information	Buttons not tactile enough
	Inform others on how I see	Useful when hiking	Control box gets too hot during use
			Picture gets too grainy and wabby when zooming
			RetiPlus and filteglassed can't be combined

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Content.localized/Templates.localized/Normal.dotm  
Tittel:  
Emne:  
Forfatter: Ingvild Stokka  
Nøkkelord:  
Merknader:  
Opprettelsesdato: 03.09.2022 14:21:00  
Versjonsnummer: 814  
Sist lagret: 23.04.2023 16:53:00  
Sist lagret av: Sindre Gården Paulsen  
Samlet redigeringstid: 392 minutter  
Sist skrevet ut: 23.04.2023 16:53:00  
Ved siste fullstendige utskrift  
Antall sider: 52  
Antall ord: 36 346 (ca.)  
Antall tegn: 188 637 (ca.)