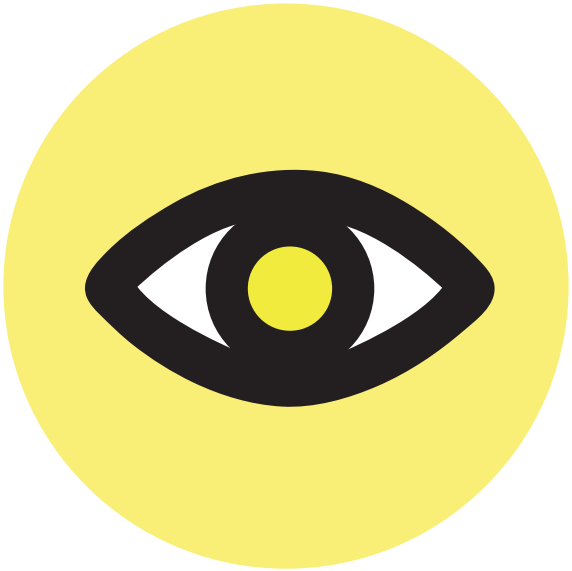
Inspiring confidence in newly diagnosed Age-related macular degeneration patients

through information provision via a web-based medium

A GRADUATION REPORT BY ROEL VAN WINSEN



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Roel van Winsen

Master Design for Interaction
Delft University of Technology
Faculty of Industrial Engineering

Supervisory team

Dr. Visch, V.T. *Associate professor*	Delft University of Technology *Department of Design Aesthetics*
Dr. Wijntjes, M.W.A. *Assistant professor*	Delft University of Technology *Department of Human Information Communication Design*
Drs. van de Weijgert, E.C.M.	Inholland University of Applied Sciences *Faculty of Engineering, Design and Computing*

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Finally, I'd like to personally thank those who opened their doors for me and would participate in my interviews. It's not nothing to let a relative stranger in your house and speak about personal things. It showed bravery and the willingness to contribute to a better future for macular degeneration patients.

EXECUTIVE SUMMARY

This graduation project is related to macular degeneration. Macular degeneration affects the macula, a central pit on the retina which is responsible for the highest visual acuity due to the densely packed cone photoreceptors. Symptoms of macular degeneration can vary in the early stage from blurred vision to abnormal dark adaptation (Jager et al., 2008) however in late stage macular degeneration symptoms can be much more invasive including partial and complete loss of the central vision. In order to cope with the loss of central vision patients could prescribe to what is called eccentric viewing. Eccentric viewing is a technique where the peripheral vision is used to see. Using eccentric viewing as a method to cope with macular degeneration requires, for optimal results, practice. This can be done through training.

This project was originally aimed at designing a training method for eccentric viewing with the use of motivating game elements. By speaking to experts from Visio and Bartimeus as well as patients throughout the research phase it became apparent that eccentric viewing was not deemed necessary. Instead other problems were addressed which had a higher priority in solving. These problems include the lack of provided information after the official diagnosis, the attitude of the ophthalmologist during the diagnosis and the perceived gap between the diagnosis and the Low-Vision clinics.

By creating a patient journey and examining the different problems that occur during that journey a choice was made to focus on a combination of the lack of information after the diagnosis and the gap between the diagnosis and the Low-Vision clinics. Six different topics of information were defined which play part in the lack of information. These six topics are: information about the condition, information about aids, make it easier, information about peer support, training / revalidation support and information about involved instances. Together these six topics cover most of the aspects surrounding macular degeneration.

To convey this information to the target group a web-based medium is used. Due to the special target group, guidelines have been defined which help in designing a website for visually impaired people. This has resulted in a framework where the necessary information can be placed in. Because of time restrictions one of the six topics which was defined was further developed. That topic is ‘Make it easier’. It resulted in a collection of tips from “experienced” macular degeneration patients on making Activities of Daily Living (ADL) easier to perform. In total 20 different tips were gathered through a brainstorm session, an online survey and telephone contact with Bartimeus. These tips were spread over three different themes: cooking, grocery shopping and public transport. Each tip was accompanied by an image, a descriptive text and a spoken quote.

Finally an evaluation test has been conducted with two participants to verify whether the proposed design succeeded. The results from the evaluation show the potential success of the design but are not conclusive. Therefore further testing needs to be done with more participants over a longer period of time.

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GLOSSARY

AMD

AMD is an abbreviation for Age-related Macular Degeneration. This abbreviation is commonly used throughout this report.

ADL

ADL is an abbreviation for Activities of Daily Living. This is a general term for regular activities performed throughout the day. This includes for example showering, cooking, grocery shopping and cleaning.

Bartimeus / Visio

Bartimeus and Visio are Low-Vision clinics, a term which is used on a regular base throughout this report. Low-Vision clinics provide information and advice about visual impairment but also different types of research, rehabilitation, education and living. One is eligible for revalidation at a Low-Vision clinic if their visus is determined to be below 0.3 (meaning that they have 30% visual capability in comparison to the average of 100%).

GP

A GP is what is considered in Dutch to be a ‘huisarts’. A GP can provide a preliminary diagnosis but has to refer to an ophthalmologist for further examination.

Ophthalmologist

An ophthalmologist is what is considered in Dutch to be an ‘oogarts’. Ophthalmologists are the only medical professionals who can provide an official diagnosis.

PROJECT INTRODUCTION

1.1 // MACULAR DEGENERATION

What is macular degeneration?

This graduation project is originally instigated by Marlies van de Weijgert, a researcher at the University of Applied Sciences who is working on her PhD with the focus on macular degeneration. Macular degeneration is an umbrella term that covers multiple types of macular diseases including Juvenile macular dystrophy, Stargardt disease, Diabetic macular oedema and Macular hole, but it is also often used in literature to describe the most common type which is Age-related Macular Degeneration (AMD). In order to avoid confusion from here on out only Age-related Macular Degeneration or its abbreviation 'AMD' will be used.

To understand what AMD is, basic knowledge of the eye is a prerequisite (see figure 1).

The eye is a very complex and ingenious organ which enables us to see. The area that provides the highest visual acuity within the eye is the fovea. The fovea is a pit at the very center of the macula which in regard is located on the retina, slightly off-center (see figure 2). The fovea is associated with the highest visual acuity due to the densely packed cone photoreceptor cells. Moving outwards from the fovea the visual acuity rapidly decreases due to a decrease in cone photoreceptor cells. If someone is diagnosed with AMD it means that this area of the eye, the macula, is damaged to a certain degree and that it loses its functionality. How the macula is damaged depends on what type of AMD the individual has.

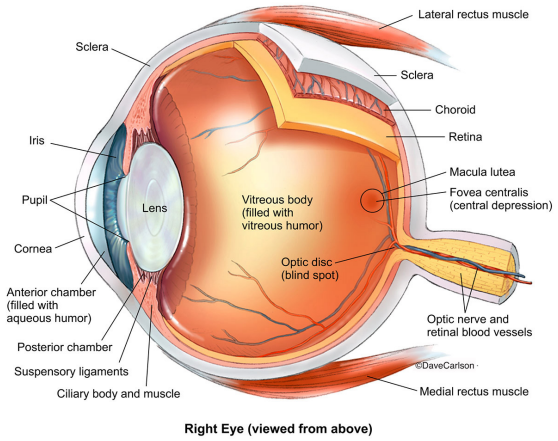


Figure 1. Anatomy of the eye (Dave Carlson, n.d.)

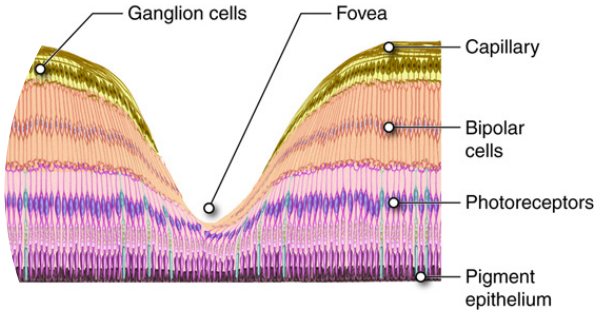


Figure 2. Anatomy of the retina (Cenveo, n.d.)

Different types

The first clinical signs of Age-related Macular Degeneration are the presence of drusen, although healthy eyes of people over 50 years of age also have drusen present. Drusen are acellular polymorphous debris in the macula and peripheral retina and start becoming a serious problem when there is an excess of them. The excess drusen can cause damage to the retinal pigment epithelium (RPE or Pigment Epithelium as seen in figure 2) which can lead to large areas of retinal atrophy. There are three different types of drusen; small (<63 um), medium (63-124 um) and large (124> um) (Jager, Mieler, & Miller, 2008). A classification system is developed which distinguishes between early, intermediate and advanced AMD, depending on the amount and size of drusen present in the eyes ("Risk factors associated with age-related macular degeneration", 2000). This type of AMD, the one where excess drusen cause damage, is also referred to as dry AMD. Individuals that are in the early stage of AMD typically do not notice much of a

difference although they may experience symptoms such as “blurred vision, visual scotomas, decreased contrast sensitivity, abnormal dark adaptation and the need for brighter light or additional magnification to read small print.” (Jager et al., 2008). Over a prolonged period of time, which can be in between months and years, individuals will gradually experience symptoms with increased severity such as central scotomas.

In 10 to 15% of the cases individuals develop what is called Neovascular AMD, also known as wet AMD. People that develop wet AMD have cells in their macula which produce growth factors of which VGEF (Vascular Endothelial Growth Factor) is the most important (according to Jumper & Rodriguez, 2017). This results in the growth of abnormal blood vessels underneath the macula. These blood vessels leak blood and fluids which causes inherently more damage in a shorter amount of time than the excess drusen do in the case of dry AMD. Therefore it is necessary to act quickly when someone is diagnosed with the neovascular version of AMD. Currently treatments are available for wet AMD but it is not possible to reverse the damage, instead it is only possible to slow down the deterioration process. The treatment consists of injecting medicine directly into the eye aimed at slowing down vessel growth.

Central vision loss

A substantial amount of individuals with AMD develop central scotomas over the course of months to years. The development of central scotomas start in the early stages of the condition but get progressively worse. They are caused by the earlier mentioned retinal atrophy (also referred to as geographic atrophy). Central scotomas are characterized by loss of the central vision. In the early stages central scotomas can be small blurred or grey spots in the central vision field. Over time these spots grow and start to merge together into larger areas of blurred or grey vision. Once an individual reaches the advanced stage of AMD these areas can become so big that it is considered to be an absolute central scotoma.This means that most of their central vision field is covered by the central scotoma which results in central vision loss. (see figure 3)

Figure 3. Normal vision vs. AMD vision (National Eye Institute, 2012)

Statistics & riskfactors

Age-related Macular Degeneration is the number one cause worldwide for irreversible blindness and visual impairment and it is predicted to affect 196 million people worldwide in 2020 (Wong et al., 2014) and about 378 thousand people in the Netherlands (“Feiten en cijfers”, 2018). As the name suggests, it becomes more prevalent as people reach an older age. Estimates are that 14% of the people in between 55 and 64 years of age suffer from AMD in the Netherlands. This estimate increases to nearly 20% in the category 65 - 75 and transcends over 35% for people of 75 and older (“Maculadegeneratie, Netvliesveroudering (slijtage), ooginjecties - Oogartsen.nl”, 2018).

Besides age, ethnicity also seems to play a major role in who is susceptible for AMD.

People from European descent have the highest chance of developing AMD at 12,3-30% as age increases. From there the percentages lower from Hispanics (10,4%) to Africans (7,5%) to Asians (7,4%) (Wong et al., 2014).

It appears that women also have a higher chance of developing AMD than men. At the age of 75 women are two times more likely to develop AMD than men due to their low estrogen level after the menopause. Besides gender a few other factors also seem to influence the possibility of developing AMD including smoking, genetics, diet, alcohol abuse, high blood pressure and sunlight exposure (“Maculadegeneratie, Netvliesveroudering (slijtage), ooginjecties - Oogartsen.nl”, 2018). (see figure 4)

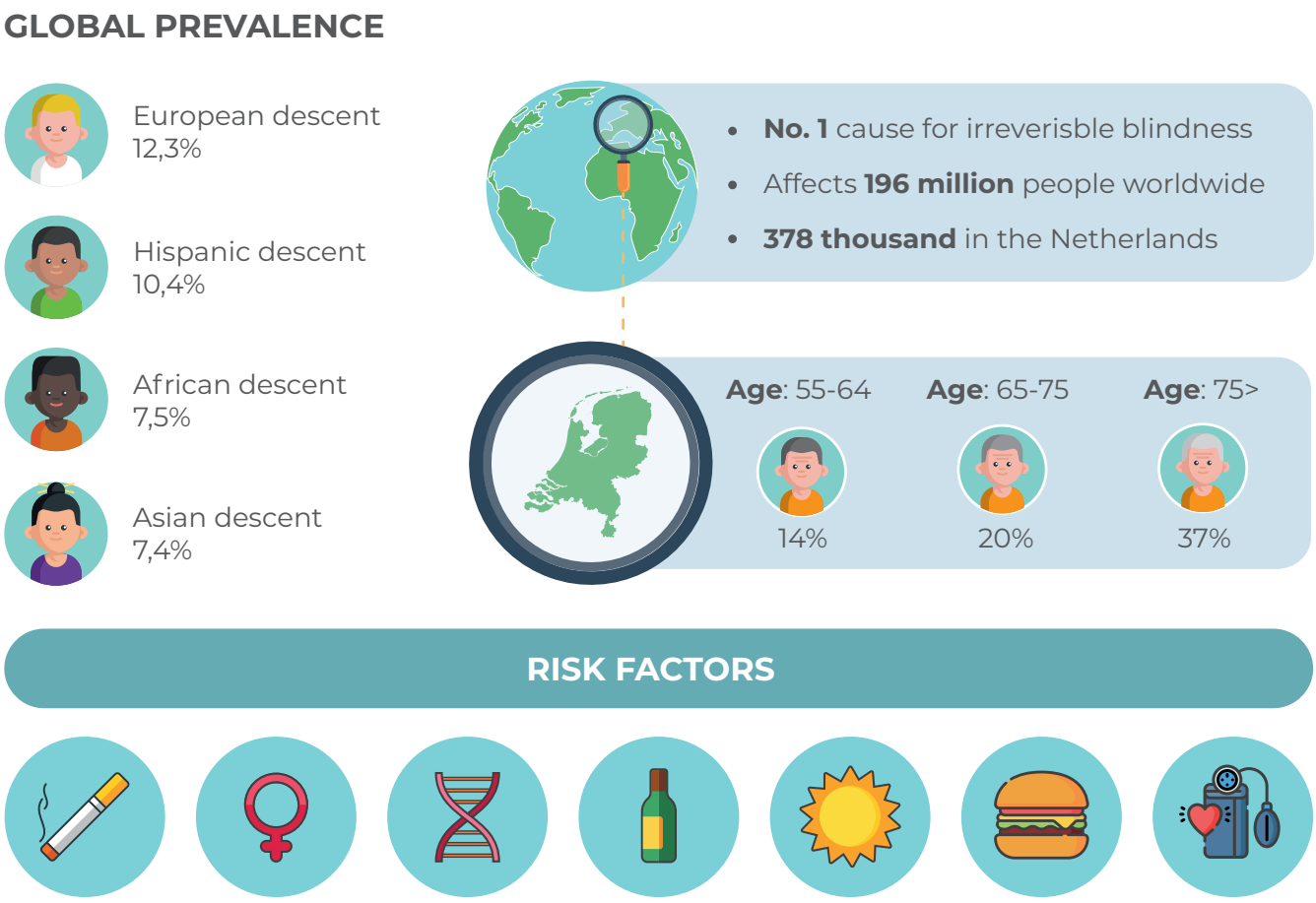


Figure 4. Infographic about statistics & riskfactors

Eccentric viewing

Originally the project brief for this graduation project aimed at creating a training method with motivating game elements to improve patient's their ability to successfully apply eccentric viewing. Eccentric viewing (EV) is a technique that AMD patients can use to cope with Central Vision Loss. When patients make use of eccentric viewing they utilize a healthy paracentral (near-peripheral) area of the retina to compensate for the lack of vision in the central field. This area is also referred to as "preferred retinal locus" (PRL). A proportion of the individuals actually prescribe to multiple preferred retinal loci designated for different situations. Individuals unfamiliar with the concept of PRL often naturally develop one, or multiple, either way. Unfortunately it is not uncommon (approximately 25%) for the naturally developed PRL to be located in an area sub-optimal for the task it is used for (Markowitz, Daibert-Nido, & Markowitz, 2018).

EV training could potentially help AMD patients with discovering the optimal locations for their PRL depending on the shape and size of the central scotoma (which is different for each individual). When an individual undertakes EV training and is guided by the instructor to find their optimal PRL (see figure 5 & 6 and appendix A.1 for an overview of identification methods) it is often referred to as a Trained Retinal Locus (TRL). Getting accustomed to a TRL feels contradictory due to the fact that it is most likely to be in a different location than the PRL an individual has developed naturally. Identifying a TRL is the first step in EV training but in order to fully utilize the TRL practice is required (see appendix A.2 for an overview of training methods). Several studies have suggested a variety of training methods which can improve eccentric viewing although A.J. Gaffney et al. (2014) presented an article which questions whether the provided evidence is of enough quality to ensure its accuracy. Nonetheless, the studies do provide promising results and Gaffney also recognizes the potential of EV training.

However, throughout the research phase of this project it became apparent that providing a training method for eccentric viewing was not deemed necessary by both experts and patients. On the other hand new problems were introduced when interviews were conducted with experts and patients which appear to have a higher need in solving. By creating a patient journey these problems could be mapped and analysed. Based on those outcomes a new direction for this graduation project was chosen which meant a shift in focus from eccentric viewing training to providing information about different aspects regarding the condition. This eventually resulted in the development of a website which provides said information. Within this website a specific category is further developed focussing on giving tips&tricks to newly diagnosed AMD patients about performing daily activities.

Figure 5. An AMD patient made aware of the location of their optimal PRL. (Macularsociety, n.d.)

Figure 6. A similar approach is used to identify the PRL (Macularsociety, n.d.)

1.2 // PROJECT APPROACH

Double Diamond approach

This graduation project follows the Double Diamond approach defined by the Design Council, a British organization, in 2005 (UK Design Council, 2005). This approach consists of four phases: Discover, Define, Develop and Deliver (see figure 7). Starting out with the Discover phase where it is about exploring the initial problem and gathering information on the topic. This phase is followed by the Define phase where the problem should be more limited and defined to allow for a clear transition into the Develop phase where a solution is proposed. Eventually the Deliver phase is reached where the proposed solution is evaluated and prepared for implementation.

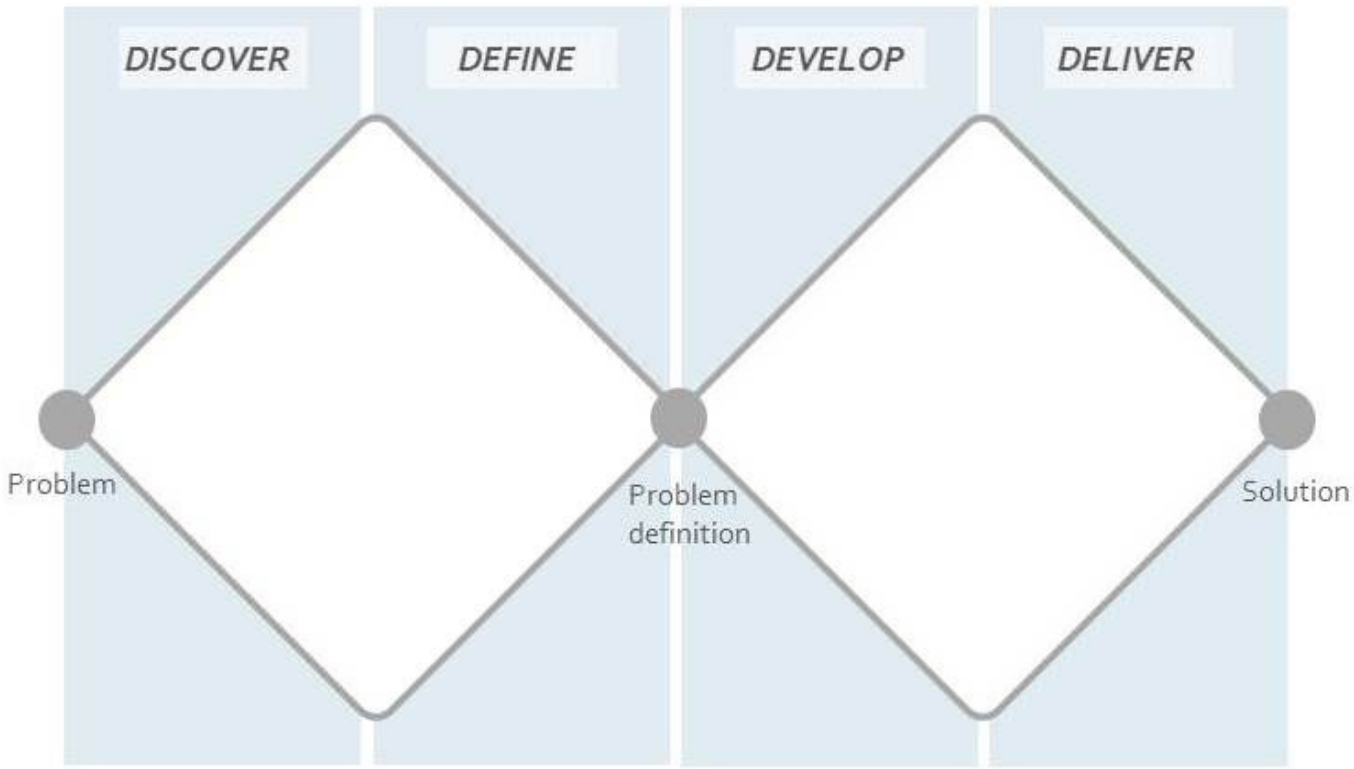


Figure 7. The Double Diamond approach (Innovationenglish, n.d.)

EXPLORE

2.1 // RESEARCH PHASE 1

Introduction

As was mentioned in the introduction chapter the original focus of this project was on creating a persuasive training method with motivating game elements for improving eccentric viewing. In order to acquire the required knowledge on this topic a literature study has been conducted in which a variety of papers was examined. These papers were mainly executed outside the Netherlands and gave the impression that this technique has a lot of potential despite the critique expressed on the accuracy of the presented evidence (A.J. Gaffney et al., 2014). To solidify the arguments made in favor of eccentric viewing training a series of interviews with representatives from Dutch Low-Vision clinics have been conducted to gain an idea of their opinions on the matter. The debate on the viability of eccentric viewing training does not only concern researchers and experts but also patients. Therefore, in addition to the expert interviews, a visit was made to a patient support group in Utrecht to verify whether the patients were familiar with the subject and whether they saw value in it. The outcomes of these sessions heavily influenced the direction of this project. In this chapter the approach and the results from the interviews and the visitation will be discussed.

Expert interviews

During both expert interviews a semi-structured interview approach has been used. This allows for an open discussion guided by several topic specific questions prepared in advance. The first interview was done with L. van den Bos, an intaker at Bartimeus in Rotterdam. As an intaker he is responsible for introducing new clients to Bartimeus and give them advice on the problems they experience. The second interview was done with J. Koopman and A. Zeilstra at Visio in Amsterdam. J. Koopman is a clinical physicist and A. Zeilstra is an occupational therapist. The interviews took approximately 60 minutes each. Notes were taken as a means of documentation.

The results // L. van den Bos

Despite his limited knowledge on the topic of eccentric viewing training he did express his doubt on the effectiveness. In his opinion patients only prescribe to eccentric viewing when they have reached the advanced stage of AMD, thus possibly experiencing absolute central scotomas obstructing their central vision. He stated that those that could benefit from eccentric viewing training often assign a PRL on their own, hence making eccentric viewing obsolete. In addition training these people would require an immense amount concentration which, mainly due to their age, is very difficult.

“Each patient is different and has unique problems for which they’ll come to us for which we do offer a wide range of rehabilitation programs, except that eccentric viewing training is not part of this range.”

- *See appendix A.3 for a more detailed write-up*

The results // J. Koopman & A. Zeilstra

Similar to what was said by L. van den Bos both representatives from Visio mentioned that eccentric viewing training was not part of their range of programs. The benefit for the patient was too little in comparison to the costs and especially those in the early stages would not gain anything from being trained in eccentric viewing. However, J. Koopman did state something interesting which was unrelated to eccentric viewing. On average the ophthalmologist only has approximately seven minutes for the diagnostic consultation in which they have to explain the results from the examination which has indicated Age-related macular degeneration. In this short timespan there is little to no time to answer questions from the patient. Visio and Bartimeus both have long waiting times for consultations, sometimes up to two months, in which they answer questions from patients. Many of these questions are basic things related to either aiding instruments or everyday tasks which do not necessarily have to be answered specifically by these Low-Vision clinics. J. Koopman expressed that a place which answers these common questions would be of much more value than an eccentric viewing training method. This would allow them to focus more on more specific questions from patients.

“It would be nice if there is something that would bridge the gap between the diagnosis and visits to the Low-Vision clinics.”

- *See appendix A.4 for a more detailed write-up*

Conclusion expert interviews

It became apparent that the experts from the Low-Vision clinics were skeptical about the benefits from eccentric viewing training. In addition J. Koopman from Visio indicated that for them there are other problems which would have a higher priority in comparison to eccentric viewing training. To add on the insights gathered from these interviews and to verify the potential benefits of eccentric viewing training with the target group a visitation to a patient support group has been made.

Patient interviews

Similar to the expert interviews a semi-structured interview approach has been used in the patients interview. The interviewing session took place at the MD (MaculaDegeneratie) café in Utrecht. This is a patient support group with monthly meetings in which everyday problems are discussed or guest speakers are invited for small lectures on different topics. Throughout the country 11 different MD cafés are present. For this particular session 12 patients were attending with Hans van den Hadelkamp as chairman. In total this session took approximately two hours.

The results // MD café Utrecht

The results from this session can be divided into two segments, the first segment revolves around eccentric viewing training and the second segment revolves around the patient experiences.

Regarding eccentric viewing training the patients were unanimously agreeing on the fact that they do not need it. They stated that they do not need training because they can adjust their PRL on their own if their situation changes. Even though they might prescribe to an inferior area of the retina they seemed convinced about their ability to do so.

The second interesting result that came out of this session is related to the experience of the patient during their disease progression. In the early stage of the condition they experienced different symptoms leading up to the general practitioner (GP) visit. One of the patients felt that her glasses were permanently steamed causing a slightly blurred vision. Another noticed that the lines on the side of the highway appeared to be wavy. Either way these symptoms were a reason to visit the GP. The experience the attending patients had with the GP were often to their dissatisfaction. To them it felt that the GP did not seem to recognize and/or acknowledge the condition. In some situations they had to insist on a referral to the ophthalmologist. On top of that, if it appears to be the wet type of AMD, an urgent referral needs be provided but that does not always happen resulting in referring times up to 8 weeks.

After being referred to the ophthalmologist and receiving the official diagnosis patients felt very insecure. This insecurity originated because of several reasons which are:

1. The attitude of the ophthalmologist during the diagnostic consultation. The ophthalmologist seemed to be only interested in providing an accurate diagnosis and treat the patient like a medical object instead of a human being.

2. The prognosis of the condition. AMD is an incurable condition which gets progressively worse over time. The emotional impact of this message is very big and could cause symptoms of depression.

3. The lack of information. After the diagnosis the patient is sometimes handed a small folder (which is added in the APPENDIX) with basic information about the condition but in some cases received nothing. They go home with no time to ask questions, no information about what they are suffering from and the prognosis that it is probably getting worse in the future.

After the official diagnosis two possible routes are taken. Either the patient is diagnosed with wet AMD resulting in injection treatment possibly on a monthly base or the patient is diagnosed with dry AMD resulting in an annual visit to the ophthalmologist. Besides those visitations the patients are on their own. The attending patients mentioned how some of them tried to go to either Visio or Bartimeus for advice but due to the long waiting times refrained from actually going, this to their disliking. Some also mentioned how they did not know what Low-Vision clinics like Visio or Bartimeus could do for them. They did however express their gratitude towards the support group. Having people around them with the same condition greatly benefitted them. They were helping each other with problems they encountered and went on trips together every once in a while.

Conclusion Research Phase 1

The results from these interviews showed that both experts as well as patients have their doubts about eccentric viewing training. On the other hand, these interviews also showed that both the statement from J. Koopman as well as the experiences from the patients reveal problems that might have a higher priority in solving. Therefore the choice has been made to put a halt on the development of an eccentric viewing training method and continue with focussing on the newly revealed problems which will be elaborated on in Research Phase 2.

2.2 // RESEARCH PHASE 2

Introduction

The first research phase was concluded with a new direction for this project. It became apparent that, even though literature shows the potential, eccentric viewing training is not considered to be a high priority especially in comparison with other problems that came to light. In order to get a better overview of these problems and to understand better what the experiences of the patient are a patient journey will be presented in this chapter. It will show the different stages that a patient goes through from the initial symptoms to actually having to live with the condition. Following this patient journey, an overview of the problems that play part in this journey will be presented linked to the different stages.

The patient journey is a result of the experiences shared by the patients that were attending the MD café in Utrecht, the input from the expert interviews and information gathered from medical websites.

Journey of an AMD patient

Stage 1A - Self discovery (dry AMD)

A distinction can be made between the self discovery stage of dry AMD against wet AMD. The type of initial symptoms as well as the severity strongly differs depending on the type. Dry AMD is the most common type and is characterized by subtle symptoms in the early stage. As described earlier in chapter 1 by Jager et al. (2008) the earliest symptoms can be blurred vision, visual scotomas, decreased contrast sensitivity, abnormal dark adaptation and the need for brighter light or additional magnification to read small print. Due to slow onset and subtleness of the symptoms it could sometimes take a while before action is taken. After recognizing that these symptoms indicate something different than the consequences of old age the next step is to visit the GP. This realization happens at a different moment for each patient.

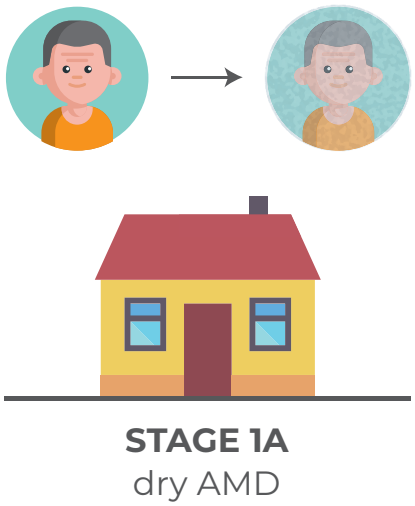


Figure 8. Stage 1A - dry AMD

Stage 1B - Self discovery (wet AMD)

In comparison to dry AMD, the onset of the symptoms of wet AMD are much quicker. The initial symptoms of wet AMD are also much more severe than those of early dry AMD. Due to the rapid damage that is caused to the macula it is important that action is taken as soon as possible.

If someone has wet AMD a specific protein (VEGF) causes abnormal blood vessels to grow underneath the macula (Rodriguez, 2017). These blood vessels are of poor quality and often have leakages causing damage to the macula. The growth of these blood vessels can be treated by injecting anti-VEGF into the eye and thus prevent further loss of the central vision. Therefore it is extremely important to recognize these symptoms and take appropriate action. The sooner one is treated with these injections the less damage is done to the macula.

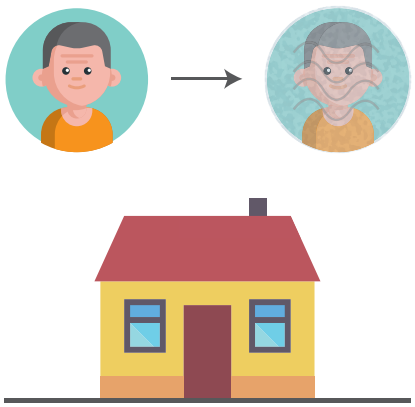


Figure 9. Stage 1B - wet AMD

Stage 2A - Preliminary diagnosis (GP)

Following the first stage of self discovery is the preliminary diagnosis provided by the GP. The GP should be able to identify the possibility of macular degeneration based on the described symptoms of the patient. The GP does not do an examination of the eye, this is done by the ophthalmologist in the hospital ("Ik heb maculadegeneratie | Thuisarts", 2015). It is an important task of the GP to also recognize the difference between dry and wet AMD. If the GP suspects wet AMD he/she should provide an urgent referral to the ophthalmologist for further examination.

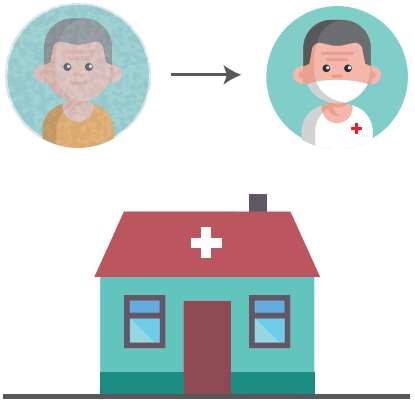


Figure 10. Stage 2A - GP

Stage 2B - Preliminary diagnosis (optometrist)

Some people might choose to visit the optometrist first if they notice that they experience unusual behavior in their eyes. The optometrist is capable of doing an examination which could determine macular degeneration as the cause. However due to the law system an optometrist is not allowed to refer a patient directly to the ophthalmologist. Therefore the patient needs to go by the GP first to receive a referral.

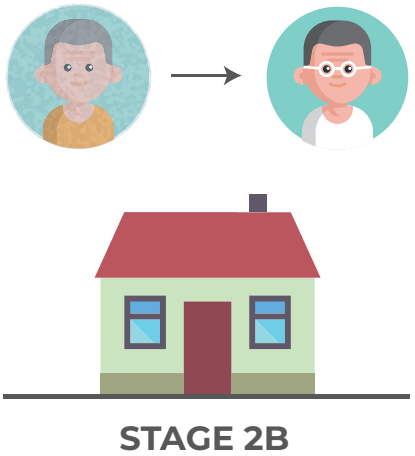


Figure 11. Stage 2B - optometrist

Stage 3 - Official diagnosis

The third stage of the patient journey is the official diagnosis. The GP has suspected AMD but the ophthalmologist has to give a definitive answer. Once the GP has made the referral the patient will visit the hospital. In the hospital the assistant could apply a variety of examination methods to identify the cause of the discomfort (see appendix A.5 for an overview). After the examination the ophthalmologist will provide the patient with an accurate diagnosis. On average this diagnostic consultation (excluding the examination) takes approximately seven minutes. Within this time the ophthalmologist will explain the results from the examination and the possible continuation with injection treatment if it appears to be wet AMD.

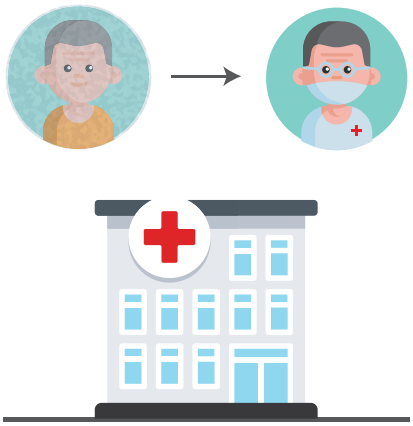


Figure 12. Stage 3

Stage 4A - Treatment

Depending on the outcome of the diagnosis a patient could be opted for injection treatment. The exact amount of times that injections are necessary differs per patient but in most cases multiple sessions are needed to reach a stable situation. In between each injection there is a time period of 4 to 6 weeks ("Injecties in ogen bij netvliesziekten (maculadegeneratie, suiker-ziekte) - Oogartsen.nl", 2019). Once the situation has stabilized the patient should check their vision with an Amsler grid on a weekly base. If it appears that the situation regresses immediate action should be taken. If there is no change then an annual visit to the ophthalmologist suffices.

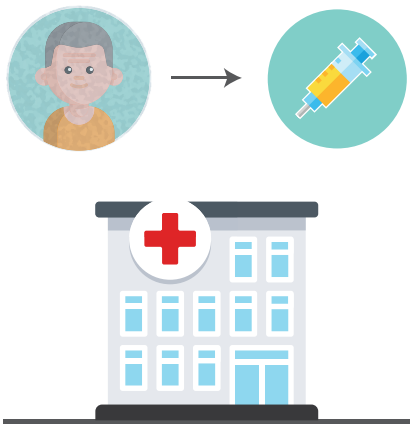


Figure 13. Stage 4A - treatment

Stage 4B - No treatment

In about 85 to 90% of the cases the result from the diagnosis is dry AMD. At this point in time there is no curative treatment available for this type of AMD. The only thing that an ophthalmologist can do is to point out the AREDS 2 guidelines (Chew et al., 2012). AREDS 2 provides a formula of high amounts of antioxidants and zinc which would potentially decrease the risk of further developing the condition. Similar to those diagnosed with wet AMD an annual visit to the ophthalmologist is advised if there is no sudden change in the situation.

Figure 14. Stage 4B - no treatment

Stage 4C - Referral to Low-Vision clinics

In general if the visus of the patient is determined to be below the threshold of 0,3 (meaning that the patient has 30% or less vision) during the examination in the hospital they qualify for rehabilitation at a Low-Vision clinic. Low-Vision clinics provide a wide range of training programs to let visually impaired people learn how to deal with their new situation. These training programs include, among other things, computer training but also for example using public transport. Beside these training programs they also offer advice on aids and answer questions specific for the individual.

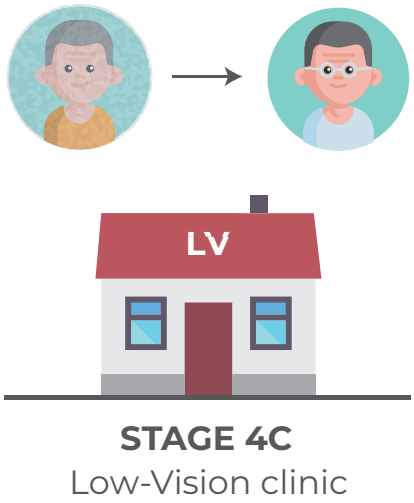


Figure 15. Stage 4C - LV clinic

Stage 5 - Living with AMD

The fifth and final stage is living with AMD. This stage is different for each person. Depending on the type of AMD and the severity of the symptoms some patients can live their lives to a normal standard for a considerable amount of time. If someone is diagnosed with AMD in only one eye then the other eye is able to compensate allowing the patient to live a relatively normal life. On the other hand if someone is diagnosed with, for example, wet AMD in both eyes then their life will inevitably change immediately.

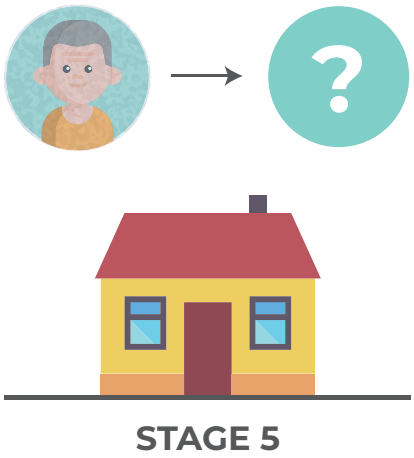


Figure 16. Stage 5

Patient experiences

The stages described above show the process of what steps a patient goes through from recognizing the initial symptoms to having to live with AMD. Within this process the patient can experience negative emotions at different stages.

A distinction can be made between negative emotions experienced due to impact of receiving the diagnosis and negative emotions experienced due to the circumstances that surround the diagnostic process.

Impact of the diagnosis

Receiving the diagnosis of AMD could have a huge impact on the emotional state of a person. According to Branch, Horowitz, & Carr (1989) the anticipation of losing ones sight is among one of the highest anxiety-provoking health stressors comparable to receiving an HIV diagnosis. Besides the emotional impact of the diagnosis, AMD is also linked to a decrease in quality of life of a patient. Brown et al. (2005) conclude that moderate AMD causes a 40% decrease in the perceived quality of life of the average patient while severe AMD causes a decrease up to 63%. The psychological impact of AMD is known to be the cause of severe depression (Casten, Rovner, & Tasman, 2004).

Quality of life

In general someone's quality of life is the extent to which their life is comfortable or satisfying in terms of health, happiness and well-being. This is influenced by a variety of factors defined in a document which is part of the Hwb resource collection (Hwb, 2014) which can be divided into four categories: physical factors, intellectual factors, social factors and emotional factors. The factors that influence the quality of life relevant for AMD patients specifically are the last two. Therefore the focus will be only on those two categories, social & emotional factors.

Social factors

Social contact

One of the most commonly heard complaints from AMD patients is the inability to recognize familiar faces in public in a late stage of the condition. Being unable to recognize others in public can create a feeling of social isolation. If other people are unaware of the situation they might suspect that they are being ignored and do not engage in a conversation.

Social support

Age-related macular degeneration patients can benefit from social support, especially among peers. A study executed in Sweden (Ivanoff, Sjöstrand, Klepp, Lind, & Lindqvist, 1996) showed that peer support can improve the ability of AMD patients to successfully perform ADLs with improved self-efficacy as a result.

Emotional factors

Dignity

This emotional factor is about treating people with respect. In 2002 a study was executed by Mitchell J. et al about the perceived quality of health care in macular disease. The results showed that out of the 1420 respondents 54% thought that their consultant was not interested in them as a person. 41% of the respondents were dissatisfied with their diagnostic consultation. This is in line with the results that came from the patients interview in Research Phase 1.

Psychological security

Being diagnosed with AMD can have a huge impact on a person's mental state. Brody B.L. (2001) demonstrated in a study that patients diagnosed with AMD are twice as likely to become depressed in comparison to healthy elderly of the same age. The cause for depression among AMD patients varies widely. It can be a direct consequence of the central vision loss which heavily impacts certain abilities which were previously considered easy. It can also be because of the initial shock and realisation that things will not go back to the way they were and could possibly become progressively worse over time. An Australian study by Wong et al. (2004) also noted the importance of one's understanding of the condition for psychosocial well-being. It is often not just one aspect that influences the mental state of an AMD patient but a combination of multiple aspects.

Autonomy

Autonomy plays a major role for patients diagnosed with AMD. The ability to have control over your own life is, to a certain extend, taken away. This factor is closely related to self-efficacy which is defined as people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives (Bandura, A., 1994). ADLs become significantly more difficult such as preparing meals, shopping, managing finances and doing light housework but also driving is at one point not possible anymore. Therefore patients will have to rely on help from the outside to remain functional. The inability to drive was reported as a major factor in loss of independence by an Australian study (Wong, E.Y.H., 2004) and considered as a factor in the progress of depression. This was supported by one of the attending patients at the MD café in Utrecht who felt socially isolated since she became unable to drive.

Circumstances of the diagnostic process

In addition to the negative experience of receiving the diagnosis patients experience negative emotions regarding the circumstances of the diagnostic process. At two important moments in the patient journey patients have indicated that they experienced negative emotions including insecurity, dissatisfaction and the feeling of unrecognition.

Stage 2a

The interviewed patients at the MD café in Utrecht have mentioned that, while visiting the GP, they felt unrecognized. In their opinion it seemed as if the GP did not acknowledge and/or recognize their condition. They stated that they had to insist on a referral to an ophthalmologist for further examination. In general this was a dissatisfactory experience.

Stage 3

After receiving the official diagnosis patients have experienced a general feeling of insecurity which is, besides the emotional impact of the diagnosis, also caused by the attitude of the ophthalmologist and the lack of information provided afterwards. The ophthalmologist is merely interested in providing an accurate diagnosis and does not seem to be interested in the human being. After the short time period that is available for explaining the outcome of the diagnosis the patient is left on their own, often with a lot of questions unanswered.

Problem space

Within the patient journey a total of five problems have been identified which could potentially be solved. The problems appear at different stages (see figure 17) within the patient journey and some even span over multiple stages. The problems are:

1 Stage 1

The first problem is related to the awareness of the general public on AMD. This condition is unknown to many while it is a prevalent issue. If someone has symptoms of wet AMD it is necessary for them to take action as soon as possible but due to the unfamiliarity with the condition this might not seem necessary to them.

2 Stage 2

The second problem that arises takes place at and after the visit at the general practitioner. Many patients leave the consult with a feeling of unrecognition and dissatisfaction. They had to insist on a referral. It is important that the general practitioner recognizes the condition and responds quickly, especially if it seems to be wet AMD.

3 Stage 3

The consult at the ophthalmologist is considered to be a negative experience due to the minimal amount of time available, the solely medical approach of the ophthalmologist and the lack of information that was provided during the diagnostic consultation and afterwards.

4 Stage 3/4/5

Due to the lack of information provided after the diagnosis many patients have questions regarding their condition. These questions vary from simple things related to the use of specific aids or more intricate questions related to carrying out specific hobbies. At this moment in time Low-Vision clinics have waiting times up to 3 months due to the large amount of people wanting advice or answers. J. Koopman from Visio has mentioned that they often answer the same general questions which could potentially be answered elsewhere to reduce the large waiting times.

5 Stage 3/4/5

Patients experience feelings of depression due to:

- The initial shock of the diagnosis and the realisation that it is irreversible
- Lack of referral/assistance and lack of information about the condition
- Their insecurity about performing ADL's and being independent / self-reliant

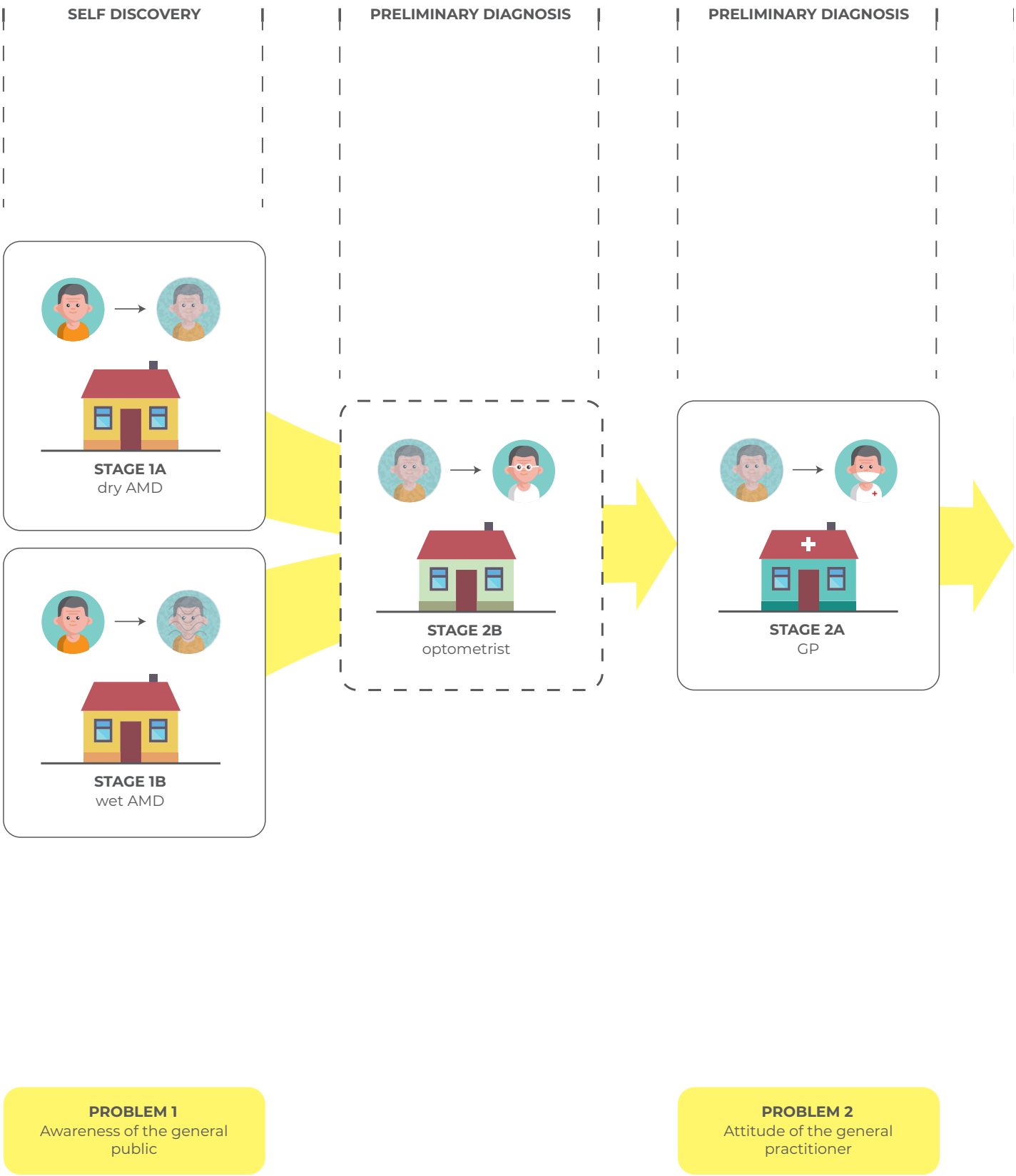
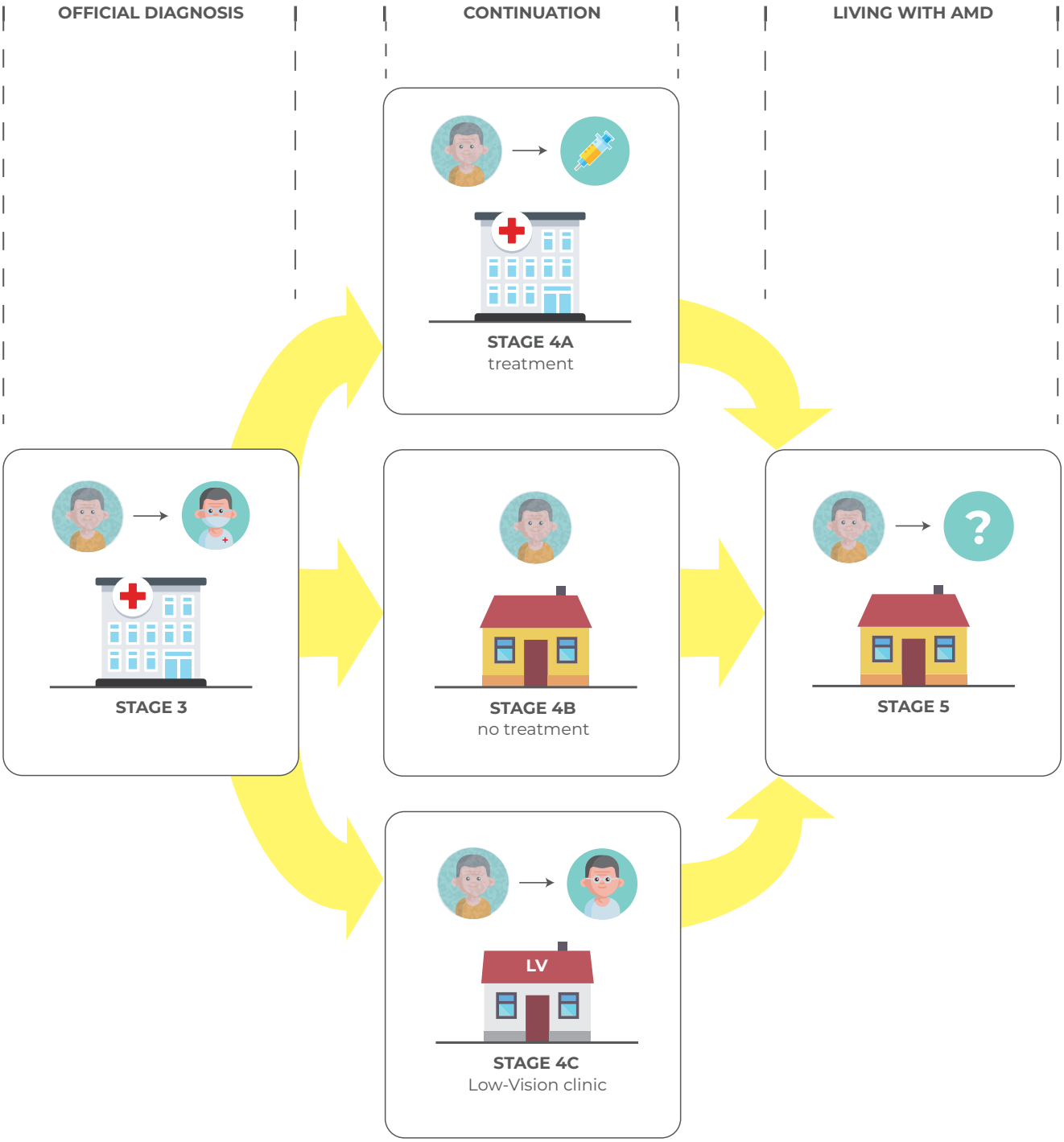


Figure 17. Patient journey visualized



PROBLEM 3
Attitude of the ophthalmologist

PROBLEM 4
Lack of information after the diagnosis

PROBLEM 5
Patients experience feeling of depression

Conclusion Research Phase 2

In this chapter the journey of an AMD patient has been described. The steps that a patient goes through from initially recognizing the symptoms to eventually living with the condition. Throughout this journey a multitude of problems arise with different causes and different possible solutions. The lack of information is something that affects the patient from the diagnosis and onwards. This also creates a problem with the Low-Vision clinics leading up to long waiting lines. Solving this problem would potentially decrease the impact of receiving the diagnosis of AMD and also lower the load on Low-Vision clinics. Therefore the focus will be on a combination of problem 4 & 5 with an emphasis on information provision.

Problems 1 to 3 defined in the problem space are also interesting but revolve less around the actual patients and more around changing the behavior of external parties such as the general public, the GP or the ophthalmologist.

The next chapter is about defining the problem and introducing a design goal as support for the rest of this project. A solution space will be defined followed by a list of requirements before entering the design phase.

DEFINE

3.1 // PROBLEM DEFINITION

Introduction

In the previous two chapters the focus was on researching the topic and acquiring knowledge about the different facets of the condition. By creating a patient journey it became possible to pinpoint specific problems which a patient encountered during that journey. A total of five problems were identified of which will be continued with problems 4 and 5. In this chapter a more indepth look will be taken into the problem. An expert interview has been conducted to determine the different topics of which patients have questions when visiting a Low-Vision clinic. A patient interview has been conducted to verify the proposed topics and medium. Following the problem definition is the design goal of this project. After the design goal a definition of the solution space is given. Next, a list of requirements is presented to transition into the design phase. These requirements are based on official and unofficial guidelines found online and guidelines suggested by a patient via an interview. Finally an analysis of existing websites is done to investigate how current macular degeneration related websites function and how they perform based on the presented guidelines.

Lack of information after the diagnosis

The problem that was identified in the previous chapter has to do with lack of information provided after the diagnosis. This lack of information may concern various topics related to the condition. In order to present an overview as complete as possible of the different types of information a second interview with L. van den Bos has been conducted to determine the topics that should make up for the lack of information. In addition to the outcomes of the interview earlier insights from other interviews have been taken into account as well including the interview with J. Koopman & A. Zeilstra and the patient interviews in Utrecht.

Interview approach

Similar to the interviews conducted in Research Phase 1 a semi-structured approach has been used. A list of questions was prepared in advance with the emphasis on frequently asked questions by patients to determine the relevant topics. In total this interview took approximately 90 minutes.

Interview results

The two main categories that came out of this interview were related to questions about the condition itself and about the use of aids. According to L. van den Bos patients did not seem to understand what it is that they are suffering from and they expressed their insecurity about the unknown progression of the condition. Many patients visit a Low-Vision clinic also to receive an aid which could ease their situation. Often, the patients think that they need new glasses while in fact they could benefit more from example new lighting. An important note is that providing advice on the right type of aid is something that needs to be done by a professional. In addition some patients have very specific questions about how and if they could still participate in their hobby or work.

Bartimeus is currently working on setting up a support group for AMD patients in Rotterdam. In the opinion of L. van den Bos peer support is certainly of value but the downside is that those support groups often do not go past ten long term members. The reasoning behind this is that many of the attending patients do not feel the need to return after a few meetings because they have retrieved the information that they were looking for or they get annoyed by the other attendees for their negative attitude.

- *See appendix A.6 for a more detailed write-up*

Information topics

The outcomes of the interview show that both information about the condition as well as information about aids is important for patients. It is, on top of that, also valuable to provide information about peer support. From the patient interviews in Research Phase 1 it became apparent that for some it was unknown what Low-Vision clinics could provide, therefore information about the different types of revalidation programs provided by Low-Vision clinics is another useful topic. Finally, to take into account what J. Koopman has said, a category which could answer frequent questions about performing ADL's to reduce their workload has also been added together with a category that provides the contact information of the different instances related to AMD such as the Ooglijn and the Maculavereniging.

All of these things combined result in the following list of topics:

1. **Information about the condition**
2. **Information about aids**
3. **Make it easier**
4. **Information about peer support**
5. **Training / revalidation support**
6. **Information about involved instances**

- *See appendix A.7 for a more detailed overview*

1. Information about the condition

One of the prime contributors to the psychosocial well-being of an AMD patient is understanding the condition (Wong et al., 2004). Therefore providing accurate information about the condition is one of the most important aspects of improving the situation. In order to prevent information overload it is necessary to provide this information in a manageable manner. Aspects that could be treated in this section are for example information about the different types of macular degeneration, prognosis of the condition, different symptoms, diagnostic process and origin of the condition.

2. Information about aids

Preventive or curative treatment for AMD does not (yet) exist. Although there is no treatment as such, there is a wide variety of aids available to assist AMD patients in their daily lives (see appendix A.8 for an overview of these aids). Many patients do make use of aids but do not realise that once their situation changes they could benefit from acquiring a new aid. This section could be used to provide general information about the different types of aids that are available. For more specific advice on what aid to use a referral to a professional is recommended.

3. Make it easier

An Australian study performed by Wong (2004) showed that the majority of AMD patients highly valued their independence and feared that they would be a burden to the people around them. Self-efficacy is of great importance but many AMD patients become increasingly insecure about performing ADLs (Activities of Daily Living) as their condition progresses. A study by Brody et al. (2001) showed that an improved feeling of self-efficacy was associated with decreased depression. This section could serve the role of providing information on how to make performing certain ADLs easier and therefore improve the patients self-efficacy.

4. Information about peer support

A study executed in Sweden (Ivanoff, Sjöstrand, Klepp, Lind, & Lindqvist, 1996) showed that peer support can improve the ability of AMD patients to successfully perform ADLs with improved self-efficacy as a result. In addition the patients interviewed in Research Phase 1 indicated that for them having peer support is of great value. They can provide insights to one another on how to deal with certain problems in daily life as well as supporting each other mentally during rough times. In this section information can be shown on the different support groups that exist in the Netherlands as well as the dates on which they come together.

5. Training / revalidation support

A large part of the pursuits of Low-Vision clinics is providing revalidation support to visually impaired people. This revalidation support consists mainly of different training programs on a variety of topics such as cooking, using public transport and using digital media. If one is eligible for revalidation at a Low-Vision clinic (rule of thumb is visus <0.3) they could participate in these training programs.

This section could become a place of reference for those seeking training possibilities and help with performing hobbies and other highly specialized tasks (for work). In addition simple home training tools can be added for self-study purposes. This could be for example related to eccentric viewing or moving target fixation.

6. Information about involved instances

The last category is about providing information on the different instances involved with macular degeneration. This will contain basic contact information of different instances such as the Low-Vision clinics, the Maculavereniging, the Ooglijn and several Low-Vision shops.

Design goal

In order to stay focussed on what is important in solving the defined problem a design goal is formulated. Defining a design goal provides support in the design phase of the project as a reference point to what needs to be solved. The design goal is as follows:

The design goal is to inspire confidence in newly Age-related diagnosed macular degeneration patients through information provision

The design goal consists of several elements. The intended goal is to inspire confidence through the design, or in other words battle the insecurity. The target group is newly diagnosed Age-related macular degeneration patients because they experience this insecurity after receiving the diagnosis. The means to achieve this goal is through information provision, as it became apparent in Research Phase 2 that lack of information is a prime contributor to the feeling of insecurity.

The question that remains is through which medium this information will be provided. In order to determine the medium a solution space needs to be defined.

Solution space

Information provision can be achieved through many different pathways. It could be done by, for example, creating a lecture series, an information booklet, a podcast, a movie, an app and many more. To make the right decision it is important to understand what the preferred attributes are in order to maximize the potential of the design.

Reach

An estimated number of 378.000 patients in the year 2020 in the Netherlands shows the frequent occurrence of macular degeneration. Ideally the design should reach as much new patients as possible to optimize the intended effect stated in the design goal.

Accessibility

The target group is visually impaired which means that not every medium is suitable for them in terms of accessibility. Auditory feedback is preferred in comparison to textual feedback as well as creating the possibility to allow the users to apply their aids for better understanding.

Completeness

The topics determined in the previous part of this chapter all hold their value and could provide different relevant information for different patients. Preferably the information should be as complete as possible. The more complete the information is, the higher the chance of it answering the questions that newly diagnosed patients have.

Medium of choice // website

A study conducted by the Pew Research Center (2017) shows that nowadays 67% of the people older than 65 make use of the internet (18 years ago this was merely 14%) and 42% owns a smartphone while roughly a third (32%) of the people older than 65 owns a tablet. These numbers will only increase in the coming years. Therefore creating an online platform is ideal for potentially reaching many people. Using an online platform allows for providing a wide variety of information with a user friendly interface and navigation. One can implement text to speech modules which gives visually impaired people easy access to this information, if reading is too difficult. Compared to a physical booklet with information, an online platform also has the advantage of easy editing in case of newly available information concerning any of the topics. It also provides the possibility to implement a search function which gives the user the option to find the specifics they are looking for. On top of that currently the ‘Maculavereniging’ has approximately 5.000 registered members which is a small fraction of the total amount of AMD patients in the Netherlands. Therefore the reach of an information booklet from the ‘Maculavereniging’ is relatively small compared to the reach of a specialized website.

Verification

To verify whether the proposed topics and medium meet the expectations of the user group an interview has been conducted with one of the regular attendees at the MD café in Utrecht, H. Bokhorst. During a two hour interview the topics and medium of choice have been discussed in a semi-structured way.

Interview results

The outcomes of the interview show that the proposed topics are all, in the opinion of H. Bokhorst, of value. Especially the category of 'make it easier' was in his opinion really valuable. He recognized the problem that lies after receiving the diagnosis and agrees on the fact that information provision is insufficient. To bring all of these topics into one place, one package, is going to be really helpful. Using a website as a medium for this information provision is an excellent choice if it does not interfere with already existing websites such as www.maculavereniging.nl.

"It is really nice to have one complete package which you can go to for all of your information"

He emphasized that it is very important for the effectivity of the information transfer to pay close attention to the way the information is presented to the user. He proposed a serie of guidelines which should be considered when designing an online platform for visually impaired people. These guidelines are:

1. Do not show large heaps of text, this is too intensive to work through
2. Provide a clear overview with graspable subjects
3. Layer the information in such a way that you can find the details if necessary but show the basic information first
4. Stay away from using forums, it is the same as with large heaps of text
5. Display the different subjects from the top down, this enables easier reading
6. Make it so that one can easily find what they are searching for
7. Integrate a text to speech module
8. Provide the option to view the website in different color contrasts
9. Do not provide too many different subjects at once, six is the maximum

- *See appendix A.9 for a more detailed write-up*

3.2 // LIST OF REQUIREMENTS

Introduction

In order to design a website optimized for usage by elderly and the visually impaired several guidelines are available. A distinction can be made between official guidelines set by a collective of individuals and international organizations under the name of WCAG (Web Content Accessibility Guidelines) developed through the W3C (World Wide Web Consortium) process and unofficial guidelines set by independent parties. The unofficial guidelines are based on a lecture given by Nikki Kerber from the University of Baltimore and on the results of the interview with H. Bokhorst.

WCAG 2.1 Guidelines

The most recent set of guidelines for accessible web development are named WCAG 2.1. These consist of 13 different guidelines divided over four separate categories. The goal of these recommendations is to make websites more accessible for people with disabilities but implementing these will often result in overall better accessibility for all users ("Web Content Accessibility Guidelines (WCAG) 2.1", 2018). The guidelines are formulated as follows:

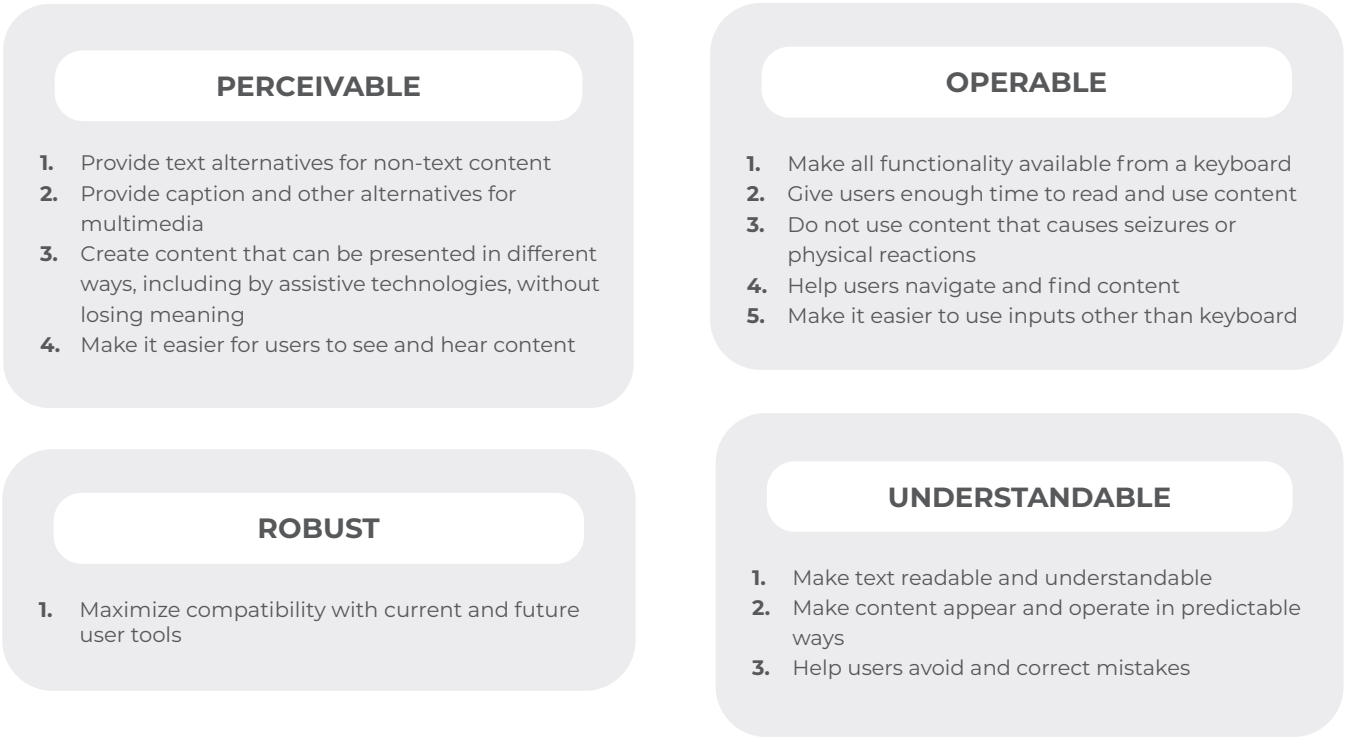


Figure 18. WCAG 2.1 guidelines

These guidelines are considered to be an international standard which is implemented by many government instances including the Dutch government. They are not mandatory for non-government websites but are nonetheless recommended.

Website design for senior citizens // Nikki Kerber

Nikki Kerber at the University of Baltimore presents a list of design requirements in a lecture. This lecture was part of a course named Interaction Design & Information Architecture (IDIA) and it includes a list of guidelines divided over five categories (Kerber, 2012).

GENERAL GUIDELINES

1. Break information into short sections
2. Give clear instructions and number each step
3. Minimize the use of jargon and technical terms
4. Use single mouse clicks
5. Allow additional space around clickable targets
6. Use 12- or 14-point type size
7. Make it easy for users to enlarge text
8. Use high-contrast color combinations
9. Provide a speech function
10. Provide text-only versions of multimedia content
11. Minimize scrolling
12. Choose a search engine that uses keywords and doesn't require special character or knowledge of boolean terms

INTERACTION DESIGN

1. Use conventional interaction elements
2. Make it obvious what is clickable and what is not
3. Make clickable items easy to target and hit
4. Minimize vertical scrolling; eliminate horizontal scrolling
5. Ensure that the back button behaves predictably
6. Let the user stay in control
7. Provide clear feedback on actions
8. Provide feedback in other modes in addition to visual

INFORMATION ARCHITECTURE

1. Make the structure of the website as visible as possible
2. Clearly label content categories; assist recognition and retrieval rather than recall
3. Implement the shallowest possible information hierarchy
4. Include a site map and a link to it from every page

VISUAL DESIGN

1. Make pages easy to skim or scan
2. Make elements on the page easy to read
3. Visually group related topics
4. Make sure text and background colors contrast
5. Use adequate white space

INFORMATION DESIGN

1. Make it easy to find things on the page quickly
2. Focus on writing on audience and purpose
3. Use the users' language; minimize jargon and technical terms

Figure 19. Nikki Kerber guidelines

Patient guidelines // H. Bokhorst

In addition to the guidelines proposed by Nikki Kerber another set of guidelines are suggested by H. Bokhorst during the verification interview. The guidelines are very similar to those of Nikki Kerber and show the values of a patient when looking at website design for a visually impaired audience. These guidelines are as follows:

H. BOKHORST	GUIDELINES
1. Do not show large heaps of text, this is too intensive to work through	5. Display the different subjects from top down, this enables easier reading
2. Provide a clear overview with graspable subjects	6. Make it so that one can easily find what they are searching for
3. Layer the information in such a way that you can find the details if necessary but show the basic information first	7. Integrate a text to speech module
4. Stay away from using forums, it is the same as with large heaps of text	8. Provide the option to view the website in different color contrasts

Figure 20. H. Bokhorst guidelines

Statement of Requirements

The following 23 guidelines will serve as a Statement of Requirements.

STATEMENT OF	REQUIREMENTS
1. Break information into short sections	13. Ensure that the back button behaves predictably
2. Minimize the use of jargon and technical terms	14. Let the user stay in control
3. Allow additional space around clickable targets	15. Make the structure of the website as visible as possible
4. Use 12- or 14-point type size	16. Clearly label content categories; assist recognition and retrieval rather than recall
5. Make it easy for users to enlarge text	17. Implement the shallowest possible information hierarchy
6. Use high-contrast color combinations	18. Include a site map and a link to it from every page
7. Provide a speech function	19. Make pages easy to skim or scan
8. Minimize scrolling	20. Make elements on the page easy to read
9. Use conventional interaction elements	21. Visually group related topics
10. Make it obvious what is clickable and what is not	22. Make sure text and background colors contrast
11. Make clickable items easy to target and hit	23. Use adequate white space
12. Minimize vertical scrolling; eliminate horizontal scrolling	

Figure 21. Statement of Requirements

These proposed guidelines are a selection of those defined by Nikki Kerber. The guidelines proposed by H. Bokhorst overlap with these and are therefore also taken into account. Several of the proposed guidelines by Nikki Kerber have been left out because it is irrelevant for this project (for example General Guidelines #12 which speaks of search engines) The WCAG 2.1 guidelines are left out because they are more back-end related and would serve better as a recommendation for future implementation of the design.

3.3 // ANALYSIS OF EXISTING WEBSITES

Introduction

An analysis of existing websites is done to examine how existing websites dedicated to providing information about macular degeneration function. This analysis will consist of four parts. Firstly a content comparison is made to see how specific topics are structured in terms of layering details and grouping information. Secondly the navigational structure of the website is assessed to identify how the pages transition into one another. Thirdly the websites will be compared to the previously defined Statement of Requirements. Finally the weak points of the website will be addressed and points of improvement will be defined. The goal of this analysis is to analyse how websites designed for the visually impaired function and to learn from the things they do good as well as bad.

www.maculavereniging.nl

The first website that will be discussed is the website of the national organisation related to macular degeneration in the Netherlands. The national organisation is lead by people that suffer from AMD. This means that the website is also created and maintained by AMD patients.

1. Content & layering

For the content comparison only the relevant chapters of the websites will be taken into account. These are the chapters that provide the patient with information related to the topics defined earlier this chapter. For www.maculavereniging.nl these relevant chapters are ‘Wat is macula-degeneratie’ and ‘Leven met macula-degeneratie’.

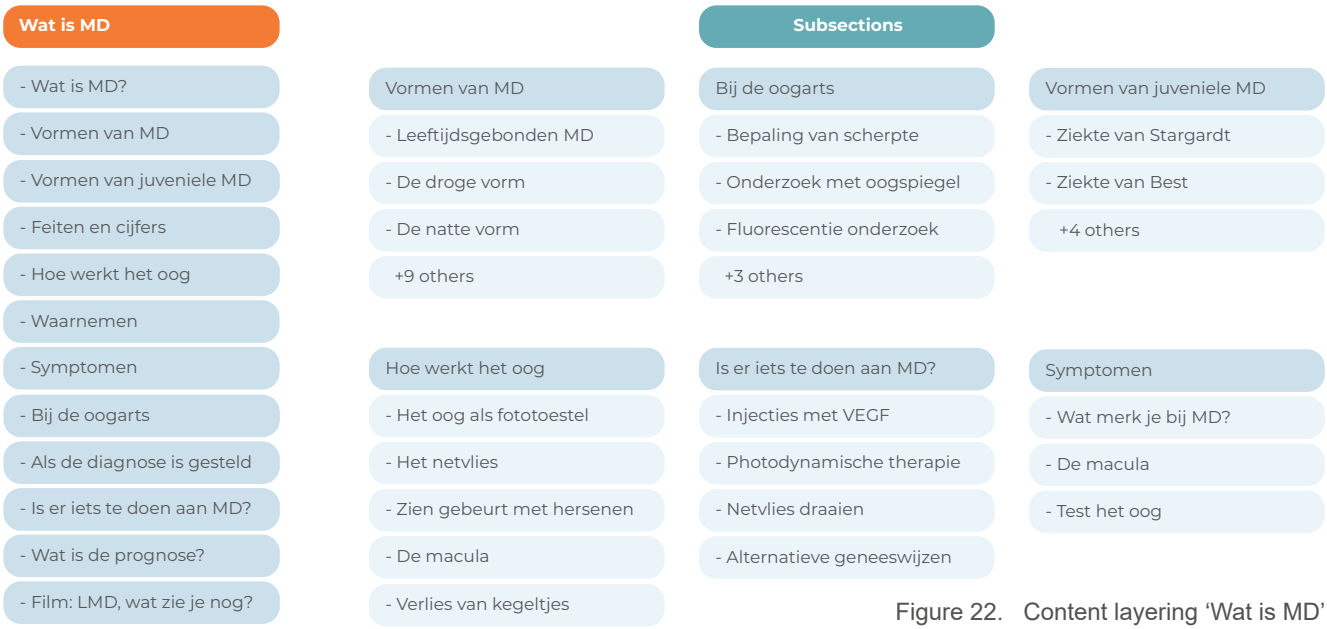


Figure 22. Content layering ‘Wat is MD’

Looking at the first chapter, ‘Wat is macula-degeneratie’, what stands out is the extensive list of topics that are shown (see figure 22). A total of 12 topics are addressed in this chapter of which 6 have their own list of subtopics. This chapter is introduced with a general text about the implications of AMD. From there the user can navigate through the different topics.

Figure 23. Content layering 'Leven met MD'

The second chapter, 'Leven met macula-degeneratie', is more condensed in comparison to the first with only 6 topics of which 3 have their own subtopics. (see figure 23)

2. Navigational structure

Each page provides a breadcrumb trail **(1)** indicating where you are. Due to the ever present menu bar **(2)** at the top of the page it is easy to return or navigate to another topic. For each topic **(3)** the list of subtopics **(4)** is in the same location which provides consistency and recognizability. If the user is viewing a subtopic which includes subsections **(5)** the website minimizes a subsection once another one is opened. In the menu bar a search box **(6)** is present which allows the user to search for more specific terms. (see figure 24)

Figure 24. Navigational structure Maculavereniging

3. Statement of Requirements

When comparing www.maculavereniging.nl to the Statement of Requirements to analyze its performance on accessibility for visually impaired users it implements 18/23 guidelines (see figure 25). It does not minimize scrolling, it does not have a back button, the information hierarchy is not as shallow as possible (especially in the 'Leven met macula-degeneratie' section of the website) and not all the pages are easy to scan/ skim.

GUIDELINES	Implemented:
1. Break information into short sections	YES
2. Minimize the use of jargon and technical terms	YES
3. Allow additional space around clickable targets	YES
4. Use 12- or 14-point type size	YES
5. Make it easy for users to enlarge text	YES
6. Use high-contrast color combinations	YES
7. Provide a speech function	YES
8. Minimize scrolling	NO
9. Use conventional interaction elements	YES
10. Make it obvious what is clickable and what is not	YES
11. Make clickable items easy to target and hit	YES
12. Minimize vertical scrolling; eliminate horizontal scrolling	NO
13. Ensure that the back button behaves predictably	NO
14. Let the user stay in control	YES
15. Make the structure of the website as visible as possible	YES
16. Clearly label content categories; assist recognition and retrieval rather than recall	YES
17. Implement the shallowest possible information hierarchy	NO
18. Include a site map and a link to it from every page	YES
19. Make pages easy to skim or scan	NO
20. Make elements on the page easy to read	YES
21. Visually group related topics	YES
22. Make sure text and background colors contrast	YES
23. Use adequate white space	YES

Figure 25. Statement of Requirements Maculavereniging

4. Weak points / points of improvement

The first weak point of this website is related to the page 'Wat is macula-degeneratie'. There are twelve different topics which the user can go through. As H. Bokhorst mentioned during the interview, showing more than six topics is too much. It requires too much attention from the user to skim through all of the twelve topics.

The second weak point is the location of certain specific subjects. For example information about aids is located at 'Leven met macula-degeneratie' and then 'Ervaringsverhalen' while such an important topic would preferably be located on an easier to find location. This is an issue with the layering and prioritisation of the information.

The third weak point is the absence of changing color contrasts. A text enlarger has been implemented but the user is unable to change the color scheme of the website.

The second website that will be analyzed is the British variant named Macular Society. Macular Society, similar to the 'Maculavereniging', is runned by people that either suffer from some type of macular degeneration or have someone in their close proximity that suffers from macular degeneration.

1. Content & layering

Macular Society is different content wise compared to the website of the 'Maculavereniging' in that its purpose is not only to inform patients but also recruit donors and attract researchers.

The main menu consists out of four elements of which two are relevant for this project. Those two are 'Understanding macular disease' and 'Get support'.

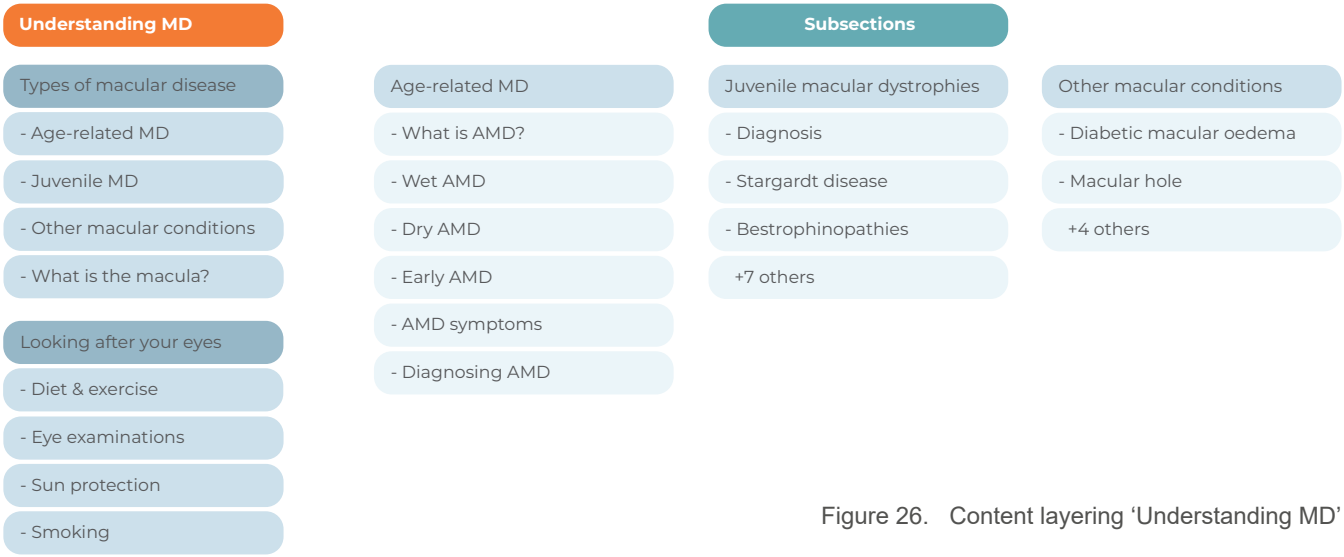


Figure 26. Content layering 'Understanding MD'

The first segment of the website, 'Understanding macular disease', is separated into two categories with four topics each (see figure 26). Three of these topics have subtopics which vary from six to ten. The separation between the two categories is based on information about the condition and information about factors that influence the probability of developing macular degeneration.

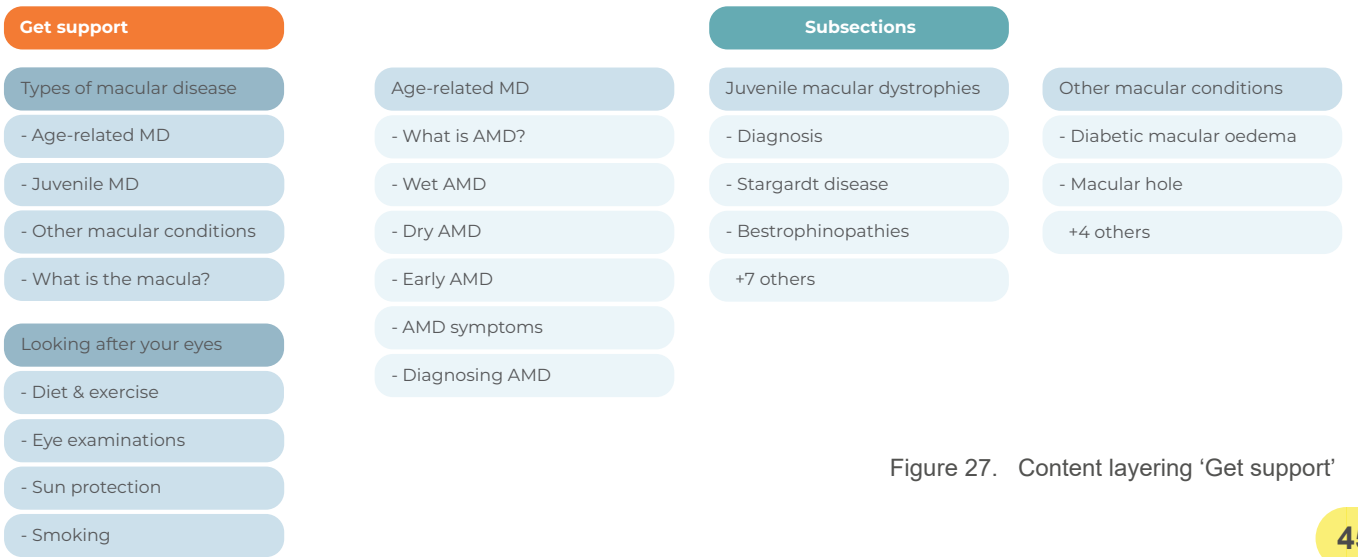


Figure 27. Content layering 'Get support'

The second segment of the website, 'Get support', is aimed at providing assistance to those who are diagnosed with a type of macular degeneration. This segment consists of three categories (see figure 27). The first category provides information on the different types of support available for macular degeneration patients, this includes counselling, treatment buddies and more. The category provides information on living with macular degeneration. This includes tips on how to sustain yourself after the diagnosis but also information about aids and your rights as a visually impaired person. The final category provides information about the organization itself and what they do.

2. Navigational structure

Every page has a breadcrumb trail **(1)** included which provides an indication of the location within the website. Each page has a header **(2)** with accessibility options **(3)** and the main menu **(4)** presented below. The main menu functions as a dropdown menu **(5)** which shows the respective topics for each category. The topics and subtopics are both shown as interactive blocks **(6)** accompanied, in most cases, by a picture and as a vertical menu **(7)** on the right side of the page. (see figure 28)

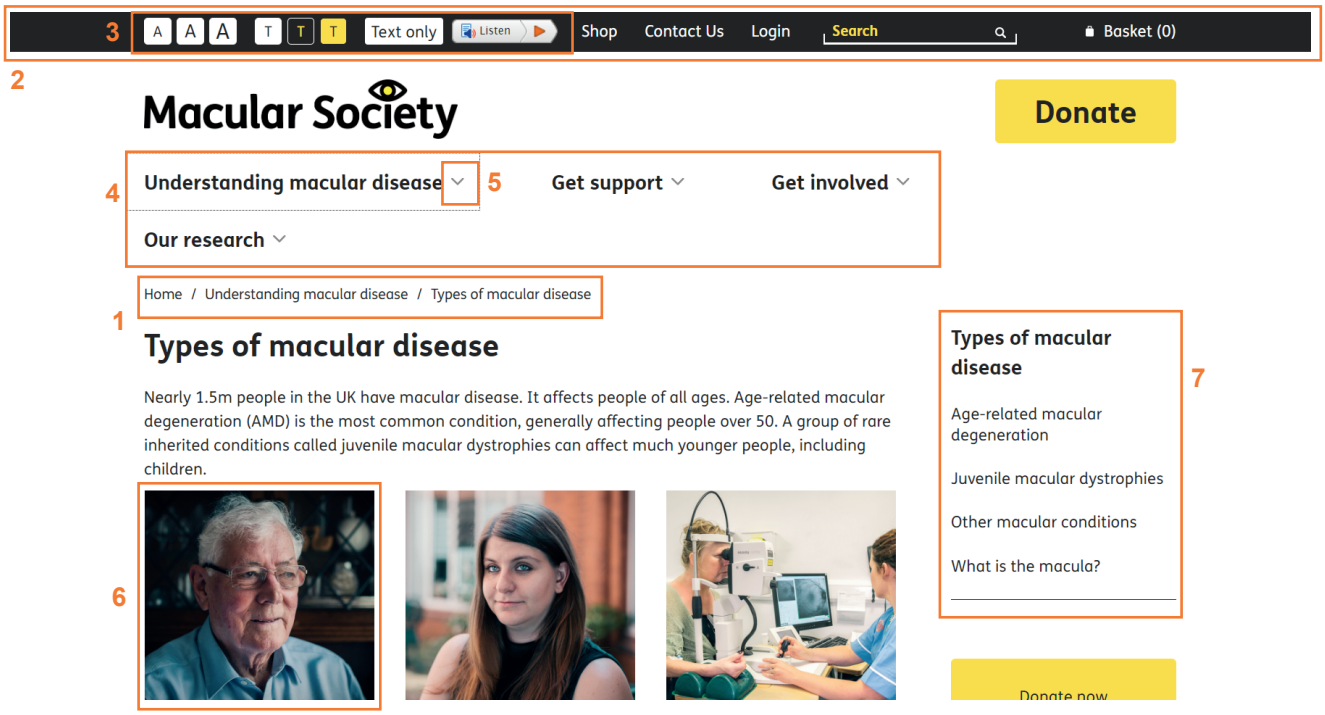


Figure 28. Navigational structure Macularsociety

3. Statement of Requirements

When comparing www.macularsociety.nl to the Statement of Requirements to analyze its performance on accessibility for visually impaired users it implements 20/23 guidelines (see figure 29). It does not minimize scrolling and it does not have a back button.

GUIDELINES	Implemented:
1. Break information into short sections	YES
2. Minimize the use of jargon and technical terms	YES
3. Allow additional space around clickable targets	YES
4. Use 12- or 14-point type size	YES
5. Make it easy for users to enlarge text	YES
6. Use high-contrast color combinations	YES
7. Provide a speech function	YES
8. Minimize scrolling	NO
9. Use conventional interaction elements	YES
10. Make it obvious what is clickable and what is not	YES
11. Make clickable items easy to target and hit	YES
12. Minimize vertical scrolling; eliminate horizontal scrolling	NO
13. Ensure that the back button behaves predictably	NO
14. Let the user stay in control	YES
15. Make the structure of the website as visible as possible	YES
16. Clearly label content categories; assist recognition and retrieval rather than recall	YES
17. Implement the shallowest possible information hierarchy	YES
18. Include a site map and a link to it from every page	YES
19. Make pages easy to skim or scan	YES
20. Make elements on the page easy to read	YES
21. Visually group related topics	YES
22. Make sure text and background colors contrast	YES
23. Use adequate white space	YES

Figure 29. Statement of Requirements Macularsociety

4. Weak points / points of improvement

There are three possible weak points within this website. The first one is related to the segmentation of the different topics. Due to this segmentation it can be difficult for the user to find the relevant information. The second weak point is the fact that this website is not designed for one specific user group. In addition to patients it is also aimed at donors and researchers resulting in additional elements irrelevant for certain users. The third weak point is related to the main menu. The main menu could be hard to identify due to its positioning on a white background. There is no clear separation between the different topics besides a dropdown arrow.

Takeaways analysis

The takeaways from the analysis are that information provision should be divided into small categories but not too many (for example 12 different topics in the first website). Yellow/black/white is a desirable color scheme that optimizes color contrast. Accompanying different topics with images allow for a clear overview and presenting an additional vertical menu improves the accessibility. The presented information should be separated in short sections of text to prevent information overload. Finally, grouping related information provides a clear overview. These takeaways in combination with the Statement of Requirements provide a solid base for the next chapter.

DEVELOP

4.1 // WEBSITE FRAMEWORK

Introduction

In the previous chapter the problem of lack of information has been defined and divided into six segments: information about the condition, information about aids, make it easier, peer support, training / revalidation support and information about involved instances. After this definition a design goal has been set which aims on inspiring confidence in newly diagnosed macular degeneration patients. By appointing specific attributes to which the design should confirm a choice has been made for the medium that will be used, a website. Finally, a Statement of Requirements has been made which shows 23 guidelines which the design should take into account regarding the visually impaired target group.

In this chapter this setup will be translated into a design. At first a general design for the website will be presented with an explanation for the different design elements according to the previously defined Statement of Requirements. This builds the framework where one of the six segments can be made in more detail. This specific segment will be 'Make it easier'. The reasoning behind this is that there is limited amount of time available for this project and in comparison to the five other topics 'Make it easier' introduces new content instead of rearranging already existing content and placing it in the proposed framework. The content of this segment will consist of tips&tricks gathered from "experienced" macular degeneration patients in performing ADLs. These tips&tricks could potentially make the lives of newly diagnosed patients easier and answer questions that otherwise would have to be answered by Low-Vision clinics. In order to shape the tips&tricks three elements are introduced which are quotes, images and descriptive texts. An experiment has been conducted to verify what type of images are best interpretable by macular degeneration patients. Following this chapter is an evaluation chapter to verify whether the proposed design could fulfill its premise.

General website design

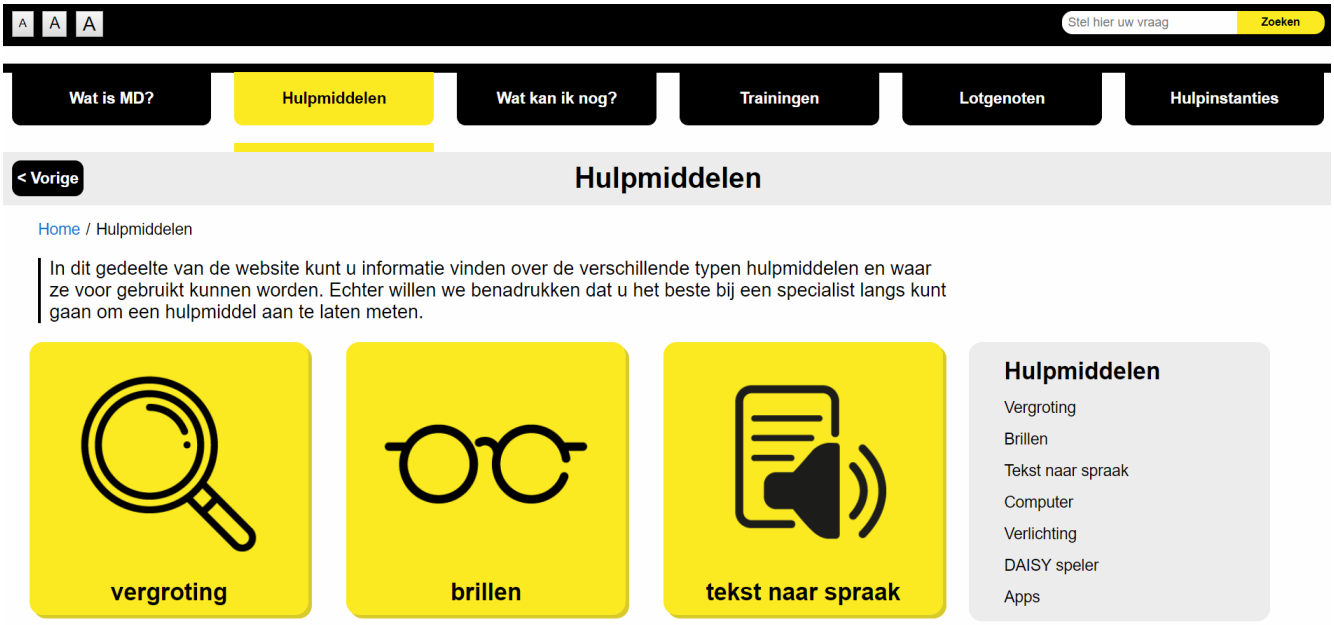


Figure 30. General website design

Presented on the previous page is a screenshot from one of the main pages of the website (see figure 30), in this case the page which provides information about aids. This image will serve as a reference point when explaining the different elements appearing on the page. It should be noted that the layout of each of the six main topics is similar and that the same design principles have been applied. First four design principles will be discussed which apply to the entire page followed by an explanation for each of the elements visible on the page.

General design principles

Color contrast

A specific color palette has been used throughout the website which is optimal for visually impaired users. Black and white is the most commonly used color contrast but for visually impaired people black and yellow work even better. That is also why this color combination is seen in both the Dutch as well as the British macular degeneration website. Therefore a combination of black, white and yellow will be applied throughout the website. Whereas yellow will function as a highlighting color which indicates the important elements on each page.

User control

All clickable elements on the page will show either a color change or an underlining in different weights upon hovering to give an indication of the location of the mouse. It can be difficult for a visually impaired user to control their actions if their location on the page is hard to define. By providing reactive elements the user gains more control and receives feedback on their actions.

Consistency

To make the website predictable and easy to use consistency has been applied where possible. Elements appear on similar locations and information is shown in a consistent manner. It is important to stay consistent to prevent surprises which in return can cause confusion.

Manageable information

It is disadvantageous to show large portions of information at once for a visually impaired audience. Therefore it is important to minimize the amount of text on each page to only the essential parts. The pages such as the one shown as a reference only contain a small introductory text and short titles for the different subjects. Once the user goes more into the specific subjects the amount of text will increase but will stay limited to only the necessary amount. By adding layering in the provision of the information small portions of text can be added without causing information overload.

Different design elements

The header

On the top of each page is a static header bar with important accessibility elements. In the reference image shown at the beginning there are currently three buttons which can be used to adjust the font size on the entire page. This functionality is a recurring element on websites dedicated to the visually impaired. In the top right is a search box which allows the user to specifically find content on the page without having to navigate through all the sections. Eventually there should also be an option to change the color contrast wherein only two colors are used across the entire website (black/yellow and yellow/black).

Figure 31. Header design

The menu bar

One of the most important sections for the navigational quality of a website is the main menu. In most modern day websites the main menu is often hidden behind a hamburger menu icon which unfolds upon clicking or hovering. Hiding the main menu when designing for visually impaired users is not desired. It is important to give the user a clear idea of the available topics and enable them to easily navigate through those topics at all time. This principle is seen in similar websites as well. Some of the early concepts are:

Figure 32. Main menu concepts

These examples are all horizontally placed at the top of the page but it is also possible to position the main menu vertically on the side. It became apparent that is the lesser of both options due to the permanent decrease of space on the page because if you place it vertically, ideally, you want to keep it static.

A second consideration was how it should be indicated which chapter the user is currently in. In the examples above it is done via either a separate font color or a contrasting background color. In the final design a contrasting background color in comparison to the other menu items was chosen. When hovering over one of the other menu items it changes color to the same color combination as the active menu item. In order to separate those two a yellow bar on the bottom of the active menu item was added.

The title bar

Below the main menu is a grey horizontal bar which presents the title of the current page. This is implemented to help the user in understanding where within the website he/she is located. On the far left of this bar there is a previous button always located on this exact spot on each page.

Figure 33. Title bar design

The breadcrumb trail

A final indication for the user's location within the website is a so called breadcrumb trail. This is a simple line of text showing the pages that are layered on top of the current page. As soon as the user progresses deeper into the website it will show exactly where they are. This is also the final element which is consistently the same on all pages.

The content blocks

In order to show the different topics big yellow blocks with an accompanying icon such as the one below have been used:

Figure 34. Content blocks design

The reason for this choice is that using this kind of blocks provides a good separation between different topics and increases readability. A vertical menu is added on the side. This is done because each AMD patient is in a different position and has different symptoms. Some with relatively good sight are able to interpret the blocks well and recognize the icons but others have troubles keeping the overview on elements of this size. H. Bokhorst mentioned that it is easier to navigate throught items when they are vertically stacked if your sight is well below average. A similar principle is seen on www.macularsociety.org. The icons used in these blocks portray the activity or subject in a simple fashion and are meant to be in the same style throughout the website to remain consistent.

All of these elements together make up for the framework which can be used in further developing the category 'Make it easier'.

- *See appendix A.10 for early design concepts*

4.2 // MAKE IT EASIER

Introduction

One of the six categories that is defined in the previous chapter is ‘Make it easier’. According to J. Koopman many patients visit a Low-Vision clinic with simple questions on how to deal with AMD in daily life. In order to reduce the amount of simple questions asked to them and give them room for answering more specific questions this category is introduced. The idea is to provide newly diagnosed AMD patients with tips&tricks from “experienced” patients with the intended goal to make performing ADLs easier. These tips&tricks were gathered through three different channels. First, a brainstorm session with AMD patients has been conducted. Second, an online survey has been put out on a Facebook page for visually impaired people and thirdly, Bartimeus was contacted for additional input.

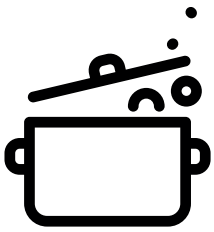
Brainstorm session approach

This brainstorm session took place at the MD café in Utrecht. Seven patients were attending and the session took 40 minutes to complete. As a preparation five themes related to day-to-day activities were defined which included: cooking, public transport, grocery shopping, personal hygiene and cleaning. The patients were asked to provide insights on how they perform those activities and what they need to pay extra attention to. Due to time restrictions only 3 out of the 5 themes have been treated.

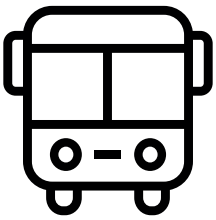
- *See appendix A.11 for the brainstorm set-up*

Brainstorm session results

From this brainstorm a total of 15 tips&tricks divided over the 3 themes cooking, public transport and grocery shopping were defined. 4 tips&tricks related to cooking, 4 related to public transport and 7 related to grocery shopping.



4



4

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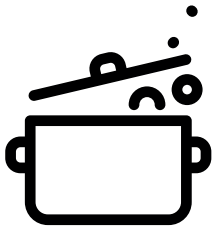
Online survey approach

In addition to the results from the brainstorm session an online survey has been conducted to retrieve more content for the category. The online survey was shared with the members of ‘Lotgenoten met een oogaandoening en slechtzienden’ Facebook page, a group of nearly 900 people. The setup of the survey was similar to the brainstorm session. An introductory text was included followed by the five themes that were part of the brainstorm as well.

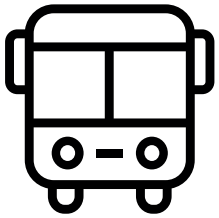
- *See appendix A.12 for the used survey*

Online survey results

In total this survey resulted in an additional 3 tips&tricks. Despite the nearly 900 members of the Facebook group only a very small portion actually completed the survey. From the answers that were given only 3 were actually introducing relevant information.



1



1

1

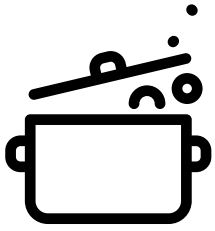
Bartimeus contact approach

As a final attempt to broaden the range of tips&tricks for this category contact has been made with Bartimeus. A phone call was made in which the concept was explained.

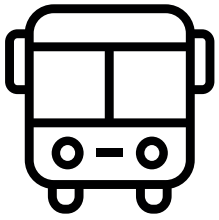
Bartimeus contact results

The representative from Bartimeus referred to their website where a selection of tips are available. These tips were provided by the visitors of the Ziezo fair and documented by Bartimeus.

Many of the tips were unrelated to the earlier introduced topics but it did result in an additional 2 tips&tricks. The tips that are not included could eventually be added at a later stage.



2



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‘Make it easier’ design

The gathering of the tips&tricks resulted in a total of 20 tips&tricks divided over 3 themes. The next step is to implement these tips&tricks into the website to make them functional. The first page that is shown when visiting the category is shown below.

Figure 35. ‘Make it easier’ design

On this page a small introductory text is included to briefly explain the idea behind the category. Following that text are three buttons similar in their graphic representation compared to the buttons on different pages within the website such as aids. These three buttons represent the different themes in which the content is placed. In addition to the three buttons a vertical menu has been added which is also similar to the other pages. When clicking one of the three buttons the user is shown a new page, for example the one below.

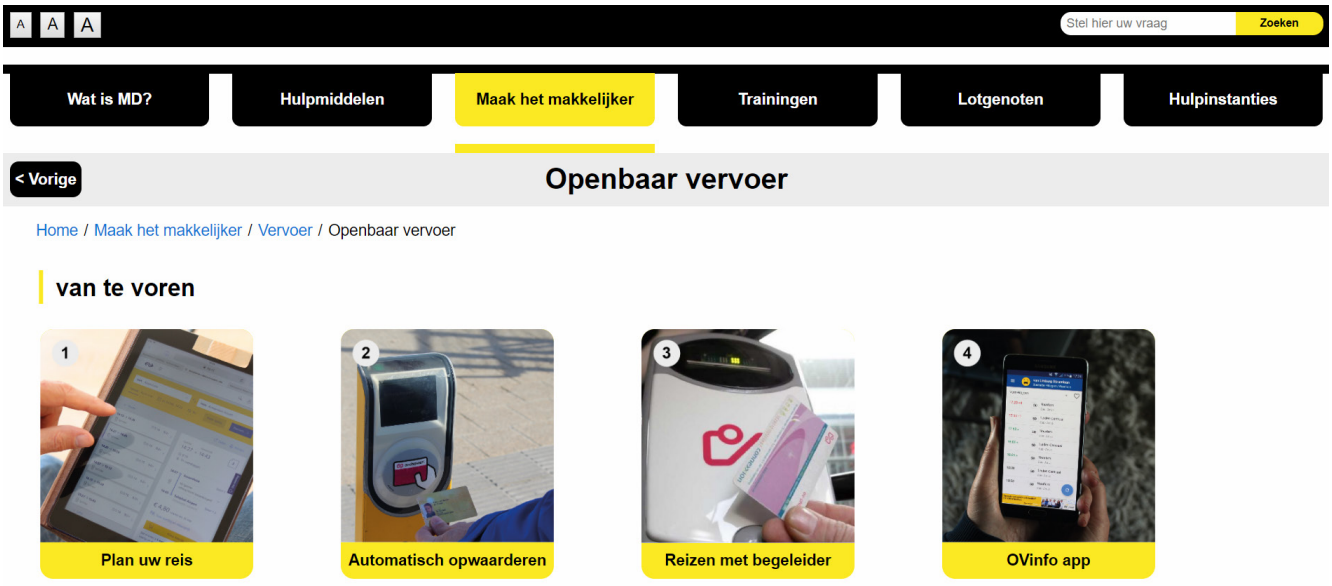

Figure 36. ‘Public transport’ design

On this page the different tips&tricks related to the specific theme are displayed. Each tip is shown with a thumbnail, short title and number. The thumbnail picture serves as support for the content of the tip while the number in the top left corner serves as an indicator for the patients whose vision is insufficient for keeping an overview of the entire page. When clicking on one of the tips a pop-up window will appear with the actual content of the tip as is seen below.

Figure 37. 'Modal tip' design

The content of the tips consists of three different elements. On the left side is a photograph representing the described situation. On the right side is a descriptive text right below the title followed by a written quote from a patient supported with an audio file which reads the quote out loud. (see image 37)

The images

Each tip is supported with an image. In order to determine what kind of image is best interpreted by patients an experiment has been conducted with the patients from the MD café in Utrecht.

Experiment approach

For this experiment three sets of images have been prepared in advance. The sets are based on the different contexts which the images represent. A distinction was made between a human-to-human interaction, a human-to-product interaction and a context impression. Each of these situations was visualized with a normal photograph, a photograph with the background out of focus and a line illustration. During the experiment each patient was shown the three different images per situation and was asked to pick the one which they found to be best interpretable. In total five patients have participated for a duration of approximately 20 minutes.

See appendix A.13 for the experiment images

Experiment results

The results from this experiment were almost unanimous. After introducing each patient to the different situations and showing them the related images the general consensus was that in all of the three situations the normal photograph was preferred. The line illustration was clear but lacked color contrast and the photograph with the background out of focus was distracting because they already experience blurred vision in real life making it harder to interpret.

Based on the outcomes of the experiment the decision has been made to produce photographs of the different situations. For each tip the situation was assessed and a label was added for what kind of interaction should be displayed. The labels that were attached to the different tips are either H-P (human-product interaction), H-H (human-human interaction) or CO (context). Some of the tips have overlapping labels such as ‘travelling with a companion’ where it is both H-H and H-P due to the required card that the companion needs. In those cases the interaction has been chosen which represents the descriptive text best. In order to produce consistent photographs for the different situations each label has their own guideline. The H-P labelled photographs should display the interaction between the person and the product without too much interfering content in the background of the photograph. It should provide a hint of the context but the main focus is on the actual interaction. Examples of these are:

Figure 38. Contactless payment

Figure 39. Using a large knife

The H-H labelled photographs, which is only one in the current set of tips&tricks, have a similar approach as the H-P photographs with the difference being an interaction between two people. An example of this is:

Figure 40. Dare to ask

Finally the CO labelled photographs show a context in which the tip takes place. There is no point of focus in these photographs. Examples of these are:

Figure 41. Go to the same store

Figure 42. Organized storage

The quotes

The goal of including a spoken quote is to make the content of this category more personal. The assumption is that by hearing someone say the actual quote the user would feel more engaged to the subject. Each quote is individually recorded and a separation is made between a male voice and a female voice for the purpose of diversity. To make the quotes sound less hollow context sounds have been added which represent the different locations at which the quote takes place. Context sounds have been recorded at the train station, in the supermarket and in a kitchen during meal preparation. On top of those context sounds, specific sound bytes have been added to accentuate certain interactions. For example, the scanning sound at a self-check counter is implemented but also the sound of a stove being

The description

Each tip is also supported with a descriptive text. The text should be condensed to prevent intensive reading but at the same time it should provide enough content to transfer the information. On average each tip is supported by two or three lines of text. If necessary a link to an external website is included for more information (for example ‘travelling with a companion’).

Conclusion Develop

In this chapter the proposed design has been discussed on two different levels. First a general framework is proposed for the entirety of the website where different design choices have been argued. The next part of this chapter was about the development of one of the six categories, ‘Make it easier’. The general visual language and content have been explained. This category consists of a selection of tips&tricks provided by “experienced” AMD patients to make ADLs easier. Each tip which is shown in this category is supported by a photograph, spoken quote and descriptive text. To verify whether this proposed design fulfills the design goal defined in the Define chapter an evaluation is necessary. This evaluation will be discussed in the next chapter.

DELIVER

5.1 // EVALUATION

Introduction

After researching the topic of macular degeneration and identifying problems that occur during the patient journey a design has been proposed which would fulfill the design goal. The essence of the design goal was to inspire confidence in newly diagnosed macular degeneration patients through providing information. The proposed design offers a website which includes information regarding six different topics related to macular degeneration. One of these topics was further developed and resulted into a selection of tips&tricks related to making ADLs easier. In this chapter the proposed design will be evaluated through a user test.

Limitations

The evaluation of the design comes with a few limitations. The evaluation should provide insights in whether the design meets the design goal and solves the problem which is defined in chapter 3. The design goal focuses on inspiring confidence in newly diagnosed patients. The first limitation is related to the first element of the design goal, inspiring confidence. Ideally, in order to verify whether the design does in fact inspire confidence, the evaluation should take place over a prolonged period of time. An increase of confidence is very difficult to measure in just one test. However, due to the limited time available the evaluation tests have been done in one session. This influences the approach of the test. The second limitation is related to the users who participate in the evaluation test. The design goal specifies that it is about inspiring confidence in newly diagnosed patients. Getting in contact with AMD patients is a challenge on its own, finding newly diagnosed patients is even more difficult. The test has been done with patients who suffer from AMD for a longer period of time which also changes the approach of the test.

Participants

The evaluation test has been done with two patients. The first participant is N. van Steijn, 87. She has been diagnosed with wet AMD over 15 years ago. The second participant is M. Kokhuis, 68. She has been diagnosed with AMD 18 years ago. Both tests took approximately 60 minutes.

Evaluation approach

Due to the limitations it is important to clearly specify the approach of the evaluation to optimize the potential of the outcomes. The test has been divided into two segments, the first segment is about verifying whether the use of tips can provide reassurance in the self-efficacy of the patient (in other words, inspire confidence). The second segment is about verifying the experience of the actual tips in terms of interpretability, visual communication, language use but also value of the content.

- *See appendix A.14 for the full evaluation set-up*

Segment 1

The test begins with a few introductory questions to identify the circumstances of the patient (How long do they have AMD? Is there a partner to help out?) followed by a series of questions which aim on taking the patient back to the period after the diagnosis and verify if they experienced problems in performing ADLs and how they dealt with them at the time. After gaining insights on the past a series of questions is asked about the present. Do they experience problems with ADLs in the present and if they do, how do they deal with them? The final part of the first segment is about questioning them whether the proposed design would have helped them in the past and if it would help them in the present. The outcomes of these questions could indicate whether the design fulfills its premise.

Segment 2

The second part of the test is about evaluating the content of the tips and how it is presented to the user. For this segment five research questions are defined:

1. Is the presented modal content (pop-up) of the tips understandable and interpretable?
2. Is the textual content presented in a mature enough way?
3. Is the textual content balanced enough (not to general, not to specific)?
4. Is the accompanying image understandable and is the size right?
5. Is the use of a spoken quote valuable and is its presentation clear?

To answer these research questions the participant will be shown three different tips, one from each theme. The participant is then asked to describe what they are seeing. Afterwards each element is discussed through questions such as:

1. What do you think the function of this element is?
2. Are you able to read / see it?
3. Does it provide sufficient information for you to understand it?
4. Do you think it adds to understanding the tip as a whole?
5. Would you change anything?

The results // N. van Steijn

The first evaluation test provided valuable insights but also came with an issue. The participant did not have AMD in both eyes meaning that one of her eyes was compensating for the lack of vision in the other. This means that she is still able to function properly in daily life and does not experience any problems with ADLs related to the condition. Therefore a scenario was proposed in which the participant had to imagine a situation where her vision would be severely impacted by AMD. By doing so the participant could imagine that it would be very difficult to function in daily life. By questioning whether it would be considered useful to receive help from "experienced" patients in terms of performing ADLs the answer was clear. She recognized the lack of information which is present after the diagnosis and having these tips would be probably one of the only ways to learn how to cope with the situation.

"Every tip that you can use to improve your daily life is welcome and very nice"

In the second segment of the test different screens are shown. For each screen the participant was asked to explain what she was seeing and how well she was able to interpret it. The presented text was well readable on all of the different screens. The different themes presented on the first page of the category were easy to identify and the link was quickly made that these themes represent the different categories of tips. Even when covering her healthy eye the different elements on the pages were recognizable. The photograph shown in the pop-up screen was sometimes hard to identify as a stand-alone but accompanied by the descriptive text and title it was clear. The maturity of the text was good and the amount of descriptive text provided enough information to interpret the tip.

"It is extremely difficult to deal with such a condition but you can learn how to cope with it, these tips do give you new ideas"

The spoken quote was considered a valuable addition because it is easier to remember something when you hear it, especially when you are older.

"It requires little effort to recognize what the tip is about"

- *See appendix A.15 for a more detailed write-up*

The results // M. Kokhuis

The second evaluation test generated insights both in favor as well against the proposed design. In the first segment of the test it was evaluated whether the design achieves the desired effect. The participant had a proactive attitude towards performing ADLs meaning that even though she might have felt insecure at times she did not stop doing daily activities. She mentioned that she used to be part of a calling team from the Maculavereniging where she spoke to newly diagnosed patients. These patients had a lot of questions on how to deal with their new situation. During the calls she has provided many patients with tips on aids but also Low-Vision clinics and performing daily activities. Providing these patients with a new means of retrieving the information necessary in comfortably performing ADLs is definitely of value.

"I can imagine that receiving the diagnosis can be a paralysing experience for some resulting in a lot of insecurity"

In the second segment of the test the experience of the actual tips were evaluated. The condition of this participant is significantly worse than the first participant resulting in an outcome with similar but also different results. Reading the text presented on the website is deemed very difficult. She is able to pinpoint where text is located but interpreting the content of the text is difficult. Increasing the size of the text would only make things worse, she has to depend on screen reading software. On the first page of the category she has difficulties interpreting the relationship between the three different icons representing the different themes. Only after identifying that the page is about making life easier she was able to make a link between the three icons.

The size of the photographs in the thumbnails is very small but nonetheless understandable in combination with the title below. When opening a specific tip and thus increasing the size of the photograph it becomes much easier to understand. The participant expresses her doubts on the effectivity of the spoken quotes. On one hand she feels that it has value to do so but it might be more beneficial if the spoken part explained how to practically deal with a specific problem. An example of this is to show how a specific app works instead of mentioning that it is available to use. This could be solved by adding a small appendix which explains exactly how things work. Adding a link to an external website for specific tips is also very useful and in some cases really necessary (for example for travelling with a companion or automatic charging). The presented text is mature enough in its presentation and, with the exception of few, complete enough in transferring the information.

"It can be a very useful website with the things you already present. The themes that are part of the current website are very important themes"

- *See appendix A.16 for a more detailed write-up*

5.2 // DISCUSSION OF THE RESULTS

Due to the limitations that played a role during the evaluation tests it was difficult to get concrete verification on the success of the proposed design. By adjusting the evaluation approach to the available participants insights were still gathered. Both evaluation tests showed the potential of the design and the participants could imagine that the actual user group can benefit from the proposed design. However, neither of the participants were able, for different reasons, to answer all of the questions of the first segment. Therefore the evaluation of the design is based on questions where they had to imagine what it would be like as a newly diagnosed patient. The second participant had phone contact with many new patients during her time as a member of the call team from the Maculavereniging. She recognized the struggles of the new patients and understood the problems they encountered. Providing an accessible way for new patients to retrieve information on how to perform ADLs without having to call with someone from the call team is in her opinion an added value.

The research questions defined in the second segment of the evaluation approach can be answered positively however doubts were expressed on the added value of the spoken quote by the second participant. The problem does not lie with the fact that it is a spoken quote but more with the content that is expressed through the quote. Neither of the participants seemed to value the spoken quote based on the fact that it was something that was said by an actual patient. However, the first participant did feel that hearing someone say something makes it easier to remember.

According to the participants the textual parts of the category were formulated in a mature enough way and many of the descriptive texts were complete enough with the exception of few. Some of the tips could benefit from including an external link that provides more detailed information on the topic such as the tip about automatic charging or travelling with a companion. The image accompanying the tip was in both cases easy to interpret. However, without the text it was deemed difficult to understand according to the second participant.

In general the outcomes of these evaluation tests are promising but a conclusive statement is difficult to make due to the circumstances of the tests. Ideally a user test is conducted where the actual target group is used over a longer period of time to really see whether the intended effect is achieved. In addition it would be beneficial to include more participants. In this case only two persons participated which is too little to conclude whether the proposed design is successful.

CONCLUSION

6.1 // CONCLUSION

The design goal set in chapter 3 was to inspire confidence in newly diagnosed Age-related macular degeneration patients through information provision. This goal was set because it became apparent in the research phase of this project that newly diagnosed patients experienced a lack of information in the period after the diagnosis. In order to solve this problem a framework for a website dedicated to providing information has been proposed wherein one specific category was further developed. This category includes tips&tricks from “experienced” AMD patients on how to make performing ADLs easier.

The framework proposes a set of six different topics related to AMD based on different interviews which have been conducted throughout this project. These six topics are:

1. **Information about the condition**
2. **Information about aids**
3. **Make it easier**
4. **Information about peer support**
5. **Training / revalidation support**
6. **Information about involved instances**

Each topic was examined and the content for each topic was defined. The information related to five of these topics were already available elsewhere but not contained in one place. The topic which introduces new information is ‘Make it easier’. Therefore that specific topic has been further developed. The content for that specific topic was gathered through a brainstorm session with patients from the MD café in Utrecht, an online survey and telephone contact with Bartimeus. This has resulted in a total of 20 different tips spread over three categories: public transport, grocery shopping and cooking.

The visual communication of the website was based on a set of guidelines defined in chapter 3 which were the result of different sources including an AMD patient and a researcher from the University of Baltimore. By doing an analysis of existing websites dedicated to providing information on AMD insights were gathered in how to present the content and what to take into consideration when designing a website for visually impaired users.

In order to shape the category of ‘Make it easier’ an experiment has been done to verify what type of supportive images AMD patients find easiest to interpret. In addition spoken quotes have been added with the intended goal of personalizing the content and make it more relatable for the users.

At last an evaluation test has been conducted with two participants to verify whether the design meets the design goal. In order to do so a test plan was written with the emphasis on two different segments, one focussed on verifying the value of providing tips and one focussed on verifying whether the proposed visual representation was sufficient. Due to limitations that accompanied

the evaluation test it was difficult to get conclusive results. The evaluation test did, however, show the potential of the design. By allowing the participants to imagine and recollect what it is like to be a newly diagnosed patient, they recognized the added value of the proposed design. In addition one of the participants expressed her critique on the visual representation of the tips.

Does the proposed design bridge the gap between the official diagnosis and the Low-Vision clinics? The main concern expressed by one of the representatives from Visio was the fact that often similar questions are asked which can be easily answered elsewhere. These questions are non-specific and apply to a large group of people. In order to let the Low-Vision clinics focus more on the individuals specific questions related to hobbies or work an alternative place for answering the general questions would be preferred. The proposed design offers information on many different aspects of the condition and could be this desired place.

Does the proposed design inspire confidence in newly diagnosed patients? Theoretically speaking, yes. If one considers the fact that lack of information is a contributor to feeling insecure, providing all the necessary information in one place would improve the confidence of a patient. However, it is not objectively proven that this specific design inspires confidence in newly diagnosed patients although it does look promising. In order to get the necessary verification additional steps are required.

6.2 // RECOMMENDATIONS

This graduation project provides the first step for a platform which could improve the situation for AMD patients after they have received the diagnosis. In order for it to live up to its potential additional steps are required.

Additional tests

As was mentioned in the discussion part of chapter 5 additional tests are required to verify if the proposed design meets its intended purpose. Ideally these tests would be conducted with people who were actually recently diagnosed with AMD. The tests would preferably be conducted over a longer period of time to verify whether these patients could actually benefit from the provision of tips long term. Besides testing the value of the specific category of 'Make it easier' the other categories should also be included in the test. The visual representation and segmentation of the information in the other categories should be tested. Only then a statement can be made on the success of the design.

Future implementations

The part of the website that was developed during the Develop phase is now online. Newly diagnosed patients have access to the tips that are provided in the 'Make it easier' category. However, the other categories of the website are still incomplete. The design has been send to the Low-Vision clinics as well as the Maculavereniging with an additional explanation. Ideally one or more of these parties would see the potential of the design and would further develop it. These parties have the resources to take the design to the next level and implement the information on the other topics.

Expanding

As of this moment the category 'Make it easier' has 20 different tips spread over 3 themes. In the future this category could be expanded with more tips and more themes. Examples of themes that could be added are: cleaning, personal hygiene, participating in traffic, use of digital media, practicalities inside the house and many more. Since the knowledge for these tips comes from actual patients it should be possible for the patients to submit their tip(s) so they can be implemented by the overseeing party.

Keeping it up-to-date

The world of macular degeneration is a fast changing world. New aids are introduced on almost a weekly basis and new initiatives are started every once in a while. The party that continues with this idea should maintain the website on a regular base and implement new information.

WCAG 2.1 guidelines

In chapter 3 the WCAG 2.1 guidelines have been introduced. These guidelines are the official standard for accessibility of websites. As an individual with little to no experience programming it was not possible to implement these guidelines. However, if a bigger party picks up the idea and further develops it, it is necessary to implement these guidelines.

6.2 // REFLECTION

This project was a very intriguing process for me from start to finish. It was the first time that I had to commit myself to such a relatively large task individually. Throughout the project I have learned a lot about myself, as a designer. I can recognize my strengths but also weaknesses. The first phase of the project was in my opinion the most interesting part of this project. Diving into a subject without any prior knowledge is very exciting. There is so much to learn and understand about a specific topic that it is easy to lose yourself in that process and forget to stay focussed on the task at hand. After about a month of progress it became apparent that the current course of the project had to be adjusted based on the input of the patients. This, to me, showed the value of user research. Listening to your target group can provide so many insights which would otherwise be overlooked.

Initially it was not difficult to adjust myself to the new course of the project. In fact, it instigated a new period in which I was able to dive into a new aspect of the subject. After gaining the necessary knowledge on the subject a phase started in which I felt less comfortable. I had acquired the insights that showed that a website might be the best solution and I was eager to start with it but all throughout this design phase I felt that something was missing. That I had overlooked something which could have taken my design to the next level. Despite these feelings I started with the design and similar to the research phase lost myself in the world of programming. I'm confident in saying that I spent too much time trying to figure out how to code the website instead of focussing on other more important things.

Having access to a supervisory team was very helpful for me as it reminded me of what was actually important at times. I'm a great fan of critique and feel that it helps me getting better at the things that I do. It's important, although difficult at times, to not interpret critique on a personal level. As I do realize now, at the end of the project, is that you can't know everything and that incorporating influences from other people is very important in improving your design.

One of the major struggles I experienced throughout the project was retrieving quantifiable results. User testing is something in which I see a lot of value but adequately performing a user test is, at least for me, a challenge. I'm a big fan of opening the discussion and see where it leads. I prefer improvising on the spot instead of meticulously preparing something. Sometimes improvising is a good thing but if you're looking for very specific information it can be insufficient. In addition I also struggle with conveying the insights and information that I have gathered through text. This report has been rewritten a fair amount of times but I still feel that it could be improved at some points.

In general I'm positive about the results of this graduation project. I feel that an important issue has been brought up and the proposed design has the potential to mitigate that issue. By speaking with different stakeholders throughout the project I've been able to gather information which covers multiple aspects of the subject. In the end I feel that a nice result is delivered.

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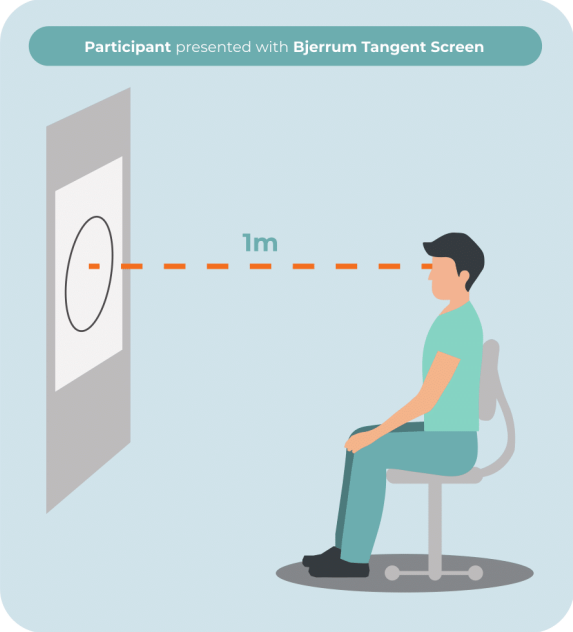
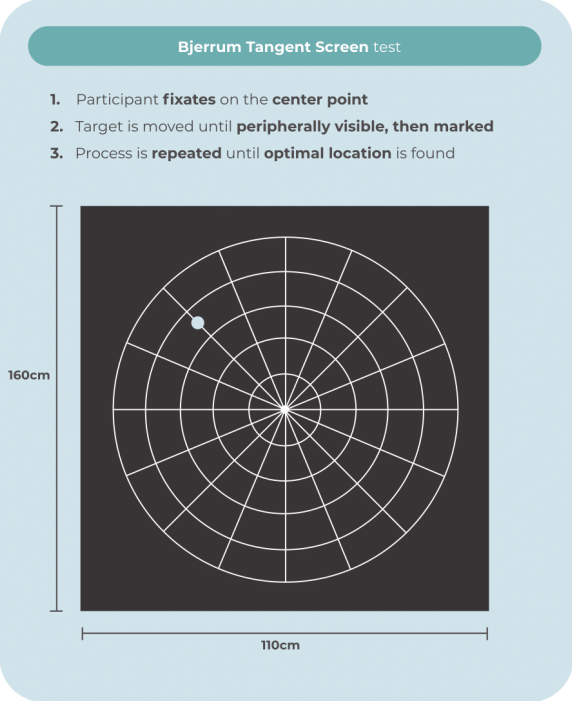
APPENDIX

Bjerrum Tangent Screen test

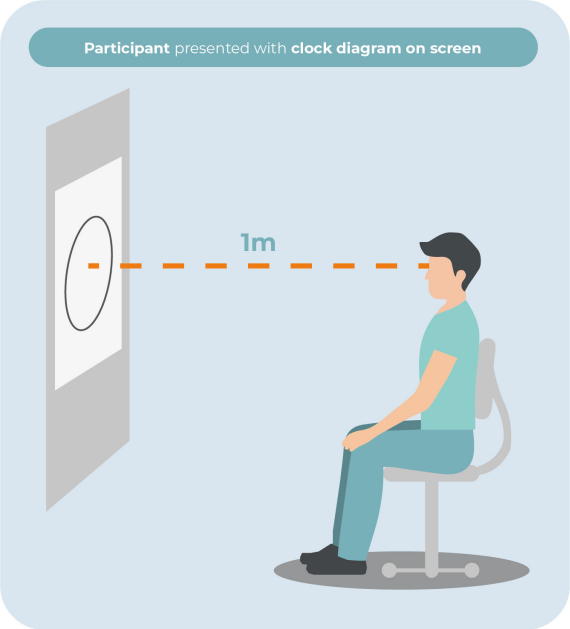
Introduced in 1889 by Jannik Peterson Bjerrum, the Bjerrum Tangent screen quickly gained popularity and is still used to date. It is a large black velvet sheet measuring approximately 160x110 centimeters with radial lines with 15 degree intervals and circles with 5 degree intervals. By attaching a small target disk on top of a black wand the instructor can reveal the target disk on different points on the screen. The participant is instructed to keep their focus on the center point for the duration of the test. Each time the participant notices the target disk that location is pinpointed. After all radials have been covered the ideal location for eccentric viewing can be determined.

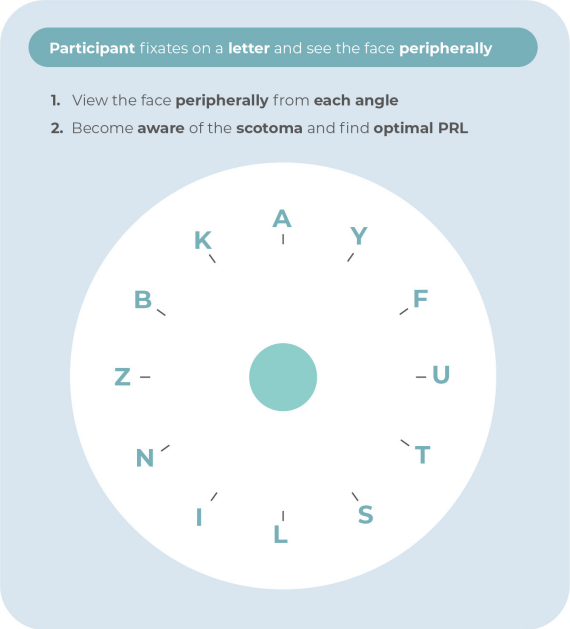




Clock diagram method

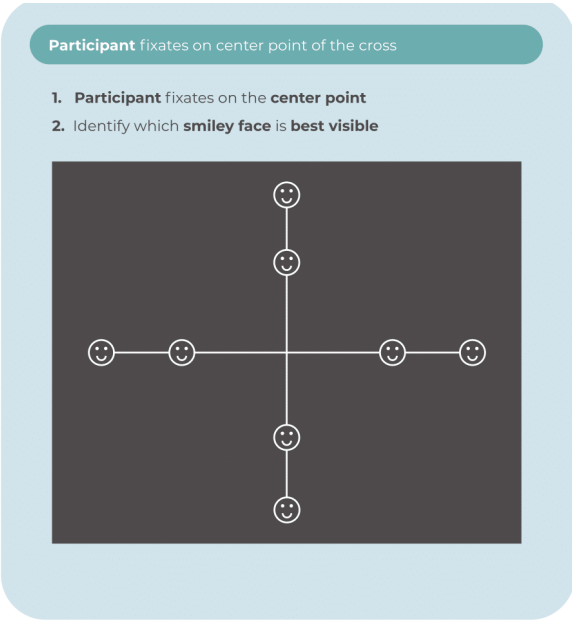
Relatively similar in its procedure is the clock diagram method mentioned in a journal publication by C.P. Janssen and P. Verghese. It displays a clock with a random selection of letters on the locations where you would normally find numbers. The participant fixates on the center of the clock and indicates which number(s) are best visible.





Eccentric Viewing Resource Kit

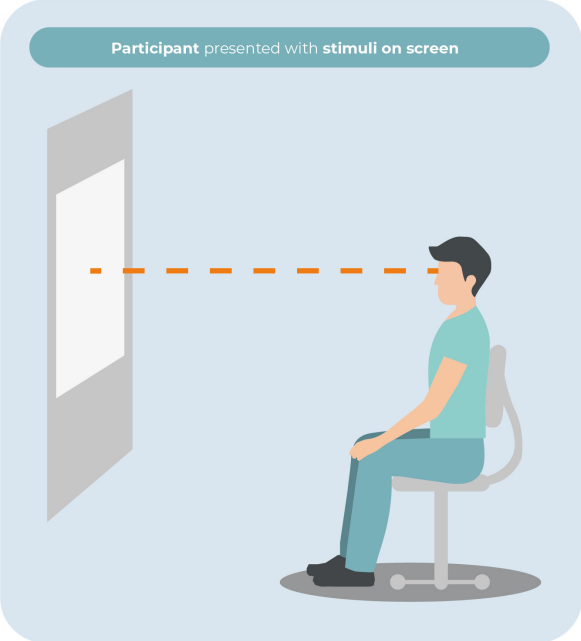
Developed by Kerry Fitzmaurice in 1993, the Eccentric Viewing Resource Kit is one of the most popular tests in Australia to quickly identify the eccentric viewing direction of an individual. It consists of a very basic diagram which shows two axes with four smiley figures per axis. The participant fixates on the center point of the diagram and indicates which smiley figure is best visible. This gives a good indication of what direction on the retina is most suitable for eccentric viewing.

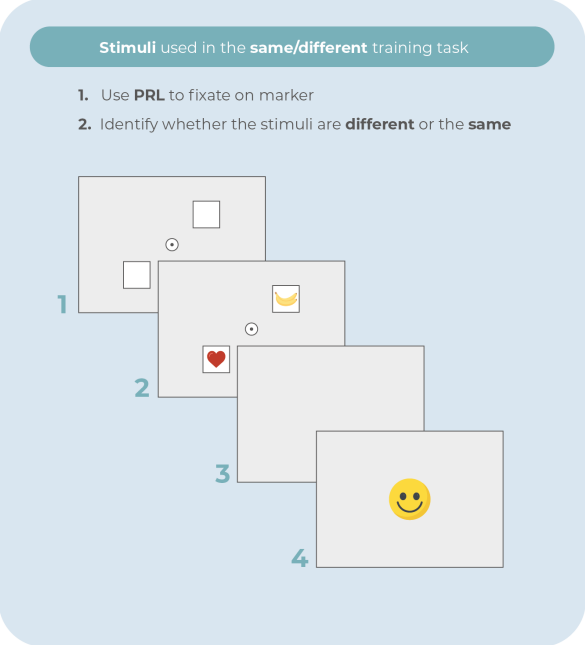


A.2 // ECCENTRIC VIEWING METHODS

Training method Janssen & Verghese

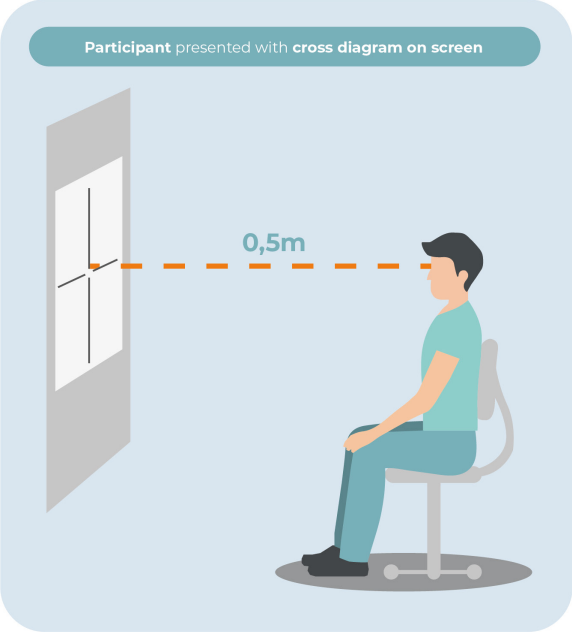
Described in an article in the Journal of Vision in 2016, Janssen & Verghese introduced a training method where the participant has to recognize whether two shown silhouettes are similar or different. Both silhouettes are shown diagonally of eachother where in the middle point a marker is shown which is used as a fixation target for the participant's PRL. Over the course of multiple training rounds the time that the silhouettes are shown decreases as well as the size they appear in.

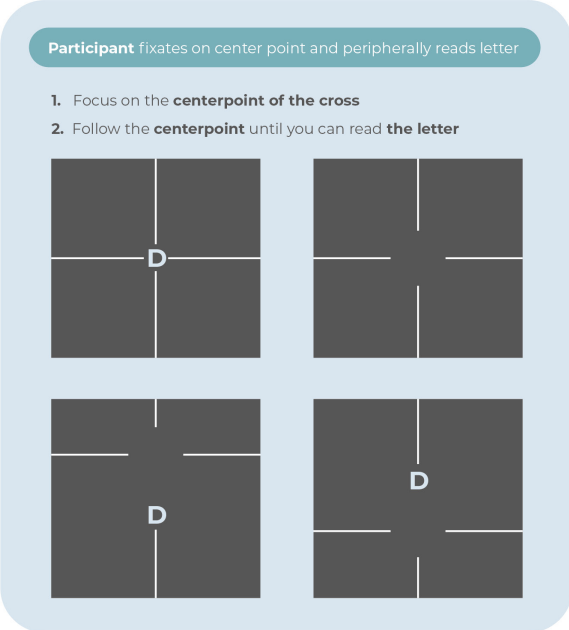


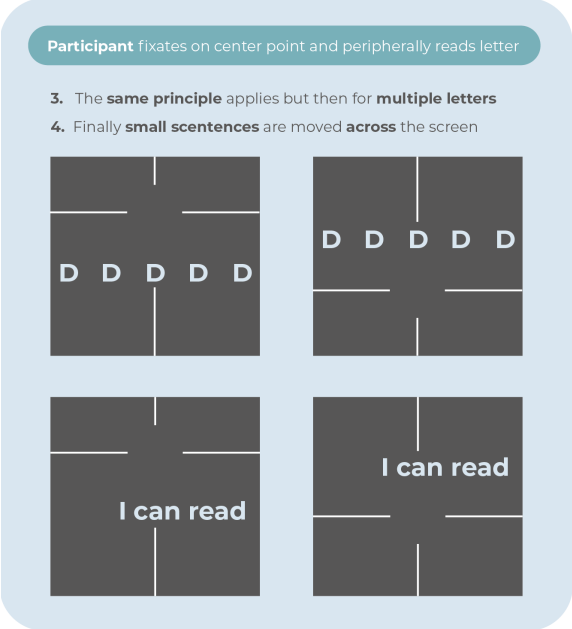


Training method Frennesson, Jakobsson & Nilsson

In 1995 C. Frennesson, P. Jakobsson & U.L. Nilsson described a method for eccentric viewing training which is depending on a different principle compared to the previously described method. This method is more aimed towards improving reading capabilities.





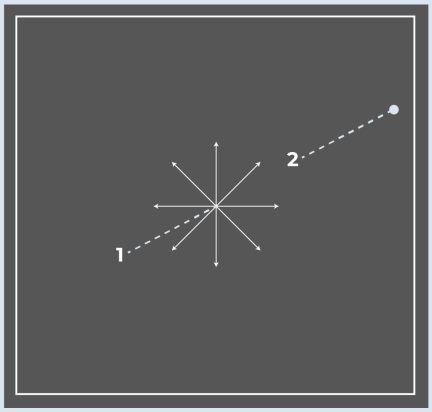


Training method Fitzmaurice & Vukicevic

K. Fitzmaurice and M. Vukicevic wrote an article about at home eccentric viewing training. For this purpose they used a program previously developed by Fitzmaurice (EccVue). This program walks the participant through all the steps to properly train eccentric viewing. Four modules are included wherein each module provides more advanced training or training for a different purpose.

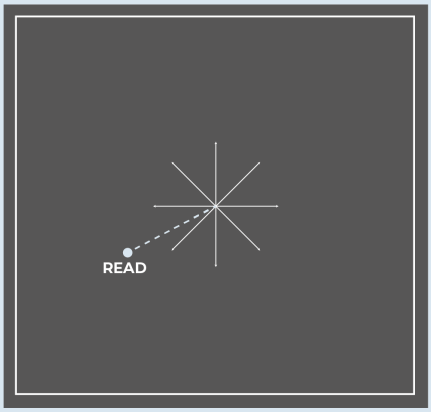
Eccvue Module 1 - Eccentric stimulation exercises

1. **TRL** is determined via **Bjerrum Tangent** screen test
2. Target **1** is projected on **TRL location**
3. Target **2** is projected as a **reference point** for fixation movement



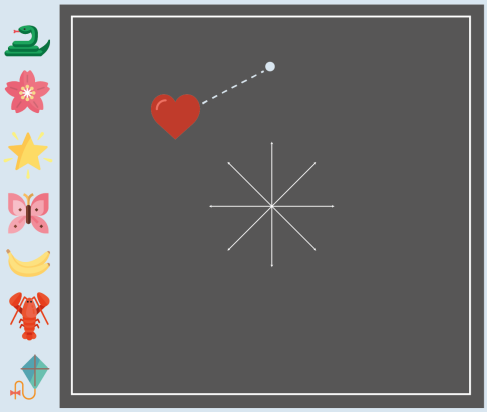
Eccvue Module 2 - Eccentric practice exercises

1. A word of **3-8 characters** with **adjustable printsize** is shown
2. It is **projected** on the **TRL location**
3. It provides **practice** in eccentric viewing for **reading material**



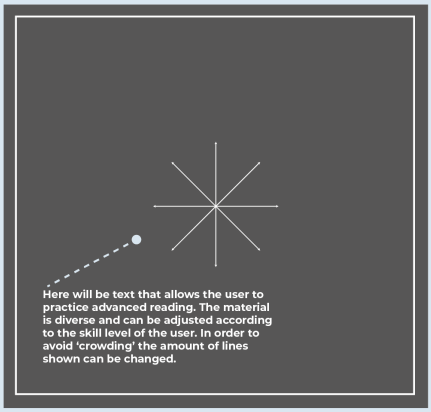
Eccvue Module 3 - Shape exercises

1. A **shape** from a **selection of 40** is shown **randomly or placed**
2. The **size** of the shape can be **adjusted** (6/60 or 6/36)
3. It provides **practice** in eccentric viewing for **recognizing shapes**



Eccvue Module 4 - Text exercises

1. A **narrative** can be selected (17 options, varying length & content)
2. **Print size** and **number of shown lines** can be adjusted
3. It provides **practice** in eccentric viewing for **advanced reading**

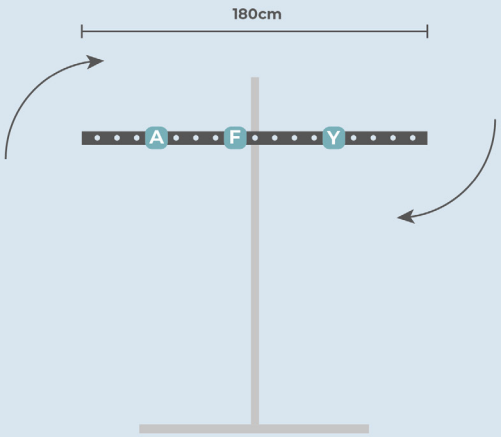


Old methods

Introduced in a paper from 1986 by G.L. Goodrich and E.B. Mehr three methods were described as a result of the outcomes of a clinical experiment that was experienced as unpleasant due to bright flashes. These three are physical models where one is a bar on a stand, one is based on a rotator principle and one is a magnetic clock face with attachable letters.

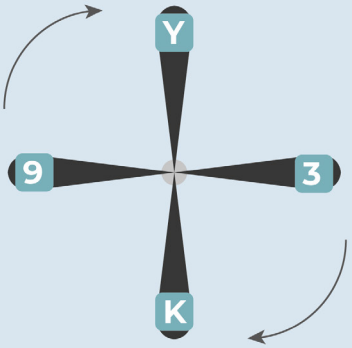
'Stand with bar' training technique

1. Bar has **multiple holes** where **letters** can be put in
2. **Angle** of the bar can be changed to **train in oblique angles**



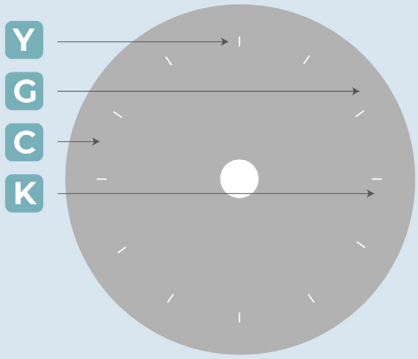
'Rotator' training technique

1. Rotator has both **letters and numbers** attached
2. **Rotation** adds a **tracking component** to the task



'Magnetic clock' training technique

1. A **metallic clock** face is shown
2. **Magnetized letters** can be attached at **different positions**



A.3 // L. VAN DEN BOS WRITE-UP 1

This afternoon I've visited Bartimeus at the Maasstad hospital in Rotterdam. Lex van den Bos is an aiding instruments adviser and we had a nice conversation about Macular Degeneration for about 2 hours. We talked about quite a few subjects which chronologically come down to:

Bartimeus is involved in Low-Vision rehabilitation. Lex mentioned the same thing as the intaker from Visio, namely that each patient that comes in has a different problem and also a unique status. Bartimeus offers a variety of services which include prescribing aiding instruments but also training trajectories for problems that patients encounter such as mobility training or training for digital media.

EV training is not part of the rehabilitation program within Bartimeus. Lex told me that patients only use EV when they have an absolute central scotoma (which means that it is impossible to see anything through the scotoma or in other words, when someone is in the end stage of MD). He also mentioned that it is often the case that someone has a different PRL for each eye which overlap and create only a small point of fixation. Sometimes he was considering just advising someone to cover one eye in order to fully utilize the PRL of the other.

We also talked about the instruments that they provide and how smartphones and tablets slowly take over all the functionalities that these instruments offer. Enlargement screens and magnifying glasses become obsolete. This is also the case with text to speech translators. He showed me a wide variety in glasses that patients can use (most often yellow tainted glasses). He told me about a research project in which they've developed a glass which uses 15 prisms to redirect the light onto the PRL instead of the fovea.

His opinion on EV training was slightly sceptical. In his opinion people that benefit from EV often assign a PRL themselves which they can utilize in a decent way. But he supports my idea and gave me a book from a former colleague which focuses on Eccentric Viewing and the creation of a special glass which allows people to "see" directly in front of them again.

Patients that suffer from MD have a hard time distinguishing colors and contrast, so his advice was to use as much black on white as possible and avoid colors. The 0,3 visus threshold that is determined by law in order to apply for insurance cover is in his opinion "bullshit" because someone that has a visus of 0,5 could experience their condition as worse than someone with a visus of 0,1. It's completely dependent on the person. In general, assigning a number to something in this branche is speculative. Having 160% vision because you can read one small letter is no guarantee that your entire macula has that percentage. This causes problems with the communication between optical specialists in a hospital and them.

Patients that suffer from MD are a difficult target group because it requires an immense amount of concentration to train for an extended period of time. He refers to his low vision colleagues as top sportsmen. I've been referred to Anthon Verezen who did the research on EV and to Corinne who is an ergotherapeut within Bartimeus. I'm also planning on attending a conference in Utrecht revolving around Macular Degeneration and future implementations.

A.4 // VISIO WRITE-UP

Today we (me and Marlies) visited Visio in Amsterdam to have a conversation with two persons that work there (Jan and Anouk). They sat down with us to discuss the matters at hand. Similar to the Macula Café visit we got a lot of new insights. We first spoke about the possibilities of eccentric viewing training and whether or not it is of any use for MD patients. The consensus was that they thought it was not necessarily something MD patients could benefit from. Especially the people that are in the early stages of MD. They do offer training trajectories in terms of rehabilitating viewing but this is for people with NAH (Niet Aangeboren Hersenletsel). In their opinion MD patients could benefit way more from something that fills the void in between the official diagnosis and the point at which a patient reaches out to either Visio or Bartimeus. The optical specialist in the hospital on average has 7 minutes per person. This means that they have time to do some tests and provide an official diagnosis but that's it. There is no time for an explanation or guide for these people. This leaves them in a void. Providing sufficient information on frequently asked questions and support in figuring out how certain aids work has more value in their opinion. Also referring the patient to a low vision clinic at the right moment in time is important.

A.5 // DIAGNOSIS EXAMINATION METHODS

Diagnosis

After the initial recognition a person's next step is to visit the general practitioner. The general practitioner will not be able to provide an official diagnosis but he/she can refer the person to the hospital where an ophthalmologist will further evaluate the situation. Once at the ophthalmologist a number of research methods can be applied to identify the cause of discomfort. The possible methods are as follows:

1. **Determine visual acuity**
2. **Retina research with an ophthalmoscope**
3. **Visual field research**
4. **Fluorescein Angiography research**
5. **Optical Coherence Tomography**

Determine visual acuity

In order to determine the visual acuity of a patient the Snellen chart is used. This is a card with a set of letters of different font sizes. The patient is instructed to sit at a distance of 6 meters and read each row of letters until it becomes impossible to recognize the letters. At that point the ophthalmologist can determine what the visual acuity is of the patient expressed in either a number between 0 and 2 (Dutch notation system) or between 0/200 and 20/10 (International notation system) depending on what row of letters on the chart was still readable.

In case of the Dutch notation system 0 means 0% visual acuity, 1 means 100% visual acuity (the average human being) and 2 means 200% visual acuity which indicates twice the average visual acuity. A visual acuity of 0,5 indicates that the patient is not allowed to drive anymore, a visual acuity of 0,3 indicates that the patient is visually impaired by law.

Retina research with an ophthalmoscope

An ophthalmologist can use an ophthalmoscope to view the structure of the retina behind the pupil to identify whether the macula (located centrally on the retina) is damaged or not. The ophthalmoscope is a device which uses a small bright light and a magnifying lense to provide a visible image of the retina. In order to properly view the retina the pupil has to be dilated by using eye drops. The effects of the eye drops will last a few hours in which one can experience a slightly blurred vision. This type of research is often done at the first meeting with the ophthalmologist and it is crucial in determining whether one has Macular Degeneration or not.

Visual field research

A field of vision research is done to determine what parts of the retina are still healthy and what parts have deteriorated. This type of research is often done with the use of a Bjerrum Tangent screen test or a Humphrey field analyser test.

Another possible method is the Goldmann Field Test but this requires a more skilled perimetrist and is less available than the other two. An easier but less accurate method involves the earlier mentioned Amslergrid.

Fluorescein Angiography research

Fluorescein angiography is used to identify abnormal blood vessels and leakages in the eye and thus identify the wet type of AMD. Pigmental fluid is injected into the arm which spreads throughout the body and therefore also in the eye. By using a normal camera with visible light an image of the blood vessels in the eye can be created. Similar to the retinal research with an ophthalmoscope the pupils need to be dilated.

Optical Coherence Tomography

A relatively new technique which is applied to identify anomalies in the retinal structure of the eye is Optical Coherence Tomography (OCT). This technique enables a specialist to create section view of the retina which can be examined for anomalies like the presence of fluid, bleeds and macular holes. The goal of this method is to enable a specialist to give an accurate diagnosis and/or to determine the course of action in case of treatment (for example with wet AMD).

A.6 // L. VAN DEN BOS WRITE-UP 2

Lex is overgestapt naar Bartimeus om mensen te helpen en patiënten te behoeden van teleurstellingen. Bij zijn vorige werkgever was er alleen het aanbod wat ze zelf hadden en bij Bartimeus kan hij alle beschikbare hulpmiddelen voorschrijven en laten proberen. Het aanbieden van hulpmiddelen via een website is “verdomd lastig” omdat mensen het niet ter plekke kunnen proberen. Alle hulpmiddelen op één plek is onbegonnen werk, “dan ben je een halve dag aan het scrollen voordat je er doorheen bent”. Je kunt wel verschillende typen hulpmiddelen weergeven en hun gebruik en toepassing toelichten. Het is een mooi streven maar je kunt jezelf een hoop tijd besparen door “groepjes te maken”. Uitleggen wat ze kunnen en waar ze voor zijn maar niet “even googlen en bestel maar”. Mensen weten ook niet goed wat ze nodig hebben, een mevrouw had een leesbril maar gebruikte nooit verlichting. De verlichting hielp uiteindelijk heel goed, zij heeft nog helemaal geen uitgebreide hulpmiddelen nodig. Licht is het meest onderschatte hulpmiddel.

Het is bijna belangrijker om de nadelen van een hulpmiddel te noemen ipv de voordelen want zodra iemand de nadelen accepteert en begrijpt wordt het 9 vd 10 keer een succes. Hulpmiddelen, de nadruk ligt op hulp. Het helpt maar het lost het probleem niet op.

“zou het kunnen werken, zo’n overzicht?”
Je moet de voor- en nadelen laten zien, maar die zijn voor iedereen anders.
worldwidevision

Jansen&Jansen in Ridderkerk heeft veel verstand van hulpmiddelen vooral optisch (dus geen digitale)
vanMeurs in Rotterdam -> ook eerst optisch de oplossing zoeken

Een goede oogarts zal na de diagnose ook eventueel doorverwijzen naar Visio of Bartimeus.

Mensen komen hier allemaal binnen en willen beter lezen, maar onze taak is om de mensen te lezen. De mens staat niet altijd centraal in zorgland of hulpmiddelen land.

Persoonlijk voelt ie zich het prettigst als ie zwart/wit kan zijn, niet in het grijze gebied. Mensen willen zich graag optrekken aan het grijze gebied.

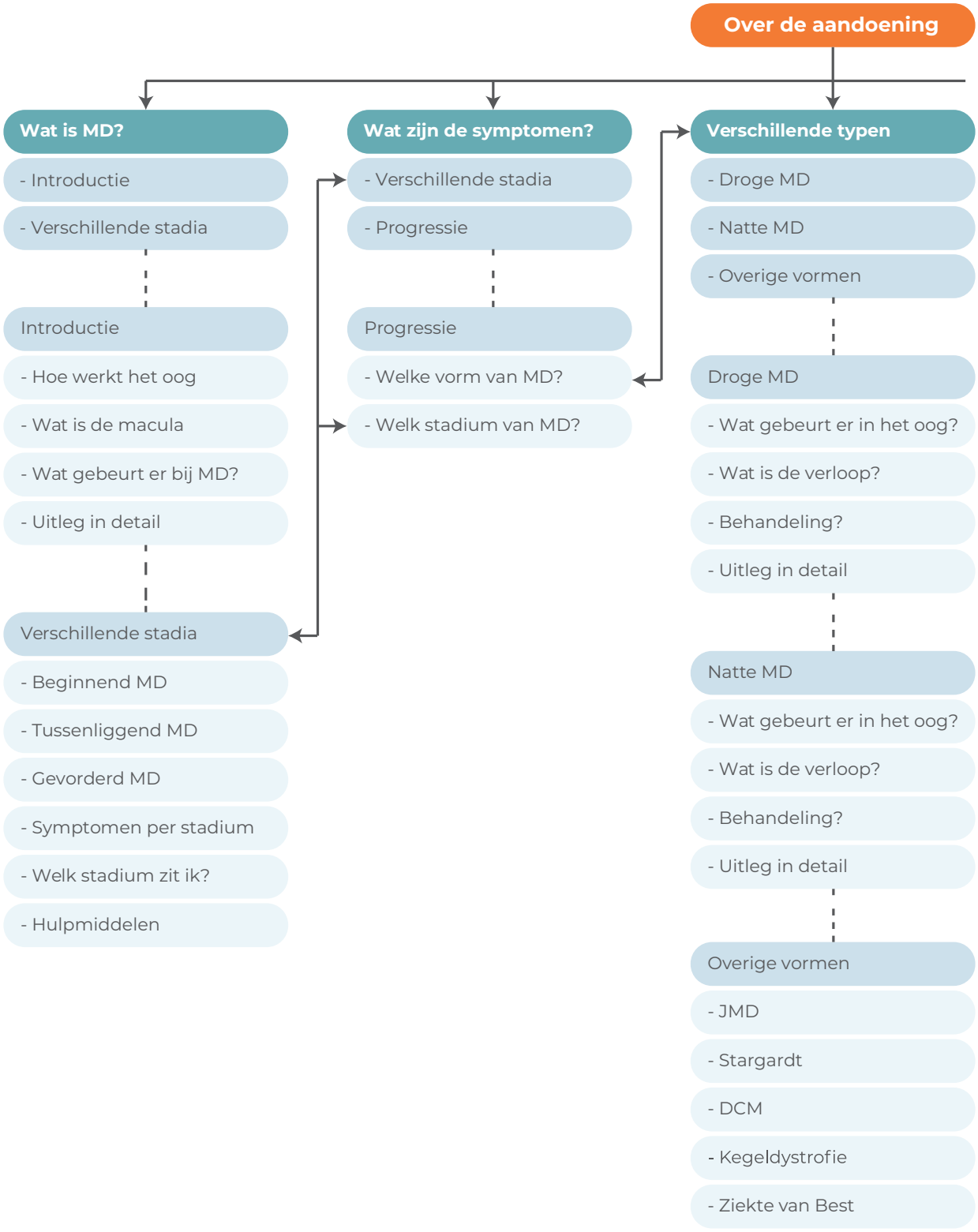
Support groups zijn in wezen heel erg goed alleen is het wel lastig om ze te laten uitbreiden. Bartimeus gaat binnenkort in Rotterdam ook een nieuwe groep beginnen en dan zijn er misschien 8 vaste mensen maar daar blijft het ook bij. Mensen kunnen zich ook gaan irriteren aan elkaar door de verschillende mentaliteiten. Maar een soort buddy groep kan wel zeker heel waardevol zijn, als het werkt. In de regio heeft Bartimeus ook contact met vrijwilligers om bijvoorbeeld te gaan wandelen oid.

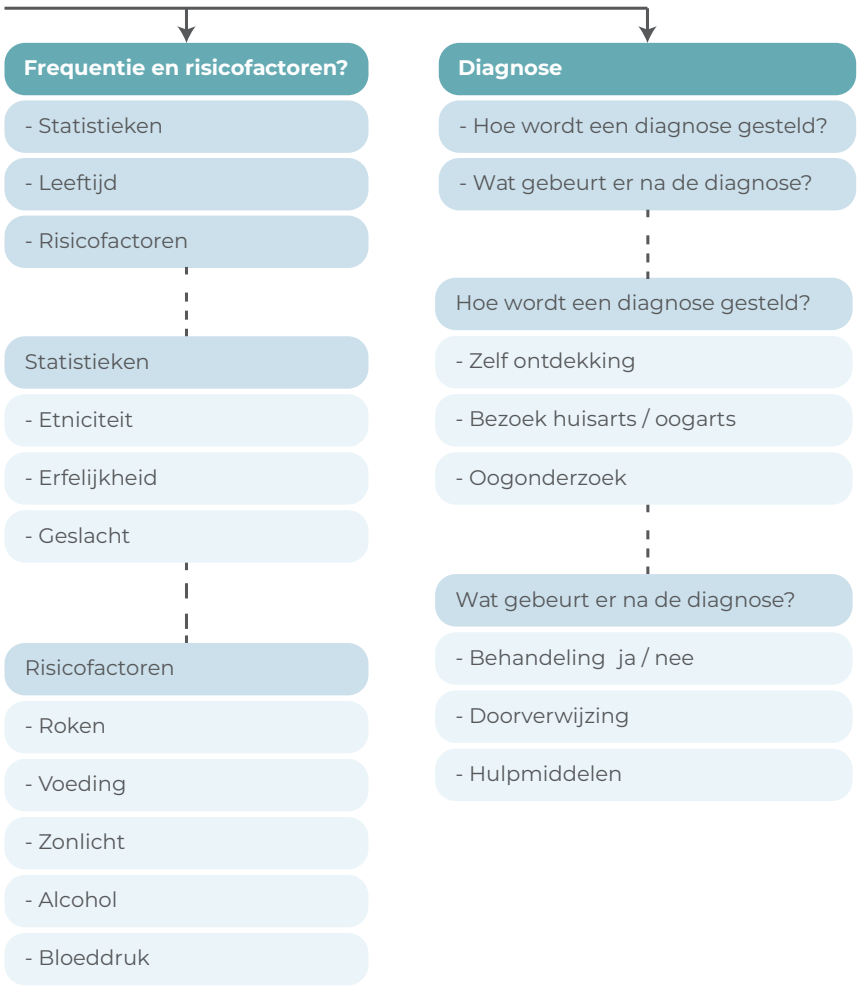
Low Vision rehabilitation kan beter worden verwoord als revalidatiecentrum voor slechtzienden en blinde mensen -> visuele revalidatie

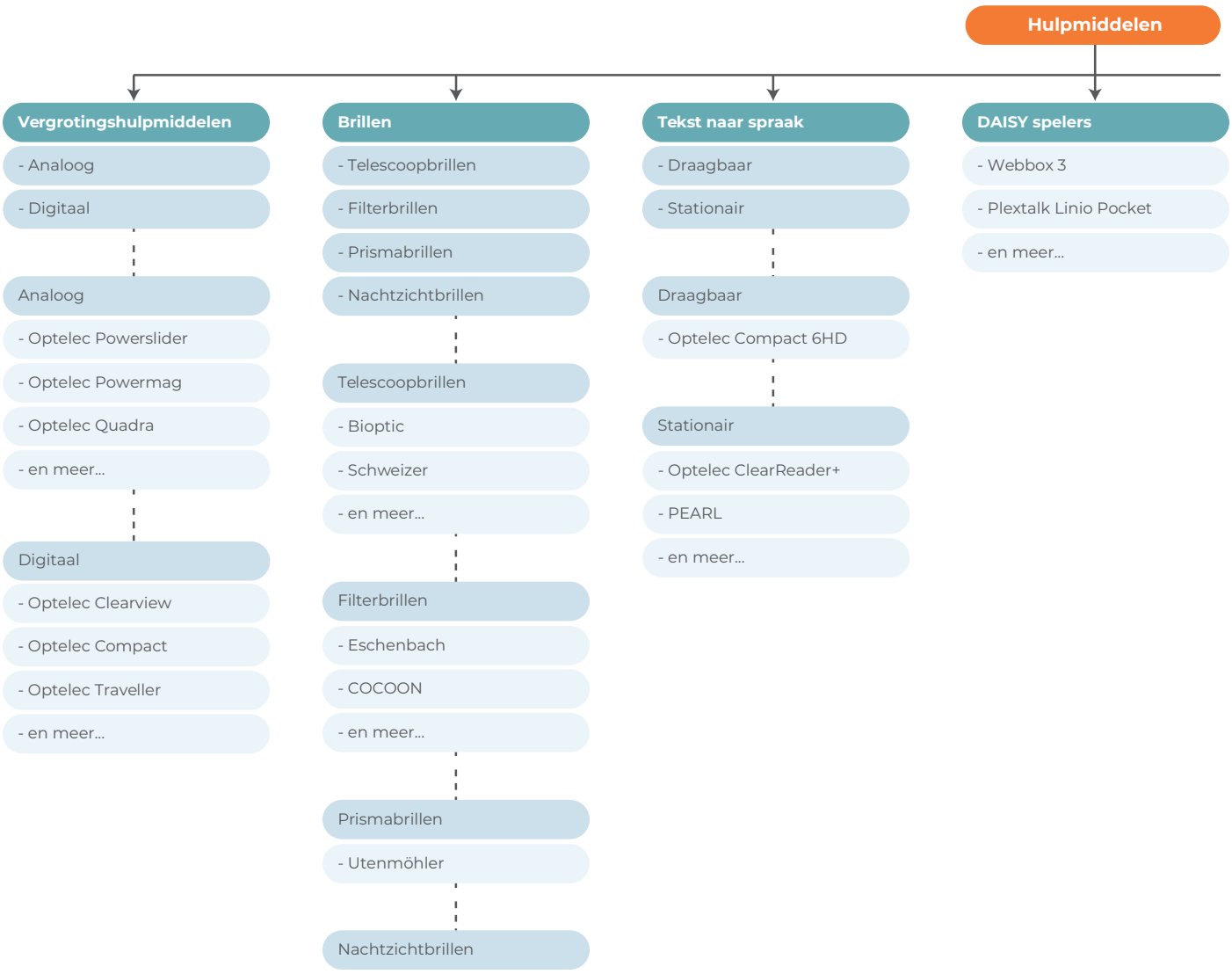
Uiteindelijk is iedereen bij Bartimeus of Visio welkom als er een onopgelost zichtprobleem is. De oogarts moet wel een verwijzing geven maar dan ben je altijd welkom. Als de opticien nog een bril kan voorschrijven heb je hier nog niets te zoeken.

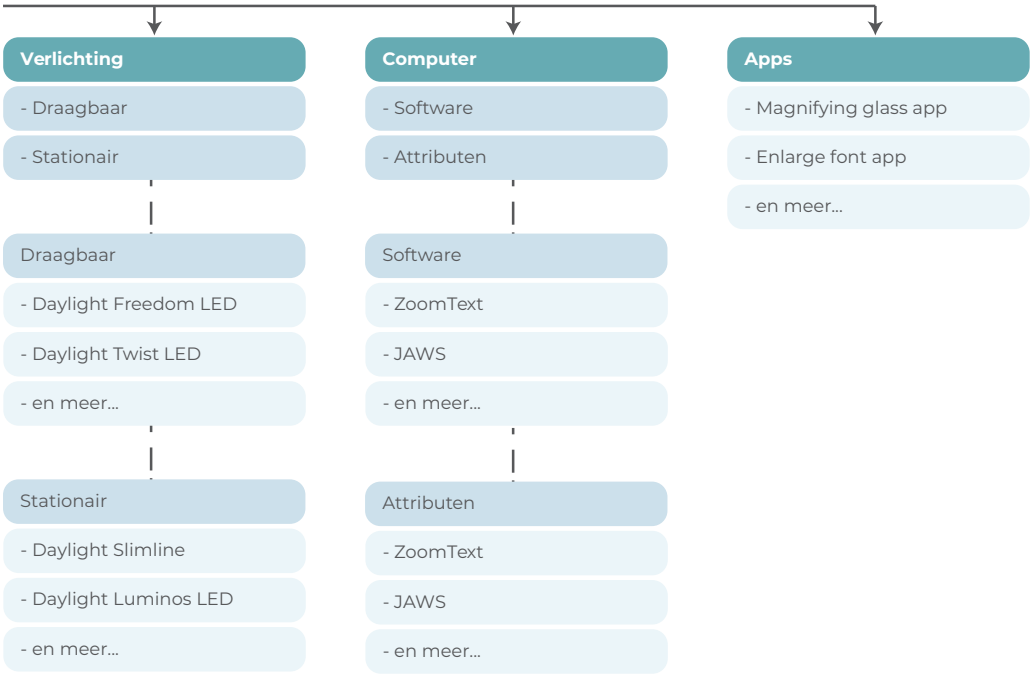
Lex is van mening dat elke vorm van extra informatie van waarde is. Hij benadrukt wel dat het waardevol kan zijn om dit te valideren bij de maculavereniging omdat zij in Nederland het leidende orgaan zijn.

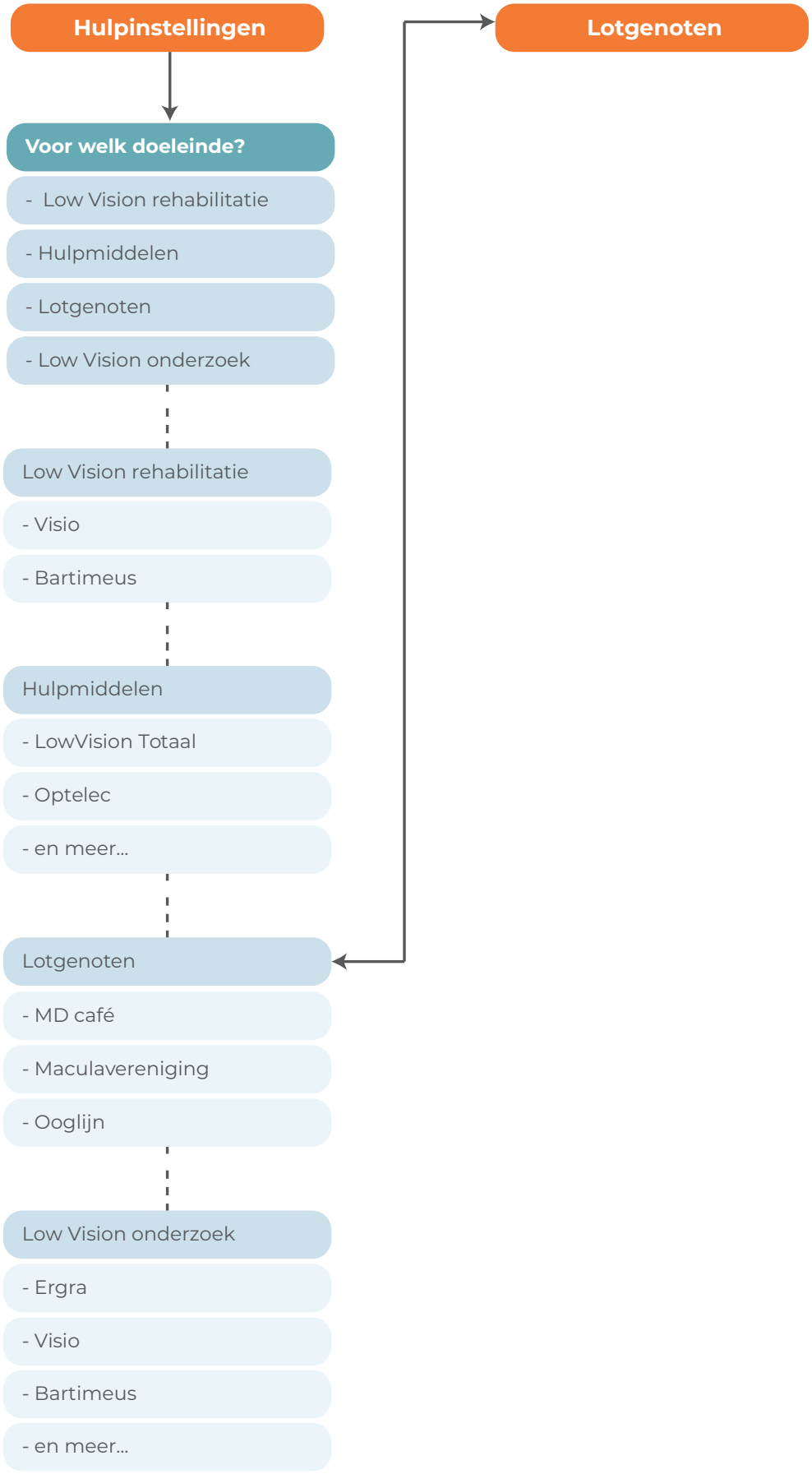
A.7 // FLOWCHART TOPICS




Frequentie en risicofactoren?
- Statistieken
- Leeftijd
- Risicofactoren
Statistieken
- Etniciteit
- Erfelijkheid
- Geslacht
Risicofactoren
- Roken
- Voeding
- Zonlicht
- Alcohol
- Bloeddruk
Diagnose
- Hoe wordt een diagnose gesteld?
- Wat gebeurt er na de diagnose?
Hoe wordt een diagnose gesteld?
- Zelf ontdekking
- Bezoek huisarts / oogarts
- Oogonderzoek
Wat gebeurt er na de diagnose?
- Behandeling ja / nee
- Doorverwijzing
- Hulpmiddelen


Hulpmiddelen
Vergrotingshulpmiddelen
- Analoog
- Digitaal
Analoog
- Optelec Powerslider
- Optelec Powermag
- Optelec Quadra
- en meer...
Digitaal
- Optelec Clearview
- Optelec Compact
- Optelec Traveller
- en meer...
Brillen
- Telescoopbrillen
- Filterbrillen
- Prismabrillen
- Nachtzichtbrillen
Telescoopbrillen
- Bioptic
- Schweizer
- en meer...
Filterbrillen
- Eschenbach
- COCOON
- en meer...
Prismabrillen
- Utenmöhler
Nachtzichtbrillen
Tekst naar spraak
- Draagbaar
- Stationair
Draagbaar
- Optelec Compact 6HD
Stationair
- Optelec ClearReader+
- PEARL
- en meer...
DAISY spelers
- Webbox 3
- Plextalk Linio Pocket
- en meer...


Verlichting
- Draagbaar
- Stationair
Draagbaar
- Daylight Freedom LED
- Daylight Twist LED
- en meer...
Stationair
- Daylight Slimline
- Daylight Luminos LED
- en meer...
Computer
- Software
- Attributen
Software
- ZoomText
- JAWS
- en meer...
Attributen
- ZoomText
- JAWS
- en meer...
Apps
- Magnifying glass app
- Enlarge font app
- en meer...


Hulpinstellingen
Lotgenoten
Voor welk doeleinde?
- Low Vision rehabilitatie
- Hulpmiddelen
- Lotgenoten
- Low Vision onderzoek
Low Vision rehabilitatie
- Visio
- Bartimeus
Hulpmiddelen
- LowVision Totaal
- Optelec
- en meer...
Lotgenoten
- MD café
- Maculavereniging
- Ooglijn
Low Vision onderzoek
- Ergra
- Visio
- Bartimeus
- en meer...


Wat kan ik nog?
Verschillende categoriën
- Vervoer
- Winkelen
- Koken
Vervoer
- Openbaar vervoer
- en meer...
Winkelen
- Boodschappen doen
- Kleding kopen
- en meer...
Koken


Trainingssectie
Type trainingen
- Revalidatietrainingen
- Kijktrainingen
Revalidatietrainingen
- Computertraining
- Kooktraining
- Verkeersdeelnametraining
- Smartphonetraining
- en meer...
Kijktrainingen
- Progressie tool
- Visual Acuity tool
- Bewegend target training
- Eccentric viewing training
- TRL training

A.8 // AIDS OVERVIEW

Aids

Dry AMD, the most common type, is unfortunately untreatable. Individuals have less contrast sensitivity, see less color contrast and may experience central scotomas reducing their central vision field. In order to ease the life of individuals with AMD that experience these symptoms a wide variety of aids are available. These aids assist people with tasks they are unable to perform properly, mainly related to tasks that require reading. In this chapter I will lay down an overview of available aids.

Magnification aids

Due to the central vision loss reading becomes much harder. There are several ways to cope with this problem of which magnification is one. Another possibility is reading with a very small reading distance (sometimes as little as 1 or 2 centimeters) to ensure that the letters appear in a readable size on the peripheral area of the retina. By magnifying the reading material there is no need to keep the text as close to your eye.

Within the sector of magnification aids a distinguishment can be made between two different types namely analog and digital magnification. Analog magnification uses lenses to enlarge images or text while digital magnification uses a camera and a display. Analog aids are much cheaper than digital aids but they are less effective because they do not offer the possibility to have different magnification settings. High-end digital magnification aids also offer a contrast feature which allows the user to interchange a white background and black text to ensure easier reading.

Glasses

There are various types of glasses available for people with AMD. These glasses have different applications depending on the type of glasses. In general a distinguishment can be made between 5 types of glasses namely, sunglasses, filter glasses, telescope glasses, prism glasses and nightlight glasses. Sunglasses are used to prevent initial damage to the eye due to ultraviolet radiation. Filter glasses are used to increase color contrast, mostly by using yellow tinted glass. Telescope glasses are used for magnification for example during reading. Prism glasses, in theory, are able to redirect incoming light onto a different part of the retina to bypass a central scotoma. Nightlight glasses are used for better vision in darker areas.

Text to speech

When an individual has reached the advanced stage of AMD it might become impossible to properly read. In this scenario text to speech aids have been developed. These instruments can read basically every image that it is shown and translate the text on said image into spoken words. This could be helpful for instance when reading the newspaper or a magazine.

DAISY players

Another option when reading becomes too difficult is a DAISY (Digital Accessible Information System) player. A DAISY player is an instrument that allows for storage and playing of audiobooks. It allows for selection of chapters and paragraphs but also for adjusting reading speed. Some versions also offer other functionalities such as reading subtitles out loud.

Lighting

AMD patients may experience decreased contrast sensitivity, therefore extra lighting can help in reducing the load on your eyes.

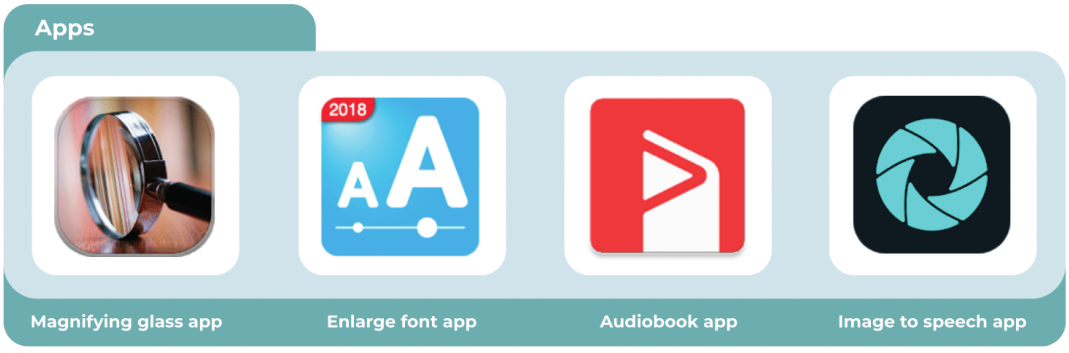
Computer related

Many elderly people are in possession of either a computer and/or a tablet. Using a digital device like this might become problematic when visually impaired. Therefore a multitude of solutions are available to make computer use easier

Apps

After having spoken to a representative from Bartimeus (Lex van den Bos) it became apparent that the popularization of smartphones are revolutionizing this sector. Most modern day smartphones have excellent cameras which can offer almost the same quality of magnification as the ones specifically made for this purpose.

Besides the magnification options image scanning and audiobooks are also included in the app store. High-end smartphones have about the same price tag as high-end magnification aids but they offer a much greater variety of other options.



A.9 // H. BOKHORST WRITE-UP

Harm is 20 jaar geleden geopereerd aan z'n hersenen waarbij er een aantal dingen zijn misgegaan. Er is een deel van z'n hersenen uitgeschakeld omdat er een epileptische aard zat. Alleen zijn rechter hersenhelft functioneert. Het gaat gepaard met een hoop problemen, maar je leert er mee leven. Korte termijngeheugen is aangetast. Er was een jaar nodig om te herstellen. Door de complicaties werd het onmogelijk om nog te kunnen werken binnen zijn ICT domein. Na een jaar werd Harm ook nog slechtziend door MD. Het gaat stapsgewijs slechter. Elke keer moet hij een nieuwe klap incasseren, dat went nooit. Het kan zijn dat er 6 a 7 jaar geen verandering plaatsvindt. Je wordt nooit blind maar je bent wel sociaal blind, je ziet en herkend geen mensen op straat. Je wereldje wordt wel beperkt. In eerste instantie dacht hij, mensen herkennen mij wel maar dat is ook lang niet altijd zo. Je zoekt aansluiting bij gelijksoortige, bijvoorbeeld door de landelijke vereniging. Lotgenoten contact is zeer waardevol. Je wisselt ervaringen uit en kan elkaar hulpmiddelen laten zien. Je blijft toch ongemerkt op de hoogte van nieuwe ontwikkelingen.

Harm is ook actief bij een MD groepje in Zwolle. Eens in de twee maanden komen ze bij elkaar. Je hebt wel een vast groepje, sommige komen een paar keer maar hebben daar genoeg aan gehad. Je hebt wel iemand nodig die initiatief toont anders valt het snel uit elkaar. Soms als je samen ergens heen gaat kan het ook teveel worden, dan gaan ze gewoon een drankje doen.

Harm had een man ontmoet in harderwijk en deze man was 75 en had net de diagnose gehad. Hij raakte in een depressieve toestand door alle veranderingen. Je moet daar wel mee dealen en dat is heel erg lastig. Het is ook frustrerend dat mensen het niet aan je kunnen zien, je moet het steeds weer herhalen dat je het hebt. Het onbegrip heeft er ook toe geleid dat de MD patiënten zich afgesplitst hebben van de blindenvereniging.

De maculavereniging verbaast zich er ook wel eens over dat er maar zo weinig leden zijn. Mensen zijn soms ook onvoldoende op de hoogte van het bestaan ondanks dat het bij oogartsen wordt gepromoot. Je moet ontzettend veel extra energie erin stoppen wil je je huidige levensmanieren aanhouden.

Even een krantenpagina lezen is nu een hele onderneming, het moet wel interessant zijn anders doe je het niet. Je gaat steeds meer shiften, je moet je energie verdelen.

Als je alleen de stad door moet is het een hele uitdaging maar als je met elkaar bent is het een stuk beter te doen. Iedereen draagt een beetje z'n steentje bij.

Het lezen van de incheck schermpjes bij het station zijn niet te lezen maar ze kunnen wel het geluid herkennen. Bij de bus had je in eerste instantie geen verschillende geluiden, dat was voor hun erg verwarrend. Dat is doorgegeven aan de busmaatschappijen en die hebben dit vervolgens verandert. Er is zoveel informatie beschikbaar en data maar desondanks als er nieuwe dingen worden opgezet of gebouwd dan lijkt het alsof al die informatie in een keer is vergeten. Bijvoorbeeld bij de bouw van een nieuw station dat de stippen op de trap in een keer worden vergeten. Een ander voorbeeld is ook het muntgeld wat nu wordt gebruikt. Vroeger met de gulden was het voor slechtzienden beter te doen omdat de grootte duidelijk anders was maar de huidige euromunt is een stuk minder goed te onderscheiden.

De ontwikkeling dat websites toegankelijk worden gemaakt voor slechtzienden is een hele goede zaak. Ook bij geldautomaten is het fijn dat je tegenwoordig je oortjes erin kan stoppen zodat je de juiste keuzes kunt maken op basis van geluid.

Onzekerheid is een heel belangrijk woord, er ontstaat heel snel onzekerheid.

Een groot probleem voor hun is dat op websites vaak veel informatie staat. Het zou best prettig zijn als je begint met een scherm waarin een aantal kernonderdelen staan weergegeven. Door de keuzes die je maakt in het scherm kun je voorkomen dat er heel veel informatie staat. Het moet overzichtelijk zijn, een vol scherm is een probleem.

Je gaat steeds verfijnder. De mogelijkheid moet er zijn om bijvoorbeeld te kunnen zeggen dat hetgeen waarin je niet geinteresseerd bent niet getoond wordt. Daarentegen moet je ook kunnen zeggen dat je alles weer getoond wil hebben. De controle moet in de handen van de gebruiker zijn. Zes onderwerpen is geen probleem.

Als je binnen trainingen gaat kijken wil je als gevorderde bijvoorbeeld niet alle beginnerscursussen zien. Of je wilt bijvoorbeeld op computergebied alles weten over mailtjes dan moet je dat makkelijk kunnen vinden.

Vragenlijsten zijn een inspanning, maak er spraak van. Als je wat verder op de dag bent is lezen te moeilijk. Zelf kleuren kunnen instellen is een pré. Letters geel, achtergrond zwart of andersom. Harm heeft een digitale oogloep waarbij de kleuren ook kunnen worden aangepast. Deze loep is ontworpen in samenwerking met patiënten waardoor er duidelijk is wat er van zo'n product verwacht wordt. Met een functie kun je niet de hele doelgroep benaderen, je moet opties bieden. In grote lijnen zijn er wel functies die noodzakelijk zijn waaronder vergroting en spraak.

Denk je dat het idee een toegevoegde waarde kan zijn?

Google is tegenwoordig een commercieel platform, iets opzoeken is een stuk complexer geworden. Het is heel fijn om één pakket te hebben waar je terecht kunt voor je informatie. Bijvoorbeeld welke trainingen zijn er, welke organisaties geven trainingen, wat is hun telefoonnummer? Geen grote lappen met tekst.

Een lijstje met trainingen is al een hele onderneming. Welke organisatie geeft welke trainingen? Meer details kan je toevoegen op verschillende lagen. Maar in eerste instantie een overzichtelijk en goed leesbaar iets weergeven. Hetzelfde principe geldt ook voor verzekeringen, wat wordt wel en wat wordt niet gedekt? Het kost de patiënt zoveel energie om zich te verdiepen in de "spaghetti" van verschillende polissen, hulpmiddelen etc. Informatie koppelen hoeft allemaal niet heel diep uitgegraven te worden maar biedt een aantal mogelijkheden bijv. op het gebied van hulpmiddelen voorziening. In de grote hoeveelheid van informatie is kort en krachtig heel fijn voor de MD patiënt. Het moet wel iets zijn wat goed onderhouden blijft. Kijk uit voor bijv. forums, dat is heel lastig om bij te houden. Het gaat om kerndingen, waar moet ik nou eigenlijk zijn?

Na de diagnose had ook Harm de ervaring dat er geen informatie werd gegeven. Het was een hele technische benadering. Ook van de tweede oogarts werd er geen informatie gegeven. Sommige oogartsen zijn aangesloten bij de maculavereniging maar er zijn er genoeg die dat niet zijn, deze zijn nog steeds niet in staat voldoende informatie te geven. In Harm's opinie is het echt een probleem.

Organisaties zoals Meeveluwe zijn essentieel om "ons" soort mensen werkende te houden. Zij bemiddelen met de werkgever. Mentaal is het onbeschrijfelijk zodra de diagnose is gesteld. Je hele wereld gaat op z'n kop. Alles valt weg en je komt letterlijk thuis te zitten. Je moet leren begrijpen wat je nou is overkomen in lichamelijk opzicht. (rond 1:04:00)

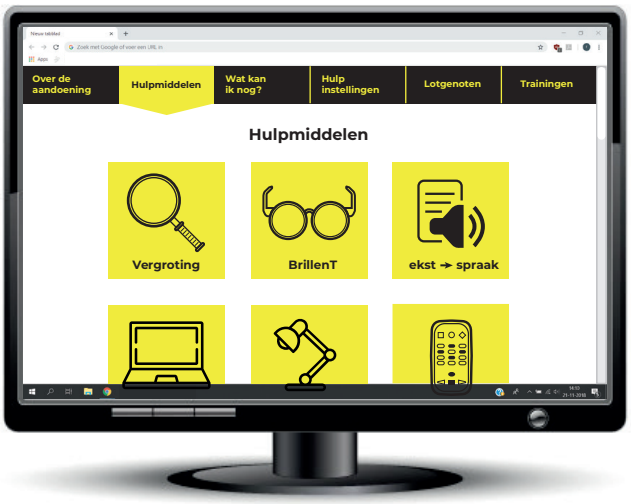
De dokter had meer moeten zeggen: Wat dan? Het is niet alleen op technisch vlak, maar ook wat voor sociale gevolgen het heeft en wat voor impact het heeft op je mentale toestand. Oogartsen en neurologen zijn pure techneuten. De gebruiker zijn ze niet in geïnteresseerd. Waar moet je zijn na de mokerslag? Bij mijn pakket. Heb je vragen dan kun je daar terecht.

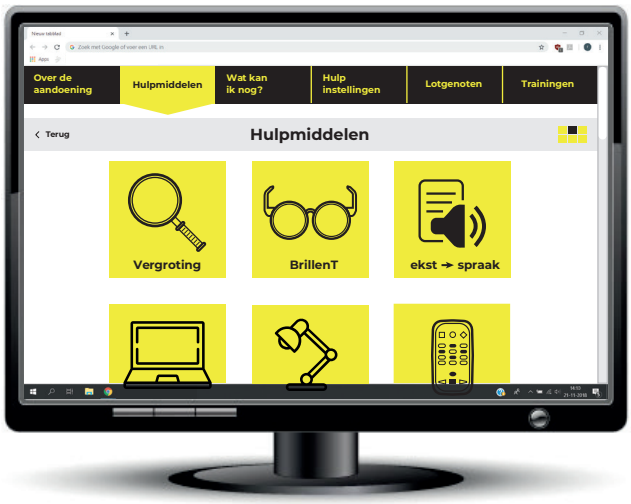
Je bent al het zelfvertrouwen aan het kwijtraken, door te zien wat je als patiënt nog kan helemaal top. Het is heel belangrijk. Aangeven in het pakket wat er nog kan is echt mentaal ondersteunend. De misconceptie dat een loep alles oplost is verkeerd, een loep ondersteund maar kost alsnog heel veel energie. Van elkaar kun je leren, dat is ook de insteek van de landelijke vereniging. Essentiële dingen: Hoe doe je een winkelbezoek, hoe gebruik je vervoer?

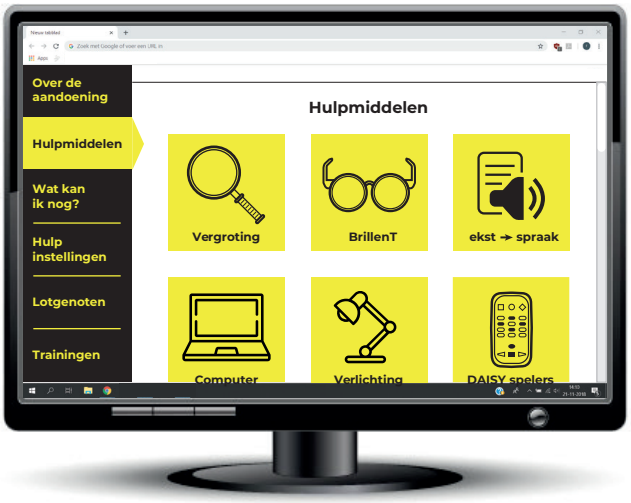
Veel mensen gebruiken ook de Webbox. Het scherm is weggelaten en alles wordt uitgesproken. Als je per scherm goed overzichtelijke kleine onderdelen laat zien dan kom je er wel.

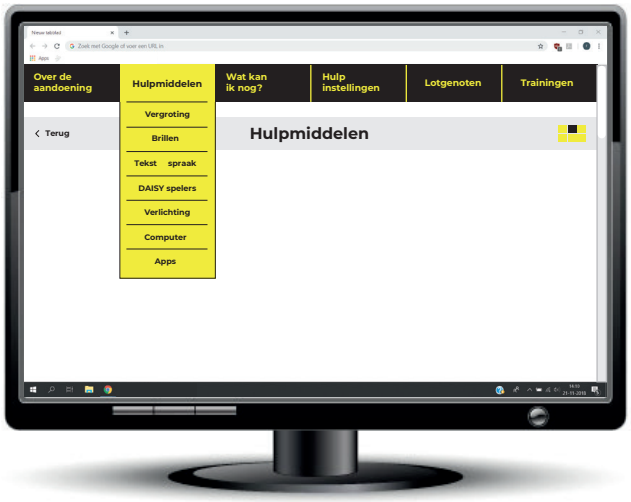
Menigeen zegt zet alles maar kaarsrecht onder elkaar ipv verschillende blokken. Dan kun je regel voor regel lezen. Teksten zien de meeste mensen niet, maar icoontjes wel. Zodra je ergens op klikt moet het voorgelezen worden. Niet al te veel flitsen laten zien, dat is lastig. Het vergroten van een item is wel heel prettig. Dus zodra je ergens je muis op hebt hangen dat dan het voorwerp vergroot. Je moet heel makkelijk beginnen en van daaruit ga je verfijnen. Links in tekst de keuzemogelijkheden en rechts in blokjes formaat is een hele goede optie!

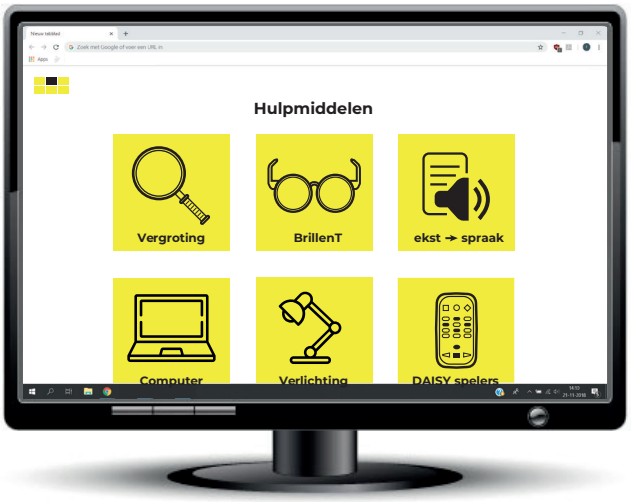
A.10 // EARLY DESIGN CONCEPTS

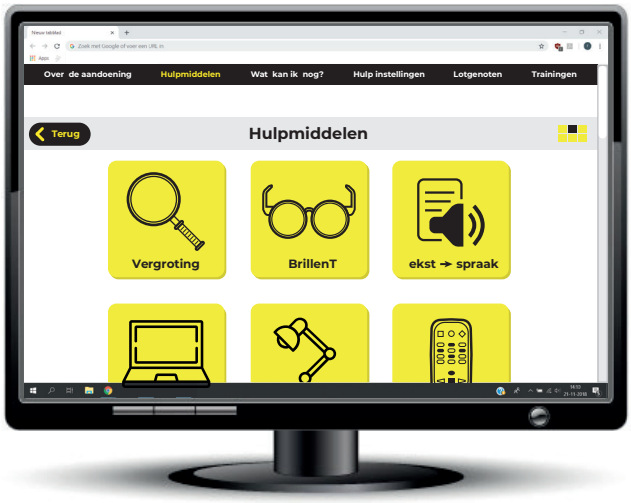


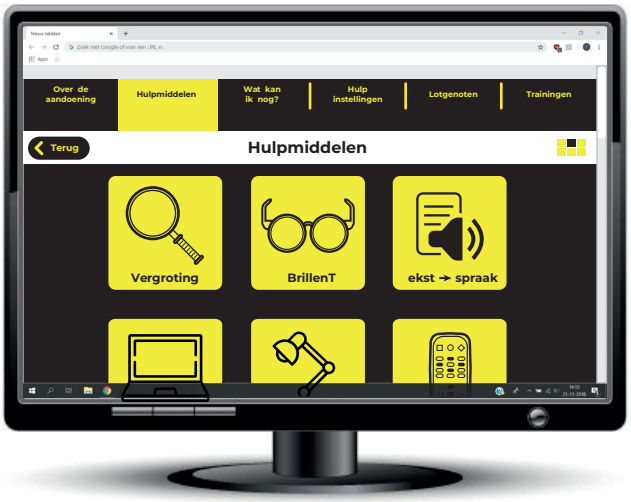


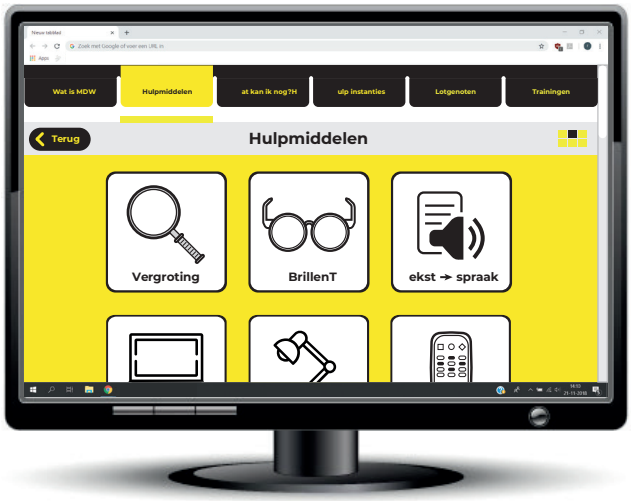


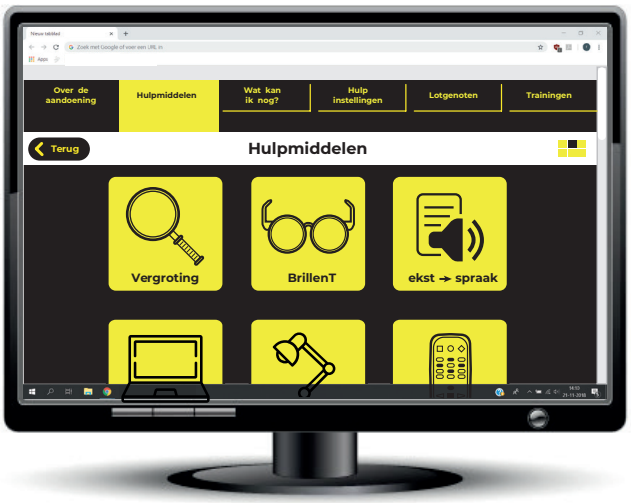







Over de aandoening
Hulpmiddelen
Wat kan ik nog?
Hulp instellingen
Lotgenoten
Trainingen
Terug
Hulpmiddelen
Vergroting
BrillenT
ekst → spraak


Wat is MDW
Hulpmiddelen
at kan ik nog?H
ulp instanties
Lotgenoten
Trainingen
Terug
Hulpmiddelen
Vergroting
BrillenT
ekst → spraak


Over de aandoening
Hulpmiddelen
Wat kan ik nog?
Hulp instellingen
Lotgenoten
Trainingen
Terug
Hulpmiddelen
Vergroting
BrillenT
ekst → spraak


Wat is MDW
Hulpmiddelen
at kan ik nog?
Hulp instanties
Lotgenoten
Trainingen
Terug
Hulpmiddelen
Vergroting
BrillenT
ekst → spraak


zoeken
MACULA DEGENERATIE
Wat is MD?
Hulpmiddelen
Wat kan ik nog?H
ulp instanties
Lotgenoten
Trainingen
Welkom!
Deze website is er voor u.
Klik op een van de onderstaande onderwerpen voor meer informatie.
Wat is MD?
Hulpmiddelen
Wat kan ik nog?

A.11 // BRAINSTORM APPROACH

Hartelijk dank dat ik hier aanwezig mag zijn en dat jullie naar mij willen luisteren. Ik ben sinds de vorige keer dat ik hier was al aardig opgeschoten met mijn project. Naar aanleiding van wat ik hier de vorige keer heb gehoord samen met wat ik verder nog in mijn onderzoek ben tegengekomen heb ik besloten om mij te focussen op het moment net na de diagnose.

Er ontstaat na de diagnose gesteld door de oogarts een soort moment van onzekerheid. Het is onduidelijk wat je precies onder de leden hebt en wat je in de toekomst nog zult kunnen doen. Je leven zoals je het kent wordt plotseling omgegooit. Sommige dagelijkse taken lijken in eerste instantie misschien een lastige opgave maar blijken na een periode van gewenning toch nog te doen. In die komende 20 minuten zou ik het graag met jullie over deze taken willen hebben. Ik wil namelijk nieuwe macula patiënten laten zien dat er misschien meer mogelijk is dan ze op dat moment denken. Aan de hand van jullie ervaringen en oplossingen kan ik dit vormgeven ten behoeve van het zelfvertrouwen van nieuw gediagnosticeerde.

Aan de hand van een vijftal thema's zou ik graag van jullie horen of er bepaalde situaties / dagelijkse taken in jullie op komen. Voordat we beginnen zou ik jullie willen vragen of het oké is als ik de discussie opneem met een audio opname. Deze opname zal ik alleen gebruiken om achteraf nog eens te kunnen luisteren wat er is gezegd. Daarnaast zou ik het erg fijn vinden als u één voor één kunt spreken zodat we kunnen horen wat iedereen te zeggen heeft en het houdt het ook overzichtelijk.

1 **Boodschappen doen**

2 **Gebruik maken van openbaar vervoer**

3 **Koken**

4 **Persoonlijke hygiëne**

5 **Huishouden**

A.12 // ONLINE SURVEY

Beste groepsleden,

Ik ben Roel van Winsen, een masterstudent aan de TU Delft. Ik ben bezig met een project waarbij ik een website ga maken voor mensen met Macula Degeneratie (een veelvoorkomende oogaandoening waarbij het centrale zichtveld wordt aangetast). Een onderdeel binnen deze website heet ‘wat kan ik nog?’ waarbij ik tips & tricks wil laten zien voor het uitvoeren van bepaalde dagelijkse handelingen zoals koken, huishouden of gebruik maken van het OV. Dit wil ik doen om nieuw gediagnosticeerde een steuntje in de rug te bieden in een toch al moeilijke tijd. Een voorbeeld is bijvoorbeeld automatisch opwaarderen op een persoonlijke OV-chipkaart te zetten om niet meer bij de automaat op te hoeven laden.

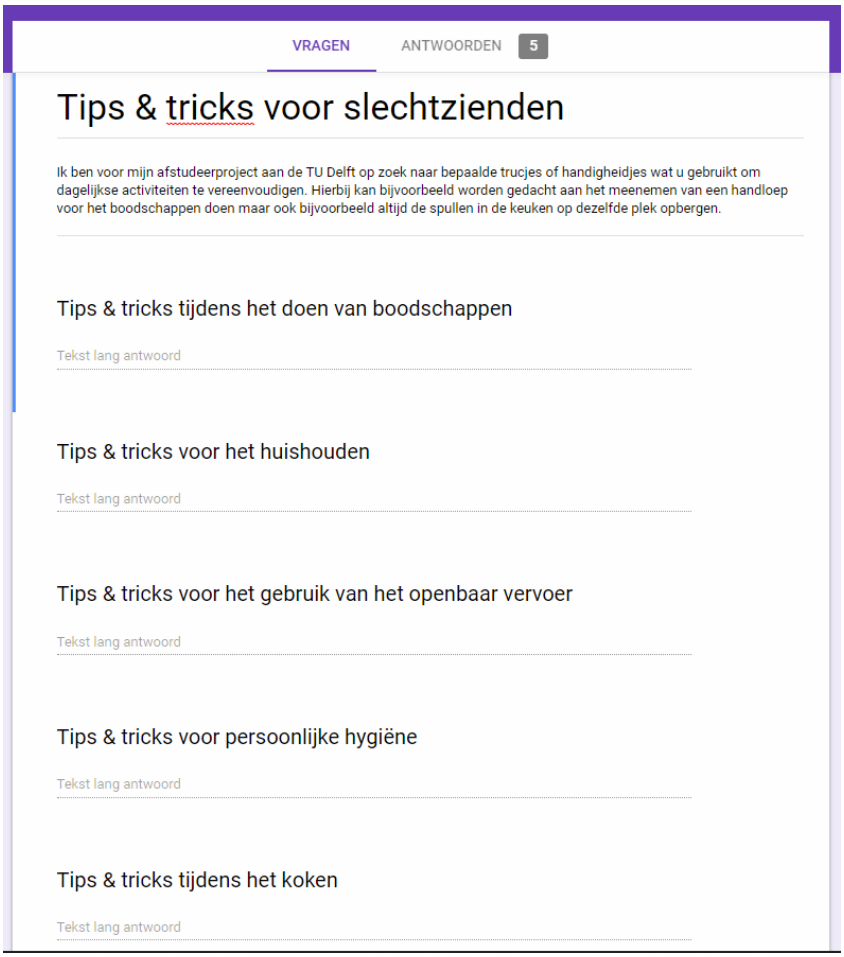
Nu vroeg ik me af of jullie als deskundige mij misschien zouden willen helpen met jullie inzichten? Ik heb een formulier bijgevoegd waar jullie antwoorden anoniem in kunnen plaatsen. Er zijn 5 categorieën maar voel u niet verplicht ze allemaal in te vullen, alle beetjes helpen!

Ik heb aan Wendy gevraagd of ik hier mocht plaatsen en heb daarbij haar goedkeuring gehad.

Alvast hartelijk dank en als u vragen heeft, schroom niet!

Met vriendelijke groet,

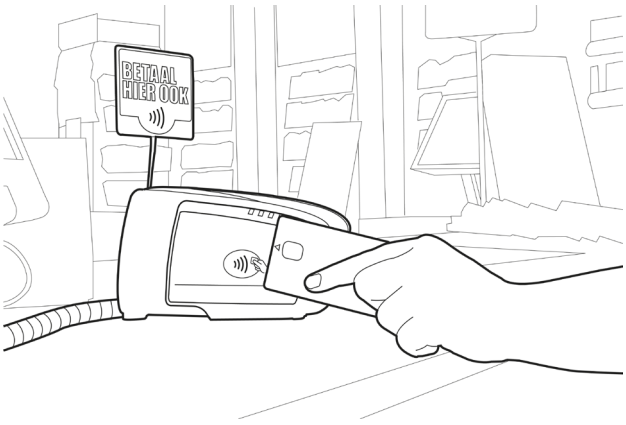
Roel van Winsen



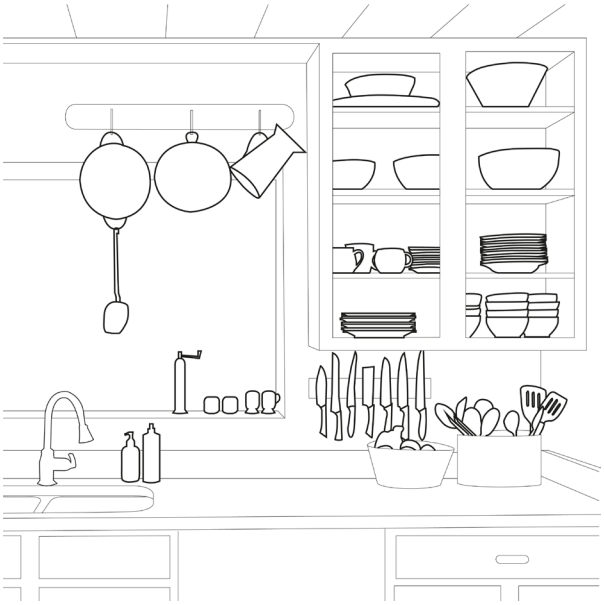
A.13 // EXPERIMENT IMAGES

Durf te vragen (H-H interaction)

Contactloos betalen (H-P interaction)



Alles op dezelfde plek (CO - context)



A.14 // EVALUATION APPROACH

Segment 1

"Dankuwel voor uw tijd en deelname aan deze test. Ik doe voor mijn masteropleiding aan de TU Delft een project over, wat u naar alle waarschijnlijkheid al weet, macula degeneratie. In dit project heb ik een website ontworpen voor nieuw gediagnosticeerde MD patiënten. In het komende uur wil ik u wat vragen stellen en samen met u naar de website kijken. Ondanks dat u dan misschien geen nieuwe patiënt bent weet u wel hoe het is om de aandoening te hebben. Dat maakt u de expert op dit gebied en ben ik heel benieuwd naar uw mening. Ik wil hierbij ook benadrukken dat er geen foute antwoorden zijn in deze test. Als u bijvoorbeeld iets niet weet is dat absoluut geen probleem."

I'd like to start with sketching a situation in which I'd like the test persons to imagine going back to the time where they were diagnosed with MD. Since it might be a long time ago for some of the test persons iit could be hard to actually remember what it was like. Therefore I'll provide a quick introduction to the average emotions that play a role in a MD diagnosis if they can't remember it properly.

"Het krijgen van de diagnose macula degeneratie wordt veelal ervaren als een negatieve ervaring. Oogartsen stellen de diagnose en vaak is er daarna geen of weinig tijd meer voor vragen. Afhankelijk van de variant (droog of nat) zal er een vervolgtraject zijn met injecties om het proces van verslechtering te remmen. Verder is er weinig aan te doen. In sommige gevallen zal de patiënt een informatiefolder ontvangen met een verwijzing naar de Maculavereniging maar daar blijft het vaak ook bij. Het krijgen van de diagnose zorgt bij veel mensen voor onzekerheid, frustratie en verwarring onder andere door het gebrek aan informatie."

Introduction questions

1 Hoelang heeft u al MD?

2 Als u merkt dat nu iets niet meer lukt door uw aandoening wat doet u dan?
Hulpmiddelen / begeleider / iemand die u helpt / LV-kliniek

3 Heeft u een partner (of iemand anders) die u ondersteund?

Follow-up questions

1 Kunt u zich nog voor de geest halen of er in de tijd na de diagnose bepaalde dagelijkse handelingen waren waarvan u onzeker werd in het uitvoeren ervan? Hierbij kunt u denken aan zelfstandig boodschappen doen, koken, persoonlijke hygiëne, het huishouden, gebruik maken van het openbaar vervoer etc.

2a In het geval van ja, wat voor soort handelingen waren dat in uw geval? Wat zorgde ervoor dat u onzeker werd in die situaties? Kunt u zich voorstellen dat andere patiënten dit ook zo ervaren / ervaren hebben?

2b In het geval van nee, kunt u zich voorstellen dat nieuw gediagnosticeerde onzekerheid ervaren in het uitvoeren van bepaalde dagelijkse handelingen? Waarom ervaren ze deze onzekerheid dan in uw optiek?

2c Zijn er nu bepaalde dagelijkse handelingen waarover u onzeker bent in het uitvoeren ervan door uw aandoening? Zo ja, wat voor handelingen zijn dat dan? Hoe gaat u hiermee om?

"De reden dat ik deze vragen stel is dat het namelijk geregeld voorkomt dat mensen met maculadegeneratie in de beginfase van de aandoening onzeker worden over hun zelfredzaamheid. Dit heeft te maken met een veranderde situatie waarin de progressie van de aandoening onzeker is. Kan ik de dingen nog blijven doen die ik nu nog kan? Wat gaat er veranderen? Omtrent de genoemde zelfredzaamheid heb ik nog een aantal vragen."

3a Doet u nu zelf boodschappen?

3b Zo ja, zijn er dan bepaalde dingen waar u specifiek op moet letten? Heeft u dit zelf moeten uitvinden of was er iemand die u hierbij heeft geholpen? Hoe heeft u dit ervaren?

3c Zo nee, weet u nog op welk moment u bent gestopt? Wat was de reden hiervoor?

4 Stel nu dat er in de beginfase van uw aandoening iemand was geweest die al langere tijd MD heeft die u had verteld wat zij doen om een dergelijke situatie te vergemakkelijken, zou dit u geholpen hebben? Geeft de wetenschap dat andere MD patiënten in een verder stadium nog zelfstandig boodschappen kunnen doen u meer zelfvertrouwen in uw eigen kunnen?

5a Kookt u zelfstandig?

5b Zo ja, zijn er dan bepaalde dingen waar u specifiek op moet letten? Heeft u dit zelf moeten uitvinden of was er iemand die u hierbij heeft geholpen? Hoe heeft u dit ervaren?

5c Zo nee, weet u nog op welk moment u bent gestopt? Wat was de reden hiervoor?

6 Stel nu dat er in de beginfase van uw aandoening iemand was geweest die al langere tijd MD heeft die u had verteld wat zij doen om een dergelijke situatie te vergemakkelijken, zou dit u geholpen hebben? Geeft de wetenschap dat andere MD patiënten in een verder stadium nog zelfstandig kunnen koken u meer zelfvertrouwen in uw eigen kunnen?

7a Maakt u zelfstandig gebruik van het openbaar vervoer?

7b Zo ja, zijn er dan bepaalde dingen waar u specifiek op moet letten? Heeft u dit zelf moeten uitvinden of was er iemand die u hierbij heeft geholpen? Hoe heeft u dit ervaren?

7c Zo nee, weet u nog op welk moment u bent gestopt? Wat was de reden hiervoor?

8 Stel nu dat er in de beginfase van uw aandoening iemand was geweest die al langere tijd MD heeft die u had verteld wat zij doen om een dergelijke situatie te vergemakkelijken, zou dit u geholpen hebben? Geeft de wetenschap dat andere MD patiënten in een verder stadium nog zelfstandig het openbaar vervoer kan gebruiken u meer zelfvertrouwen in uw eigen kunnen?

Segment 2

Besides the emotional value of the tips&tricks section it is also important to verify whether the proposed means of communication are sufficient. There are a few questions surrounding this that need to be answered:

1 Is the presented modal content of the tips understandable and interpretable?

2 Is the textual content presented in a mature enough way?

3 Is the textual content balanced enough (not too general, not too specific)?

4 Is the accompanying image understandable? Is the size right?

5 Is the use of a spoken quote valuable? Is its presentation clear?

To answer these research questions the participant will be shown three different tips, one from each theme. The participant is then asked to describe what they are seeing. Afterwards each element is discussed through questions such as:

1 What do you think the function of this element is?

2 Are you able to read / see it?

3 Does it provide sufficient information for you to understand it?

4 Do you think it adds to understanding the tip as a whole?

5 Would you change anything?

A.15 // N. VAN STEIJN WRITE-UP

Eerst naar ziekenhuis door klachten, er zat vocht in het oog dus injectiebehandeling was nodig.
De klachten vallen tot nog toe mee.
Tijdens schemering is het zicht wazig, de vlek zit in één oog.
Oogarts heeft aangeraden 1 keer per week naar een Amslergrid te kijken
Als het goede oog achteruit gaat, meteen aan de bel trekken
Als ze met dr slechte oog kijkt ziet ze nog een hoop maar je kunt niet focussen
Ze had eerst een zonnebril die over haar eigen bril heen kan maar dat is zo donker
Eerste symptoom waren een soort schitterende eikenblad motief in haar zicht tijdens het stofzuigen. Daarvoor is ze naar de dokter geweest maar daar kwam nog niet meteen iets uit naar voren.
Later heeft de oogarts gezegd dat ze littekentjes op haar netvlies heeft.
De vlek in haar oog speelt nog geen grote rol.
Ze heeft er in het dagelijks leven nog geen last van, het goede oog is nog 90%
Ze is niet bekend met Visio of Bartimeus
Ze kan zich wel goed voorstellen dat mensen met MD in beide ogen het heel lastig hebben.
Als je dan boodschappen gaat doen wordt het ineens wel heel moeilijk.
Voor haar is het prettiger om meer dan een keer per jaar naar de oogarts te gaan voor controle, ook ter geruststelling
In het oude huis keek ze een keer naar het dak van de buren en toen liep de dakrand niet meer recht, dat is ook een indicatie.

Schetsen scenario
Kan iemand daar baat bij hebben?
“Nou ik geloof zeker van wel anders kun je niet functioneren”
“Iedere tip waar jij mee om kan gaan is heel fijn”
Je krijgt de boodschap dat het maculadegeneratie heet een daar moet je het dan mee doen.
De waarde van de tips:
“Ja nou ik geloof van wel want daar moet je het bijna alleen maar van hebben als je het aan beide ogen hebt, iedere tip is welkom”

De tekst van de website is goed leesbaar
De verschillende thema’s zijn helder en N. van Steijn herkende ze meteen
De indicatie van waar de muis op het scherm is dmv oplichtende randen is zeer duidelijk
Door haar goede oog af te dekken kan ze nog steeds de verschillende onderdelen zien ondanks dat het wel vaag is
Het openen van de modal laat de tip “overzichtelijker” zien. De foto op zichzelf geeft nog niet genoeg informatie maar icm de beschrijvende tekst is het duidelijk. De tekst is volwassen genoeg geschreven.
“Het zal ongetwijfeld helpen, dat geloof ik wel”
“Als het je gezegd wordt, je vergeet toch al zoveel als je oud bent, dat het ook meer blijft hangen”
“Het is wel mooi aangegeven zo”
“Het kost weinig moeite om erachter te komen waar het om gaat bij de tips”
“Het is verschrikkelijk lastig maar je kan toch dingen leren om ermee om te gaan, je krijgt wel ideëen”
Sommige dingen zijn vrij logisch maar daar heeft ze nog niet over nagedacht omdat het gelukkig nog niet zover is.

A.16 // M. KOKHUIS WRITE-UP

Ze heeft de aandoening eigenlijk al haar hele leven. Het is een gevolg van hele hoge myopie. Ze kan in de verte heel moeilijk zien. Rond haar 50e kreeg ze de eerste verschijnselen van macula degeneratie. Toendertijd waren er nog geen mogelijkheden voor behandeling met injecties. Haar partner is een grote steun in het dagelijks leven. Boodschappen doen, doen ze bijna altijd samen (als ze alleen gaat neemt ze wel altijd haar loep mee). Ze probeert eerst zelf oplossingen te zoeken zodra iets niet meer lukt. Als ze bijv een nieuw apparaat koopt wil ze het wel degelijk zelf kunnen bedienen.

Na de diagnose zat ze helemaal in een dip. Ze kon het helemaal niet plaatsen in het begin. Ze had een hele goede oogarts die haar meteen op Bartimeus heeft gewezen. Bartimeus had voor haar nog wel een gekke naam, ze dacht altijd dat het een blindeninstituut was. Ze is fantastisch opgevangen echter wel lange wachttijden. Ze heeft samen met een vriendin via Bartimeus het MD café opgezet. Ze was lid van een groep van 10 waarmee ze uiteindelijk hebben besloten om elkaar niet meer los te laten, dit was in 2000. Het was ontzettend leuk. Een aantal mensen in die groep zaten bij de maculavereniging, daardoor heeft ze zich daarbij ook aangesloten. Aan de hand daarvan heeft ze het macula café opgezet in utrecht. Na vijf jaar is ze ermee gestopt. Na het MD café is ze bijna 10 jaar lang onderdeel geweest van het belteam van de maculavereniging.

De paniek die haar overviel toen ze de diagnose kreeg sloeg toe. Oke hoe moet ik dit nu gaan doen, ik ben pas 50. Hoe kan ik ermee omgaan als ik straks bijvoorbeeld kleinkinderen krijg? De dagelijkse handelingen zoals koken en boodschappen doen is ze gewoon blijven doen ondanks de diagnose. Uiteindelijk heeft ze een week of 6 echt in een dal gezeten en toen heeft ze haar schouders er weer onder gezet en gekeken naar de dingen die ze nog wel kan doen. Daarna is het op nog een aantal momenten weer slechter geworden alleen is de emotionele impact niet meer zo groot geweest als toen net na de diagnose.

Door de bepaalde dagelijkse taken gewoon te blijven doen dan blijft het in je systeem zitten. Ze kan zich goed voorstellen dat de diagnose een soort verlamming teweeg brengt bij sommige mensen. Het krijgen van tips is zeker een toegevoegde waarde, die moet je gewoon krijgen. Heel veel dingen ontdek je zelf gaandeweg ook wel. Bij het belteam heeft ze veel contact gehad met nieuwe patienten die vol zitten met vragen. Die mensen hebben veel waardering geuit door de tips die ze hen kon geven over hulpmiddelen maar ook over bijvoorbeeld Bartimeus. Mensen hebben vaak dezelfde vragen zoals hoe moet ik nu verder of hoe gaat dit nu verder? Het feit dat ze een lotgenoot aan de telefoon hebben is voor die mensen vaak al een opluchting.

Voor de participant is het herkennen van de titel vrij lastig. Het herkennen van de verschillende symbolen gerelateerd aan de thema's is wel te doen. Ze kan wel precies aanwijzen waar tekst staat alleen kan ze de tekst niet lezen. Als de tekst groter zou worden wordt het uit elkaar getrokken en dan kan ze er helemaal niks mee. Ze vind het lastig om het verband te zien tussen de verschillende icoontjes. Door de kennis van het feit dat het over maak het makkelijker gaat zijn de icoontjes wel te interpreteren maar in eerste instantie is dit erg lastig.

De verschillende thumbnails zijn te herkennen maar sommige foto's hebben voor haar een andere betekenis. Het feit dat het vergroot kan worden door erop te klikken is al behoorlijk. Dat maakt het al veel makkelijker om te begrijpen. Het laten uitspreken van een echte uitleg is waardevol voor slechtzienden, wat nu wordt uitgesproken is voornamelijk het opperen van het probleem. Het zou handig kunnen zijn om een uitleg te geven over hoe een bepaald apparaat bijvoorbeeld gebruikt kan worden. Eventueel een bijlage maken met een beschrijving van hoe iets werkt. Het toevoegen van een link naar een externe website zou wel een goede kunnen zijn. Ze ziet wel een toegevoegde waarde van een uitgesproken quote, het verduidelijkt het plaatje.

Spraak is wel verduidelijkend, zelf heeft ze ook een spraakapplicatie op haar computer. Als je het niet nodig hebt dan hoef je het niet te gebruiken maar dat het er is is wel fijn. Het taalgebruik is voldoende en de tekst maakt goed duidelijk waar het om gaat. Maar een link is echt belangrijk.

Tijdens het koken zorgt ze er wel voor dat haar aanrechtblad netjes opgeruimd is. Contrasten zijn ook erg belangrijk. De tips zijn zeker waardevol genoeg. Het zou wel een zinvolle website zijn denk ik met tips van dit soort dingen. De categorieën die je hebt zijn wel heel belangrijk al.