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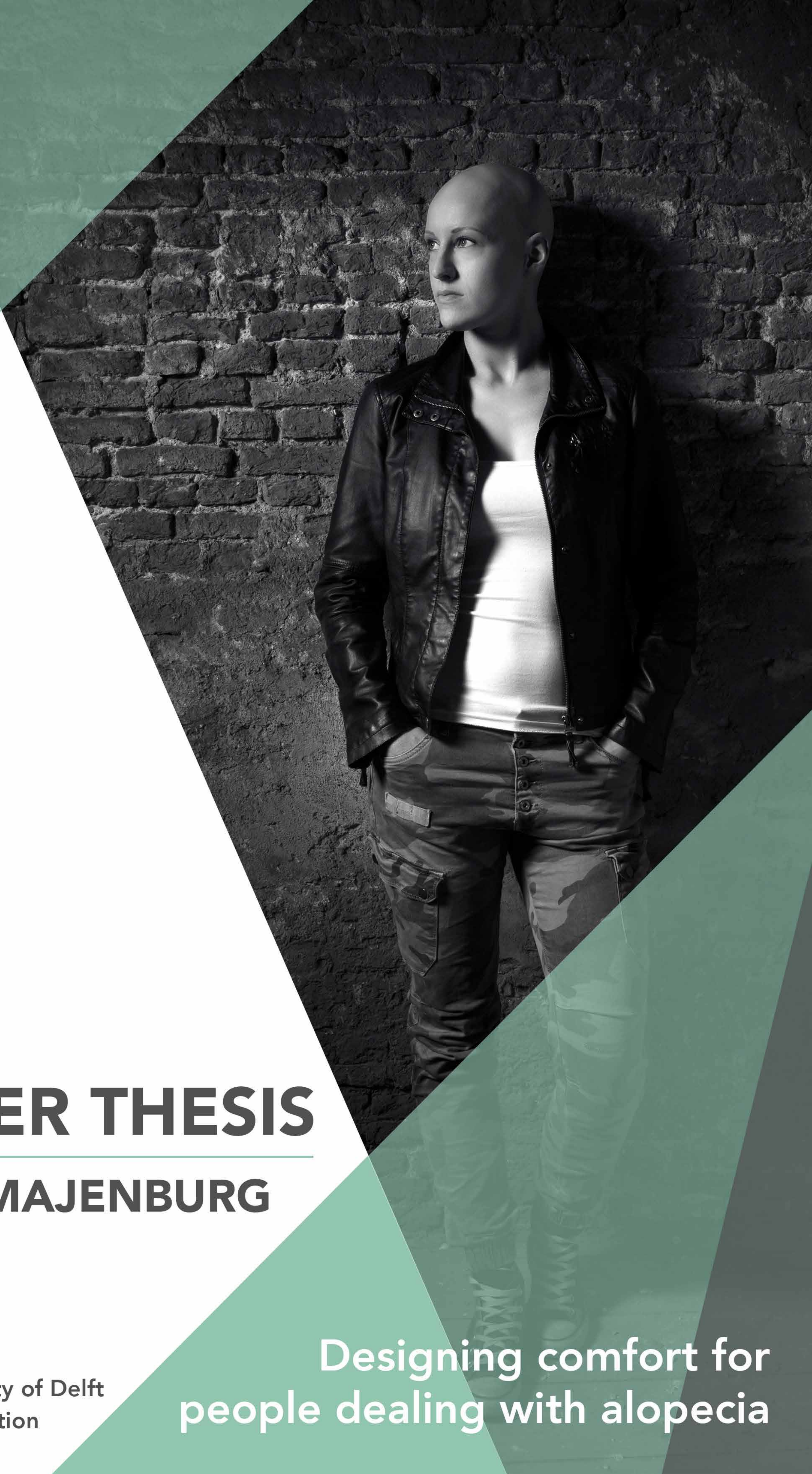

MASTER THESIS

TESSA MAJENBURG

Technical University of Delft
Design for Interaction

Designing comfort for people dealing with alopecia

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Master thesis
MSc. Design for Interaction
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MSC DESIGN FOR INTERACTION
INDUSTRIAL DESIGN ENGINEERING
SPECIALIZATION MEDISIGN
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DESIGNING COMFORT FOR PEOPLE DEALING WITH ALOPECIA

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ABSTRACT

Title: Designing Comfort for People with Alopecia

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This Master Thesis describes a graduation project developed to investigate how to help people when disrupted life events occur and how to create strategies to empower them in coping with the situation. It is in connection with the research developed by the PhD candidate Patrizia D'Olivo. To date not many strategies were developed to empower people who suffer of the alopecia condition. Thus, the project attempted to help people with alopecia feel comfortable in their everyday lives by designing coping strategies for the individual with alopecia and anyone he feels close with.

In this project different research and design methods were applied, like interviewing, surveys, a co-creative session and design evaluation with assistance of the Alopecia Vereniging. Context and user research deepened the knowledge on the topic and classified the problems the target group encounters. The disrupted life event of alopecia and the population affected by this condition encounter a lot of problems that differ according to the level of severity and risk. It was evident that the communication between the person with alopecia and anyone he feels close with should be stimulated and improved.
Different design explorations combined with a concept evaluation study and a co-creative session showed the desired features for the final design. The proposed design 'Imagine alopecia' gives people close to someone with alopecia a better understanding of the impact of the condition and stimulates the communication between them.

The design evaluation study confirmed that the target group feels that the design has the potential to improve the communication between them and the people they feel close with. In addition, also the people close to someone with alopecia believe in the added value of the design. However, to validate the effect of the design on communication, it should be evaluated by letting people use the design in real life situations.

PREFACE

As an Industrial Design Engineering student, I strive to design products that have a function and really contribute to someone's life. This is why I started the master Design for Interaction at the Technical University in Delft in 2015 with a medisign specialization. I am especially interested in user experience and user testing and I like it when I can make people interact with each other because of my designs. Improving people's lives is what satisfies me, especially when it comes to people who are in need of improvement because of medical reasons, as I have my own experiences with medical setbacks.
I started searching for a graduation project but could not find projects that interested and motivated me enough. In the meantime, in January 2016, I started suffering of alopecia universalis. The idea of making a graduation project out of this event started when I was combining a beanie with extensions in order to not always have to wear an uncomfortable wig so after a while I recognized a big need for more research and products for people suffering of alopecia. I decided it was good to make the best out of my new situation and make this subject my graduation project. Because I suffer of alopecia myself (currently alopecia areata), I had a unique chance to really dive into the experiences of other people with alopecia without them feeling burdened by talking to someone who does not understand them.

I got in contact with my mentor, PhD candidate Patrizia D'Olivo who's focus specifically addresses the use of communication and optimism as meaningful means to foster self-confidence and strengthen coping behaviors in disrupted life events. She especially focuses on children with cancer. In both disrupted life events, the target group gets faced with losing hair but the whole context and prospects are different. It directly became clear that my project could give interesting additional insights to her research. The project also seemed interesting for Huib de Ridder, who already wanted to be my supervisor for a project for pediatric cancer and so the project started.

I want to thank all people who were involved in this project. I especially want to thank, all participants and their family members who joined my research, co-creative session and design evaluations, all people involved from the Alopecia Vereniging, my supervisory team and my friends and family.

All participants and their family members because you were willing to share your experiences and time, made it possible for me to do my research, co-creative session and design evaluations and gave me new and special friendships. A special thanks to the people who were willing to let me use their pictures in this project and thesis.

All people involved from the Alopecia Vereniging because you were willing to help me in my project by giving me information and helping me to organize and realize the research, co-create session and design evaluations. I especially want to thank Marion Kremer, for all her input, inspiration and help.

My supervisory team, Patrizia D'Olivo and Huib de Ridder, because you provided me with good and critical feedback and helped me realizing this design project, despite the setbacks and sometimes confronting moments of the project.

My friends and family, because you let me use your pictures for the design and because you helped me through this project by supporting me as the project could sometimes be confronting. With your support this project helped me personally growing.

Stefanie Annique Photography

EXECUTIVE SUMMARY

The Design for Interaction graduation report 'Designing Comfort for People with Alopecia' was carried out for the Technical University of Deft. It was done with the assistance of the Alopecia Vereniging and adds to the research of the PhD candidate Patrizia D'Olivo. In this project different research and design methods were applied, like interviewing, surveys, a co-creative session and design evaluation.
The research question for this project is: How to make people with alopecia feel comfortable in their everyday lives?

CONTEXT & RESEARCH PROBLEM

In the first part of this graduation project, the introduction and the context & research problem, the design context is explored. The design goal in the assignment was 'I want to make people with alopecia feel comfortable in their everyday life.' The condition alopecia itself, its care procedures, available treatments and psycho-social impact are further explored. Also the socio-ecological (Bronfenbrenner, 1992) framework is discussed. This framework means to discover how the user deals with the situation personally (personal level), how this influences his close relationships (interpersonal level) and how this affects the closest networks of people with whom he relates in the everyday life (organizational level).
The research question for the context and user research was: 'How to make people, aged between 16 and 35 years old, who suffer of alopecia feel comfortable in their everyday lives?' This means to discover what makes people with alopecia happy or comfortable and what their problems and needs are in their everyday lives.

ANALYSIS

In the analysis, the second part of the project, the different studies which were done in the context are described. In the first study, the youngsters activity day of the Alopecia Vereniging was visited to get an introduction in the context of young people suffering of alopecia. The people of the Alopecia Vereniging and the potential participants for the second study were met. After this first study, the target group was narrowed down to young people with alopecia between 16 and 25 years old. The second study consisted of interviews with ten different young people with alopecia and an interview with the (recently former) chair of the association. The chair of the Alopecia Vereniging provided more information about the activities, insights, wishes and needs of the association. The interviews with the youngsters provided insight in problems, needs and things which makes them happy in their every day life.
The study was analyzed by transcribing the interviews, making statement cards, comparing timelines and drawing conclusions from combining the results. After the interviews the target group was narrowed down further to young people with a later age at onset of alopecia.
The conclusions made clear there were a lot of different problems, needs and things that made the participants happy or sad. One of the big problems was a lack of good communication between the young individual with alopecia and the people he feels close with. So the design goal would have to go into the direction of improving this communication.

CONCEPTUALIZATION

With the findings of the analysis phase, the design brief was made. The main goal from the design brief is:

Design a product or product-service system which makes people, aged 16-25 who suffer of alopecia with a later age at onset in life, feel comfortable in their everyday lives by designing coping strategies for the individual with alopecia and anyone this individual feels close with.

How to talk openly about the condition without offending the other person?
It was found that there are three different levels of communication possible for the design to improve the communication: explanation or show, discuss and experience.
With this design brief and insights the ideation and conceptualization started. Different ideas were generated by brainstorming, making 'How can you's and using moments. The most viable and innovative ideas were selected, some were combined and they got worked out to three rough concept directions. These concept directions were determined by looking at the different communication levels.

CONCEPT EVALUATION

The three concept directions were further detailed to three concepts with two concepts in two different platform versions. The further detailing was done in order to have them evaluated at the national Alopecia Vereniging spring conference. People close to someone with alopecia were also involved in the evaluation because they will also be involved in the use of the design. On the conference day, nine people with alopecia and six people close to someone with alopecia participated to evaluate the three different concepts by filling out a questionnaire and scoring the three concepts on different aspects after getting an explanation of all the concepts and having the possibility to see mock-ups of them.

CO-CREATION

With the insights of the concept evaluation on the conference day of the association, two concepts were chosen and improved. Also an integrated version of both the concepts was made. A more sketch like version of the concepts was made to get evaluated by six participants in a co-create session. This co-create session was done during a holiday weekend with six young people from the youngsters activity day, organized by one of them. The sketch version concepts were evaluated and their own thoughts and ideas on the concepts were asked by a discussion and letting them draw. After this, also further worked out detailed versions of the two concepts and the integrated concept were evaluated with mock-ups. This detailed version served to also evaluate the visual style of the concepts. It was clear that the integrated version of the concepts was best for all participants.

FINAL DESIGN

The integrated version of the concepts was chosen by all participants and after the co-create session it was worked out to the final design according to their input. The final design, 'Imagine alopecia', is a mobile application which makes it possible for people with alopecia to let other people experience and understand more of what alopecia is like. On the application, the user can let other people go through a hair loss process and see an alopecia filter followed by questions about activities which the user is able to select himself. Through hair loss process and activities, the other person gets faced with different open questions and decisive moments the person with alopecia also had to face. This makes this person think of what he would do in the same situation. With this design, interaction and communication get stimulated between the individual with alopecia and the person close to him. Furthermore, the person with alopecia can use the hair and make-up filter on the application to try out different wigs and make-up to see what looks good on him.

IMPLEMENTATION

The design is a mobile application and uses the technology of face detection to apply a static filter to it. The user needs to take a clear picture of himself which will be transformed in different ways during the course of the story in the app. The development could for example be financed by crowd funding or in collaboration with international alopecia associations. The Alopecia Vereniging can publish about the application on its website, social media accounts and on events. Also doctors can advise patients to download the application. As this design is about the impact of losing hair, the application could well be used in the chemotherapy context and also be transformed to be available for other conditions in which people have to deal with stigma because they cause a difference in appearance.

DESIGN EVALUATION

On the national alopecia fair, organized by the Alopecia Vereniging, the final design got evaluated. In total nine people with alopecia and eight people close to someone with alopecia participated in the design evaluation. On the fair there was an A1 poster to explain the design and there were two mobile phones and a tablet with a semi-working prototype of the design so the participants could try out the application after which they were asked to fill out a survey. With the results of the design evaluation, the last adjustments were made to the final design and recommendations were written.

CONCLUSION & DISCUSSION

Finally, the project report ends with a conclusion and discussion about the design and project.

CONTENTS

CHAPTER

01

Stefanie Annique Photography

INTRODUCTION

IN THE INTRODUCTION, THE ALOPECIA CONDITION WILL BE BRIEFLY EXPLAINED. MORE DETAILED INFORMATION WILL BE PROVIDED IN THE SECOND CHAPTER. FURTHERMORE, THE DESIGN GOAL, APPROACH AND INVOLVED PARTIES WILL BE DISCUSSED HERE.

1.1 DESIGN GOAL

This Master Thesis describes a graduation project developed to investigate how to help people when disrupted life events occur and how to create strategies to empower them in coping with the situation. It is in connection with the research developed by the PhD candidate Patrizia D'Olivo. Specifically, this graduation project takes as a reference the disrupted life event of the alopecia condition.

Focusing on the disrupted life event of the alopecia condition means focusing on people who suffer of alopecia within a society in which 2% suffers of alopecia, of which 5% with total hair loss (Mirzoyev, Schrum, Davis, & Torgerson, 2014). Alopecia can happen to people who never had hair loss before, therefore, their daily life can get severely impacted. Moreover, the population affected by this condition encounter a lot of problems that differ according to the level of severity and risk. Thus, the project tried to help this target group in overcoming daily obstacles by deepen knowledge on the topic and classify the problems they encounter. In the second chapter 'Context & research', the condition alopecia and its consequences will be further explained.

The design goal was to design a product or product-service system (e.g. a tool, service, product, interactive product, etc.) which makes people with alopecia feel comfortable in their everyday life.

DESIGN GOAL

Design a product or product-service system (e.g. a tool, service, product, interactive product, etc.) which makes people with alopecia feel comfortable in their everyday lives.

1.2 APPROACH

The first step of the project was to explore the context of the assignment and learn about the target group. More research was done to dive into an understanding of what the condition alopecia means, which studies are done within the subject, which solutions are out there already, what associations like the Alopecia Vereniging discovered and developed until now and what they do for people who suffer of the condition.

To learn about the context and target group, there are techniques available like interviews (single or in in groups), context mapping, brainstorming etc. By looking into methods applied before, interviews and context mapping seemed to offer interesting possibilities of application and flexibility. Especially interviews seemed important in learning about this target group, therefore those were executed in collaboration with the Alopecia Vereniging. The association has 370 members aged under 35 who are currently dealing with the condition and is open to new creative ways of finding solutions that they can propose and test with who is suffering of this condition.

The second step was to find solutions in the design phase. The results from the first step were used to create ideas for solutions. There are different techniques available to involve the target group in this like participatory design, creative sessions, co-design, etc.

The target group was contacted on the annual Alopecia Vereniging conference to investigate which concept directions were appreciated and which factors should be considered.

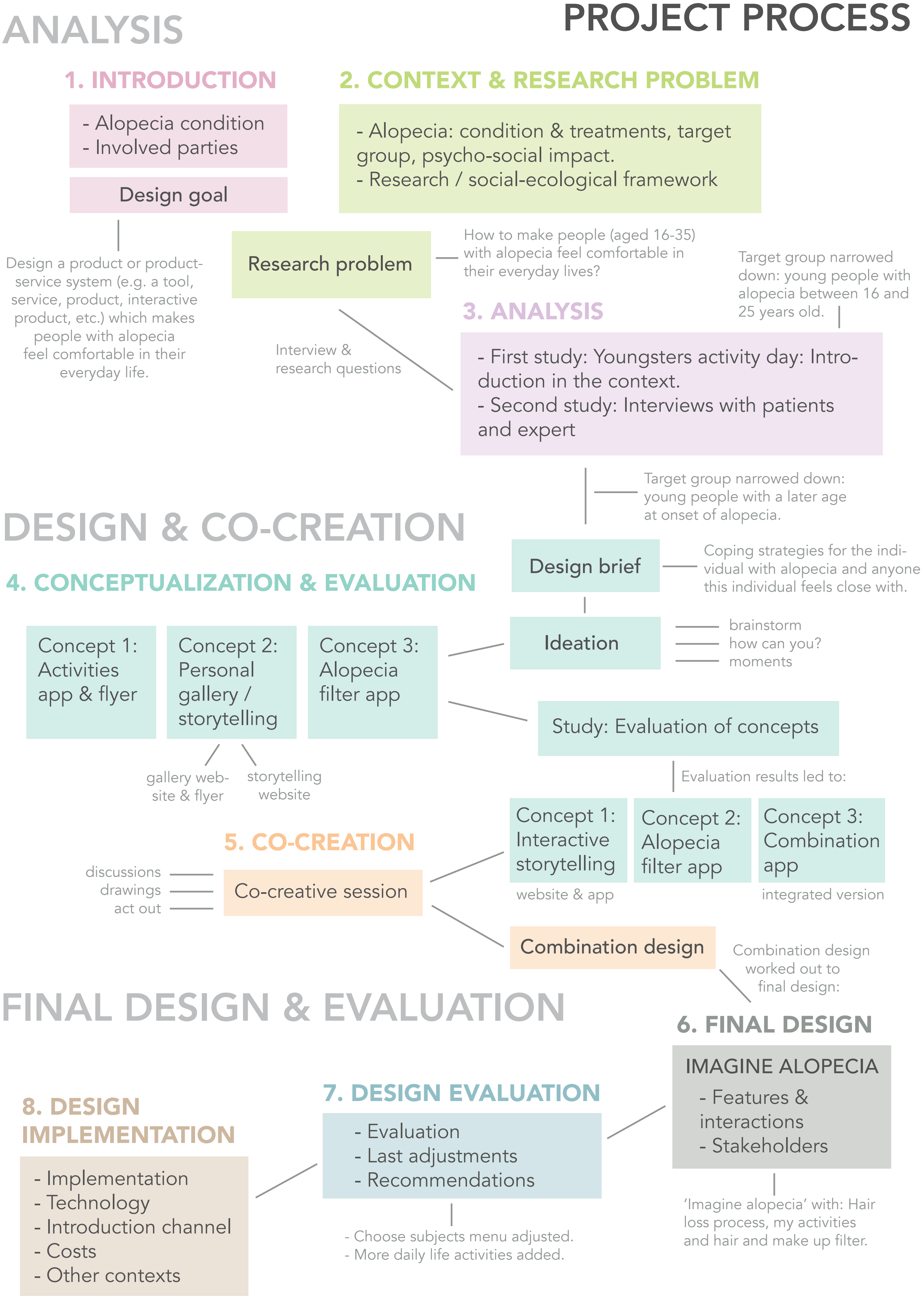
The third step was to find out what the user group thinks of the concepts and the final design. The concepts were evaluated with the user group in a co-creative session. Improvements were made according to the outcome of this test. Later also the final design was evaluated by the user group on the annual Alopecia Vereniging fair.

Also online surveys were used after the Alopecia Vereniging fair to reach more people of the target group to evaluate the final design.

The study was carried out by considering the sensitivity of the setting (Crabtree et al., 2003 & Vines et al., 2013). In fact, diving into this topic meant to deal with the dilemma of preventing stigmatization of the user group and on the other hand defining them as the specific target group because they are suffering of this condition.

The next page shows an overview of the project process.

PROJECT PROCESS



ANALYSIS

1. INTRODUCTION

- Alopecia condition
- Involved parties

Design goal

Design a product or product-service system (e.g. a tool, service, product, interactive product, etc.) which makes people with alopecia feel comfortable in their everyday life.

2. CONTEXT & RESEARCH PROBLEM

- Alopecia: condition & treatments, target group, psycho-social impact.
- Research / social-ecological framework

Research problem

How to make people (aged 16-35) with alopecia feel comfortable in their everyday lives?

Interview & research questions

Target group narrowed down: young people with alopecia between 16 and 25 years old.

3. ANALYSIS

- First study: Youngsters activity day: Introduction in the context.
- Second study: Interviews with patients and expert

Target group narrowed down: young people with a later age at onset of alopecia.

DESIGN & CO-CREATION

4. CONCEPTUALIZATION & EVALUATION

Design brief

Coping strategies for the individual with alopecia and anyone this individual feels close with.

Ideation

brainstorm
how can you?
moments

Concept 1: Activities app & flyer

Concept 2: Personal gallery / storytelling

gallery website & flyer

storytelling website

Concept 3: Alopecia filter app

Study: Evaluation of concepts

Evaluation results led to:

Concept 1: Interactive storytelling

website & app

Concept 2: Alopecia filter app

Concept 3: Combination app

integrated version

5. CO-CREATION

discussions
drawings
act out

Co-creative session

Combination design

Combination design worked out to final design:

FINAL DESIGN & EVALUATION

6. FINAL DESIGN

IMAGINE ALOPECIA

- Features & interactions
- Stakeholders

'Imagine alopecia' with: Hair loss process, my activities and hair and make up filter.

7. DESIGN EVALUATION

- Evaluation
- Last adjustments
- Recommendations

- Choose subjects menu adjusted.
- More daily life activities added.

8. DESIGN IMPLEMENTATION

- Implementation
- Technology
- Introduction channel
- Costs
- Other contexts

Figure 1.1: Project process overview

1.3 ALOPECIA CONDITION

Alopecia is a general term used for hair loss. It is an autoimmune disease which affects the hair follicles. The body's immune system mistakenly attacks a part of the body itself instead of an infection or a disease. In the case of this condition the hair follicles are attacked (NIH, 2015). According to the literature, there are three main forms of alopecia. Alopecia areata (figure 1.2) is the most common and well-known form which results in sudden, patchy hair loss across the scalp. Large areas of the scalp can be affected but areata rarely results in total baldness. The name alopecia areata gets sometimes also used in general for the alopecia condition. The other two forms are alopecia totalis (figure 1.3) and alopecia universalis (figure 1.4). Alopecia totalis results in total loss of the hair on the scalp, universalis affects other body hair as well (The Belgravia Centre, n.d.). Except for these three main forms of alopecia there are other versions of alopecia as well. Examples of other forms of alopecia are alopecia androgenetica and alopecia traumatica. Alopecia androgenetica is hair loss caused by a sensitivity of the (male) dihydroxy-testosteron hormone (DHT) and is hereditary in most cases. Also women can suffer of alopecia androgenetica. This form is recognized by a receding hair line or hair loss on the top of the head and the process is irreversible. Alopecia traumatica is hair loss caused by external factors like for example fire or wounds and scars (Alopecia Vereniging, 2016).


Figure 1.2: Alopecia areata*

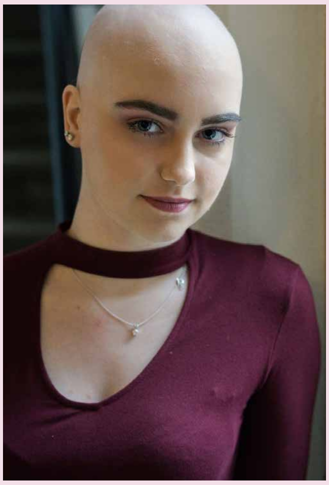


Figure 1.3: Alopecia totalis*

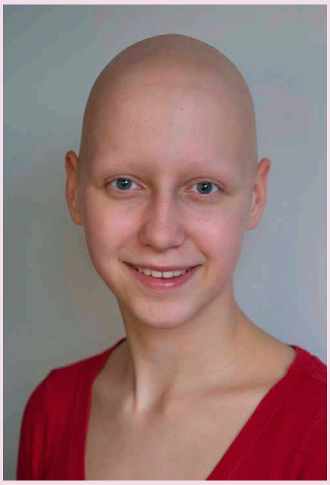


Figure 1.4: Alopecia universalis

1.4 INVOLVED PARTIES

The graduation project is carried out partly made possible by the Alopecia Vereniging. Alopecia Vereniging is a Dutch national independent association of and for people with chronic hair loss (alopecia). The association organizes different activities, has a magazine (figure 1.5) for members and is active on the web and social media, both for members in specific as well as for non-members. The help of this association was extremely important in order to gather knowledge on the topic and facilitate the connection between the designer and the targeted population.


Alopecia
MAGAZINE
Voor mensen met haarverlies

HAARWERKEN
De voor- en nadelen van synthetisch of echt haar
HAARBLOOPERS en anekdotes
"Is dat de nieuwste mode? Nee, mijn haarwerk zat andersom!"
ONDERZOEK naar alopecia areata
Is er een relatie tussen haarverlies en voeding?
Is CBD (cannabisolie) een wondermiddel?
Kevin Boor (29) heeft alopecia areata en probeerde het uit

De patiëntenreis is als een orkaan... zorg dat jij in het oog komt te staan!

Figure 1.5: Example Alopecia Vereniging magazine.

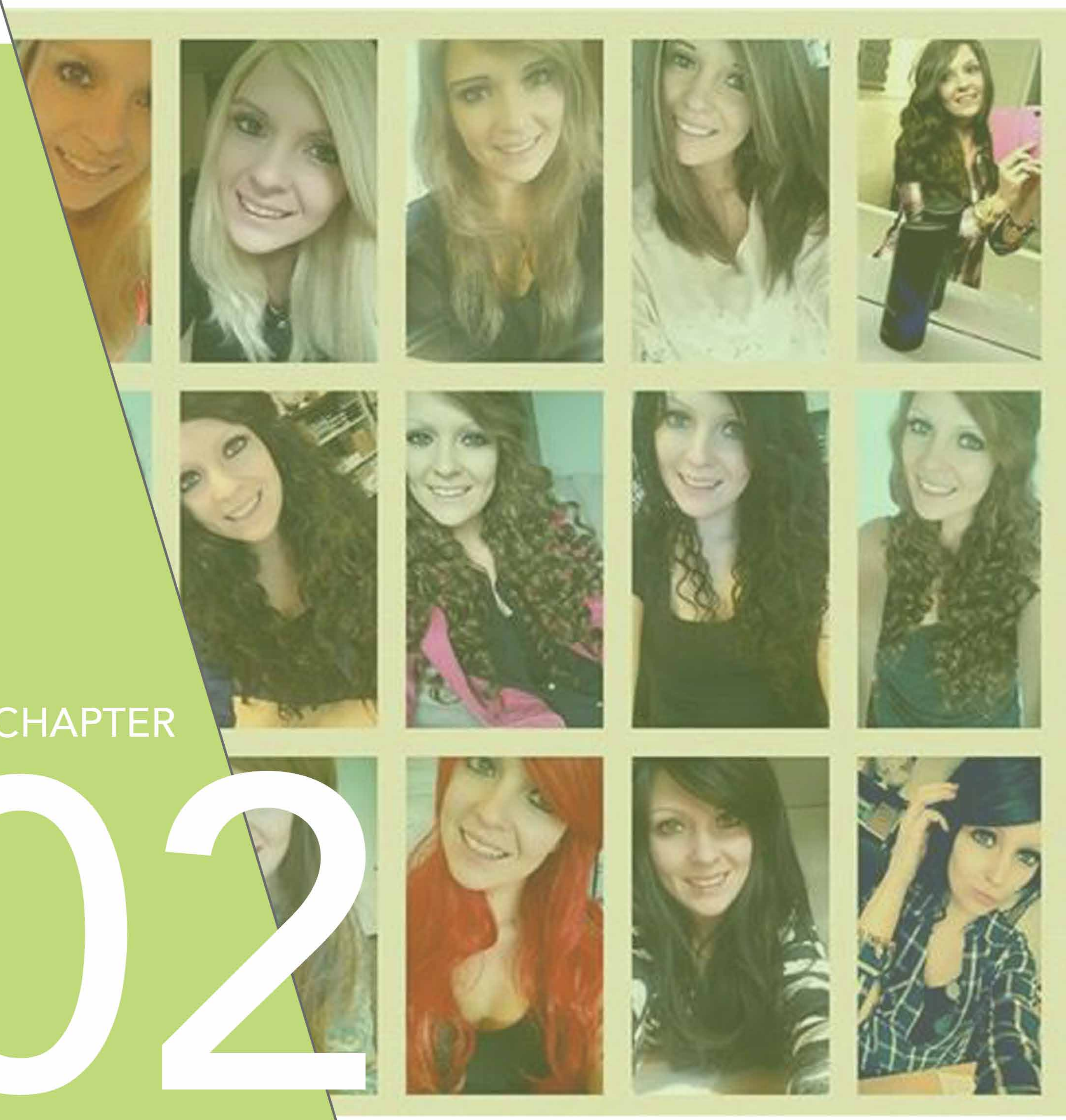
Alopecia
VERENIGING

Figure 1.6: Logo Alopecia Vereniging

1.5 CONCLUSION

The design goal of this project is to *design a product or product-service system (e.g. a tool, service, product, interactive product, etc.) which makes people with alopecia feel comfortable in their everyday life.* Alopecia is an **autoimmune disease** which causes hair loss. The three main forms of alopecia are alopecia areata, totalis and universalis. The project is carried out with help of the **Alopecia Vereniging**. In the next chapter, the condition will be further explained in more detail and a research framework will be discussed.

* Photos by Stefanie Annique Photography



CHAPTER 02

CONTEXT & RESEARCH PROBLEM

THIS SECOND CHAPTER DEFINES THE TARGET GROUP AND GIVES MORE DETAILED INFORMATION ABOUT THE ALOPECIA CONDITION. IT LOOKS INTO THE PHYSICAL AND PSYCHO-SOCIAL ASPECTS OF THE CONDITION, ITS CARE PROCEDURES & TREATMENTS, SOCIAL DEVELOPMENTS. FURTHERMORE IT DISCUSSES THE RESEARCH / SOCIAL-ECOLOGICAL FRAMEWORK AND RESEARCH PROBLEM.

2.1 ALOPECIA

2.1.a TARGET GROUP

The group of people with alopecia that is addressed with the project is aged between 16 and 35 years old. This age group values physical appearance for which there are not a lot of specific solutions. This group results to be quite interesting due to the developmental phase in which they are in. People in the late stage of adolescence and young adults that find themselves suddenly dealing with alopecia can experience a lot of discomfort and stress. The age range will be reduced and specified later in the report. Four different personas were made which can be found in appendix 2-1. These personas were made in order to document the present knowledge in a tactile and relatable way and to explore the different way young people can cope with alopecia, which could serve as inspiration later in the project.

2.1.b CONDITION & TREATMENTS

In the first chapter the alopecia condition itself was briefly explained. This chapter section gives more detailed insight in the physical and psycho-social aspects of the condition.

There are different physical and psycho-social aspects of suffering of alopecia. Literature research was done to gain more insight in what already has been researched on the condition alopecia itself and the psychological consequences of it. This is an overview of some aspects and main findings from the literature.

PHYSICAL ASPECTS

As hair follicles stay preserved in alopecia areata, recovery of hair growth is possible, even within long-term cases of alopecia. According to Messenger, McKillop, Farrant, McDonagh & Sladden (2012), a study from Japan reported that in 80% of the cases there was a spontaneous recovery within one year. However, other studies report that 34-50% of people suffering of alopecia recover within a year. Almost all of them will go through one episode of the condition where after 14-25% progress to alopecia totalis or universalis.

The literature shows that there are some negative indicators for recovery of the hair loss:

- Presence of atopy (& atopic eczema)
A link is found between atopy and the severity of alopecia. 'When atopy or autoantibodies are present alopecia areata always runs a severe course' (De Weert, Temmerman & Kint, 1984);

- Ophiasis and/or onychodystrophy (malformation of nails)
Waard-van der Spek, Oranje, Raeymaecker & Peereboom-Wynia (1989) found that the ophiasis pattern of alopecia and onychodystrophy (nail dystrophies) are most frequently found in patients under 16 and these patients have a poor prognosis. Ophiasis is a form of alopecia areata characterized by a band like hair loss at the circumference of the head (UMCU, 2016);

- Juvenile vs. maturity
A second negative indicator is the age during onset of the condition. According to Waard-van der Spek et al. (1989) juvenile-onset alopecia is more severe and has a less favourable prognosis than maturity-onset alopecia. In this study juvenile was considered as younger than 16 years old and maturity as 16 years and older. Figure 2.1 shows that the onset of juvenile alopecia areata was mostly between ages 5 and 11 and the onset of maturity was mostly between 20 and 30 years old (see marked section). The target group mostly lies within that section. 65% of the juvenile alopecia had a severe form of alopecia, while the percentage of maturity alopecia was 46%. Furthermore, alopecia totalis occurred more frequently among juvenile alopecia (25% vs. 7%);

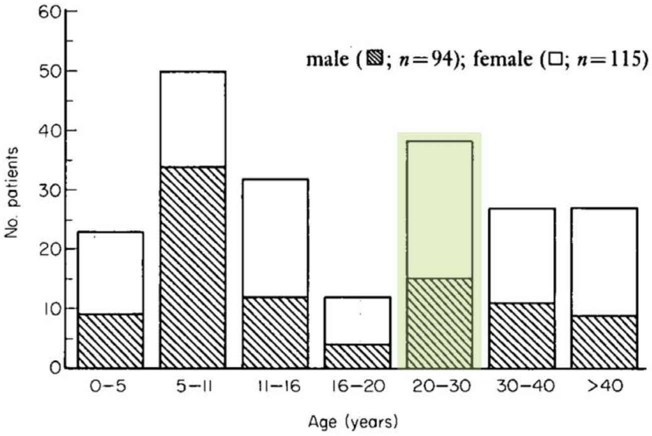


Figure 2.1: Study population distribution by sex and age at onset of alopecia areata.

- Severity of hair loss

The severity of the hair loss during pathogenesis is a strong predictor of the long-term course of alopecia. Patients with a more severe form of alopecia areata are more likely to report worsening patterns of the condition such as alopecia totalis or alopecia universalis. Full recovery of alopecia totalis or universalis is unusual and happens in less than 10% of the cases (Messenger et al., 2012).

There are indications that psychosomatic factors might be playing a role in alopecia. Waard-van der Spek et al. (1989) noticed psychosomatic factors in 29% of juvenile and 17% of maturity onset alopecia cases. Psychosocial factors preceding the onset of alopecia may have played a role in the course or in the pathogenesis of alopecia.

RECENT DISCOVERY

A new study by the University California San Francisco, published online May 26, 2017, suggests that defects in Tregs could be responsible for alopecia. Tregs are regulatory T cells which are a type of immune cell generally associated with controlling inflammation. The Tregs directly trigger stem cells in the skin to promote healthy hair growth so without these Tregs hair follicles cannot be generated. It was previously thought that the hair growth process was stem cell-dependent.

'*After his team first observed hair loss in Treg-deficient mice, Rosenblum learned that the genes associated with alopecia in previous studies are almost all related to Tregs, and treatments that boost Treg function have been shown to be an effective treatment for the disease. Rosenblum speculates that better understanding Tregs' critical role in hair growth could lead to improved treatments for hair loss more generally.*' (Weiler, 2017).

CARE PROCEDURES & TREATMENTS

The general care procedure for the alopecia condition consists of a first visit to a general practitioner (GP). This doctor can propose the person with alopecia an unproven treatment or can redirect the person with alopecia to a dermatologist and the GP and/or dermatologist can ask the person whether he would like to visit a psychologist for professional support in this situation.
There is currently no proven cure for alopecia areata. The condition differs per person and its course is unpredictably. There are some treatments available but these treatments can work for one person but do nothing for the other (NIH, 2015).

The National Alopecia Areata Foundation of the USA (NAAF, 2017) describes the following available treatments for different forms of alopecia:

- *Treatments for mild alopecia:*
    - - Intralesional Corticosteroid Injections
    - - Topical Minoxidil
    - - Anthralin Cream or Ointment
    - - Topical Corticosteroids
- *Treatments for severe alopecia:*
    - - Oral Corticosteroids
    - - Topical Immunotherapy
    - - Immunomodulators (Drugs to block the immune response)

GENETIC FACTORS

There is evidence which indicates that genetic factors may play a role in the etiology of alopecia. A study by Van der Steen et al. (1992) showed that in 7% of the severely affected people with alopecia one of the parents was affected. Furthermore, 3% of the siblings had developed alopecia and 2% of the children, of which their lifetime risk was calculated to approach 6%. For these children, a severe type of alopecia is however to be expected only in about 2%.
A study by Blaumeiser et al. (2006) showed that the estimated lifetime risks were 7.1% in siblings, 7.8% in parents and 5.7% in individual's children. Also the risk in second-degree relatives was slightly higher than the population risk. The study also indicates genetic factors might contribute to the age at onset of alopecia.

RELATED CONDITIONS

According to the medical literature, a history of atopy and autoimmune diseases is associated with an increased risk of alopecia (Barahmani, Schabath, Duvic & Registry, 2009).
Atopic Dermatitis is seen in 9-26% of people with alopecia areata. Atopic dermatitis is a chronic, itchy inflammatory skin disease (Bolduc & Lui, 2016; De Weert, Temmerman & Kint, 1984). This skin condition deserves daily proper treatment. When someone has hair loss, normally the solution adopted for daily activities consists of a scarf or hat, wearing a hair-piece or wearing a wig. Unfortunately these solutions can easily irritate the skin and this becomes a source of concern as a big percentage of people suffering of alopecia deal with atopy.

Furthermore, people with alopecia as well as relatives of them have a higher risk on immunologic diseases. In a study by Wang et al. (1994), various chronic diseases were compared among individuals with alopecia and their first degree relatives. There is an increased prevalence of thyroid disease, vitiligo, Addison disease and pernicious anemia. Among relatives, there is also an increased risk for Type 1 (insulin-dependent) diabetes. The study by Lyakhovitsky, Shemer & Amichai (2015) also revealed a significant association between alopecia areata and thyroid function abnormalities and anti-thyroid- auto-antibodies.

2.1.c PSYCHO-SOCIAL IMPACT

Literature shows that 'psychiatric disorders are more common in people with alopecia than in the general population, suggesting that those with alopecia may be at higher risk for developing a serious depressive episode, anxiety disorder, social phobia, or paranoid disorder (Hunt & McHale, 2005). A study determined that 74% of patients with alopecia areata under evaluation had one or more lifetime psychiatric diagnoses (Koo, Shellow, Hallman & Edwards, 1994).
There are different factors in the lives of people suffering of alopecia that have psychological consequences, they are listed below. Of course every person reacts differently to situations than another so there are different psychological consequences for each individual.

- Uncertainty and powerlessness
Two factors that create discomfort in the lives of people with alopecia are the uncertainty of the condition in terms of length and the sense of powerlessness in not being able to avoid a possible relapse. They are never sure whether the hair loss will once recur and if their will grow back as the course of the condition is unpredictable. Alopecia can turn into a chronic condition; even after years of no hair loss, total hair loss can occur again and this can make people feel insecure, ashamed and stigmatized for the rest of their lives (Bergfeld, 2010). They feel powerless because they do not have any control over the situation. In fact many people suffering of alopecia try to find solutions while there are no real proven treatments to the condition yet found;

- Unpredictability
Most people with alopecia do not report a triggering factor preceding the hair loss. The hair loss suddenly just starts and this turns the condition into a life disrupting event for which causes and the timeline of recovery are unknown;

- Discomfort
A lot of people with alopecia feel the need to hide their condition. In a study by Willamson, Gonzalez & Finlay (2001), nearly all patients (97%), attempted to disguise their hair loss. However, the solutions to hide it (hair piece, wig, scarf), prevent them from doing all activities they want to do. For instance, activities for which you wear a helmet, swimming, outdoor activities, etc. can become (more) difficult for them;

- Helplessness
Like mentioned before, the general care procedure consists of a first visit to a GP. This doctor can redirect the person with alopecia to a dermatologist and the GP and/or dermatologist can ask the person whether he would like to visit a psychologist for professional support in this situation. However, Williamson, Gonzalez & Finlay (2001) found that 40% of their patients 'reported feeling that their doctors had been either 'insensitive', 'dismissive' or 'unsupportive' when dealing with their case.' Also another 18.5% of the patients felt that the doctor did no tests and offered no treatment for their condition.
But doctors can feel helpless because there are few effective and save treatments available. In their paper they state that the first health-care professional that the patient consults with his condition should be trained to give appropriate and supportive advice.

- Stigma
Finally, people with alopecia have to deal with communicating their condition to a context of people without this problem. Their problem can be stigmatizing and this will influence the way they will interact with other people. It might be hard for them to make people understand their struggles in daily life and make them understand their limitations. This can easily occur with an external network of people but it can occur even with close networks such as family, peers and colleagues.

PSYCHOLOGICAL TREATMENT & HELP

Mobile apps can psychologically help people in dealing with the alopecia condition. However, there are not so many apps available. There are some examples like the 'Alopecia Symptoms and Suggested Treatment' app available in the Itunes app store. This app helps people to learn about forms of alopecia and its symptoms. It includes information for natural remedies for alopecia (O'Brien, 2015). Another app which might be useful for people with alopecia is the Tranceform 3T app. This app helps people towards self-awareness, goal achievement and positive change. It deals with relaxation, confidence and ego-strengthening (Terrence the Teacher, 2014).

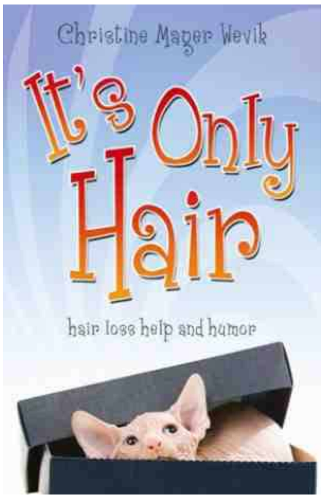


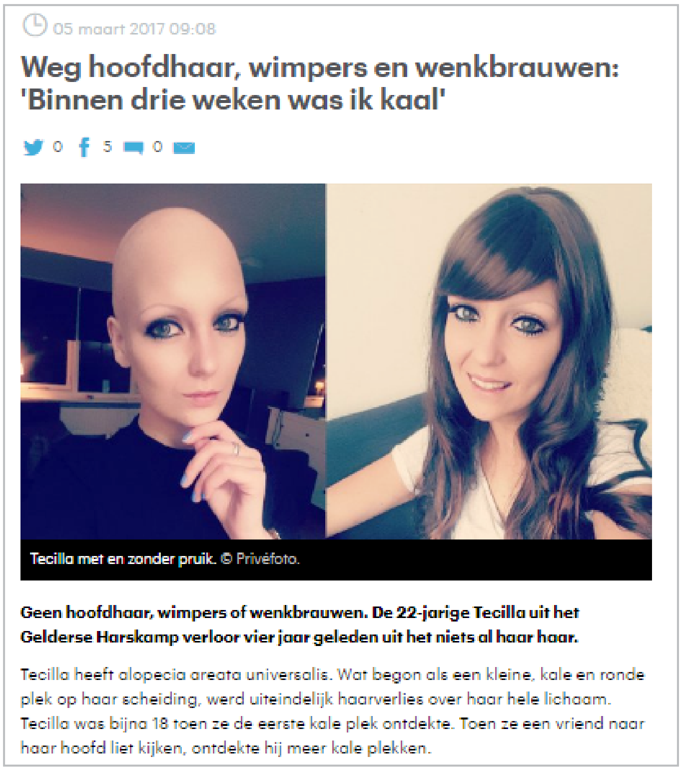
Figure 2.2: Example book about alopecia.

There are different books written about the alopecia condition. These books can share experiences of people with alopecia and can help people cope with the condition. Some examples of books that are available are: 'It's only Hair' (see figure 7), 'Boldly Bald Women', 'Head-On Stories Of Alopecia' and 'If Your Hair Falls Out, Keep Dancing' (NAAF, 2016).

All over the world there are different charities, societies or support groups for people suffering of alopecia. For example, in the Netherlands this is the Alopecia Vereniging, in the USA this is the National Alopecia Areata Foundation and there is Alopecia UK in the United Kingdom. These societies provide information about the condition, provide support and organize activities. Within the societies there are sometimes local support groups as well.

DEVELOPMENTS IN SOCIETY

There are different developments present in society that show that alopecia is getting more attention. In the Netherlands for example, in January and February 2016 there was an exposition in the Hague of photography of bald women, named 'Ode aan de kale vrouw' (van Dijk 2016) and recently women with alopecia universalis had been invited in the late night talk show RTL Late Night (Blue Circle, 2016).
There also seems to be more attention for alopecia in magazines and newspapers (see figure 2.3 & 2.4).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Weg hoofdhaar, wimpers en wenkbrauwen: 'Binnen drie weken was ik kaal'

Tecilla met en zonder pruik. © Privéfoto.

Geen hoofdhaar, wimpers of wenkbrauwen. De 22-jarige Tecilla uit het Gelderse Harskamp verloor vier jaar geleden uit het niets al haar haar.

Tecilla heeft alopecia areata universalis. Wat begon als een kleine, kale en ronde plek op haar scheiding, werd uiteindelijk haarverlies over haar hele lichaam. Tecilla was bijna 18 toen ze de eerste kale plek ontdekte. Toen ze een vriend naar haar hoofd liet kijken, ontdekte hij meer kale plekken.

Figure 2.3: Part of a newspaper article (RTL Nieuws, 2017).

Social media

Social media tend to actively help raise awareness for the alopecia condition. September has been declared to be alopecia awareness month (#AlopeciaAwareness). During this month people can share their story or host and event in order to let their community better understand alopecia and understand what it is like to live with this condition. The National Alopecia Areata Foundation (NAAF), an American foundation, set up SeeUs. This campaign is an initiative 'to reduce the stigma and difference and celebrate the uniqueness and resiliency of people living with the alopecia condition'. People with alopecia can start a fundraising around an activity. (NAAF,2016).

Around the world, on the first Saturday of August it is the International Alopecia Day™. This day people with alopecia can celebrate pride and raise awareness (World Alopecia Community, 2016).

Celebrities & charity
Another development in society concerns the trend of women shaving their hair. There seems to be a resurgence of the female buzz cut. More and more celebrities choose to shave their heads or have a short hair cut. For ages, the amount of hair on the head was relative to the attractiveness of a woman. This new trend lets women show their self-confidence and facial features are more striking (Helpern, 2016). Another reason why both men and women sometimes shave their head is for charity. People can shave their head as a fund raiser. They can set targets like 'If I can raise €500.- I will shave my head'. This happens more often in friend groups when someone within the friend group has a medical condition. They can for example donate the money towards cancer research.

REAL LIFE

'Ineens viel al mijn haar uit'

Het begon met één kaal plekje, maar al snel was haar hele hoofd kaal. Pien (14) heeft de ziekte alopecia. Hierdoor is ze nu voor de tweede keer bijna al d'r haar kwijt en draagt ze vaak een haarwerk.

Pien: 'Het begon heel onschuldig toen een vriendin tijdens het vlechten van mijn haar een kaal plekje bij me ontdekte. Ik was negen jaar en helemaal gezond, dus het was eerst niet iets waar we meteen van schrokken. Maar na dat kale plekje volgden er nog meer en soms lagen er 's morgens allemaal plukken haar op mijn kussen. De huisarts stuurde me door naar een dermatoloog en een kinderarts die met een diagnose kwamen: ik had de aandoening alopecia, waardoor al mijn hoofdhaar uitviel.'

Geen behandelingen
'Toen ik hoorde wat ik had, zei dat me niks. Ik kende niemand met alopecia, dus het klonk allemaal nieuw en eng. Het is ook een aandoening waar nog steeds niet veel over bekend is. Hoe alopecia ontstaat weten ze niet en er zijn geen behandelingen voor.
Er zijn wel zalfjes die je op je hoofd kunt smeren om de haargroei te stimuleren, maar daar kun je erge blaren van krijgen en het is niet bewezen dat ze werken.
Ik heb samen met mijn ouders ervoor gekozen om geen pijnlijke middeltjes te gaan proberen. Ik besloot af te wachten wat er qua haaruitval zou gebeuren en ervoor te zorgen dat ik meer zelfvertrouwen zou krijgen. Dat deed ik onder meer door een keer in de twee weken te gaan praten met een orthopedagoog, een soort psycholoog. Dat hielp me heel erg. Door sterker in het leven te staan, zou ik met de alopecia om kunnen gaan en er niet onzeker door worden.'

Kort knippen
'Toen de kale plekken begonnen op te vallen, besloot ik mijn haar kort te knippen. Dat was best moeilijk, omdat ik altijd lang en mooi haar had gehad dat echt bij me hoorde. Nadat het was geknipt, begon het helemaal uit te vallen en was ik daarna zo goed als kaal. Haar hebben is zo vanzelfsprekend dat je het pas mist als het er niet meer is.
Het is vreemd om aan mensen uit te leggen waarom je kaal bent, want alopecia maakt je verder niet ziek. Ik was dus gezond, maar ik had tegelijkertijd wel iets.
Gelukkig zat ik op de basisschool in een fijne klas waar ik niet werd gepest, omdat ik steeds meer kale plekken kreeg. Ik heb het mijn klas verteld en iedereen had er juist begrip voor. Ik heb nooit nare opmerkingen gehad, iets waar ik erg blij om was. Want het is al moeilijk genoeg om mee om te gaan, zonder dat je hiermee ook nog eens wordt gepest.'

Kaal koppie
'Na een tijdje een zo goed als kaal koppie te hebben gehad, begon in groep acht mijn haar weer terug te groeien. Dat kan zomaar gebeuren bij alopecia en natuurlijk had ik dat gehoopt. Dat het terugkwam, vond ik geweldig, maar ik was de hele tijd bang dat het nog een keer uit zou vallen. Ik hield steeds in de gaten hoeveel er uitviel tijdens het borstelen of douchen. Maar het bleef groeien en zag er mooi uit.
Toen ik naar de middelbare school ging, had ik dus weer een mooie bos haar. Ik hoopte dat het nooit meer uit zou vallen en ik dit maar een keer mee had hoeven maken. Maar toen ik een paar maanden op de middelbare school zat, begon het weer. Dat was wel echt moeilijk, want als tienermeid begon mijn uiterlijk steeds belangrijker te worden. Ook op deze school heb ik het aan mijn klas verteld en werd er goed op gereageerd. En toen er zoveel haar was uitgevallen dat ik het niet meer kon verbergen, ben ik een haarwerk gaan dragen.
Een haarwerk nemen was voor mij een belangrijke stap. Als jonge meid zit een hoop van je identiteit in je haar. Als je dan weer haar krijgt, voelt dat heel fijn. Alsof je jezelf weer herkent in de spiegel.'

56 GIRLZ

Hoofd schudden
In principe kan ik met een haarwerk alles doen. Het ziet er echt uit, blijft goed op zijn plek zitten en kan gestyled worden. Alleen als ik wild doe, kan het loskomen. Dat had ik bijvoorbeeld op een gala van school. Toen ging ik met mijn hoofd schudden op de muziek en vloog ineens mijn haar eraf. Gelukkig sprongen mijn vriendinnen gelijk om me heen, zodat ik het weer goed vast kon zetten voordat iemand het kon zien. Het was de eerste keer dat zoiets gebeurde en ik leerde erdoor dat ik er wel rekening mee moet houden. Ik moet bijvoorbeeld ook niet met harde tegenwind gaan fietsen of zo.
Maar ik ben er niet de hele dag mee bezig. Het blijft eigenlijk altijd wel zitten en is tot nu toe alleen die ene keer losgekomen. Natuurlijk wel echt op het meest foute moment, maar dankzij mijn vriendinnen zag niemand het en konden we er na afloop samen zelfs om lachen.
Ik schaamde me trouwens absoluut niet naar mijn vriendinnen toe, want zij accepteren mij zoals ik ben. Het maakt ze niet uit of ik haar heb of niet, ik blijf voor hen altijd gewoon Pien.'

Nooit accepteren
'Hoe alopecia ontstaat weten ze niet, maar er is een verband tussen het hebben van stress en het ontwikkelen van deze ziekte. Waarschijnlijk dat ik daarom weer haaruitval kreeg toen ik naar de middelbare school ging.
Ik probeer stress dus zo veel mogelijk te vermijden. Zo ben ik open geworden over hoe ik me voel, zodat ik het niet allemaal opkrop vanbinnen.
Ik ben trots op hoe ik ermee omga. Want het doet toch wel echt wat met me. Het is een ziekte die ik nooit kan accepteren en waar ik steeds weer mee word geconfronteerd. Ik kan bijvoorbeeld niet onder de douche staan om mijn haar te wassen. Daarvoor moet ik het haarwerk van mijn hoofd halen en het in mijn handen wassen. Op dat soort momenten besef ik weer wat ik heb. Een ander nadeel is hoe het haarwerk voelt als het warm is. Dan wordt dat plastic kapje waar het aan vastzit heel broeierig op mijn hoofd. Dan zit ik in de klas en wil ik niks liever dan het even af doen. Maar dat gaat niet en op die momenten is het best even slikken.'

'Op het meest foute moment kwam m'n haarwerk los...'

Best apart
'Het leek me leuk om anderen te ontmoeten die hetzelfde hebben. Daarom ben ik vorig jaar naar de Open Dag van de Alopecia Vereniging gegaan. Dat vond ik best apart om mee te maken. Eerst kende ik niemand die dit had en dan ben je ergens waar zoveel mensen het ook hebben. Ik heb met een meisje contact gehouden die even oud is als ik. Het is soms toch fijn om iemand te kunnen spreken die het echt begrijpt, omdat ze hetzelfde meemaakt.
Op dit moment is de linkerkant van mijn hoofd kaal, heb ik in het midden een dikke pluk en kleine plukjes aan de rechterkant. Mijn wenkbrauwen en wimpers heb ik nog en daar ben ik blij om, want deze kunnen ook uitvallen door alopecia.
Ik hoop dat mijn haar snel weer begint te groeien, omdat het me heerlijk lijkt om weer echt normaal te zijn in elk opzicht. Ik wil zo graag een mooie bos hebben waar ik elke storm mee buiten kan lopen, zonder bang te hoeven zijn dat het los komt. Of gewoon weer een keer de wind voelen die door mijn haren gaat. Het lijken kleine dingen, maar juist die mis ik het meeste.'

GIRLZ 57

Figure 2.4: Article in Girlz Magazine (Alopecia Vereniging, 2016).

2.2 RESEARCH FRAMEWORK

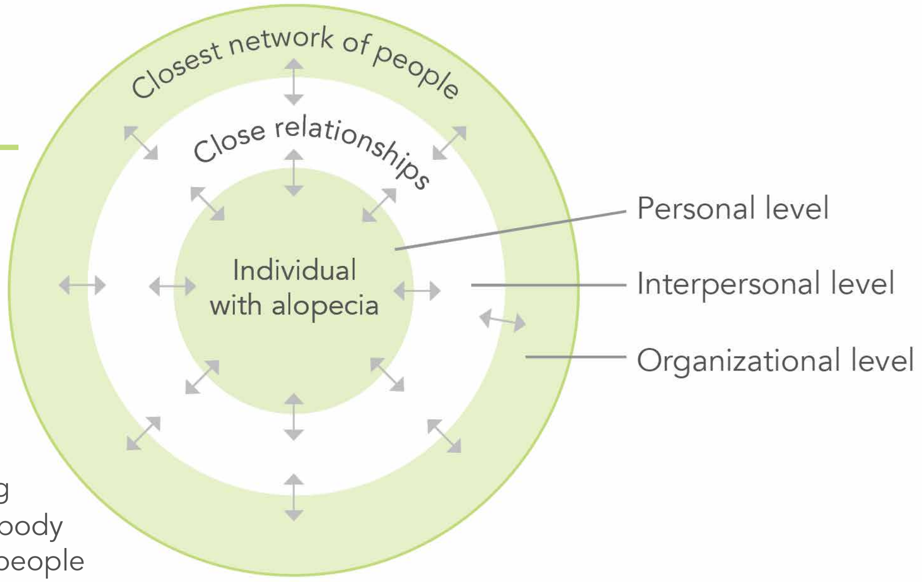


Figure 2.5: Socio-ecological framework based on Bronfenbrenner (1992)

In connection with the research developed by the PhD candidate Patrizia D'Olivo, the focus of this project specifically addresses the use of communication and optimism as meaningful means to foster self-confidence and strengthen coping behaviors. Through a 'Research-Through-Design' approach she is trying to understand how it is possible to embody these features in daily objects to help people dealing with adverse events to maintain a life as normal as possible. The advantage of this 'Research-Through-Design' approach for this project is that it allows to make contributions to research based on findings in the research part of the design project. While applying this approach she is using a socio-ecological (Bronfenbrenner, 1992) perspective to look at the problem and disentangle its complexity. This means to discover how the user deals with the situation personally (personal level), how this influences his close relationships (interpersonal level) and how this affects the closest networks of people with whom he relates in the everyday life (organizational level), see figure 2.5. These close relationships are for example family members or friends. People in the closest network can for example be class mates, colleagues or acquaintances.

2.3 RESEARCH PROBLEM

When looking at the design goal stated in the previous chapter and the set target group, the literature research done and the psycho-social impact listed in this chapter, the research question can be formulated:

RESEARCH QUESTION

How to make people, aged between 16 and 35 years old, who suffer of alopecia feel comfortable in their everyday lives?

For this, field research (described in chapter three), was done to find out what are the things that young people wish for while suffering of alopecia, what are their main problems concerning their condition and what are the things that make them happy or able to cope with the condition. The focus lies on the use of communication and optimism as meaningful means to foster self-confidence and strengthen coping behaviors.

When applying the socio-ecological perspective (Bronfenbrenner, 1992), the problems for the person with alopecia, as well as for his relationships and network, can be researched according to different levels:
How does the user deals with the situation personally (personal level), how does this influence his close relationships (interpersonal level) and how does this affect the closest networks of people whom he relates in everyday life (organizational level)?

2.4 CONCLUSION & REFLECTION

This chapter described different physical aspects and psycho-social impact factors of alopecia, developments in society and defined the target group and discussed the research problem & framework.

PHYSICAL ASPECTS

• Negative indicators for recovery of the hair loss:
- **Juvenile-onset** alopecia is more severe and has a less favorable prognosis than maturity-onset alopecia.
- When **atopy or autoantibodies** are present alopecia areata always runs a severe course.
- An **ophiasis pattern** of alopecia and **onychodystrophy** (nail dystrophies) are most frequently found in patients under 16 and these patients have a poor prognosis
- Patients with a more **severe form** of alopecia areata are more likely to report worsening patterns of the condition.

• As hair follicles stay preserved in alopecia areata, **recovery of hair growth is possible**, even within long-term cases of alopecia. There are indications that **psychosomatic factors** might be playing a role in alopecia.

• **Genetic factors:** There is evidence which indicates that genetic factors may play a role in the etiology of alopecia.
They might also contribute to the age at onset. People with alopecia as well as relatives of them have a higher risk on immunologic diseases. There is an increased prevalence of thyroid disease, vitiligo, Addison disease and pernicious anemia. Among relatives, there is also an increased risk for Type 1 diabetes. Furthermore, a history of atopy and autoimmune diseases is associated with an increased risk of alopecia. Atopic Dermatitis is seen in 9-26% of people with alopecia areata.

• **Care & treatments:** The general care procedure for alopecia consists of a first visit to a general practitioner who will redirect the person with alopecia to a dermatologist. The GP and/or dermatologist asks the person whether he would like to visit a psychologist. There is currently no **proven cure** for alopecia areata.

• A new study by the UCSF suggests that defects in Tregs could be responsible for alopecia. This finding could lead to **improved treatments** for hair loss more generally.

PSYCHO-SOCIAL IMPACT

• **Psychiatric disorders** are more common in people with alopecia than in the general population.

• Different factors in the lives of people suffering of alopecia that have psychological consequences:
- **Uncertainty** (length of condition) and powerlessness (possible, unavoidable relapse) create discomfort in the lives of people with alopecia.
- **Unpredictability**: Most people with alopecia do not report a triggering factor preceding the hair loss. The hair loss suddenly just starts and this turns the condition into a life disrupting event.
- **Discomfort**: A lot of people with alopecia feel the need to hide their condition but the solutions to hide it (hair piece, wig, scarf) can make activities difficult or impossible.
- **Helplessness**: People with alopecia can feel like doctors are not providing enough sensitivity, support, tests or treatments. However, doctors can feel helpless because there are few affective and save treatments available.
- **Stigma**: People have to deal with communicating their condition to a context of people without this problem. It can be stigmatizing and this will influence the way they will interact with other people.

• **Developments in society:** Alopecia seems to get more and more attention on different media and there seems to be a trend of short and shaved hair, especially among celebrities. Another reason for shaving is charity.

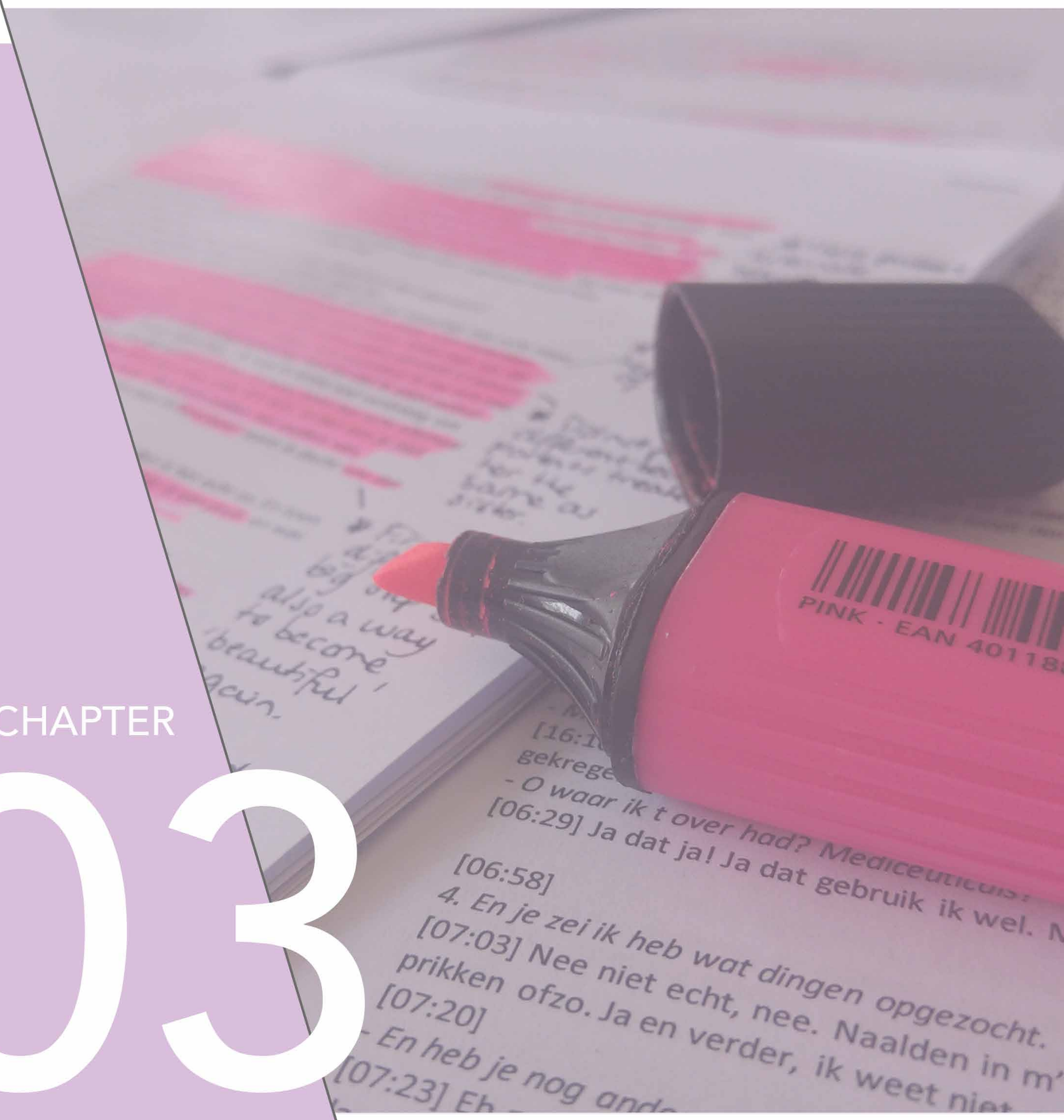
RESEARCH PROBLEM & FRAMEWORK

The research question is: *How to make people, aged between 16 and 35 years old, who suffer of alopecia feel comfortable in their everyday lives?*

For this, field research will be done with the target group: what are their main problems concerning their condition and what are the things that make them happy or able to cope with the condition? The focus lies on the use of communication and optimism as meaningful means to foster self-confidence and strengthen coping behaviors. When applying the socio-ecological perspective (Bronfenbrenner, 1992), the problems for the person with alopecia, as well as for his relationships and network, can be researched according to the personal, interpersonal and organizational level.

CHAPTER

03



ANALYSIS

CHAPTER THREE DESCRIBES TWO DIFFERENT STUDIES: THE INTRODUCTION IN THE CONTEXT AT THE YOUNGSTERS ACTIVITY DAY AND THE INTERVIEWS WITH THE PATIENTS AND THE EXPERT TO FIND OUT PROBLEMS, NEEDS, WISHES AND THINGS THAT MAKE PEOPLE WITH ALOPECIA HAPPY. EACH STUDY IS DESCRIBED WITH A SET-UP, ANALYSIS & RESULTS AND A CONCLUSION.

As discussed in chapter two, the research question was: How to make people, aged between 16 and 35 years old, who suffer of alopecia feel comfortable in their everyday lives?
Field research was done to find out what are things that youngsters wish for while having alopecia, what are their main problems concerning their condition and what makes them happy. There were different ways of researching the field. Different study cases with different methods and different ways to approach people were used. All the different levels of the social-ecological framework (see chapter two) were addressed with these different studies. In order to address the different framework levels, a study with young people with alopecia, a study with people with alopecia and their family and/or friends and a study with a stakeholder of the Alopecia Vereniging were done. Only meeting with people suffering of alopecia is not enough as they are much influenced by the other levels in the social-ecological framework. For example, the way they communicate with a doctor when first showing their alopecia condition or their first contact with the association can be important. This chapter describes studies with young people with alopecia and a stakeholder of the national association.
In this chapter, each study is described consisting of three parts, the set-up, analysis and conclusion of the study. The first study describes the youngsters activity day, the second study describes the individual in-depth interviews as well as the interview with the stakeholder or expert. The study with people with alopecia and their family and/or friends is described in the fourth chapter.

3.1 FIRST STUDY: INTRODUCTION IN THE CONTEXT

The first study was the introduction in the context of alopecia among people of the target group and this was a meeting at an event. The event was an activity day for people aged between 15 and 25 years old, organized by the Alopecia Vereniging. During the event it was possible to meet young people with alopecia and talk about their social network. It was also possible to see how the young people with alopecia interacted together and ask them to join in a next study.

3.1.a SET-UP

The activity day was held at the 12th of November 2016 at 'de Avontuurfabriek' in Loosdrecht, a building with a lot of different activities for groups. When the young people arrived at the building, there was an opportunity to talk to the other people while having a drink and some appetizers. The youngsters were asked to introduce themselves to the group by telling their name, age , type of alopecia and the age at onset of their condition. There were 20 young people at the activity day with varying ages of 15 till 24 years old. During this introduction the youngsters were told about the project and research. They were told about the opportunity to sign up for an in-depth research later on during dinner. After the introduction the group was split in two. One group went for laser gaming and one group went for the escape room activity. After these activities, the whole group came together for some 'all in the game' activities like an obstacle course and living table soccer, see figure 3.1 (Alopecia Vereniging, 2017). After those activities the whole group went stone grilling around two big tables, see figure 3.2. During the dinner it was possible to speak with different people with alopecia. After this dinner, the potential participants were give a flyer to introduce them to the interviewer. If they liked they could write down their contact details on the back to join the research with an in-depth interviews. People who signed up for this would be contacted to plan an in-depth interview. The flyer which was created for this day can be seen in figure 3.3 and more detailed in appendix 2-2. It includes pictures without wig on and a short introduction of 'the interviewer's' story to make the potential


Figure 3.1: All in the game activity at the activity day.

Figure 3.2: Dinner youngsters activity day.

participants feel safe to share their story. The flyer also included questions about the potential participant's alopecia in order to schedule interviews with participants with different forms of alopecia and different ages at onset.
The organizers of the activity day for young people with alopecia asked all the youngsters for their names and phone numbers in order to create a WhatsApp group. The day after the activity day the group was created. Furthermore, there were some general questions for the potential participants. These general questions served to get to a conversation to get to know the person with alopecia better and to get a better idea of what kind of questions are appropriate for the in-depth interview.
General questions for the activity day:

1. What is your name and age?
2. What do you do in daily life? Study or work (and what)?
3. Why did you join the Alopecia Vereniging?
4. What kind of alopecia do you have?
5. What age did you have when it first started? Did your hair ever recur?
6. Do people you see in daily life know about your condition?

TESSA MAJENBURG
MASTER STUDENT INDUSTRIEEL ONTWERPEN

Beste bezoeker van de Alopecia Vereniging Jongerendag,

Ik ben Tessa Majenburg en ik ben 24 jaar oud. Voor mijn master afstudeerproject van de studie Industrieel Ontwerpen ben ik bezig een product te ontwerpen voor jongeren (vanaf 16 jaar oud) met alopecia Ik zelf heb sinds begin 2016 alopecia universalis en ik wil graag iets bijdragen.

Om dit product te ontwerpen wil ik graag meer inzicht krijgen in het leven van jongeren met alopecia. Ik heb mijn eigen ervaringen maar ben heel benieuwd hoe andere jongeren alopecia ervaren.

Zou je mij hierbij willen helpen door achterop je gegevens in te vullen. Dan kan ik je bereiken om binnenkort een uitgebreid interview te plannen!

GEGEVENS

Als je graag wil meehelpen met het ontwikkelen van een product voor jongeren met alopecia met een uitgebreid interview en eventueel later nog wat onderzoekjes (zoals evaluaties van ideeën), vul dan alsjeblieft de volgende informatie in. Ik zal binnenkort contact met je opnemen om een datum af te spreken om een uitgebreid interview te doen. De inhoud van het interview en de resultaten van het onderzoek blijven geheel anoniem.
☐ Ik ga akkoord dat anonieme gegevens (wazig gemaakte foto's, gecodeerde interview data of wazig gemaakte video's) worden gebruikt voor mijn verslag en onderzoeksdoeleinden.

Naam:

Leeftijd:

Adres:

E-mail adres:

Telefoonnummer:

Vorm van alopecia:
Bijvoorbeeld alopecia areata (pleksgewijs), alopecia totalis (haaruitval van hoofdhaar), alopecia universalis (haaruitval op gehele lichaam) of alopecia androgenetica (mannelijke kaalheid).

Leeftijd toen alopecia begon:

Is het haar wel eens teruggekomen? Zo ja, hoe lang?

Bedankt!!

Figure 3.3: Flyer for potential participants during first study.

3.1.b ANALYSIS & RESULTS

The flyers the potential participants filled out were documented. The form of alopecia of the participants was noted to make sure to include different forms of alopecia. In order to plan visits to the participants for in-depth interviews, they were mapped according to their place of living, see figure 3.4. In this way, a convenient travel could be planned for the second study, the in-depth interviews.
Furthermore, the conversation in the WhatsApp group was read well to see the different reaction to the activity day by the young people with alopecia. Also a personal reflection of the youngsters dat was written, see appendix 1-1.

Most of the young people seemed to enjoy the activities and everyone was open to each other about the alopecia subject. During the last group activities, some people put off their wigs because the activities were not easy wearing a wig but some did not want to take off their wig. One girl left during the activities with the whole group because it was emotionally too much for her to stay. It was the first time she met people who also suffer of alopecia.

One girl of the group did not want to join for the in-depth interview but apart from her everyone showed enthusiasm for participating. In total there were 16 young people who filled in the flyer because they wanted to join in the research and one other girl who was not able to come to the activity day wanted to join. This girl was met during the swimming event organized by the Alopecia Vereniging. Among the sixteen young people who signed up, there were seven people with alopecia universalis, two people with totalis and seven with areata. The participants for the in-depth interviews are all from different places in the country, figure 3.4 shows this.

In the WhatsApp group conversation, all the people in the group were enthusiastic about the activity day. In the screenshots in appendix 1-2 can be read that they wished for more days like this. An example of such a screenshot can be seen in figure 3.5. The youngsters said they think that they are the ones who at least do understand them and that they want to organize something like this themselves but that it is difficult that everyone lives far from each other.

Figure 3.4: Mapped out locations of potential participants.

[redacted]

[redacted] [redacted]
Hoop echt stiekem dat we dit vaker kunnen doen! Was zoo leuk en fijn 13:07

[redacted]
Jaa precies 😊 13:07

[redacted] [redacted]
Zo'n gevoel van samen 1 🙊 13:08

[redacted]
Jaa precies 13:11
Jullie begrijpen het teminste :D 13:12

[redacted] [redacted]
Het is ook helemaal niet ongemakkelijk met jullie, ook nu niet 13:12

[redacted] [redacted]

Figure 3.5: Screenshot WhatsApp group.

3.1.c CONCLUSION

From the enthusiasm at the youngsters activity day, the amount of people who signed up to join for the in-depth interviews and the enthusiasm in the WhatsApp group can be concluded that the young people enjoyed to spend time with other young people who suffer of alopecia. However, this group of people did of course sign up for the activity day so there was already a need among them to meet fellow sufferers.

3.2 SECOND STUDY: INTERVIEWS WITH TARGET GROUP & EXPERT

In order to obtain knowledge of the way young people live and deal with alopecia and which problems, needs or wishes they have, in-depth interviews with the target group were planned.
In order to get to know more about the Alopecia Vereniging, its wishes and needs and everything involving members and the association, a meeting with the chair of the association was planned.
These insights were used to create the design brief and start the ideation phase.

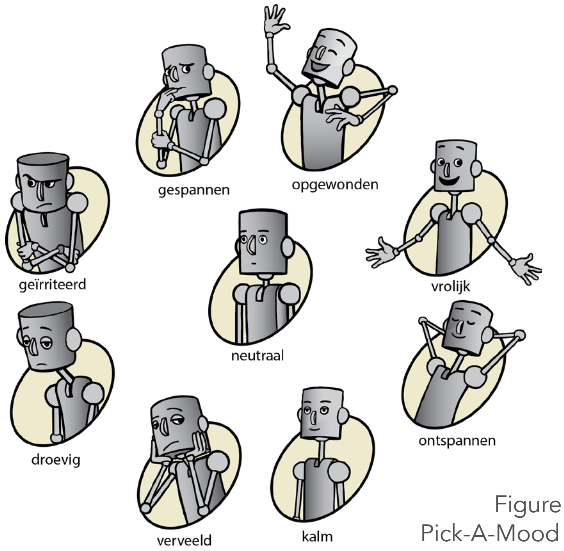


Figure 3.7:
Pick-A-Mood tool

3.2.a SET-UP

INTERVIEWS WITH TARGET GROUP

Different young people who signed up to participate in the interview study were contacted. With the places of living, form and age at onset of alopecia and their availability in mind, ten participants were planned to be visited. Sometimes two participants were planned on one day when they lived near to each other.

On the scheduled day the participants were visited for the in-depth interview. Most interviews were at the participant's home so they could freely talk in private and this way it was more quiet for audio recording the interview. During this interview, questions were asked in combination with a word and picture sheet (see figure 3.6 & appendix 1-3). This sheet contained different words and pictures that have to do with lives of young people. The pictures and words are randomly ordered on the pages. After some interview questions, the participant was asked to choose one or more pictures or words that support the answer to the question. They were told they could use the picture and word sheet whenever they wanted whenever they felt they need it to answer a question.

Figure 3.6: Picture and wordsheets.

They were also introduced with the Pick-A-Mood tool (Desmet, Vastenburg & Romero, 2016), see figure 3.7 and appendix 2-3. With this tool, the participants could quickly, intuitively and accurately select a mood which expresses the mood which fits the moment or feeling they describe. They were told they could use the tool whenever they needed in order to make it easier for the participant to express his mood and the mood of the different participants could be compared, if used proportionally. The robot character was chosen from the available characters in the Pick-A-Mood tool because this character looks neutral (it has no hair) and it is not gender specific.

The general questions and the in-depth interview were held in Dutch so that the participants could easily talk about their condition without a language border.

Before the interview started, the participant received an informed consent (see appendix 2-4) that explains the goal of the research and what will happen to the data that will be obtained. For participants younger than 18, also an informed consent for a parent was given (see appendix 2-5). On the informed consent, the participants were also asked if it was okay if audio was recorded during the interview and if pictures could be taken and used. They could also choose to let the picture only get used blurred or unrecognizable.

The word and picture sheets served to get to know association people have with their condition. The set of pictures and words the participants got to

see are the same for all different participants. This was done because each person with alopecia has a different severity of the condition, a different age at onset, a different attitude to the condition and different circumstances in which the person deals with alopecia. Thus, because there are already many varieties, the same set of pictures was chosen as a stable factor to see the difference in what kind of pictures would be chosen for the different collages. The words and pictures were selected using word clouds of associations with the alopecia condition. These word clouds can be found in appendix 2-6.
After each in-depth interview, the selected pictures and words the participant mentioned will be put together with a short description of what the picture or word means to the participant.

The interview questions (see appen are divided in clusters so the statements cards that were made of the transcripts could be compared between different participants more easily. Also chosen pictures and words from the sheets could be linked to the clusters. The clusters are:

- Practicalities
- Emotions
- Social Life

The social life cluster also has two extra clusters which were applicable to some of the participants, namely questions about the youngsters activity day and questions about relationships and dating. The interview questions can be found in appendix 1-4.

On the interview day the participant also received some blank A4 pages and pencils. The participant was told to draw or write down anything they wanted whenever they wanted to explain themselves during the interview.

Timeline
Apart from the interview questions, the participants were asked to fill a timeline of their alopecia condition so the timelines could be compared after all the interviews were conducted.. The participant received an A4 page with a blank timeline. After receiving this sheet, the following questions were asked:

- Can you draw a timeline of an evaluation of yourself and your alopecia? For example, an event which made you lose your hair, recurrence of hair, losing hair again, choosing a new wig, more bald patches, telling colleagues about alopecia, etc.

- In the timeline, can you mention and draw some moments which were extreme in emotions? These can also be positive emotions.

- In the timeline, can you mention and draw some moments in which extremely hindered your daily life?

- In the timeline, can you mention and draw some moments in which your social life was extremely affected by your alopecia?

Figure 3.8: Blank timeline

INTERVIEW WITH EXPERT

The meeting with an expert, Marion Kremer (see figure 3.9), the (recently former) chair of the Alopecia Vereniging, was planned in Delft on the 2nd of March, 2017. For this meeting interview questions were set-up. These questions served as guidelines for a conversation with the chair to cover the different intended subjects and questions to talk about. The questions mainly covered subjects like obligations, dreams, goals and activities of the association, reasons people sign up, sign out or contact the association and problems and difficulties of the association. The interview also covers contact between members a lot and involves psychosocial aspects as well as involving people close to someone with alopecia because those are directions the project could head into. The questions and subjects were specified for the chosen focus group and the opinion of the chair on some suggestions for activities was asked. The interview questions can be found in appendix 1-5.
The interview with the chair of the association was audio recorded so it could be replayed and it was possible to focus on the conversation itself rather than on writing down answers during the meeting.

Figure 3.9: Marion Kremer, former chair of the AV

3.2.b ANALYSIS & RESULTS

INTERVIEWS WITH TARGET GROUP

After the interviews were conducted, the interview audio was used to make transcripts. After conducting the interviews and during transcribing them a first evaluation was written with general insights (see appendix 1-#). A summary of the insights can be read in the table at the right. This evaluation and the insights of it were used to narrow down the subject.
It became clear that participants who just or recently got faced with hair loss, had a bad time coping with it and had a big need for comfort in their everyday life. The amount of research data from the in-depth interviews was big and general so the target group was specified to people with a later age at onset. With this decision, the specified research question was:

RESEARCH QUESTION

How to make people, aged between 16 and 25 years old, who suffer of alopecia with a later age at onset in life, feel comfortable in their everyday lives?

Six out of then participants of the interviews had a later age at onset. General descriptions of them were written (see appendix 2-14). The transcripts were analyzed by marking interesting quotes and writing down comments or insights that were appealing.
Of the six participants with a later age at onset, general statements cards were made (see appendix 2-7 - 2-12). The interesting comments and insights were written down in these statement cards and all quotes belonging to those comments and insights were written down on the bottom of each. The statements cards were made in Dutch to make it easier to analyse them. Each statement card includes the participant number, age of the participant, age of onset, the form of alopecia and the way the person

- Insights first evaluation in-depth interviews

Commonalities among participants with alopecia:

- Participants with an early age at onset were most often better able to mentally cope with the condition but also got faced more with problems of bullying during the school period;

- The participant’s attitude matters in the way other people also behave towards the person with alopecia. The more the person accepted his alopecia, the more other people accept this condition too;

- Mostly the people with an early age of onset did not hope for recovery that much and participants with a later age at onset do;

- All participants had a need or wish to meet and speak with fellow sufferers but do not always know how to get in contact with other sufferers;

- Meeting fellow sufferers of a different age makes it harder to relate and understand each other;

- Parents also have a need for information, contact with other sufferers and contact with other parents of them. They are also stressed and insecure about the way they support their child;

- During onset of alopecia, one searches for information and can find confronting and stress causing information.

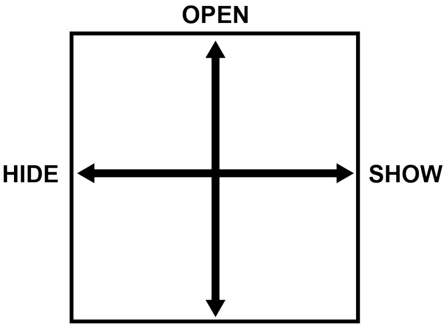
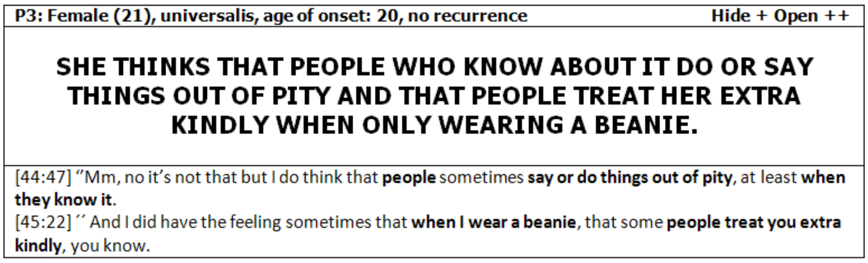


Figure 3.10: Manner of coping chart



P3: Female (21), universalis, age of onset: 20, no recurrence **Hide + Open ++**

SHE THINKS THAT PEOPLE WHO KNOW ABOUT IT DO OR SAY THINGS OUT OF PITY AND THAT PEOPLE TREAT HER EXTRA KINDLY WHEN ONLY WEARING A BEANIE.

[44:47] “Mm, no it’s not that but I do think that **people** sometimes **say or do things out of pity**, at least **when they know it**.
[45:22] ´´ And I did have the feeling sometimes that **when I wear a beanie**, that some **people treat you extra kindly**, you know.

Figure 3.11: Example statement card (translated)

deals with alopecia (open, closed, hide, show), see figure 3.10 and 3.11.
Of the other four participants with an early age at onset, the interviews were analysed later, focusing on the way they cope with problems found among the later age of onset participants. They were noted during analysing the transcripts.

The statement cards were printed and the color bars marked in different colors for each participant to be able to better compare and cluster them. They were divided into different clusters with insights of common subjects which could in turn get clustered into the different socio-ecological levels (see chapter 2). Figure 3.13 shows the overview of clustered subjects with the levels. Some subjects can be placed under more than one level, depending of the situation within the cluster, but are here placed in one only. An example of such a cluster is 'going out & parties', in this case it depends on the situation and people involved.

Timelines
Next to the interview transcripts, the timelines themselves were compared. They were put together and the intention was to compare them, write down the most common events and create a general timeline for them. Depending on the difference, this could be one timeline or multiple timelines of specific ways of dealing.
However, the timelines were all so different that it was not possible to generalize.

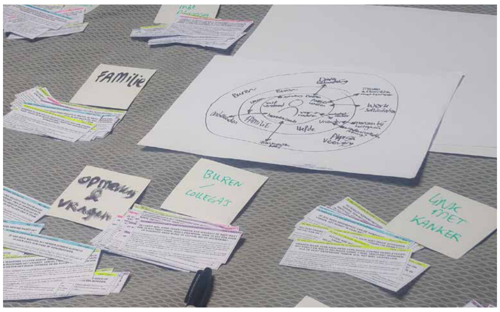


Figure 3.12: Analyzing statement cards

Instead of generalizing, there was a focus on moments. These were moments of shifts in dealing with alopecia, moments of change in moods or important (negative or positive) events and were marked pink and green, negative and positive events respectively (see appendix 1-7). These moments of shifts were written down, see appendix 1-8.

Pick-A-Mood tool
The Pick-A-Mood tool was used by several participants only for some questions. Only one participant, who was more quiet and talked less, used the tool more often to express his feelings and thoughts about certain subjects. The chosen moods were therefore only used as answers to questions and were not compared.

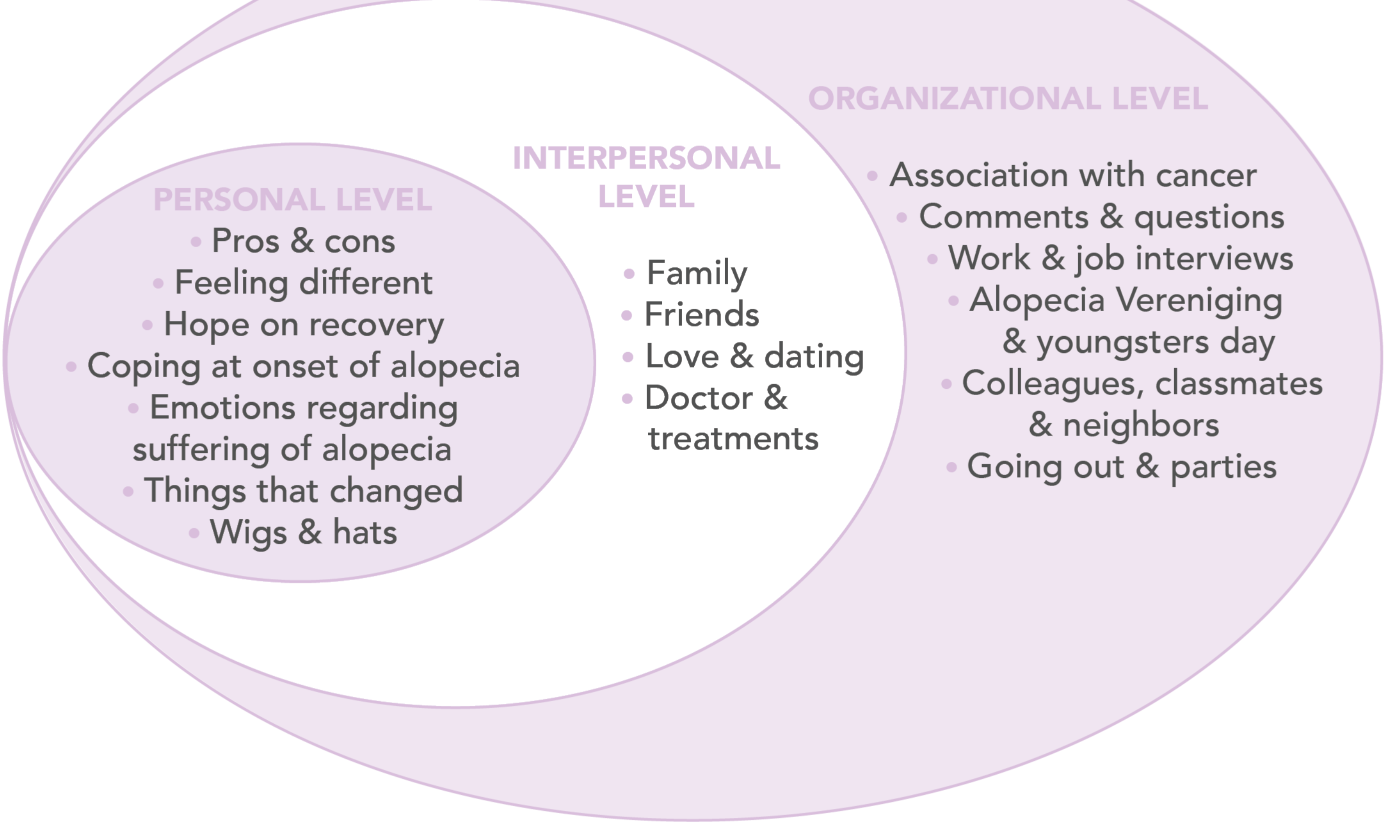


Figure 3.13: Clustered subjects interviews

Picture & word sheet

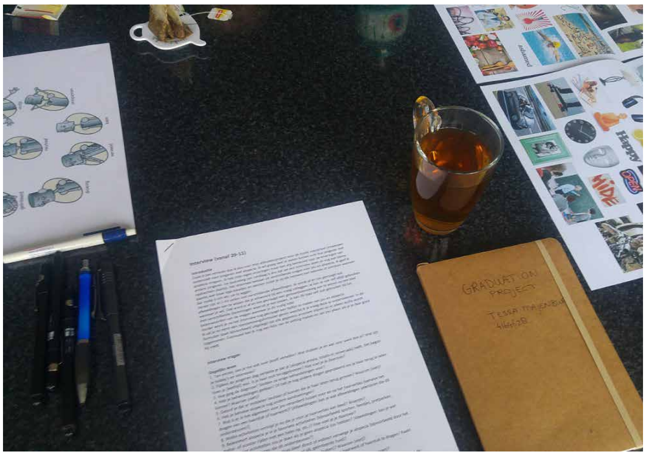


Figure 3.14: Interview set-up

The interview questions were asked in combination with two picture and word sheets. The word and pictures worked for nearly all participants well to stimulate the communication. Sometimes the participants did not know an answer to a question or thought they told everything but then they looked at the sheets to choose images that fit the question and came up with their answer or thought of other things they associated the question with. Without the sheets, the participants would have given less extended information about different subjects. Only one participant hardly saw any pictures fitting his answer and one other participant used the sheets to help herself without being asked to choose images. Like described in the previous section, the images were put together by making word clouds and associations with alopecia. A lot of pictures were ambiguous enough to get different associations of people. An example is a picture of two people travelling with backpacks looking at a view. One participant associated this with hiking, one participant associated it with vacations and travelling being difficult with a wig. Another participant associated this with the feeling of having a view over what you have been through and the ability to see that you overcame all those things already. No matter what would happen, she would make through it as she also overcame the other things. The images people chose were put together and documented with insights of what people thought of regarding the images (see appendix 2-13).


Figure 3.15: Participant holding a picture of him of before his hair loss.

Pictures of the in-depth interviews can be seen in figure 3.14 - 3.21.The interviews showed that there are a lot of different problems and concerns in the lives of people suffering of alopecia. One of the bigger problems was a lack of good communication between the young individual and the people he feels close with. Some important quotes regarding this subject (randomly ordered):

About friends:
"I don't talk about it with them often. I just think it's very hard to talk about it with them because also their lives go on and they have their own, they also have other friends. So they just deal with it in a different way."
- Male (21) with universalis for 3 years.


Figure 3.16: Interviewing participant

About doctor consult:
P7: *"That is of course difficult because that is an age of which, i'm not going to talk for her but you are in it together. And we see what is happening."*
- Mother of female (16) with areata for 3 years.

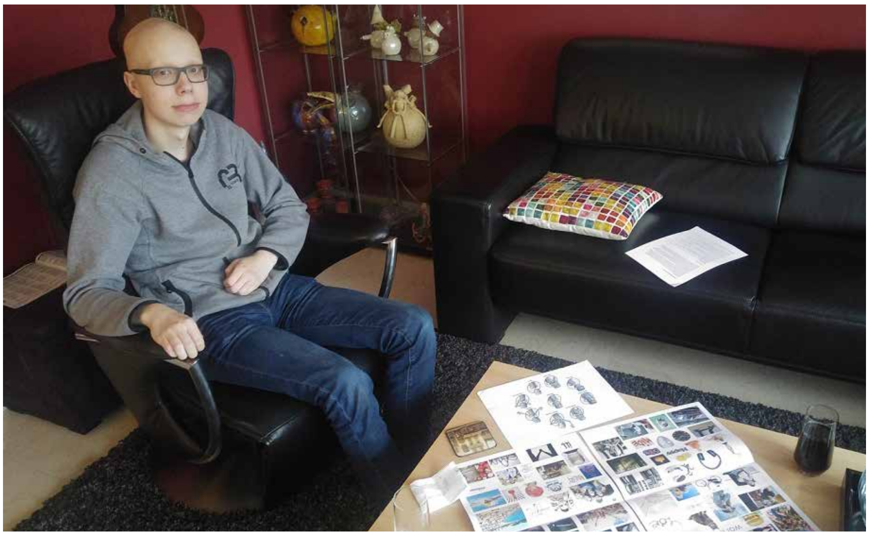


Figure 3.17: Interviewing participant

"In the beginning I thought it was very difficult because then my father said like, yes I feel bad for you but there are always people who are worse off, who are terminally ill. And at one point I said to my mother, I really don't like that he says that. For me this is the worst I suffer of, until now. To hear that, in the long term it just made me really sad. Like I am overreacting."
- Female (21) with universalis for 1 year.

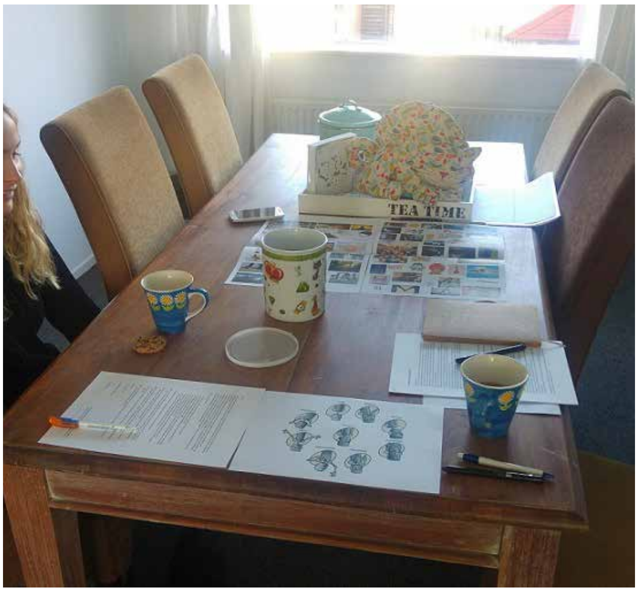


Figure 3.18: Interviewing participant

"In the beginning I tried to put a good face on for my father. He wondered if it actually did anything to me at all but I really did that for him because he was having a hard time with it. And in the beginning he had a hard time when I did not cover my head and came downstairs."
- Female (22) with universalis for 4 years

About his sister:
-*"I never really heard her ask like, how is it going with the comments, how is it going with your alopecia?"*
- *"They also ask my sister. My sister sometimes thinks it's difficult, she told me, to explain it."*
- *"And what I still notice is that my sister often, when my grandfather is ill for example, then just to be sure my parents do tell my sister but not me because I often tend to start stressing. I start to worry."*
- Male (18) with universalis for 6 years

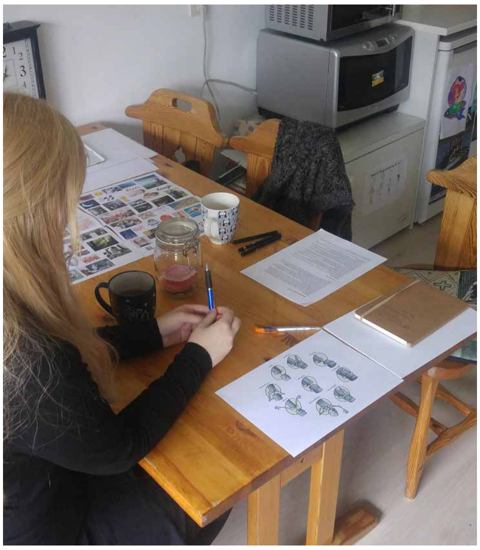


Figure 3.19: Interviewing participant

Figure 3.20: Interviewing participant

Figure 3.21: Interview participants

> *"The first time when I had those bald spots I couldn't talk about it well with my friends because it was kind of 'small' but for me it wasn't small. So they couldn't... And I didn't really dare to talk about it with them. once they were talking about hair and I said, be glad you got hair! 'Well you also have hair.' But then I thought, yes that is true but I have very big bald spots which I have to hide every day! Which barely succeeds."*
> - Female (16) with areata for 3 years.

> *"Friendship. That really changed. A lot of friendships improved, because then you notice that they really support you through everything. But I think that like five percent of my friendships broke because they thought it was weird. But those five percent, those were a tough five percent."*
> - Male (18) with universalis for 6 years

[redacted]
Praten jullie er altijd met je ouders over? Of ook iemand die wat verder staat zoals een oom of tante bv? 17:03

[redacted]
Ik heb het er soms over met mijn ouders 17:04

Maar soms ook met mijn vriendin 17:04

[redacted]
Ik met een vriendin van de familie 17:04

En af en toe met mijn ouders 17:05

[redacted]
Ik praat er ook vaak over met mijn nicht, omdat ze het zelf ook Alopecia heeft gehad 17:05

[redacted]
Oh dat is wel fijn idd 17:05

[redacted]
Ik praat er met ouders en zus veel en vooral makkelijk over, met sommige vriendinnen ook. Met mijn oma (die ook alopecia heeft) eigenlijk nooit, die praat er liever niet over. Echt jammer maarja 17:06

[redacted]
Das indd jammer 17:07

[redacted]
En jij manouk? 17:10

[redacted]
Ja het meest denk ik met m'n ouders.. Maar soms reageren die ook gewoon kut😅 17:10

[redacted]

Figure 3.22: Screenshots WhatsApp group

WhatsApp group

Apart from the interviews, also attention was paid to the WhatsApp group of the youngters day. In it, one of the girls started about the subjects of communication: *''Do you always talk about it with your parents? Or also someone who is a bit less close like an uncle or aunt for example?''* (see figure 3.22)

Some responded they talk to their parents, sister and / or friends. One said she talked to her cousin as she also suffered of alopecia and one said: *''With my grandmother (who also has alopecia) actually never, she prefers not to talk about it. Such a pity.''*

The girl who started the conversation: *''Yes I think mostly with my parents.. But sometimes they just react 'badly'.''*

INTERVIEW WITH EXPERT

The audio recording was analyzed by listening to it, making a transcript (see appendix 2-15) and writing down important insights from this. These important insights were clustered into different subjects. The different important insights per cluster are shortly explained, sometimes including an important quote of the chair. The most important insights are summarized and / or listed and a summary of all the insights about the services and information the association provides and of the activities and events she organizes is shown in figure 3.23. A more extended version of the list of insights can be found in appendix 1-9.

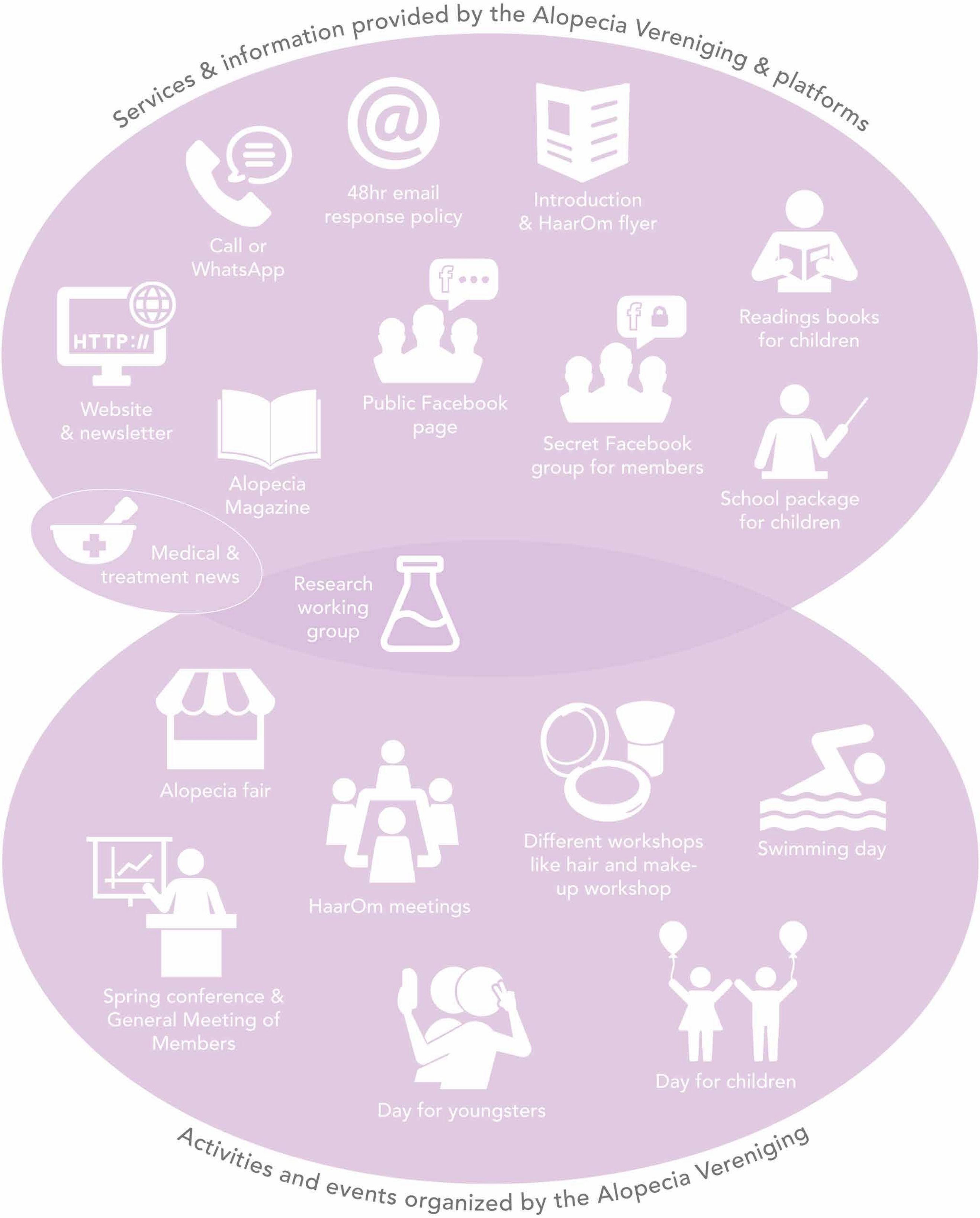


Figure 3.23: Overview activities, services and platforms of the AV.

General aspects Alopecia Vereniging

- Independence of the association
The Alopecia Vereniging (AV) made the decision the stay strictly independent. She wants to financially get organized only by the members and subsidy (and if applicable by other initiatives). She gets this subsidy because it is a patient organization which provides information and supports people. They do not want to get financially supported by commercial institutions or companies or for example by the pharmaceutical industry or wig makers. There is a big need for an independent association among people with alopecia as the condition is linked to a lot of wig makers, beauty specialists, etc. and the association looks from the perspective of the member. The AV would be their perfect target group. Marion: *''The highest bidder would get the biggest stage.''*

- Sources of information
For information the association has her website, a flyer, the alopecia magazine for members and personal contact is very important. She has a 48 hour response policy for emails and people can always call. For people calling, the association can advise people in what is best to do and what can best support the person in his case so this is very personal and custom driven. The chair has the most contact with people calling on the phone who just got faced with alopecia.

- Organized activities
Alopecia Vereniging annually organizes a swimming evening, a youngsters day, a children day, the national alopecia conference, twice a year HaarOm meetings and workshops about different subjects like hairstyle & make-up and mindfulness.

- Products & services
The Alopecia Vereniging has a school package and a reading book for children. Apart from that she does not sell anything yet, however there are future plans and ideas for products and services which really add value, things people need and cannot find elsewhere.

- Advisory role wigs
The AV does not advise which wig maker to go to for example. The boards thinks it is too personal because the personality of the wig maker also plays a role and every wig maker is specialized in different types of wigs. The association does advise people what to pay attention to and to go to a certified wig maker for which she is involved in setting up the quality criteria. Furthermore, she communicates that wearing a wig is only one option out of many possibilities and provides advice for them.

- Stigmatization of becoming part of a group
There is the problem of stigmatization of becoming a member of a group, especially in the past. *''At the moment you join a group, you actually say, I have this condition. And if you're not totally ready for that you also don't do it. But actually that moment will eventually come. And what we try to do is to show everything we publish the least negatively loaded. We try to project that positivity. And we try to avoid the word patient as much as possible because we don't feel like a patient in the end but just like an experience expert.''*
The former name of the AV was the Alopecia Areata Patiëntenvereniging (patient association).

Care procedures & familiarity of the association

- Psycho-social aspect in care procedures
The association is involved in the care procedure of alopecia. They talk to the association of dermatologists and doctors and are involved in the regulations. *''That part, those psycho-social aspects, those have to be taken into account from the beginning of the whole treatment.''*

- AV mentioned during consult
The AV tries to let doctors and dermatologists directly mention the association because of information and for contact between fellow sufferers.
''At the consult, people hear something they do not want to hear. You start to have hair loss and you think there must be a reason for that and if we know that reason then I will get a medicine and then it's recovered again. But you get to hear a total different message and that message will cause you more anxiety. And then you just have the need for people with specialized knowledge, who know a lot about it. And when you search on the internet, well then you become totally crazy. So you approach a party of which you hope like, they can provide me with more information. And then you get that when you take that immediately serious, that it can be a huge shock and you take someone by the hand from your own experience already from the beginning. And then that point of acceptation or coping with will be there much faster instead of solely having the route of medical treatment.''

- Overwhelming information at onset
People tend to get overwhelmed by all the information and possibilities when first going to a wig maker and should preferably first have contact with the association.

- Connections for familiarity with the association
The AV sends her alopecia magazine with some flyers in it for free to dermatologists, wig makers, permanent make-up specialists, etc. to make them familiar with the association and up to date with the condition. Quality criteria state to offer flyers of the Alopecia Vereniging. Furthermore AV has different other contacts, for example also with skin therapists.

Alopecia Awareness

- (Social) media
Marion Kremer collaborates to many interviews and is being involved in a lot of things like representing the patient group at medical specialists congresses and many more networking activities. The AV is also present in the media a lot because it gets better known which also results in for example health insurance companies to recognize the condition. The last year, there are a lot of media requests which makes it possible for different people to share their story. According to Marion, a couple of years ago, hardly anyone wanted to be public about the condition yet. Especially in the beginning, Marion sent out a lot of press reports for the things they were working on or doing.

- Familiarity of the condition gives peace of mind
''It really is that familiarity which causes you to have more peace of mind. It is especially that idea that people think you have cancer, that carries a heavy weight. You always have something to explain, that is just very annoying.''

- Prejudices in the professional field
The chair had her own example of making a statement by putting a bald picture and a picture with wig on her CV. Then she knows people do not have wrong expectations and she does not want to feel like she has something to explain. She would not want to work somewhere where she does not get accepted for who she really is. *''I know that a lot of women have a difficult time with it at their work, that they want to tell it or don't dare to tell it or that they are being judged but also that they are not even allowed to show them like that because they have to be representative That is tough.''*

Becoming a member

- Membership fee
The membership fee will change from 25 euro per year to a free choice in 25, 50 or 75 euro per year, depending on what you like to pay the association, which was requested by members.

- Registrations
About nine out of ten people who first contact the association, via phone or email, directly register afterwards. These are mostly people with a new need (for example onset or recurring hair loss); About 70% of the registrations comes from people who directly had contact with people of the association. Apart from that there is a big, growing group, who got directed to the AV via the dermatologist on their first consult.

- Reason for registration
The main reason for people to become a member is the need for real information and they seek confirmation: *''They would rather hear something different but when they do get that confirmation, then it is more of a resignation.''*
Secondly, people sign up for the contact with fellow sufferers, *''The feeling you are not alone''*, And they become a member for information about practicalities. Also, all days and activities the association organizes are free for members and there are a lot of people who become a member of the AV for news of developments in the medical field or about treatments.

- De-registrations
Most of the time the reason for de-registering is that alopecia is no longer applicable but sometimes those people stay member. Sometimes people deregister because they live in further located areas of the Netherlands and they think that the association does not organize enough activities there.

Contact between members

- Facebook page and group
The association has a public Facebook page on which it posts everything they do and it is about publicity and alopecia in media. It also has a secret Facebook group, this is a closed of community for members. The AV is very strict with who she allows in the group. Around 10% of the members is also member of the secret Facebook group but not everyone knows about it yet. Only members of the association who suffer or suffered of alopecia can join the group as also companies and wig makers are member of the AV. People who suffered of alopecia in the past are only present in the group at moments when someone needs something or has a question.
''You also see that people who eventually got their hair back, know how much it supported them, that they want to contribute to help other people.''

- Facebook difficulties
Difficulties with the Facebook page and secret Facebook group are that someone constantly needs to monitor it to avoid commercial messages. Furthermore, people need to be aware of social media rules concerning privacy.

- Contact for close ones
The next years the AV wants to expand the HaarOm meetings and bring people who are close to someone with alopecia in contact with each other. There are possibilities for subsidies in the field of psychosocial care for chronic somatic conditions. The first developments in psychoscial care and involving close ones are coming from Huidpatiënten Nederland. These developments are part of a project proposal in collaboration with the patient federation and the AV represents a voice in this. Huidpatiënten Nederland is an association for people with skin and hair conditions which has individual members and also specific patient associations affiliated with the association. These developments can be specified for different target groups.

- Panicking people calling
When people are panicking (for example because they just got faced with alopecia), they can call to the Alopecia Vereniging. Marion provides them a sympathetic ear and tries to give all the information they need and listens to what needs the person has. She tries to ask them questions as well so they will think for themselves again. This experience of talking to her usually leads them to feel like they want to join the association.
Sometimes she tries to bring people together to let them talk to each other when she knows people who were or are in a similar situation. She also tries to bring people together who live in Belgium. She matches these people according to their needs, stage in life, personality and / or experience with a specific (medical or psychological) treatment. There are people in the association who signed up to get contacted when someone is in need of a talk or advise. The chair knows all these people personally.

- FFA and androgenetica groups
Within the Alopecia Vereniging, there are some separate smaller groups of people who suffer of the same, different types of alopecia, like the inflammation FFA or alopecia androgenetica. These were all women who were brought together.

- Bringing people together with similar ways of coping
It is not necessary to bring together people who cope with alopecia in a similar way but it is good to keep it in mind. *''It does happen that I think of someone and then I think, well the personality does not really fit together. That has nothing to do with the type or experience but then I really look at the personality. And I also think like well better not. Suppose someone is very insecure and I know the other is quite dominant, then you should bring them together. There is a chance you will get the opposite effect then.''* But people should also have the possibility to pull each other up so they should not be too much the same when they are both closed.
'' I do think it is very important that you give everyone the space to cope with it the way they want or think they have to do. And there are people who are not good at that, who want to impose their own truth on someone.''

- Bringing people together with different ways of coping
The chair notices that it happens that people who cope with alopecia in a different way already come together on activities. In a group you always have some people who are more positive and some who are very negative. And they help each other.

Organized activities & meetings

- Mental support activities
Alopecia Vereniging organizes HaarOm meetings for people for mental support. These are meetings in which people talk with each other about different subjects. The chair said: *''Contact between fellow sufferers actually often already helps a lot, a lot more than most psychiatrists can do.''*
But when people need more support, the association refers them to for example a psychologist. They also always try to involve the subject of mental support in the workshops on the national conference. *''But you often already see that when we are in contact, that they can call and can ask their questions and possibly join the secret Facebook group, that it already helps and supports a lot.''*
The HaarOm meetings are more focused on people who have a hard time coping with alopecia. However, when people start to grow and cope better with the condition, they do not show up again. Each year the association proposes a follow-up HaarOm because everyone will be in a different stage but people do not feel the need for that or the need is smaller.

- Specified workshops
Sometimes the AV organizes workshops for a more specific group of people of the association.

- *Youngsters day*

On the youngsters day the AV tries to only organize nice things because the chair thinks that having deeper conversations is something that should come naturally on such a day.

- *Children / family day*

The annual day for children and families is organized with fun activities for children. ''We take the parents separately, we try to do something for them too. And that is to split those two groups because parents of children with alopecia are more worried about what is happening and is my child able to do that? You would almost say overprotective. So by separating those group, you give the children space to be themselves. And those parents you take them away and try to support them in another way.''

- *Initiatives by youngsters*

The AV would like young members to show initiatives in coming up with ideas about for example their own fora, meeting days, etc., according to their needs. The association would make those things possible then. The chair thinks that youngsters participate more in everything, more clearly have and express their voice and show their need and wishes.

- Activities for people who cope well

People who cope well with the condition also have a need to talk about for example daily frustrations and also for them there need to be advantages of being a member. For example the hair, style and make-up workshop attracts more people who cope well with the condition. The problem is that the need to go to meetings is less present.

Needs of the association & future plans

- There is a need for a webmaster and communication manager who can analyze the online channels.
- There is a need for more volunteers and one who can be responsible as a contact person for the volunteers.
- The new chair has a working group about research and works on international contacts. This year the intention is to build contact with Columbia, where there is a medical examiner.

Wish for explanation tool

Furthermore, the chair told about the wish of the association to have something which explains alopecia to a context of people who do not know about the condition. Marion mentioned an example of the video 'Alopecia Areata - Why does my hair fall out? This video was produced by the Australia Alopecia Areata Foundation (AAAF), see figure 3.24. It is a video which helps children aged between 4 and 12 to understand and explain their alopecia and shows a cartoon like child who gets faced with alopecia and contains videos of other children and young people talking about their alopecia (Australia Alopecia Areata Foundation, 2015). Marion said this video will get translated into Dutch and the association would like to have something similar in general to explain the condition. Such a video can also explain and show for example that it is totally normal that the hair loss just suddenly starts. She said it can show the hair loss process.

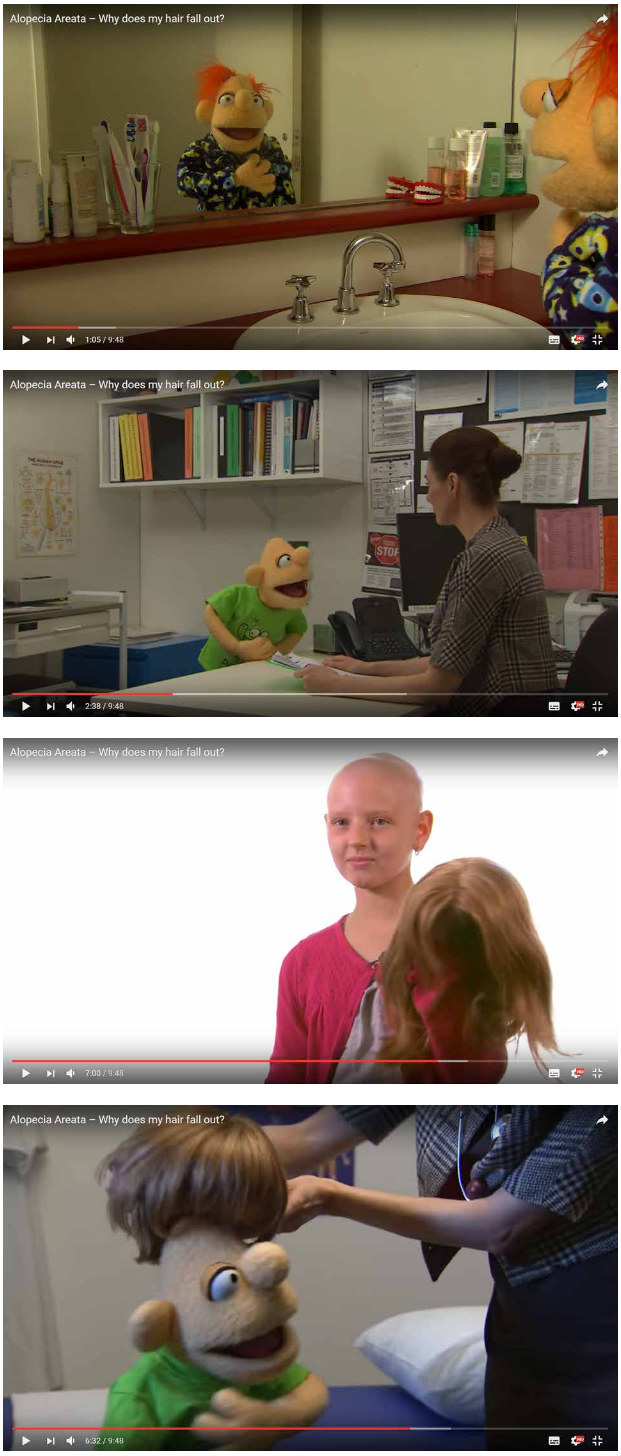


Figure 3.24: Alopecia video produced by AAAF.

3.2.c CONCLUSION

The interviews with the target group and the former chair of the Alopecia Vereniging gave a lot of different insights and results. It can easily be stated that there are lots of different problems and concerns in the lives of people who suffer of alopecia and that there is a clear need for comfort in their everyday lives. Furthermore, the interviews showed that there are a lot of different problems and concerns in the lives of people suffering of alopecia. One of the bigger problems was a lack of good communication between the individual with alopecia and his close ones. As for the Alopecia Vereniging, there are a lot of different thing she is working on and there is a limited amount of volunteers. When focusing on what the association is involved in, directly linked to members or people who just got faced with hair loss, it is easier to narrow down. When doing so, the association is mainly involved in improving the care procedure, setting up quality criteria for specialists, giving people mental support and information and providing the opportunity to meet fellow sufferers.

There were a lot of different problems and aspects to improve the everyday lives of people with alopecia so to focus on one of them for the ideation phase, both the insights of the in-depth interview and the interview with the expert should be put together while keeping in mind the focus of the project.

Some of the methods used in the interviews were eventually not used as intended but nevertheless successful. The word & picture sheets could for example be used for creating mood boards but the sheets were a good way to stimulate people to talk about their experiences. They also gave more insights into different situations and activities, of which the participants would normally not have thought of to start talking about. Also the Pick-A-Mood tool eventually just served as a tool which could help people when they needed to explain their feelings but almost all the participants were well able to talk about this without a tool.

A point for discussion of the in-depth interviews with the target group is the fact that nine out of ten participants were members of the Alopecia Vereniging who attended the youngsters day. This could have led to results showing a higher proportion of severe cases of alopecia because those people tend to visit events more. Nevertheless, the target group was, after the first evaluation of the interviews, narrowed down to people with a later age at onset because these people had a hard time coping with their condition so the participants fit within the target group.

3.3 CONCLUSION & REFLECTION

The first study, the introduction in the context, showed that young people enjoy to spend time with other young people who suffer of alopecia. They have this need to talk to others because they feel like people without alopecia do not understand them well enough.
The second study consisted of the in-depth interviews with the target group and the expert.
After conducting ten in-depth interviews with young people suffering of alopecia, the target group was narrowed down to young people of 16-25 years old who suffer of alopecia with a later onset in life. This was done because this group had a hard time coping with their alopecia.
Furthermore, the interviews showed that there are a lot of different problems and concerns in the lives of people suffering of alopecia. One of the bigger problems was a lack of good communication between the young individual and the people he feels close with.

The interview with the expert showed that the association is involved in improving the care procedure, setting up quality criteria for specialists, giving people mental support and information and providing the opportunity to meet fellow sufferers. One of the clear wishes of the AV is to have something which helps people to explain their alopecia to others, something which makes others understand the condition. Another clear wish was to involve people who are close to someone with alopecia in the events because they are an important factor too. The psycho-social aspects are also important for the association and she is busy to involve these in the care process.

To focus on one problem or need to continue to the ideation and conceptualization phase with, the insights of the different studies were put together while keeping in mind the focus of the project: ‘communication and optimism as meaningful means to foster self-confidence and strengthen coping behaviors’. When doing so, there is an opportunity for improving the communication of young people suffering of alopecia and other people. It is hard for them to explain their problem and the impact it has on their everyday life, what limitations they experience and to make clear what kind of support they need. This matches well with the wishes of the AV to involve close ones in events and to have something to explain the condition to other people. So the design goal would have to go into the direction of improving this communication.

CHAPTER

04

CONCEPTUALIZATION & EVALUATION

THE FOURTH CHAPTER DESCRIBES THE DESIGN BRIEF AND THE IDEATION AND CONCEPTUALIZATION PHASE WITH AN EXPLANATION OF THE DIFFERENT CONCEPTS. ALSO THE EVALUATION OF THE CONCEPTS ON THE NATIONAL ALOPECIA CONFERENCE WILL BE DISCUSSED.

4.1 DESIGN BRIEF & IDEATION

As mentioned in chapter 3, there is an opportunity of improving the communication of young people suffering of alopecia with other people who do not suffer of the condition.
When applying a socio-ecological (Bronfenbrenner, 1992) perspective to the insights from the research analysis, the problems and results for the person with alopecia and his relationships and networks can be analyzed (see also chapter 2.2 & 2.3):
How does the user deal with the situation personally (personal level), how does this influence his close relationships (interpersonal level) and how does this affect the closest networks of people whom he relates in everyday life (organizational level)?

Communication with close people
One insight most participants had in common was that they had troubles to explain their feelings and difficulties about suffering of alopecia to others. It is hard to explain their problem and the impact it has on their everyday life and what limitations they experience and to make clear what kind of support they need. The people with alopecia also worry whether they can talk about their condition or not as they do not always want to bother other people with their problem and do not want to evoke worries for their close ones. This problem can influence the way they interact with other people.
When applying this perspective, regarding the interpersonal level, the people the participant feels close with do not always know how to provide the right support and when to provide support. The psychological effect of hair loss can be compared to grief as in both cases the person has to deal with a loss which changes life significantly. Parkes & Prigerson (2013) describe that when a person is in grief, other people do not always know how to deal with a person in grief and so can avoid the person which results in the person getting even more socially isolated. More information and inspiration for the design process can be read in the blue square below.
The other party can also get the feeling that the person with alopecia does not care about the problem or cares too much about the problem because they might for example underestimate the impact of alopecia. They can also get a feeling of getting ignored or not being important when the person with alopecia does not seek for help.

Grief: Restoration orientation
The psychological effect of hair loss can be compared to grief as in both cases the person has to deal with a loss which changes life significantly. When looking at grief, Parkes & Prigerson (2013) describe two different orientations towards grief:

> *''Of course, not all of the changes that follow bereavement are losses. In the ongoing flux of life human beings undergo many changes. Arriving, departing, growing, declining, achieving, failing – every change involves a loss and a gain. The old environment must be given up, the new accepted. People come and go; one job is lost, another begun; territory and possessions are acquired or sold new skills are learnt, old abandoned; expectations are fulfilled or hopes dashed – in all these situations individuals are faced with the need to give up on mode of life and accept another. If they identify the change as a gain, acceptance may not be hard, but when it is a loss or a 'mixed blessing' they will do their best to resist the change. Resistance to change, the reluctance to give up possessions, people, status, expectations – this, we believe, is a major component of grief. An important contribution to our understanding of grief has been made, in recent years, by Stroebe and Schut (1999) who see grief as involving two orientations, a loss orientation and a restoration (or change) orientation. When oriented towards loss we look back, when oriented towards restoration we look forward. Since it is not possible to look back and forward at the same time, bereaved people must oscillate between these two orientations.''*

For people having to deal with alopecia, the restoration orientation is more valuable. It helps the person to accept the change as he has no influence on this change. Looking back at the time the person had no alopecia does not change anything as he cannot influence the course of alopecia. Therefore, the design should help the person to get restoration (or change) oriented and stop the resistance to change. The person should focus on the current situation.

Regarding the organizational level there are some problems like for example communication with colleagues or class mates.
So the communication between the person with alopecia and anyone who is close to that person should be improved. These others who are close to the person suffering of alopecia have to accept the problem and need to understand what kind of support they should provide and when they should provide this support. This matches with the need of the Alopecia Vereniging to involve close ones in events and to have something to explain the condition to other people. The association also thinks that psycho-social aspects are important, which are addressed with this focus.

During the analysis phase, the design goal was adjusted with a more specified target group: 'I want to make people, aged between 16-25 who suffer of alopecia with a later onset in life, feel comfortable in their everyday lives.'
When combining the focus after the research conclusions with the following focus aspects of the project;
- Make people with alopecia feel comfortable in interacting with their daily environment;
- Use communication and optimism to foster self-confidence and strengthen coping behaviors,

A more focused formulation of the design goal can be formulated:

DESIGN GOAL

Design a product or product-service system which makes people, aged 16-25 who suffer of alopecia with a later age at onset in life, feel comfortable in their everyday lives by designing coping strategies for the individual with alopecia and anyone this individual feels close with.

So after the conclusions of the analysis phase and refining the design goal, the focus for the ideation phase should lie on:
Coping strategies for the individual with alopecia and anyone this person feels close with.
This means to investigate how to talk openly about it without offending the other one.

This also means to help the person with alopecia and the other party to break the ice to start the communication about alopecia and make the communication more open between them.

Design requirements

The design should be such that it can be used when the person needs it and wants to use it. It could also be adjustable to the level of need so they can use it in the way they want to be supported at that specific moment.

- Stimulates communication
- Creates comfort for person with alopecia
- Low-demanding
- Limited complexity
- Short-term feasibility
- Accessible to person with alopecia
- Useable without external assistance
- Limited costs
- Gives the other party a better understanding

Interaction qualities:
- Comforting
- Optimistic
- Supportive
- Compassionate
- Lower-demanding
- Inclusive

Ideation

With the design brief, design goal and requirements in mind, the ideation started. Brainstorming, word clouds, a 'how can you' method and 'Momentos' were used to get different ideas (see appendix 2-16 & 17).
The concept of 'Momentos' will be used, like Rosier (n.d.) did in her Master Thesis 'Break', to describe different moments that were appealing from the research analysis. These Momentos will be used as an inspiration for the idea generation. In her Master Thesis, Rosier described Momentos as specific moments experienced by the user in his daily life. They point out details of the user such as feelings, experiences, needs and goals during specific moments. These Momentos will be used instead of Personas as the variety of experiences among the participants was too big to be able to generalize them as Personas. Therefore it is more valuable to look at different specific moments for different participants as inspiration for idea generation in order to make these ideas more valuable to a user group with a lot of variety. However, when selecting the most relevant ideas, it is good to look from a bigger perspective to see what would be interesting for a lot of people of the target group. Momentos will be used from the statement cards (see appendix 2-7 - 2-12) and the timeline insights (see appendix 1-7 & 1-8).

Apart from these Momentos, another look was given on the timelines and statement cards in order to see what kind of solutions there are already out there for participants who do not experience the problem like or as much as other participants. The statement cards of the participants were investigated to see what things, activities or thoughts make the participants happy, positive or support them and the insights were written down (see appendix 1-10).

Different ideas coming from all the ideation activities can be found in appendix 2-17. Some of the most promising ideas were selected and combined to three concept directions (see appendix 2-16 - 2-19.

THREE CONCEPT DIRECTIONS

1. Interactive storytelling app
    - Interactive story game
    - Video story telling
    - Picture gallery story telling
2. Alopecia reminder app
3. Encourage close ones to experience something similar.

These concept directions were the starting point for the conceptualization.

Timeline insights
Shifts in the way of dealing and in emotions from the timelines that fit the specified design focus are:

- *First time among people with wig:* The first time going outside the house, to work or school or going out with a wig is exciting and the participants can look up to it. They feel like everyone is watching them and able to see their hair is fake.
- *Support or extra stress by relationships:* Relationships can be supportive when the boy- or girlfriend accepts the alopecia but can be extra stressful when not accepting it.
- *Stop wearing scarves:* One participant does not wear scarves ever since her ex-boyfriend did not accept her like that. It made her think differently about not wearing a wig, with hair you are 'bigger'.

Supportive surprise party: A surprise party organized by friends helped a participant a lot after she lost her hair.

- *Hat day at school:* A 'hat day' was organized for a participant because she was allowed to wear a hat in school. For this day, she chose for an information email explaining her condition and the event. This event and informing email removed her awkward moments of actually not being allowed to wear a hat at school.

Support by friends: Good friends who support the participant in bad times can make a big difference.

- *Acceptance:* One participant accepted her alopecia and started wearing different looking wigs when everyone knew about it and some friends shaved their heads. Another participant accepted his alopecia a year after his new class mates accepted him with it.

4.2 CONCEPTUALIZATION

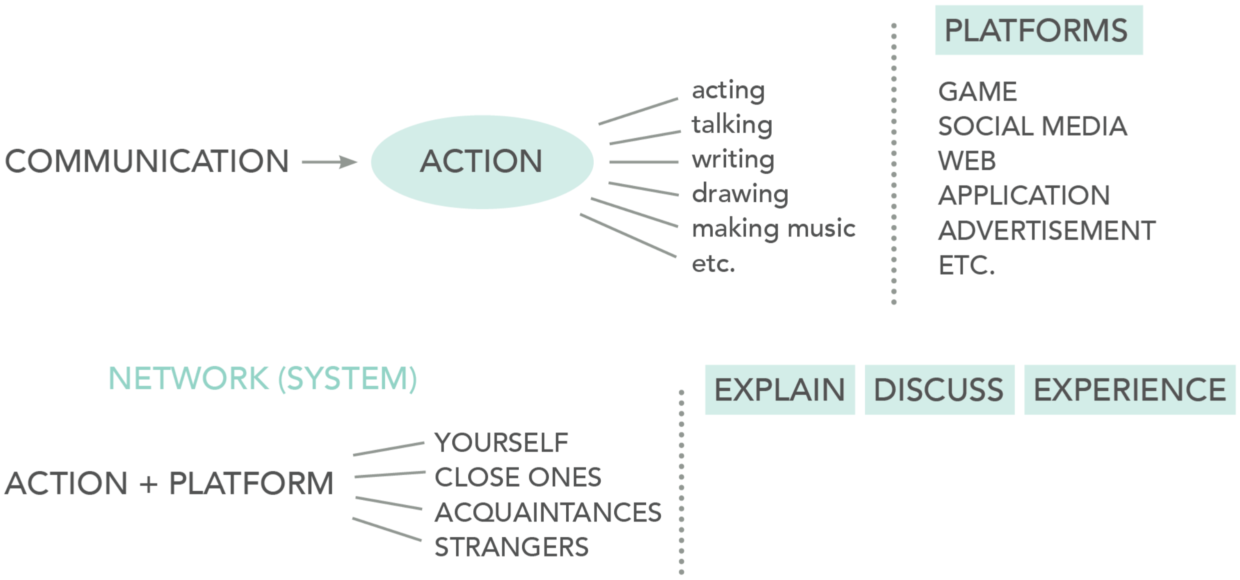


Figure 4.1: Concept direction exploration scheme

To explore the three different concept directions on different levels of communication, actions, different addressed people and different platforms, different schemes were made (see figure 4.1) and so different concept versions were developed. The three different levels of communication were:

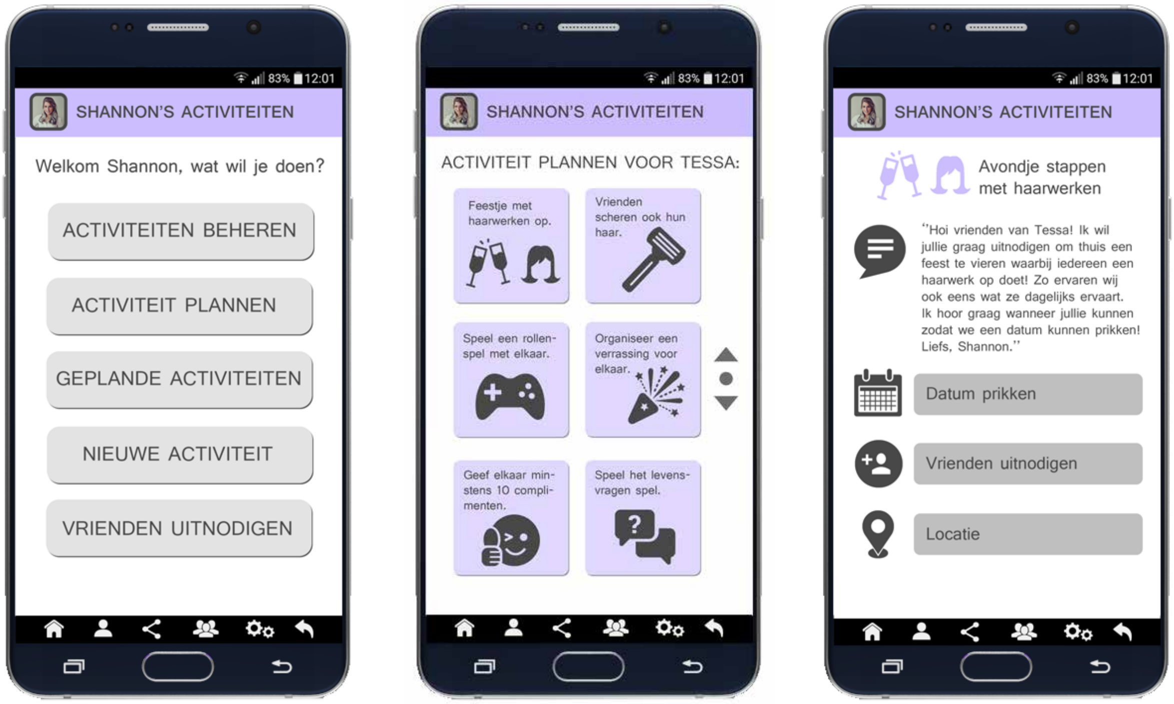
- Explanation / show
- Discuss
- Shared Experience

For example, the video 'Alopecia Areata - Why does my hair fall out?' (see chapter section 3.2.b) produced by the Australia Alopecia Areata Foundation (2015) only uses the explanation / show level of communication. People can of course discuss the video but the video itself is only explanatory, it does not contain questions or aspects which directly stimulate a discussion. However, a purpose of the video could be a school presentation which evokes discussion.

The three concept directions that were developed were further detailed into different versions of the three concepts with different platforms. For each concept, it was explored which platforms were available and suitable for the specific concept. The three provisional concepts with their different versions will follow in the next three sections. These different concept (versions) were later evaluated (see chapter section 4.3).

4.2.a CONCEPT 1

Concept 1 consists of two versions: concept 1.1 Activities app and concept 1.2 Activities flyer.



"Hoi vrienden van Tessa! Ik wil jullie graag uitnodigen om thuis een feest te vieren waarbij iedereen een haarwerk op doet! Zo ervaren wij ook eens wat ze dagelijks ervaart. Ik hoor graag wanneer jullie kunnen zodat we een datum kunnen prikken! Liefs, Shannon."

Figure 4.2 Concept 1.1 - Activities app

Concept 1.1 - Activities app

The activities app stimulates people with alopecia and people close to them to take on more activities that also provide insight into the experience of the person with alopecia. But this can also go both sides. It stimulates communication. The platform of the concept is an app so that new activities can kept on being added and planned.

Concept 1.2 - Activities flyer

The activities flyer stimulates people with alopecia and people close to them to take on more activities that also provide insight into the experience of the person with alopecia. But this can also go both sides. It stimulates communication. The platform of the concept is a flyer / booklet because this can easily be distributed. The booklet can be created and ordered with a template on the website of the Alopecia Vereniging.

TESSA'S ACTIVITEITEN

"Hoi, zoals je misschien weet heb ik alopecia. Dit is een auto-immuun aandoening waarbij het haar uitvalt. Hierdoor loop ik in het dagelijks leven tegen veel dingen aan. Ik zou het erg leuk vinden om de volgende activiteiten samen te doen. Dit kunnen ook activiteiten zijn waarbij je bijvoorbeeld ervaart waar ik bijvoorbeeld tegenaan loop."

- ☐ SPEEL EEN ROLLENSPEL MET ELKAAR.
- ☐ GEEF ELKAAR MINSTENS 10 COMPLIMENTEN.
- ☐ ORGANISEER EEN VERRASSING VOOR ELKAAR.
- ☐ SPEEL EEN LEVENSVRAGENSPEL.
- ☐ BEZOEK SAMEN EEN ESCAPE ROOM.
- ☐ VRIENDEN SCHEREN OOK HET HAAR AF.
- ☐ GA EEN AVONDJE STAPPEN MET HAARWERKEN.
- ☐ ORGANISEER EEN AVONDJE MET HAARWERKEN.

- ☐ MAAK SAMEN EEN KAMPEERTRIPJE
- ☐ DOE SAMEN EEN SCHILDERWORKSHOP.
- ☐ DOE SAMEN EEN MAKE-UP WORKSHOP.
- ☐ DOE SAMEN EEN SURVIVAL TOCHT
- ☐ DEEL MET ELKAAR MUZIEK MET VOOR JOU BETKENISVOLLE SONGTEKSTEN.
- ☐ DOE SAMEN EEN FOTOSHOOT (KAN NORMAAL OF ALLEBEI MET HAARWERKEN).

NOTITIES

Figure 4.3: Concept 1.2 - Activities flyer

4.2.b CONCEPT 2

Concept 2 consists of two versions of which one with two platforms: concept 2.1 Personal photo & video gallery website, concept 2.1 Personal photo gallery flyer expansion and concept 2.2 Interactive storytelling website.

Concept 2.1 – Personal photo & video gallery website
The person with alopecia can use the gallery website to share photos and other images (such as art) and videos with who they want without having to place them on a social media. The personal photo and video gallery website gives other people more insight into the experience of the person with alopecia. This adds to understanding of the person's situation so that others can better support the person.
In addition, galleries can also be shared publicly in connection with the Alopecia Vereniging website, creating a library of 'alopecia diaries'.

"Dit schilderij laat zien hoe ik me voelde toen mijn vrienden en familie mij steunden toen mijn haar net was uitgevallen. Dit heeft mij heel erg geholpen."

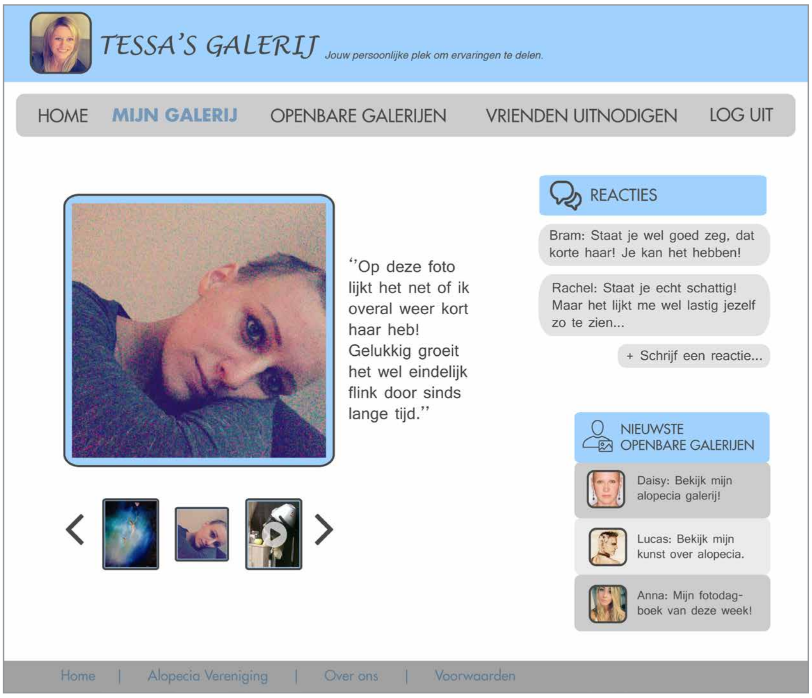
Shannon: Wat mooi, heel fijn dat we deze steun kunnen geven.

Dennis: Mooi schilderij zeg en een mooie boodschap!

Daisy: Bekijk mijn alopecia galerij!

Lucas: Bekijk mijn kunst over alopecia.

Anna: Mijn fotodag-boek van deze week!



"Op deze foto lijkt het net of ik overal weer kort haar heb! Gelukkig groeit het wel eindelijk flink door sinds lange tijd."

Bram: Staat je wel goed zeg, dat korte haar! Je kan het hebben!

Rachel: Staat je echt schattig! Maar het lijkt me wel lastig jezelf zo te zien...

Daisy: Bekijk mijn alopecia galerij!

Lucas: Bekijk mijn kunst over alopecia.

Anna: Mijn fotodag-boek van deze week!

"Deze video laat zien hoe ik mijn haarwerk een behandeling geef bij de kapsalon. Ik moet 'm dan een paar uur missen."

Bram: Ik dacht al die tijd dat je nooit meer naar de kapper hoefde!

Daisy: Bekijk mijn alopecia galerij!

Lucas: Bekijk mijn kunst over alopecia.

Anna: Mijn fotodag-boek van deze week!

Figure 4.4: Concept 2.1 - Personal photo & video gallery website

TESSA'S GALERIJ *Jouw persoonlijke plek om ervaringen te delen.*

MIJN GALERIJ

"Dit schilderij laat zien hoe ik me voelde toen mijn vrienden en familie mij steunden toen mijn haar net was uitgevallen. Dit heeft mij heel erg geholpen."

"Op deze foto lijkt het net of ik overal weer kort haar heb! Gelukkig groeit het wel eindelijk flink door sinds lange tijd."

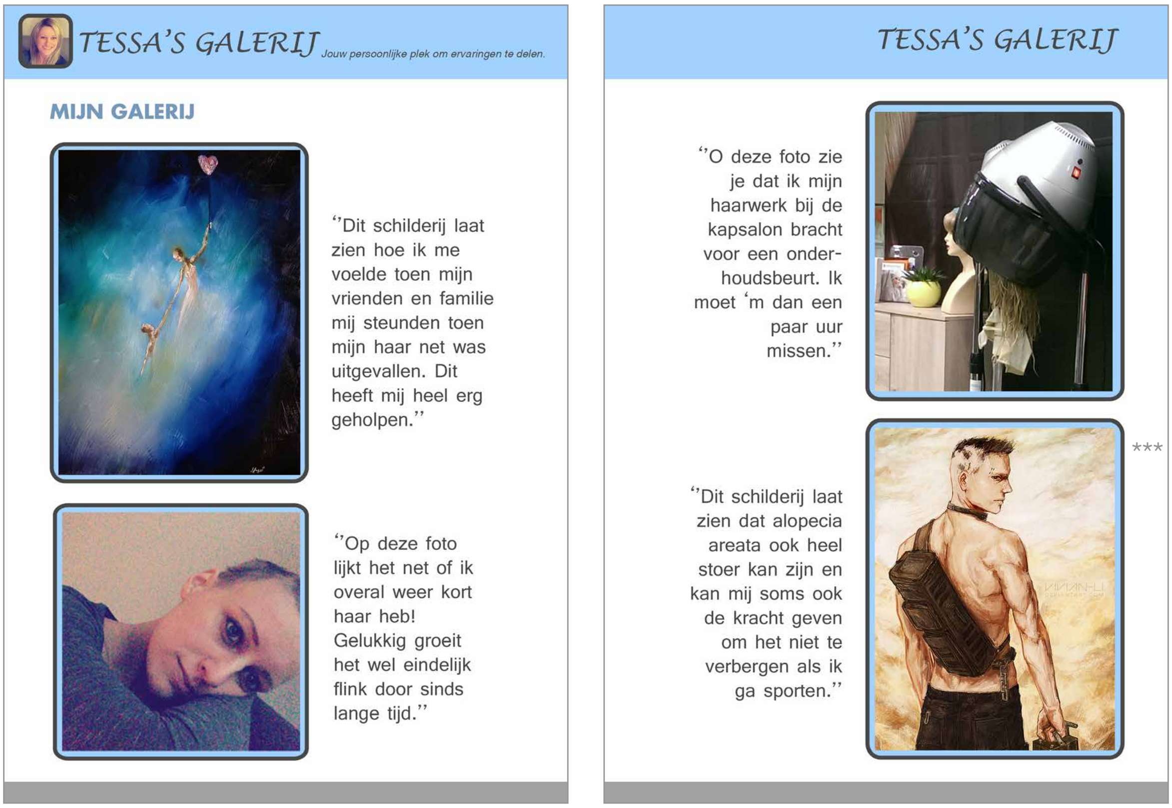
TESSA'S GALERIJ

"O deze foto zie je dat ik mijn haarwerk bij de kapsalon bracht voor een onderhoudsbeurt. Ik moet 'm dan een paar uur missen."

"Dit schilderij laat zien dat alopecia areata ook heel stoer kan zijn en kan mij soms ook de kracht geven om het niet te verbergen als ik ga sporten."

Figure 4.5: Concept 2.1 - Personal photo gallery flyer expansion

Concept 2.1 – Personal photo gallery flyer expansion
The personal photo gallery can also be printed via a template. The website gallery is then printed as a booklet so that the person with alopecia can also physically show the gallery to people.



TESSA'S GALERIJ *Jouw persoonlijke plek om ervaringen te delen.*

MIJN GALERIJ

"Dit schilderij laat zien hoe ik me voelde toen mijn vrienden en familie mij steunden toen mijn haar net was uitgevallen. Dit heeft mij heel erg geholpen."

"Op deze foto lijkt het net of ik overal weer kort haar heb! Gelukkig groeit het wel eindelijk flink door sinds lange tijd."

TESSA'S GALERIJ

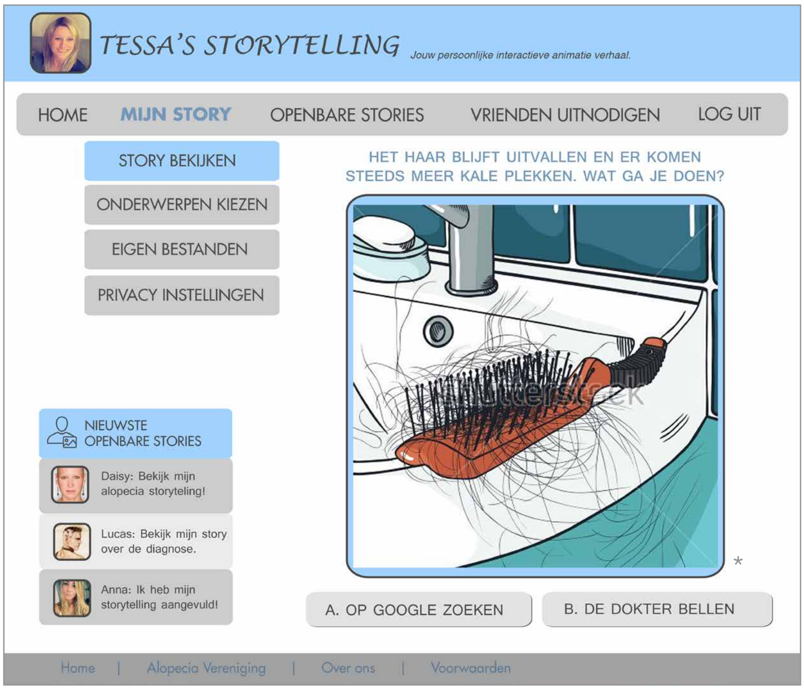
"O deze foto zie je dat ik mijn haarwerk bij de kapsalon bracht voor een onderhoudsbeurt. Ik moet 'm dan een paar uur missen."

"Dit schilderij laat zien dat alopecia areata ook heel stoer kan zijn en kan mij soms ook de kracht geven om het niet te verbergen als ik ga sporten."

***

Figure 4.6: Concept 2.1 - Personal photo gallery flyer expansion

Art by:
* Agurusa
** Maika Smit
*** Vivian-Li



HET HAAR BLIJFT UITVALLEN EN ER KOMEN STEEDS MEER KALE PLEKKEN. WAT GA JE DOEN?

*

Daisy: Bekijk mijn alopecia storyteling!

Lucas: Bekijk mijn story over de diagnose.

Anna: Ik heb mijn storytelling aangevuld!

JE ONTDEKT OP VERSCHILLENDE PLEKKEN OP JE HOOFD KALE PLEKKEN. WAT GA JE DOEN?

**

Daisy: Bekijk mijn alopecia storyteling!

Lucas: Bekijk mijn story over de diagnose.

Anna: Ik heb mijn storytelling aangevuld!

ONDERWERPEN KIEZEN VOOR JE STORY:

- ☑ HAARWERKEN
- ☐ ZELFBEELD
- ☑ DIAGNOSE
- ☑ EERSTE HAARWERK
- ☐ NEPWIMPERS
- ☐ LEGE GEZICHTSUITDRUKKING
- ☐ ASSOCIATIE MET KANKER
- ☑ BEGIN VAN HAARUITVAL
- ☑ BEMOEILIJKTE ACTIVITEITEN

Daisy: Bekijk mijn alopecia storyteling!

Lucas: Bekijk mijn story over de diagnose.

Anna: Ik heb mijn storytelling aangevuld!

Concept 2.2 – Interactive storytelling website

At the interactive storytelling website, people with alopecia themselves can choose subjects that they find important to communicate with their close ones. The chosen topics are getting merged into an interactive story in which people close to someone with alopecia can make choices themselves about different events. In this way, close ones can better replace themselves into the person with alopecia and think about the choices this person has to face. Also these "stories" can be shared publicly if the user wants to.

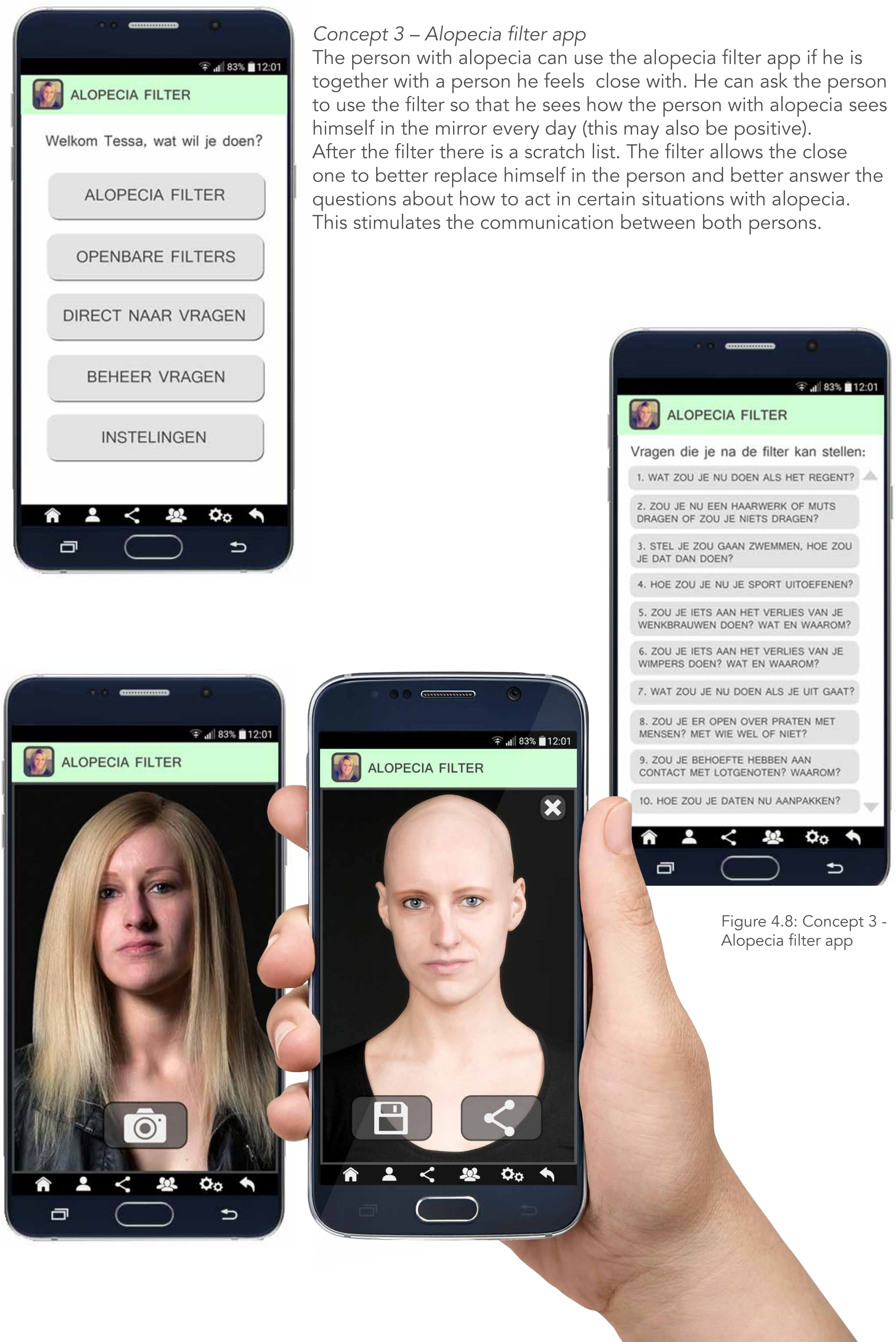
Figure 4.7: Concept 2.2 - Interactive storytelling website

Illustration by Vera Serg:
* Stockvector-id: 592688030
** Stockvector-id: 592688093

4.2.c CONCEPT 3

Concept 3 consists of one version only, the Alopecia filter app.

Concept 3 – Alopecia filter app
The person with alopecia can use the alopecia filter app if he is together with a person he feels close with. He can ask the person to use the filter so that he sees how the person with alopecia sees himself in the mirror every day (this may also be positive).
After the filter there is a scratch list. The filter allows the close one to better replace himself in the person and better answer the questions about how to act in certain situations with alopecia.
This stimulates the communication between both persons.



ALOPECIA FILTER

Welkom Tessa, wat wil je doen?

ALOPECIA FILTER
OPENBARE FILTERS
DIRECT NAAR VRAGEN
BEHEER VRAGEN
INSTELINGEN

ALOPECIA FILTER

Vragen die je na de filter kan stellen:

1. WAT ZOU JE NU DOEN ALS HET REGENT?
2. ZOU JE NU EEN HAARWERK OF MUTS DRAGEN OF ZOU JE NIETS DRAGEN?
3. STEL JE ZOU GAAN ZWEMMEN, HOE ZOU JE DAT DAN DOEN?
4. HOE ZOU JE NU JE SPORT UITOEFENEN?
5. ZOU JE IETS AAN HET VERLIES VAN JE WENKBRAUWEN DOEN? WAT EN WAAROM?
6. ZOU JE IETS AAN HET VERLIES VAN JE WIMPERS DOEN? WAT EN WAAROM?
7. WAT ZOU JE NU DOEN ALS JE UIT GAAT?
8. ZOU JE ER OPEN OVER PRATEN MET MENSEN? MET WIE WEL OF NIET?
9. ZOU JE BEHOEFTE HEBBEN AAN CONTACT MET LOTGENOTEN? WAAROM?
10. HOE ZOU JE DATEN NU AANPAKKEN?

ALOPECIA FILTER

ALOPECIA FILTER

Figure 4.8: Concept 3 - Alopecia filter app

4.3 EVALUATION OF CONCEPTS

In order to get an idea of the opinion of the target group on the different concepts and their different versions, the concept evaluation was set up and conducted at an event of the association. The results of this evaluation served to make a choice between the concepts, improve them with the conclusions of the evaluation and work them out in more detail for the co-create session.

4.3.a SET-UP

Figure 4.9: Explanation of the concept evaluation

At the Alopecia Vereniging spring conference in Bunnik, the different concept with different versions were evaluated with people suffering of alopecia as well as with people who are close to someone with alopecia. It was chosen to evaluate the concepts with different concept versions on this conference day because at this event a lot of people with alopecia gather and many of them bring relatives or friends.

Questionnaires
The to be evaluated concepts are to be used by people with alopecia and their close ones so it was necessary to evaluate them with both groups. For the evaluation at the conference, two questionnaires were made to be filled out by the two different groups. The questionnaires, see appendix 1-11 and 1-12, were made in Dutch because most people who come to the conference are Dutch and in this way they could better understand the questions and better answer them. The questionnaires for the two groups were similar but had some differences in the open questions. Apart from the open questions, both groups could score the concepts on different aspects, for which a 1-5 scale was used. The aspects were the same for both groups. By doing so, it is easy to compare the opinions on the concepts per group. The open questions were asked first so people could first think about answers themselves before seeing the different aspects they had to rate. The questionnaires included a statement about privacy and anonymously so people would not reticent to frankly answer the questions.

Evaluation day
At the conference day, there were first some guest speakers and a general meeting of members. Just before the lunch, the concept evaluation was announced in front of the public so that all visitors would know what the study was about and why it was conducted (see figure 4.9 & 4.10). During lunch, the concepts were explained to people in small groups and after the explanation

Figure 4.10: Explanation of the concept evaluation

they received the questionnaire. There were different workshops after lunch and after the workshops visitors had the opportunity to have drinks at the bar and talk to each other. During these drinks, also other small groups were given an explanation of the concepts and asked to fill out the questionnaire (see figure 4.11). Visitors of the conference were of all ages but most of the visitors were female and above the age of the target group. The concepts were however evaluated as much as possibile with participants of different gender and participants who matched the set target group.

Figure 4.11: Participants filling out questionnaires

Concept visualization

For the evaluation of the concepts it was chosen to use high fidelity prototypes and images because then people can best imagine what the concepts are and can better compare them. During the explanation, different sheets with images of the prototypes and mock-ups were shown. Small images of the prototypes were also shown above the asked scored of the questionnaire, so it was easier for participants to see what concept (version) they were giving their opinion on.

4.3.b ANALYSIS & RESULTS

The participants conducted the concept tests on the Alopecia Vereniging spring conference day during the lunchtime and drinks after the program. In total, nine people with alopecia and six people close to people with alopecia participated. Of the nine participants with alopecia, eight were women. The ages of these participants with alopecia varied from 15 to 51. Eight participants were aged between 15 and 31. Among the participants with alopecia there were two people with alopecia areata, four with alopecia totalis and three with universalis. The participants close to the person with alopecia were all family members (fathers, mothers, sister and a grandmother).

In general, people were enthusiastic about the concepts and especially about the initiative of developing something for people suffering of alopecia.
The questionnaires of the participants were analyzed by writing down all the individual answers to the open questions beneath each other per group (see appendix 1-13). In this way, the answers could be compared, graphs could be made and results & conclusions could be written down:

- **Mostly use with friends or family**

Most participants with alopecia would use the concepts with friends or family (see figure 4.12). Three younger girls would only use them with their friends. One of the girls said she would use it with her friends because family probably thinks differently than her peers. One woman would show pupils at school to teach them about differences between people.

> *"I would use it with my friends, because they are of my age. Family or parents probably think differently about certain subjects."*
> - Female with alopecia areata (16)

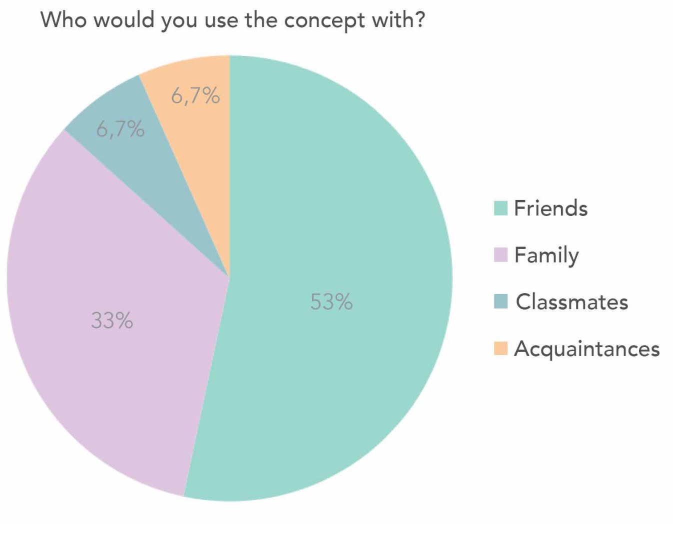


Figure 4.12: Schematic overview who people would use the concepts with

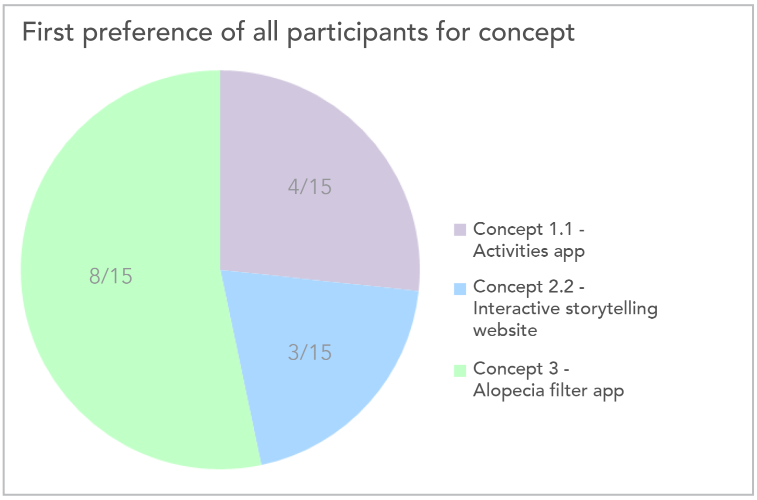


Figure 4.13

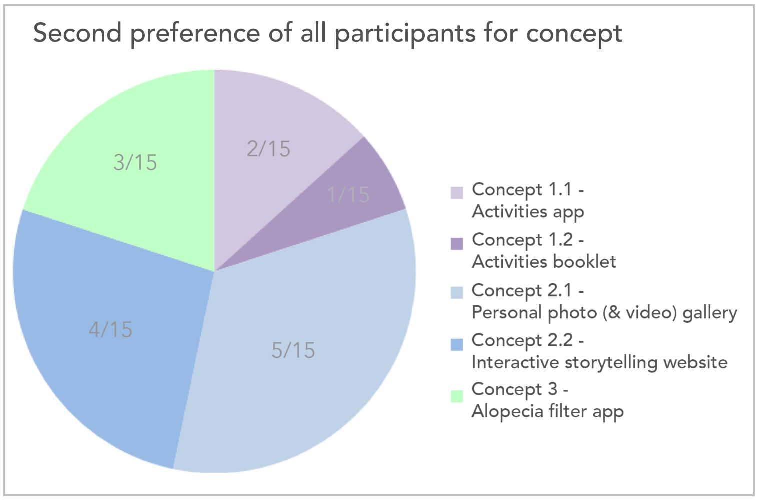


Figure 4.14

> *"Concept 2.2 gives clarity without getting personal."* - Mother of female participant (AT, 22)

> *Concept 3: "People can see what it would be like with them, it gives them more awareness or understanding. With friends it can be funny what gives the subject more levity."* - Female with alopecia totalis (22).

> *"Digital tools to make alopecia more open for discussion is a good thing." - Male with alopecia universalis (31)*

- First preference for concept

A schematic overview of the first preference for a concept of all the participants can be seen in figure 4.13 and for the second preference in figure 4.14.

Preference participants with alopecia:
Concept 3 (5/9), because of the possibility to let friends put themselves in their place and to give them more sympathy. This concept is also best imaginable in use and it is makes the subject less heavy.
Concept 2.2 (2/9), because others can put themselves in their place and have the possibility to ask themselves what the next step is.
Concept 1 (2/9, 31 and 51 years old), because it is most practical and makes you do activities.

Preference participants close to someone with alopecia:
Concept 3 (3/6), because it is nice, accessible, possible to use with a phone and requires empathy.
Concept 2.2 (2/6), gives clarity without getting personal.
Concept 1.1 (2/6)

- Second preference for concept

Preference participants with alopecia:
Concept 2.1 (3/9), because it makes you write about it and it is more convenient than writing.
Concept 2.2 (2/9), because it makes you see how others would deal in your situation and they have to think about it. It is also a good way to start a conversation.
Concept 3: (1/9), because it makes someone think about and feel what it does to you.
Concept 1.1 (2/9)

Preference participants close to someone with alopecia:
Concept 2.2 (2/6), because is possible with a mobile phone and is personal.
Concept 2.1 (2/6), because is possible with a mobile phone, is personal and requires empathy.
Concept 3 (2/6), because is especially for younger people and makes it 'light'
Concept 1.2 (1/6).

- Negative aspects

Close ones would not like to use concept 1.1 as it is too intense. They think concept 2.2 is too personal to use it with anyone other than family or friends. Furthermore they though that there are already a lot of apps with chats out there, so leave out the chat.

• Good and /or fun aspects

Participants with alopecia said they like that people can experience the same as you. Also, they like that the concepts are up-to-date, everyone can use it and they are fun to do. It is noncommittal and using digital tools to address alopecia is good. One participant likes that there or more options, as everyone thinks something else is important. One participant likes that it provides the possibility to share your story. Finally, one participant said concept 3 is very tactile.

One participant close to someone with alopecia likes that the concepts are suitable for different ages, one likes that the concept are visually well corresponding to youngsters. One participant said all three concepts are good means for self-acceptance and acceptance by the environment and one participant said concept 1 and 3 are innovative and up-to-date. Finally, one participant said concept 2.1, 2.2 and 3 are fun, especially, from a young age.

• Confronting or offending

Five out of nine participants with alopecia did not think the concepts to be confronting or offending. One girl said it could be confronting for yourself only if you have not yet totally accepted it, but not offending. One man said concept 3 looks most offending because the possibility of hilarity is present. One older woman said concept 1 is confronting and offending. One woman of 29 said all concepts are confronting but said that is necessary.

One participant who is close to someone with alopecia said concept 2.1 is confronting. Another said concept 3 is confronting as you get confronted with the facts as a family member or friend, but this concept might add to acceptance.

Two people close to someone with alopecia said the concepts are not confronting but a nice way of dealing with alopecia and they make people think.

• Chances for improvement of concepts

Concept 1:
- Combine the alopecia filter app with the activities app.
- Add more colors and pictures to the concept.
- Should not demand this much effort of other people.

Concept 2:
- Ability to chat with other members of the association in the app.
- Possibility to share the story or diary on social media.
- Preference of website version over the booklet.
- Also a preference for an app version.
- Change the word ‘storytelling’ because of association with a fairytale. Better would be ‘walk in my shoes’.
- Storytelling should also be available as a booklet for elderly.
- It should be designed as ‘light’ as possible.
- Innovative to make it different from other chats.

Concept 3:
- Add possibility to try on different wigs (different hair styles, different colors). The four out of nine participants who mentioned this were all aged 16, 20, 21 and 22.
- Link the concept to Snapchat, the Alopecia Vereniging and perhaps the alopecia-awareness month.
- Combine the filter with the activities app.
- Add make-up advice.

• General conclusions open questions:

The design should preferably be:
- tactile.
- personal.
- accessible & so that everyone can use it.
- up-to-date.
- fun to do.
- noncommittal.
- giving clarity.
- having the possibility to share your story with people.
- private (with a possibility to share it on social media).
- digitally available (not a flyer or booklet version).
- possible to use with a mobile phone.
- suitable for different ages.
- visually well corresponding to youngsters.
- a good mean to self-acceptance and acceptance by the environment.
- innovative.
- adding to acceptance.
- requiring empathy.
- able to put people in someone’s place.
- making others think of how they would act or feel.

The design should preferably:
- not have a possibility of hilarity.
- not demand too much effort of people.
- not be too personal when used besides friends or family.
- not be too ‘intense’.
- not contain a normal chat function.
- ,although serious, not be too heavy.

- Results scores

Figure 4.15 and 4.16 show the scores of the two different groups of participants in the colors of the concepts (see also appendix 1-13). Among both the participants with alopecia as well as participants close to people with alopecia, concepts 3, 2.2 and 2.1 (website) scored best. Among this last group, concept 3 scored best in every aspect. Among participants with alopecia, concept 2.2 and 3 both scored best, followed by concept 2.1 The average scores were never lower than 2,5 so all graphs start with a score of 2,5 on the vertical scale.

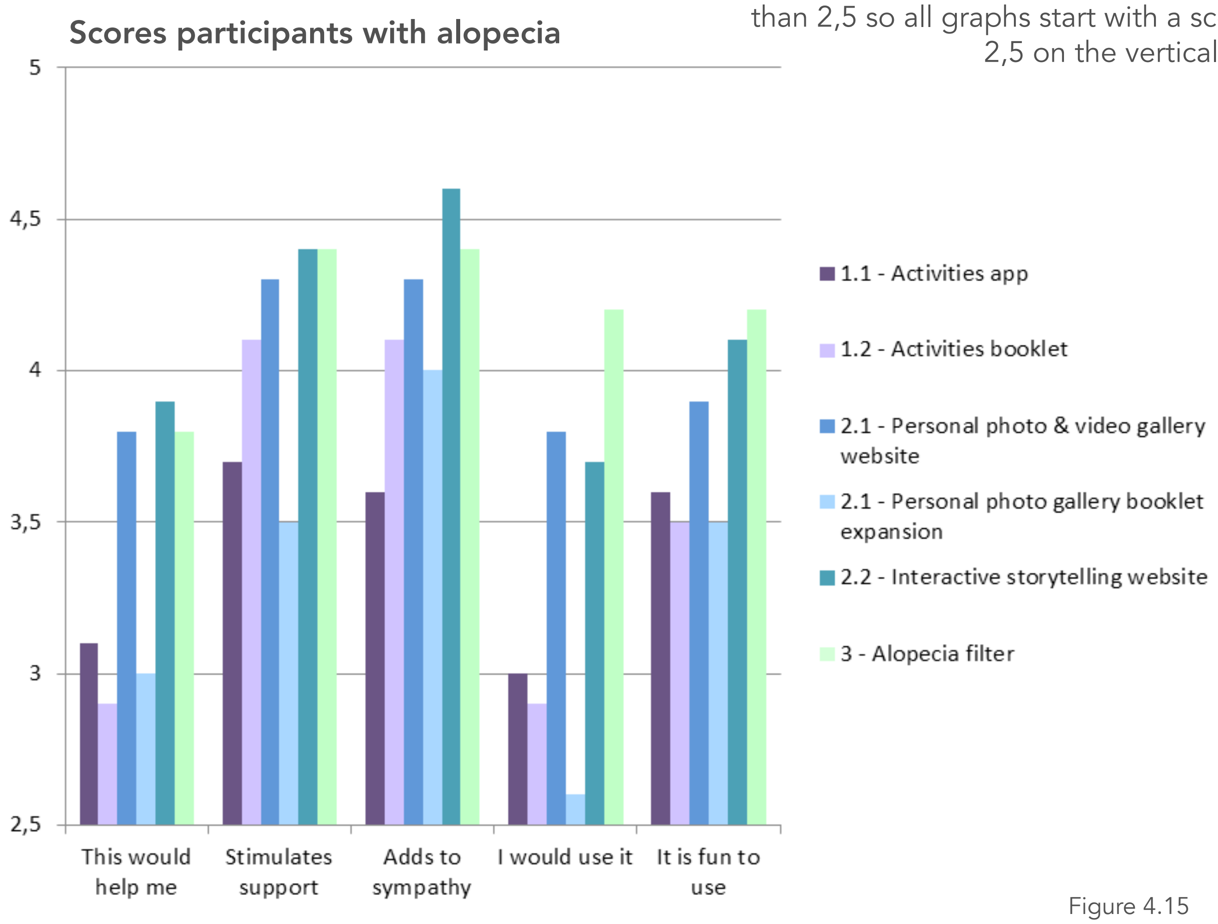


Figure 4.15

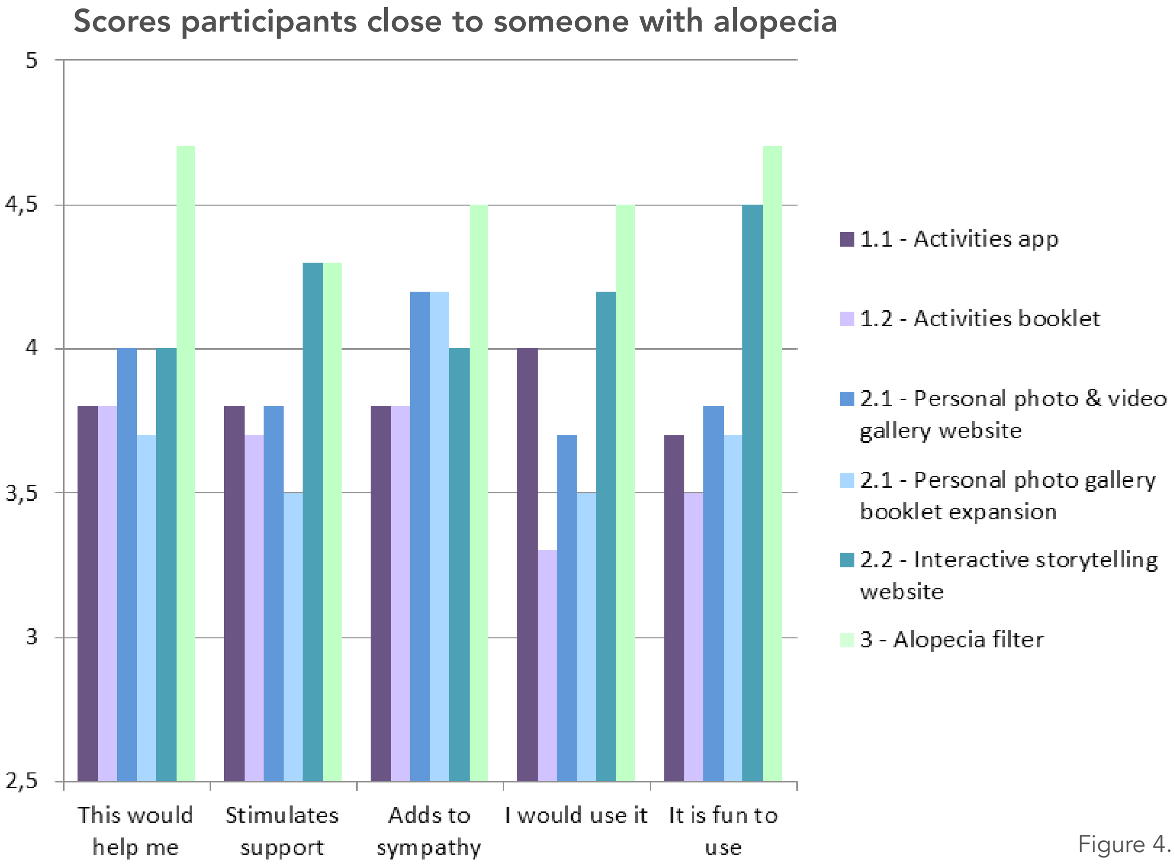


Figure 4.16

4.3.c CONCLUSION

Concerning the evaluation rsesults, the surveys results can in some cases be doubted because there was a bad differentiation between some concept versions as two concepts were numbered the same and sometimes people just wrote down the first number, so it was not clear which version they were talking about. By looking at the subjects they were mentioning it was in most cases clear which version they talked about. Most of the participants of the evaluation were suffering of a severe case of alopecia. Like the former chair of the Alopecia Vereniging said, people who are coping well with the condition show up less at events (see also chapter section 3.2.b). This could also influence the way participants perceive the concepts, they are perhaps more stigma and confronting sensitive.

When putting together the results of the open questions for a preference of all participants, concept 1.1, 2.1, 2.2 and 3 are the most chosen preferred concepts. There is about an equal amount of preference for concept 2.1, 2.2 and 3. When looking at the scores on different aspects, concept 2.2 and 3 score best.
Taking into account what comments people made about the concepts while keeping in mind the design goal and target group, concept 2.2 and 3 were chosen to get further detailed and improved regarding the results of this evaluation. Looking at the conclusions of this evaluation, it was also advisable to create a third chosen concept, an integrated version of the interactive storytelling and alopecia filter.

4.34 CONCLUSION & REFLECTION

The results of the analysis led to a focus on improving the communication between the person with alopecia and anyone who is close to that person. These close ones have to accept the problem and need to understand what kind of support they should provide and when they should provide this support. This also means to help the person with alopecia and the other party to break the ice to start the communication about alopecia and make the communication more open between them. The refined design goal was:

Design a product or product-service system which makes people, aged 16-25 who suffer of alopecia with a later onset in life, feel comfortable in their everyday lives by designing coping strategies for the individual with alopecia and anyone this individual feels close with.

So the focus for the ideation phase lied on coping strategies for the individual with alopecia and anyone this person feels close with. After ideation, the most promising concept directions were chosen and worked out to concepts with different version which were evaluated at the Alopecia Vereniging spring conference. These concept and concept versions were:
Concept 1.1 - Activities app
Concept 1.2 - Activities flyer
Concept 2.1 – Personal photo & video gallery website
Concept 2.1 – Personal photo gallery flyer expansion
Concept 2.2 – Interactive storytelling website
Concept 3 – Alopecia filter app.
After analyzing the concept evaluation, concept 2.2 and 3 were chosen to be worked out in more detail and to get improved with the insights of the evaluation. Two of those insights already directed towards a mobile application of concept 2.2 and an integrated version of both concepts.

CHAPTER

05

CO-CREATION

CHAPTER FIVE PRESENTS THE ADJUSTED CONCEPTS AFTER THE CONCEPT EVALUATION AND DESCRIBES THE CO-CREATIVE SESSION WITH A GROUP OF YOUNG PEOPLE WITH ALOPECIA. IT DISCUSSES ITS SET-UP, ANALYSIS & RESULTS AND CONCLUSION WHICH WILL CONTAIN THE DIRECTION FOR THE FINAL DESIGN.

The co-creative session was planned to obtain insight in the opinions of young people on the concepts after having them revised with the input of the concept evaluation at the conference. The co-creative session gave a group of young people the opportunity to share their ideas and thoughts on the final design.

5.1 SET-UP

With the insights of the concept evaluation, concept 2.2 and concept 3 were chosen. The evaluation results showed that concept 2.2 should also be available as a mobile application and that there should be an integrated version of both concepts. According to the insights of the design evaluation, the chosen concepts were improved and detailed and the mobile app version of concept 2.2 and the combination of both were worked out for the co-creative session.

Planned session

Some of the youngsters in the WhatsApp group of the activity day organized a weekend to the east of the country together because they enjoyed the last youngsters activity day a lot. On the 22th of April, the co-creative session was planned at the second day of the three-day long weekend. The participants were already invited to join in this session before the weekend was totally planned so they knew about the idea of the session beforehand. This co-creative session was a unique chance to get clear and honest opinions of the target group because this group already knew each other and did not feel like holding back from saying what they wanted. A planning for the session was made (see appendix 1-14) with different assignments and questions. An overview of the steps in the session:

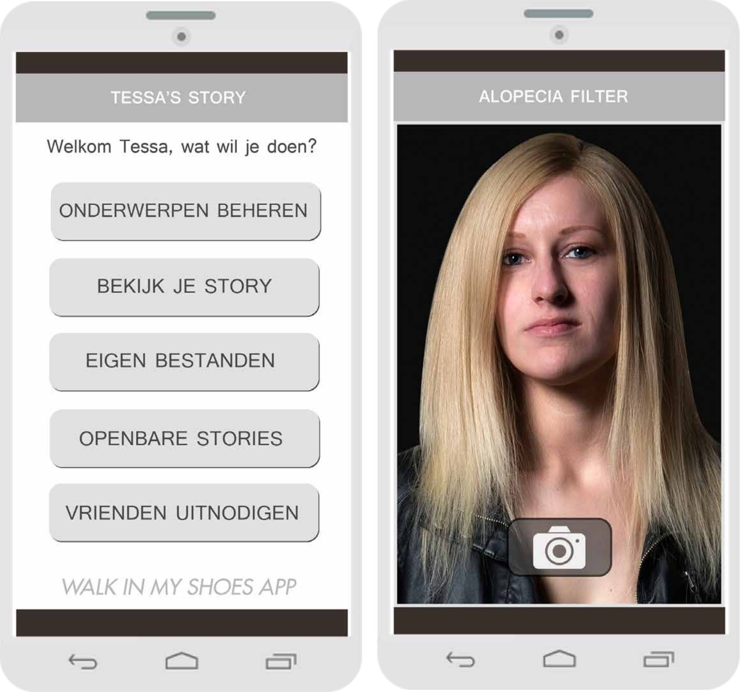
1. Explain ideas
2. Show sketch concepts and evaluate.
 - Participants draw their own design.
3. Let participants integrate the two different sketch concepts.
4. Show own integration design and evaluate.
5. Show high fidelity integrated concept and evaluate.
6. Let participants act out the use of the design (integrated version) with mock-up.

Materials

The concepts were visualized on A3 and A4 pages which were put on the table.
Pencils, blank sheets of paper and sheets of paper with mobile phone templates were provided.

The sketch versions of the two concepts were first shown to the participants so they did not get the feeling like the design was finished and nothing could be changed. After the participants drew their ideas on the concepts and the design of the integrated version of both concepts, a high fidelity version of the concepts and integrated version was shown and evaluated.
Finally, the participants were shown a mock-up of the high-fidelity integrated version of which they were asked to act out the way they would use with their close ones.
The participants were asked if they agreed to audio and video record the session.

On the next pages, the two adjusted concepts and the integrated version will be shown. An example of a sketch version of a concept is shown in figure 5.1. All sketch versions that were used in the co-creative session can be found in appendix 2-20.



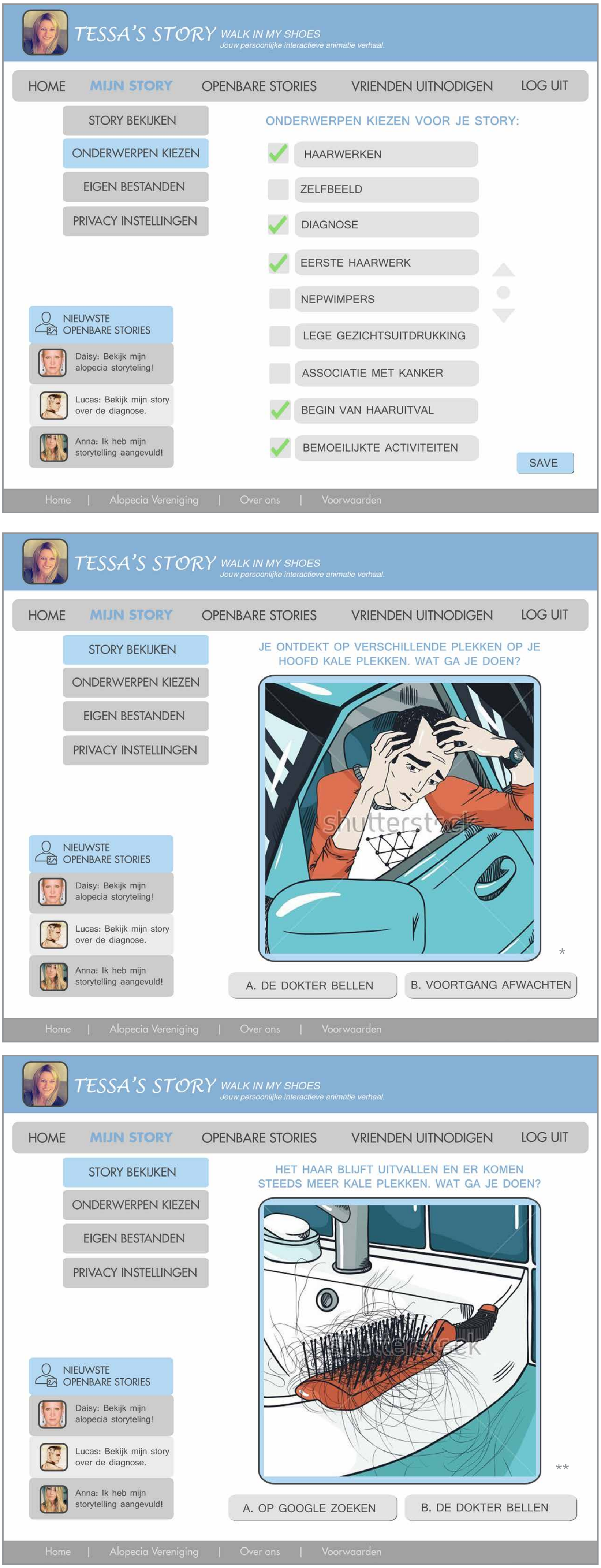
Welkom Tessa, wat wil je doen?

Figure 5.1: Examples sketch version concept*

*Phone illustration by Jerry Low
(https://www.iconfinder.com/jerrylow)

1.1 - INTERACTIVE WEBSITE: "WALK IN MY SHOES"

These new concepts 1.1 and concept 1.2 (see figure 5.1 & 5.2) were originally concept 2.2 (see chapter 4). For the co-creative session, the concept was made for two different platforms: a website and a phone application.



ONDERWERPEN KIEZEN VOOR JE STORY:

☑ HAARWERKEN
☐ ZELFBEELD
☑ DIAGNOSE
☑ EERSTE HAARWERK
☐ NEPWIMPERS
☐ LEGE GEZICHTSUITDRUKKING
☐ ASSOCIATIE MET KANKER
☑ BEGIN VAN HAARUITVAL
☑ BEMOEILIJKTE ACTIVITEITEN

Daisy: Bekijk mijn alopecia storyteling!

Lucas: Bekijk mijn story over de diagnose.

Anna: Ik heb mijn storytelling aangevuld!

JE ONTDEKT OP VERSCHILLENDE PLEKKEN OP JE HOOFD KALE PLEKKEN. WAT GA JE DOEN?

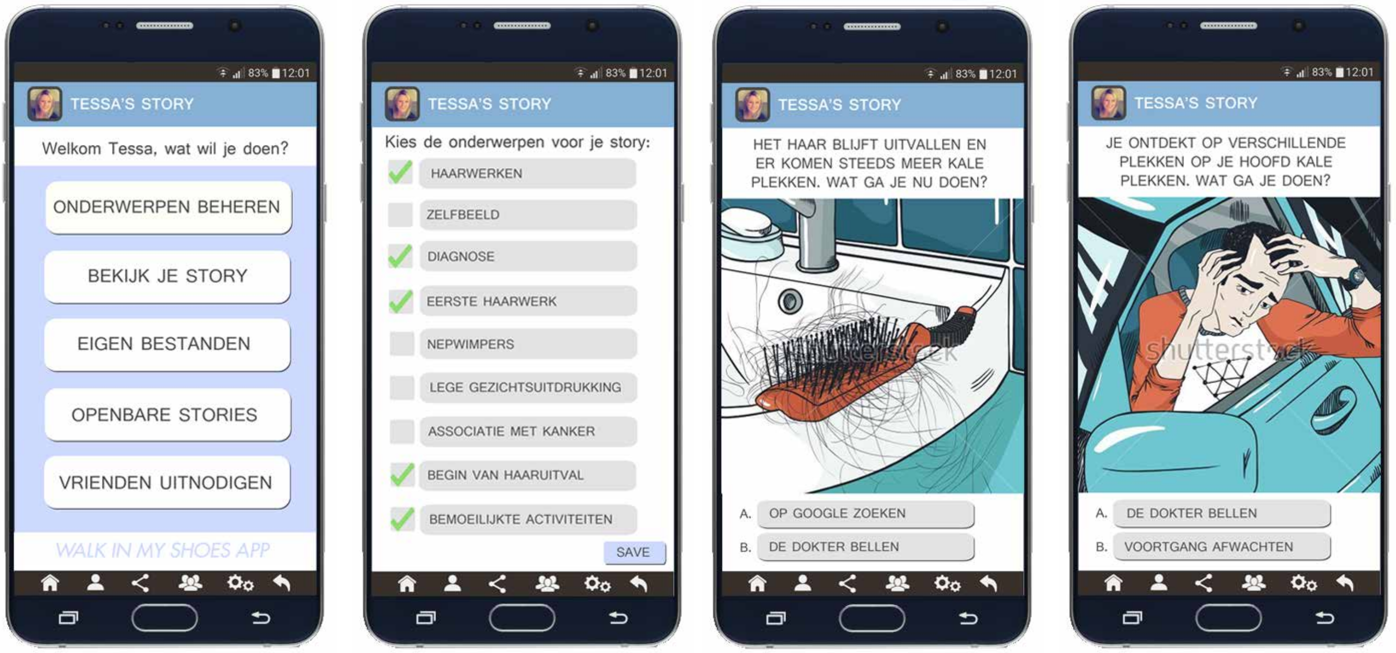
A. DE DOKTER BELLEN
B. VOORTGANG AFWACHTEN

HET HAAR BLIJFT UITVALLEN EN ER KOMEN STEEDS MEER KALE PLEKKEN. WAT GA JE DOEN?

A. OP GOOGLE ZOEKEN
B. DE DOKTER BELLEN

Figure 5.2: Concept 1.1 - Interactive website

1.2 - INTERACTIVE APP: "WALK IN MY SHOES"



TESSA'S STORY

Welkom Tessa, wat wil je doen?

ONDERWERPEN BEHEREN

BEKIJK JE STORY

EIGEN BESTANDEN

OPENBARE STORIES

VRIENDEN UITNODIGEN

WALK IN MY SHOES APP

TESSA'S STORY

Kies de onderwerpen voor je story:

- ☑ HAARWERKEN
- ☐ ZELFBEELD
- ☑ DIAGNOSE
- ☑ EERSTE HAARWERK
- ☐ NEPWIMPERS
- ☐ LEGE GEZICHTSUITDRUKKING
- ☐ ASSOCIATIE MET KANKER
- ☑ BEGIN VAN HAARUITVAL
- ☑ BEMOEILIJKTE ACTIVITEITEN

SAVE

TESSA'S STORY

HET HAAR BLIJFT UITVALLEN EN ER KOMEN STEEDS MEER KALE PLEKKEN. WAT GA JE NU DOEN?

A. OP GOOGLE ZOEKEN

B. DE DOKTER BELLEN

TESSA'S STORY

JE ONTDEKT OP VERSCHILLENDE PLEKKEN OP JE HOOFD KALE PLEKKEN. WAT GA JE DOEN?

A. DE DOKTER BELLEN

B. VOORTGANG AFWACHTEN

Figure 5.2: Concept 1.2 - Interactive app

2. - ALOPECIA FILTER APP

ALOPECIA FILTER

Welkom Tessa, wat wil je doen?

ALOPECIA FILTER

HAARWERK FILTER

MAKE-UP FILTER

DIRECT NAAR VRAGEN

INSTELLINGEN

ALOPECIA FILTER APP

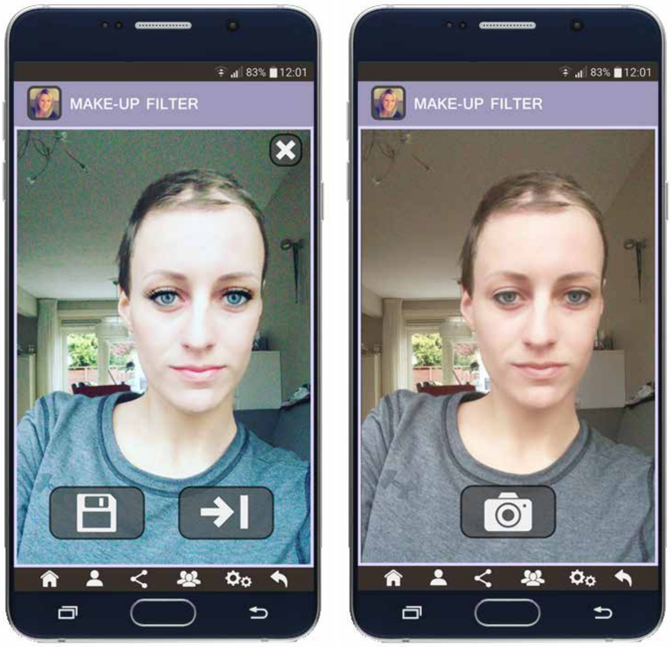
ALOPECIA FILTER

ALOPECIA FILTER

ALOPECIA FILTER

Vragen die je na de filter kan stellen:

1. WAT ZOU JE NU DOEN ALS HET REGENT?
2. ZOU JE NU EEN HAARWERK OF MUTS DRAGEN OF ZOU JE NIETS DRAGEN?
3. STEL JE ZOU GAAN ZWEMMEN, HOE ZOU JE DAT DAN DOEN?
4. HOE ZOU JE NU JE SPORT UITOEFENEN?
5. ZOU JE IETS AAN HET VERLIES VAN JE WENKBRAUWEN DOEN? WAT EN WAAROM?
6. ZOU JE IETS AAN HET VERLIES VAN JE WIMPERS DOEN? WAT EN WAAROM?
7. WAT ZOU JE NU DOEN ALS JE UIT GAAT?
8. ZOU JE ER OPEN OVER PRATEN MET MENSEN? MET WIE WEL OF NIET?
9. ZOU JE BEHOEFTE HEBBEN AAN CONTACT MET LOTGENOTEN? WAAROM?
10. HOE ZOU JE DATEN NU AANPAKKEN?



MAKE-UP FILTER

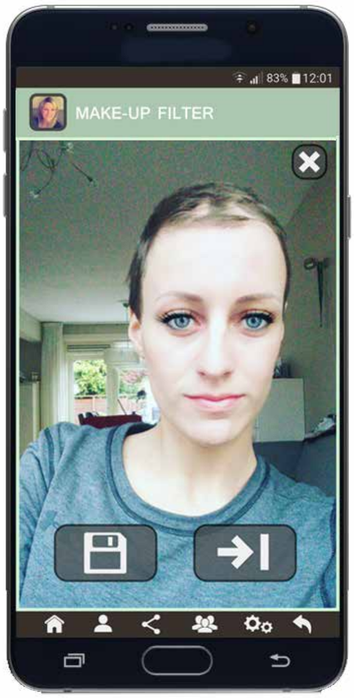
MAKE-UP FILTER

Figure 5.3: Concept 2 - Alopecia filter app

Original illustration by Vera Serg:
* Stockvector-id: 592688030
** Stockvector-id: 592688093

3. COMBINATION CONCEPT

COMBINED FUNCTIONS



POSSIBILITY TO TRY ON DIFFERENT WIGS & MAKE-UP

MORE COLOR ADDED

Welkom Tessa, wat wil je doen?

Kies de onderwerpen voor vragen:

- ☑ HAARWERKEN
- ☐ ZELFBEELD
- ☑ DIAGNOSE
- ☑ EERSTE HAARWERK
- ☐ NEPWIMPERS
- ☐ LEGE GEZICHTSUITDRUKKING
- ☐ ASSOCIATIE MET KANKER
- ☑ BEGIN VAN HAARUITVAL
- ☑ BEMOEILIJKTE ACTIVITEITEN

Figure 5.4: Concept 3 - Combination app

SITUATION QUESTIONS VISUALIZED

JE VRIENDEN VRAGEN JE MEE NAAR HET STRAND. HOE GA JE DAT DOEN?

A. IK DOE NIETS OP M'N HOOFD

B. MET EEN PET OF HAARWERK

*

AL JE WENKBRAUWHAAR IS OOK UITGEVALLEN. WAT ZOU JE DOEN?

A. TEKENEN OF TATOEËREN

B. NIETS DOEN

**

AL JE WENKBRAUWHAAR IS OOK UITGEVALLEN. WAT ZOU JE DOEN?

A. TEKENEN OF TATOEËREN

B. NIETS DOEN

***

5.2 ANALYSIS & RESULTS

There were six participants during the co-create session and later a seventh one joined. The participants were all aged between 16 and 22, with two male participants and two people with alopecia areata, one with alopecia totalis and four with alopecia universalis. Four out of six participants had a later age at onset.

The planning worked well and the co-creative session lasted more than an hour. All participants were enthusiastic to join and to came up with their ideas and thoughts on the development of the chosen concept.

The sketch versions were first shown and the participants were already surprised by the looks of it. They liked the ideas which increased their enthusiasm to join which resulted in discussions about the different subjects of the planning. The participants themselves began to talk about a combination of both presented concepts, already before the integrated version was introduced. This directed the discussion and ideas very quickly towards a mobile application.

All participants agreed that audio could be recorded. The audio was played back and every time there was a discussion or interesting saying, the part of the session was transcribed. The different insights with discussions were clustered into the subjects they belonged to. The most important results are listed below. The full version can be found in appendix 1-15. Some of the discussions were visualized to show the dynamics of the discussions.This session, to get insight from the target group, is a different method than used before and therefore also visualized in a different way.

The drawing part was hard for the participants as they mentioned they did not know well how to visualize their ideas. Some even wrote on the given templates to draw on. Only one participant used colors in her drawing, all the others used just one color which makes it hard to conclude anything about their own thought on a visual style. The most important parts of drawings with their insights were documented. The total drawings can be found in appendix 2-22. The printed screen shot of the Alopecia Vereniging website (see appendix 2-21) in combination with the high-fidelity mock-ups (see figure 5.5) worked well to get an opinion on the visual style.

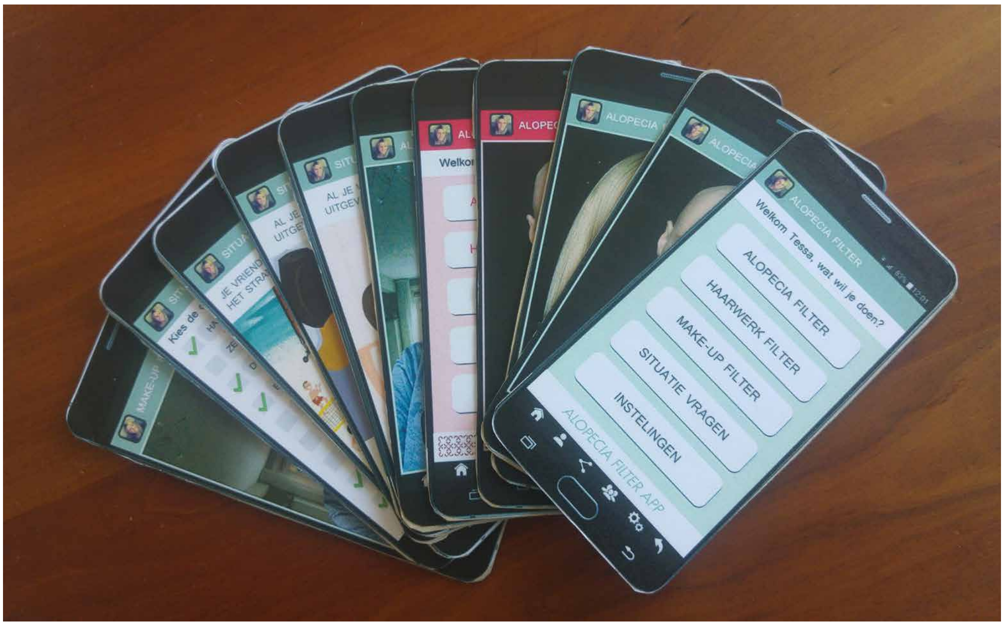


Figure 5.5: Picture high fidelity mock-up

Illustrations:
* Matt Kaufenberg
** Glow Skin Salon
*** Parkside Beauty Centre

VISUAL STYLE APPLICATION

- **Preference for a positive, realistic and serious cartoon style**

All participants agreed that a cartoon style would be best for the situation story. They thought that they would get really confronted when real people would be involved. Cartoon is more calm.

P3: ''If you're gonna use real people, you can think like, hey it's not like that for me, personally. This happens less with a cartoon style because you can better give an interpretation to it.''

Furthermore, all participants prefer a realistic cartoon style. They do not want a 'Donald Duck' or 'weird puppets', they want real people, 'with five fingers and so on'.
The participants do not want a depressive cartoon style, not like alopecia is the end of the world, but something more positive. However, it should not be too happy and should not seem like it is fun.

P3: ''It should stay serious, not depressed but also not happy because then you lose part of your message''.

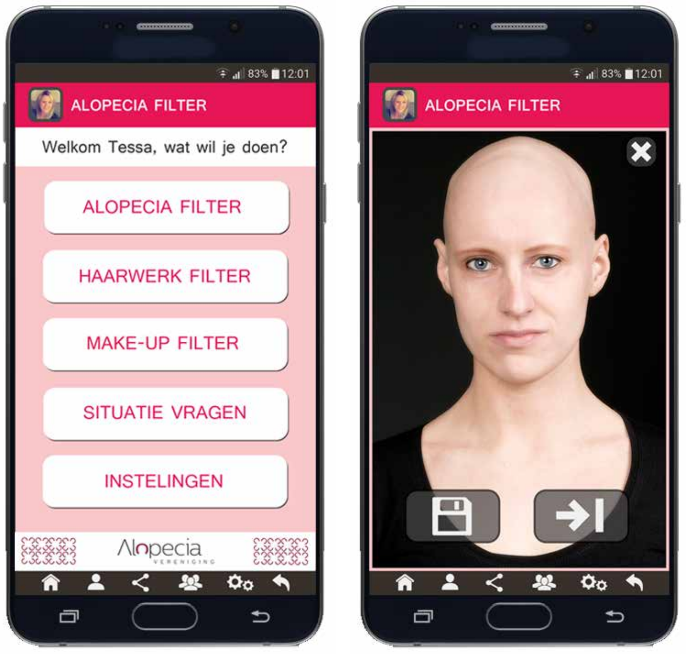


Figure 5.6: Concept in visual style of the AV

- **Preference for green over Alopecia Vereniging website style**

The participants said they prefer a green or grey style over the Alopecia Vereniging style (see figure 5.6). P6: ''*Turquoise, women like it and men are also ok with it, but pink is very girly.*'' P4: ''*Yes and very cliché!*''
Furthermore, they want bright and happy colors.

FUNCTIONS

- **Make-up filter with links to tutorials**

For participant three and five, the link between the intention of the design and the make-up filter was not directly clear. When P2 explained she started using fake lashes after only taking selfies with the make-up filter on Snapchat, they understood. P3 said:
''Maybe it is a nice addition to that, that you can see different make-up looks with it and that you link those to a Youtube movie of how you can make that look yourself. Otherwise, it looks really nice on the app, but how can I do that myself? Here you have a beauty vlogger who does that like that too.''
P6 added to that: *''Like that, you have for example this Masha of Beautyworld, she made a video of how you can cover bald spots. You could link something like that.''*

- **Hats or caps instead of wigs for men**

Participant 1 said that for men you can ask about hats or caps instead of wigs.

- **Permanent make-up**

Participant six said the make-up filter would be good for people to try different eyebrows because a lot of people do not dare to get the permanent make-up because they are scared the shape of the eyebrows will not look nice on them. With the filter, they can just easily try different shapes. P1 agreed to this.

- **Information about wigs in filter**

The participants would like the possibility of links to brands and stores in the wigs filter but for example also to just get more information about different kind of wigs because there are so many different ones. They proposed to link it to the wig information part of the Alopecia Vereniging website, so you do not have to go to random websites.

- **Link to Alopecia Vereniging**

The participants think it is convenient to link the app or website to the Alopecia Vereniging website because there is a lot of information there. *''When you think this seems interesting, I want to know more about that. And perhaps it is possible to make such a make-up tutorial yourself in collaboration with the Alopecia Vereniging.''*

- **Link to Youtube**

The participants do not care if the app has the tutorial information or links you to an external website, the links are more important. When you get directed to Youtube it is also nice that you see some related or recommended videos on the side.

SYSTEM OF THE DESIGN

Switch order in integrated design: see the result of your choices

Without mentioning the existence of an integrated version, participant four started explaining P3 that the idea is to first see the picture and that go through the story. Then, P6 said she would like to see it the other way around because people would easily say they would wait to see what happens. P3 agreed and added: *"Maybe you can have different stages in that filter app, half bald till totally bald. And then when people wait in the interactive app, they will see a picture of that. You take a picture beforehand of who will go through the story and then you see the result of your choices. Then you really go through it yourself and it becomes a lot more personal as well."*
P1: *"That is indeed nice. That when opening the app, you have to take a picture of yourself, now you have hair. And then you will answer questions and you start to lose hair and you'll see your head with some bald spots.'*

Side-line updates unnecessary

P4: *"Something substantive, I don't think you have the need to see this on the side-line at the moment you go through the timeline."*

Preference for app over website

All participants agreed that they prefer an app over a website for the design. P1: *"You'll get much more views and users on the app than on the website."*
P3: *"I also think that if you're going to combine them and during the story you will show the person who's going through it pictures of him, it's gonna be difficult on the computer because not everyone has a webcam. To what extent is a website needed and to what extent is it adding something? Nowadays everyone has a smartphone. I think the app suggests you can use it everywhere."*
P5: *"I would rather go to an app than go to a website."*
P6: *"I think an app will be used much more nowadays. I only use the Facebook app, never the website."*

Choose form of alopecia at the start

P5 mentioned she would like to be able to choose what form of alopecia she has at the beginning of the app.

Experience situations to show people with the design:

1. P4: "Your first bald spot, that you discover it or believing you have a bald spot when someone tell you about that."

2. P6: "Yes I thought I probably became stuck with it somewhere, it will just come back."

3. P5: "Or for people who suffer of it for longer, what it's like to live with it, that you don't have hair. How many things you cannot do then. I cannot remember the first spot. How much you have to think about it, how many problems you have because of it."

4. P3: "Yes things you normally don't think about but you have think about now."

5. P6: "For example a boy who did not understand how annoying a wig is, he said, that is not so different right? I said, imagine you are wearing a hat the whole day. During gymnastics I'm not going to hang upside down. Only then he realised you have think about it with everything. When you get on a bike and there is a strong wind, sh*t a strong wind. People don't think about that."

6. P3: "Yes everyday situations. Because it's mainly those small things you..."

7. P5: "Yes exercising or biking in the wind, such daily small things."

8. P1: "Theme parks."

9. P3: "Imagine it starts to rain."

10. P4: "The moment of the decision, there are so many spots now that you cannot hide it anymore."

11. P1: "Yes, you have so many bald spots, isn't it more wise to shave it off? That was the toughest moment, but also the best decision I made."

- **Order of showing a picture/cartoon depends on the situation:**

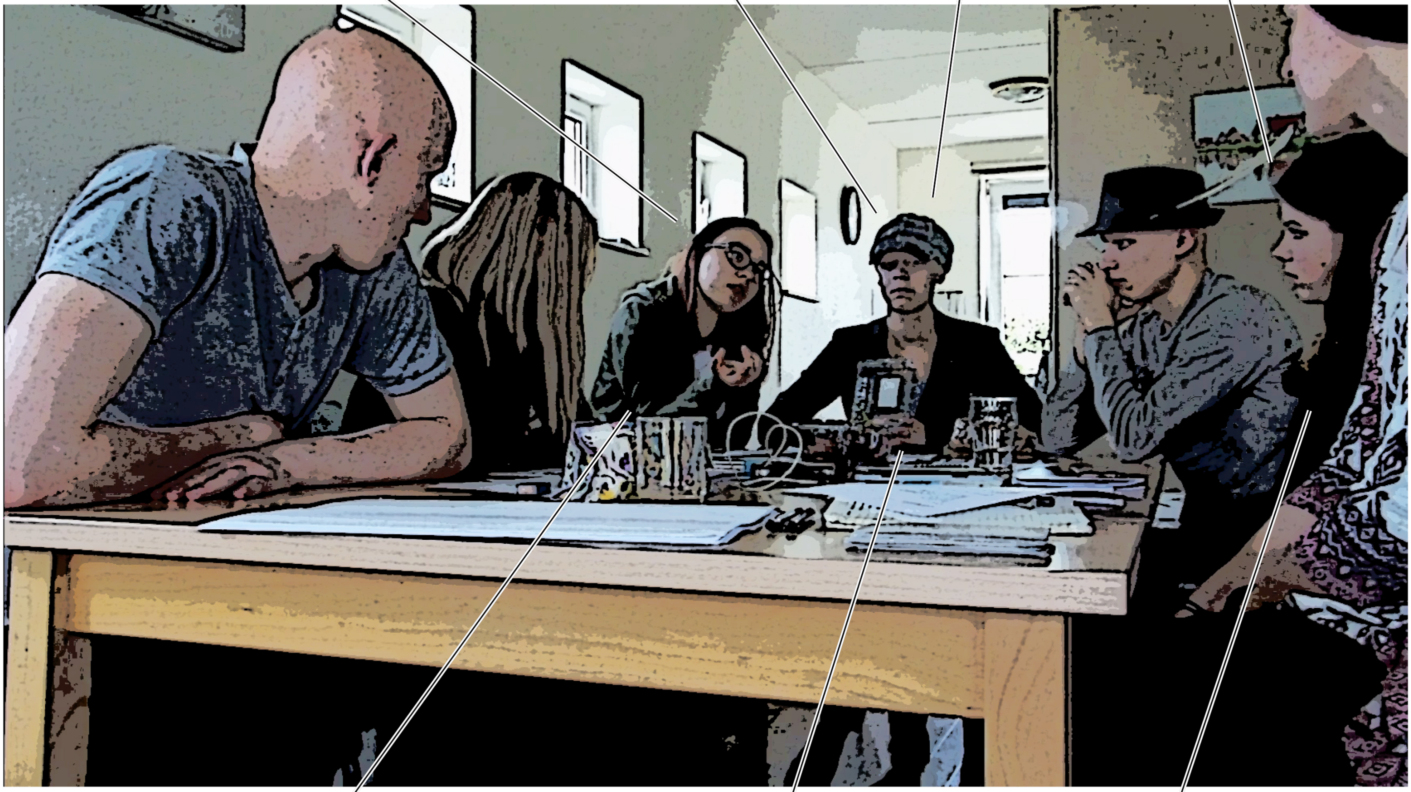
Participants think differently about the order of showing a picture or a cartoon situation first. They concluded that it depends on the situation whether you first see a picture or a *cartoon.*

1. P3: "Yes. For some first the cartoon and when you made a choice, then the picture. Because that shows more what it is about."

2. P5: "When you first answer the question and then see the picture, then you don't know what is going on."

3. P6: "But then you do see the result of it."

4. P5: "You should see that first when you ask what you would do after you see the first bald spot."



5. P3: "I don't know. Do you see the result of the choice to do nothing or to go to the doctor?"

6. P5: "But those bald spots, those you see. Then you have to make a choice."

7. P6: "It just depends on which one. You first see your bald spots, then you first need your own picture. Then you go to the doctor and you cannot see the result of that up front. So for some you have a picture beforehand and for some afterwards."

PSYCHO-SOCIAL ASPECTS

- **Usage of designs**

Participant one said he would not use the make-up filter but would use the story and alopecia filter. He said:
"I would use that alopecia filter, purely to see my class mates bald for once and to say, well that's how that feels!" P6: *"I think you can make people very conscious with that."*

- **Awareness**

Participant three says people can find the alopecia filter design very personal and maybe hard to face. She does not think that is a bad thing. She mentioned videos in which people for one day get make-up to look bald. Those people are shocked as well. She thinks it creates that sort of awareness. People will think about it very differently then.
She said the other interactive app is very personal, your own story which can be nice for people too. P2 agreed: *"Then they can see what we go through."*

- **Link with Snapchat is dangerous**

Link with Snapchat is dangerous
Some participants warned that linking the app to Snapchat can be dangerous. P6: *"With snapchat people make fun of it quite easily. You also have that witch look and then like 'O look I'm bald!' People who do not realize that it is a disease will think it is funny to see it for once."* P6 suggested to link the app to the Facebook page or website of the Alopecia Vereniging.

- **Issue of asking people to use the app and solutions**

P5: *"A lot of people with alopecia don't dare to tell their friends or family so I don't know… Some people have to find a lot of courage to for example fill this in and share it with everyone. A few years ago I was also at a youngsters day with totally different people and almost everyone wore a wig and friends and family of most of them didn't know about it."*

P3: *"Good point, share something is a big step."*
P6: *"Maybe it's a good idea when you don't need to invite friends but you have the app on your phone and you can approach someone. Then he doesn't need to download it. Imagine we would just meet for fun and like, o look you should try this for once. How would you do it? And then you also get into a conversation with each other."*
P3: *"Additionally, you also have friends who live far away. Maybe in the app you can, when you create your story, that you get a code there which you can send to your friends. If they download the app they can enter the code and they can also…"*
P6: *"Only watch out that it's the correct code, that you cannot enter something random and find someone. Or maybe a sort of QR code just like Snapchat."*
P3: *"Or a difficult long code, or a code of two parts."*
P6: *"First a code and then a name. You don't just guess that. Then you don't have think all the time like, o I have to accept, have to accept."*

- Question about self-image

Participant 6 came up with the idea of questioning someone about their self-image after showing a picture without hair. '
*'When you ask someone to shave it or not and he chose yes, then you have a bald picture. Then you could say: Do you think you are still good looking? Because then you make them realize, he sh*t."*
Participant one: *" That is really a diehard question!"*
P4: *"Yes that is really bold."* P6: *"Yes it is a hard question but with that you make people aware of what it does to you."*
P3: *"But it is also very hard for some people. It is not easy."* Participant four: *" No it is not fun and easy but I don't we should scare away people with it. That is too negative."* Participant six said *she would think it to be ingenious when someone would react positive to a picture with hair loss."*

- More personal by using own phone

Participant 4 said it is more personal to invite someone to use the app on his own phone:
"I would rather use it with my own phone. That I approach someone and say: hey you should check this out. Personally you can share it better and it is also more personal to the other when you approach someone with it yourself."

- Different ways of approaching people with the design:

2. P7: "My friends know that I don't feel bad about it, so they would be more interested like, hey how would it look on me?"

3. P2: "I actually don't know. I always ask myself how I will say something before I go somewhere. And then I get there, and it is all different."

1. P1: "Hey mate, you should try this out! See how you feel. Take a picture with this."

4. P5: "I would not dare to ask that at all. I never talk about it with anyone, one person who is around 40 years old. But apart from him I talk about it with nobody. It directly becomes awkward when I start talking about it so I try to avoid that."

INSIGHTS DRAWINGS

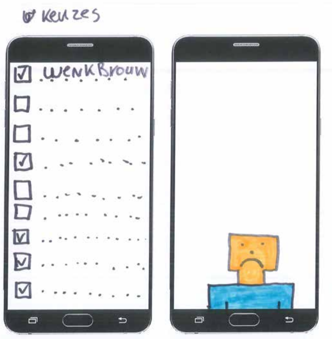


Figure 5.7: Part of drawings P1

P1: First take a picture, then start the story.

Figure 5.8: Drawings P2

P2: First take a picture, then choose what function of the app to start.

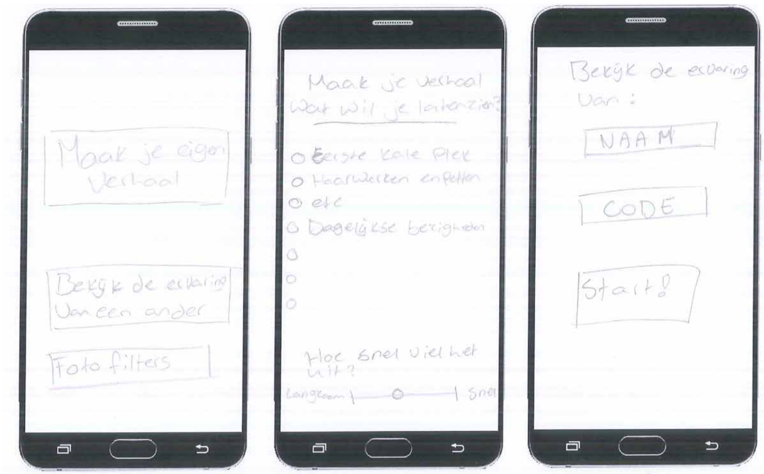


Figure 5.9: Part of drawings P3

P3:
- First take a picture, then start the story.
- Ability to share your story and see the story of other people (with alopecia).
- Share your story with people with a security code and name.

P5:
- First take a picture, then choose subjects for story and then start story.
- Question: Who will you tell about the hair loss?

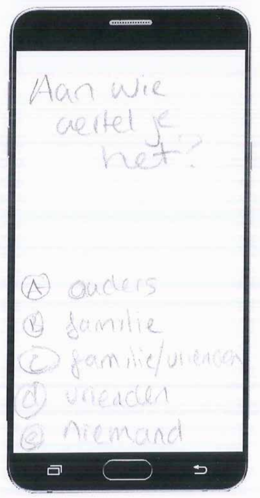


Figure 5.10: Part of drawings P5

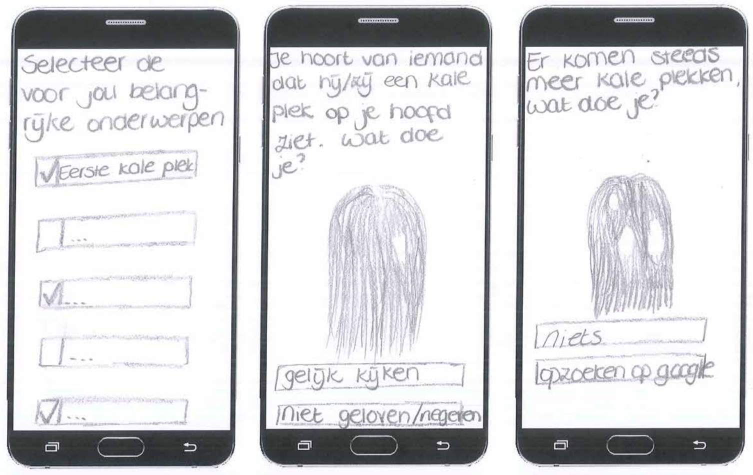


Figure 5.11: Part of drawings P6

P6: First take a picture, then choose subjects and then start hair loss process.

- Conclusions insights drawings

- All participants chose to first take a picture so this should be considered.
- Questions about who you would tell about your hair loss can be included.
- Ter personal story can be given a title and optionally be shared with other people.

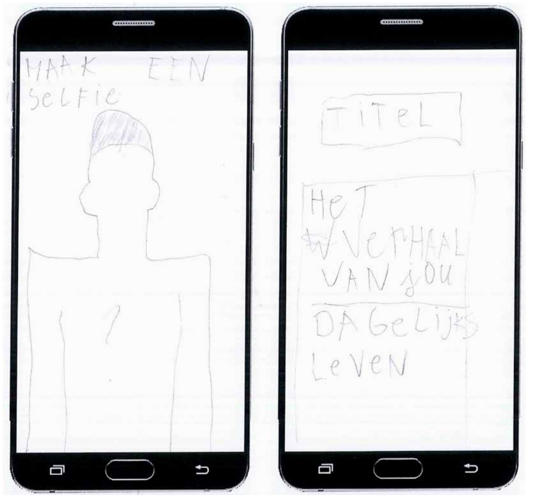


Figure 5.12: Part of drawings P4

P4: First take a picture, then choose a title for your story and then start it.

- **Conclusions co-creative session outcomes:**

Preferences

- Preference for a positive, realistic and serious cartoon style. However, it should not be too happy.
- Preference for green/grey/turquoise style over the AV website style. Especially men do not like the pink. There is a preference for bright and happy colors.
- Preference for app over a website.
- The side-line updates unnecessary when going through the story.
- Experience situation to show people include:
    - Problems and difficulties.
    - Always having to think about it.
    - Things people normally do not think about.
    - Things that are hard or not possible to do.
    - Everyday situations in which you get faced with alopecia.
    - Examples of situations or moments:
        - Exercising, biking, theme parks, swimming, rain.
        - First bald spot.
        - The decision moment when there are too many bald spots to hide it.

Wishes

- Wish for link to make-up tutorials in make-up filter part.
- Link to wig information on the AV website in the hair and make-up filter and/or links to brands and stores. In general, link the app to the AV website because there is a lot of information there.
- Possibility to link the app to the Facebook page or website of the AV.
- For people living further away, a code can be used to let them see your story when they download the app themselves.
- Also include hats or caps instead of wigs.
- Wish to first take a picture and throughout the story people see the results of their choices.
- Add ability to choose form of alopecia at the start.
- Add questions about self-image when alopecia filter is applied.
- The order of first showing a picture or a cartoon should depend on the situation in the story.

Opinions

- The make-up filter is good for people to try eyebrows before choosing for permanent make-up.
- The alopecia filter can create consciousness and awareness of the impact of alopecia.
- The situation story makes people understand what people with alopecia go through.
- Participants would use different ways of approaching people with the design.
- Using your own phone to invite someone to use the app makes it more personal and in this way there is no need to share which can be a big step.
- A link with Snapchat is dangerous because people could make fun of it easily.
- Recommended videos on the side are a positive aspect when getting directed to Youtube with a link.

5.3 CONCLUSION & REFLECTION

The co-creative session was successfully conducted leading to many different insights and point of improvements of the concepts. All participants were enthusiastic in participating and so different serious discussion developed during the session. All these participants were also present during the youngsters day and some of them were visited for an in-depth interview after that day. This might have influenced their thoughts on the design but likely to a small extent, as the in-depth interview was very general and the concepts were specified regarding a specific design goal.

It was clear that all participants had a preference for the integrated version of both concepts in the shape of a mobile application. With this choice for the combination design in mind, the different ideas, thoughts and preferences of the participants were used to make adjustments to this integrated concept version which was shown in the co-creative session. These improvements and adjustments led to the final design.

CHAPTER

06

FINAL DESIGN

THIS SIXTH CHAPTER DESCRIBES THE CHANGES TO THE TESTED CONCEPTS AND.PRESENTS THE FINAL DESIGN: IMAGINE ALOPECIA. IT DISCUSSES ITS FEATURES & INTERACTIONS AND THE STAKEHOLDERS.

After the concept evaluation, two concepts were chosen of which an integrated version was created. This combination design was preferred at the co-creative session and was the starting point to get improved and worked out to the final design: 'Imagine alopecia'.

6.1 FEATURES & INTERACTIONS

The insights and conclusions of the co-creative session, described in the previous chapter, were taken into account when working out the combination concept to the final design.

Adjustments which were made included:
- The story and alopecia filter were merged to one hair loss process: 'Imagine… Your hair loss'.
- The personal gallery aspect of choosing own subjects to show people, combined with the storytelling aspect of showing situations were also merged with the alopecia filter to one function: 'Imagine… My activities.'
- Instead of having an interactive storytelling, it was chosen to show the images with a static question beneath them.
- The order of seeing a photo with alopecia filter or a cartoon image question in the hair loss process depends on the situation. Sometimes the next step in the process results in an appearance change, sometimes a new situation will be shown as a cartoon.
- When applying an alopecia filter, it was made possible to choose between different forms of alopecia.
- The chosen color for the application is green. The combination design in the co-creative session had this and both men and women liked this color.

The main screen is shown in figure 6.1. A user flow of the design can be seen in figure 6.2. The different functions of the design will be explained on the next pages.

Figure 6.1: Main screen of the final design

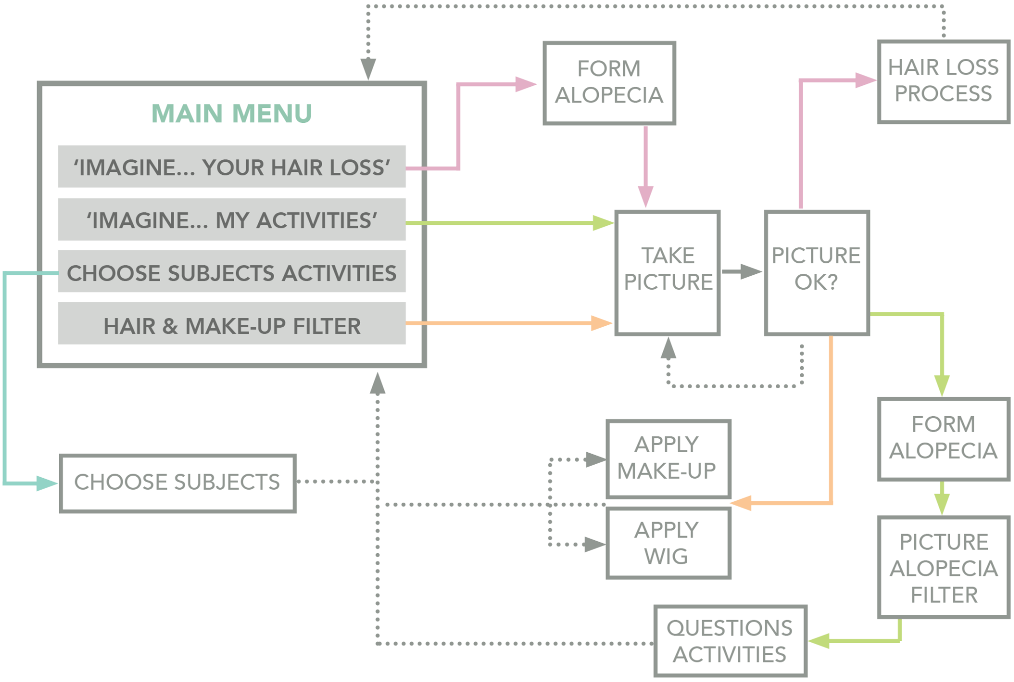
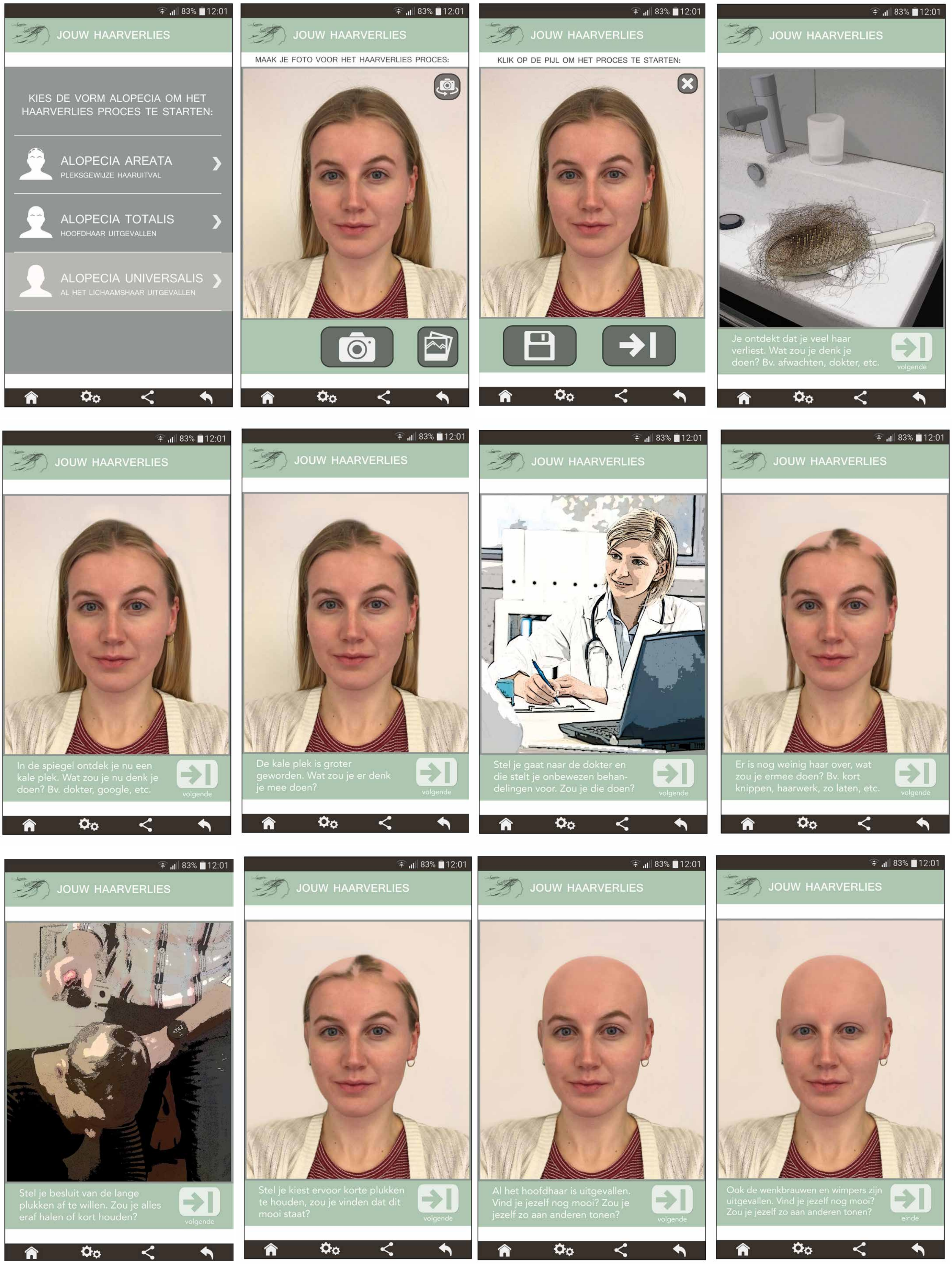


Figure 6.2: User flow of 'Imagine alopecia'

‘Imagine… Your hair loss’



KIES DE VORM ALOPECIA OM HET HAARVERLIES PROCES TE STARTEN:

ALOPECIA AREATA
PLEKSGEWIJZE HAARUITVAL

ALOPECIA TOTALIS
HOOFDHAAR UITGEVALLEN

ALOPECIA UNIVERSALIS
AL HET LICHAAMSHAAR UITGEVALLEN

MAAK JE FOTO VOOR HET HAARVERLIES PROCES:

KLIK OP DE PIJL OM HET PROCES TE STARTEN:

Je ontdekt dat je veel haar verliest. Wat zou je denk je doen? Bv. afwachten, dokter, etc.

In de spiegel ontdek je nu een kale plek. Wat zou je nu denk je doen? Bv. dokter, google, etc.

De kale plek is groter geworden. Wat zou je er denk je mee doen?

Stel je gaat naar de dokter en die stelt je onbewezen behandelingen voor. Zou je die doen?

Er is nog weinig haar over, wat zou je ermee doen? Bv. kort knippen, haarwerk, zo laten, etc.

Stel je besluit van de lange plukken af te willen. Zou je alles eraf halen of kort houden?

Stel je kiest ervoor korte plukken te houden, zou je vinden dat dit mooi staat?

Al het hoofdhaar is uitgevallen. Vind je jezelf nog mooi? Zou je jezelf zo aan anderen tonen?

Ook de wenkbrauwen en wimpers zijn uitgevallen. Vind je jezelf nog mooi? Zou je jezelf zo aan anderen tonen?

areata **totalis** **universalis**

Figure 6.3: Screens ‘Imagine… Your hair loss’

IMAGINE ALOPECIA MOBILE APPLICATION

The mobile application 'Imagine alopecia 'gives people close to someone with alopecia a better understanding of the impact of the condition and stimulates the communication between them.

IMAGINE... YOUR HAIR LOSS

In 'Imagine... Your hair loss' the person close to someone with alopecia goes through a hair loss process. The person with alopecia can choose to start a process until alopecia areata, totalis of universalis, depending on which form he would like to show the other person. When choosing for example alopecia totalis, the hair loss process continues until all hair on the scalp is gone, but will not continue to also remove the eyebrows and eyelashes. When a person with alopecia has chosen the form of alopecia, he can give the phone to someone he feels close with and ask to use this function. This person can now take a selfie and when he is okay with the photo, he can tap the continue button and start the hair loss process. In this way, the person close to him can see what alopecia would look like. This can of course also be a positive reaction, which could support the person with alopecia in a positive way.

By letting someone physically lend a phone, the people must be near each other so it is easy to start the communication when the questions appear. First, the person will see that he is losing hair. Then, his picture is edited and he sees bald spots are appearing. A cartoon picture of a doctor is shown and it is being asked if the person would go for treatments which are not proven to work. The hair loss continues and the moment you doubt to shave or not is present. Consequently, a cartoon of shaving is shown, followed by short hair with bald spots. A question about self-image is asked. When someone has selected alopecia areata, the process stops at this point.

In the hair loss process, the different moments that are included came from the discussion of the co-creative session:
The moment is included when there are a lot of bald spots and not much hair left. The user is asked what he would do in this situation.
The following quotes are part of the discussion in the co-creative session about what situations to show people in the story of the integrated version of the chosen concepts.:

* First bald spot
P4: ''Your first bald spot, that you discover it or believing you have a bald spot when someone tell you about that.''
P5: ''Or for people who suffer of it for longer, what it's like to live with it, that you don't have hair. How many things you cannot do then. I cannot remember the first spot. How much you have to think about it, how many problems you have because of it.''
P3: ''Yes things you normally don't think about but you have think about now.''
P3: ''Yes everyday situations. Because it's mainly those small things you…''
P5: ''Yes exercising or biking in the wind, such daily small things.''
P1: ''Theme parks.''
P3: ''Imagine it starts to rain.''

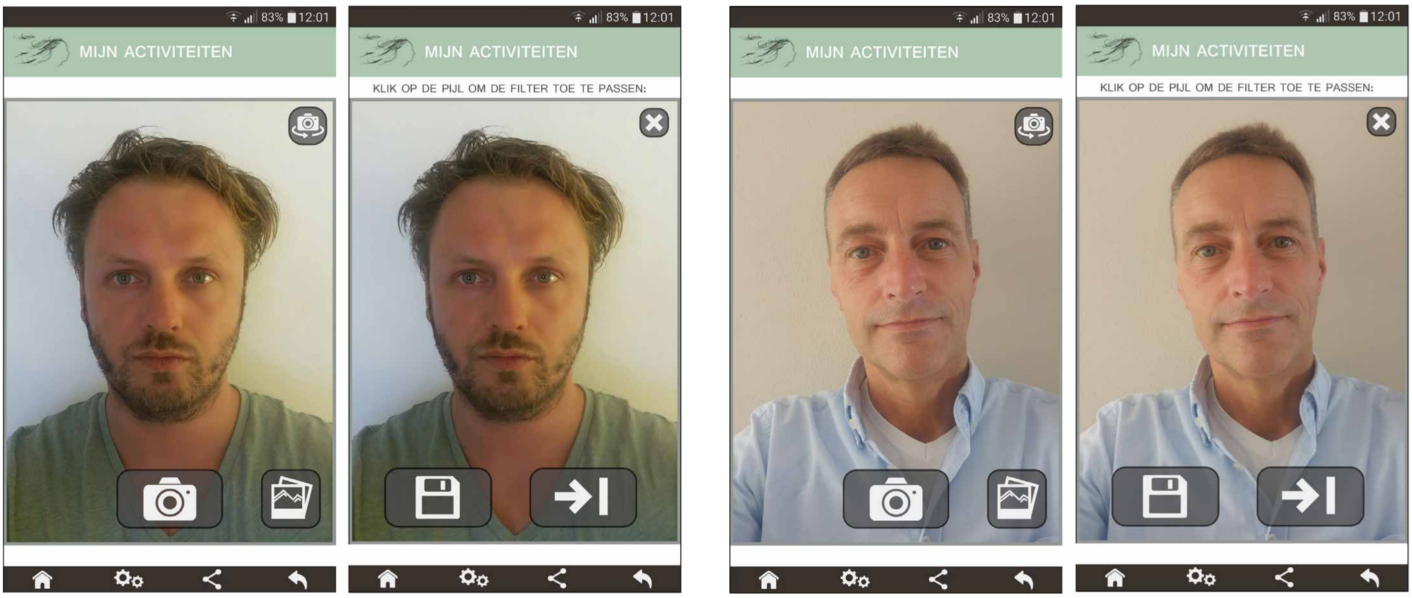
* Decision moment of shaving
P4: *''The moment of the decision, there are so many spots now that you cannot hide it anymore.''*
P1: *''Yes, you have so many bald spots, isn't it more wise to shave it off? That was the toughest moment, but also the best decision I made.''*

* Question about self-image in hair loss process
*P6: ''When you ask someone to shave it or not and he chose yes, then you have a bald picture. Then you could say: Do you think you are still good looking? Because then you make them realize, he sh*t.''*
P1: '' That is really a diehard question!''
P6: ''Yes it is a hard question but with that you make people aware of what it does to you.''
P3: ''But it is also very hard for some people. It is not easy.''

Because of this idea, the question about the self-image of the close one was included when reaching the end of the hair loss process.

'IMAGINE...MY ACTIVITIES'

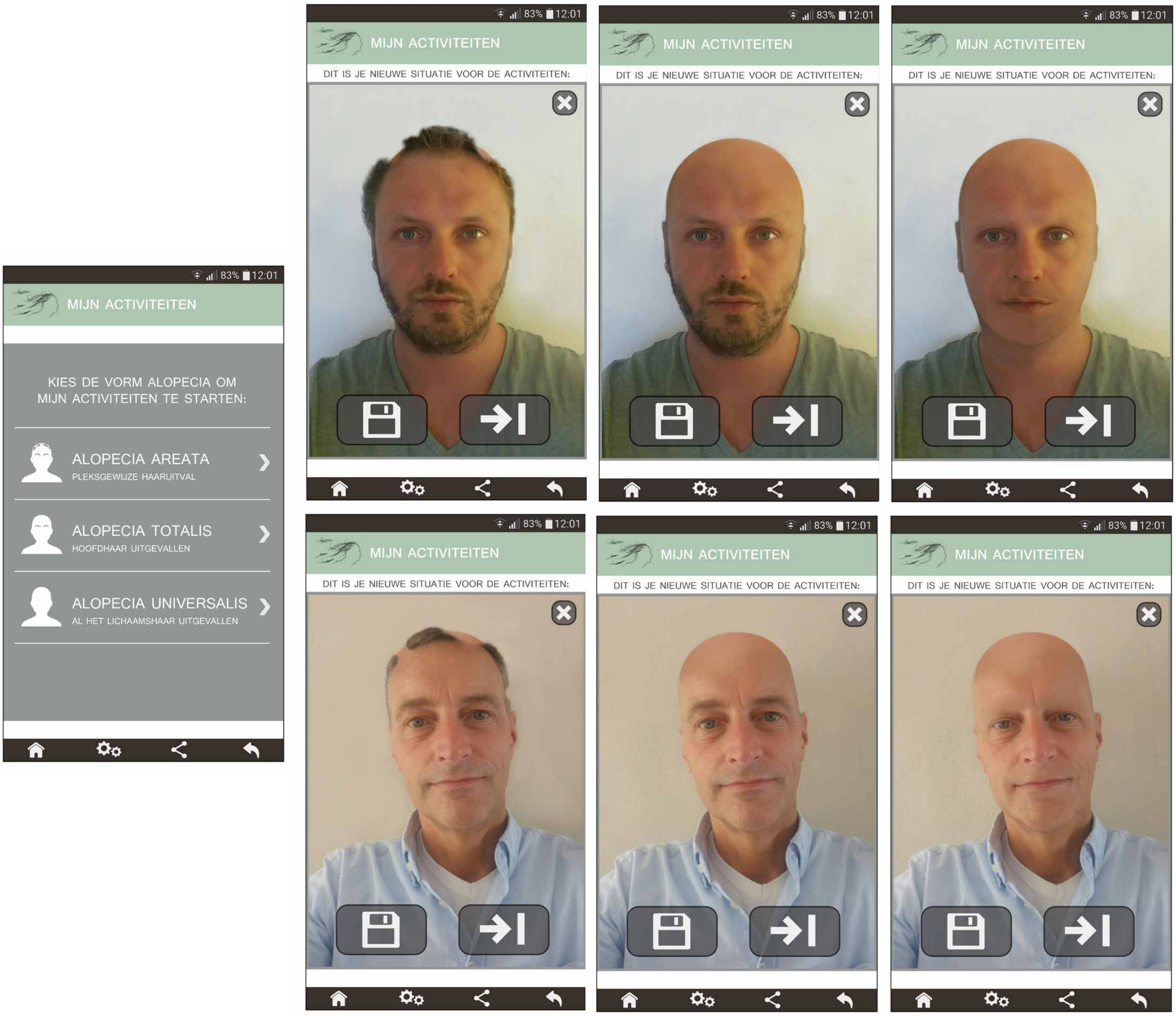
In 'Imagine... My activities' the person with alopecia can again choose a form of alopecia and then give the phone to someone he is close with to take a selfie. Then, this person gets an alopecia filter applied. The app says 'Suppose this is your new situation for the activities.' After the filter, the person can tap continue and different situations are shown in cartoon style with questions like how the person would act in this situation, see figure 6.4 and 6.5. The different activities and situation the person would like to let other people think about can be chosen in the additional menu: choose subjects for my activities (see figure 6.6). In chapter 3 was described that participants of the in-depth interview chose pictures and words on picture & word sheets which they had associations with regrading a question. An overview of the chosen



KLIK OP DE PIJL OM DE FILTER TOE TE PASSEN:

KLIK OP DE PIJL OM DE FILTER TOE TE PASSEN:

'Imagine... My activities'



KIES DE VORM ALOPECIA OM MIJN ACTIVITEITEN TE STARTEN:

DIT IS JE NIEUWE SITUATIE VOOR DE ACTIVITEITEN:

DIT IS JE NIEUWE SITUATIE VOOR DE ACTIVITEITEN:

DIT IS JE NIEUWE SITUATIE VOOR DE ACTIVITEITEN:

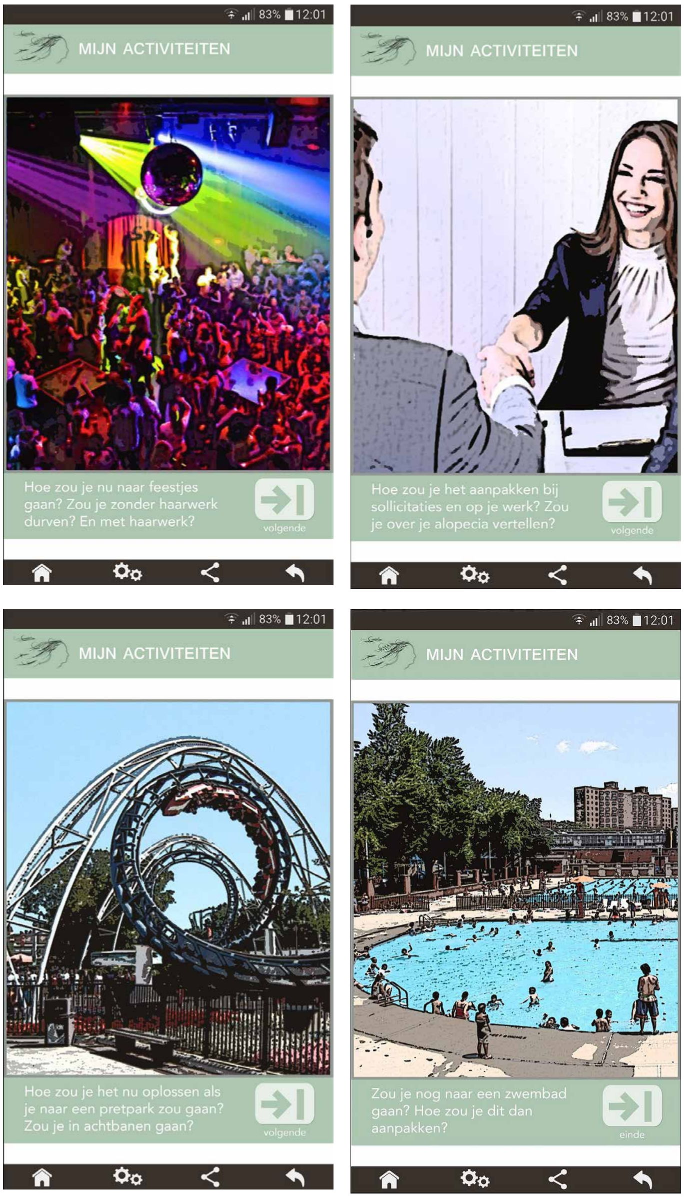
DIT IS JE NIEUWE SITUATIE VOOR DE ACTIVITEITEN:

DIT IS JE NIEUWE SITUATIE VOOR DE ACTIVITEITEN:

DIT IS JE NIEUWE SITUATIE VOOR DE ACTIVITEITEN:

areata **totalis** **universalis**

Figure 6.4: Screens 'Imagine... My activities'



Hoe zou je nu naar feestjes gaan? Zou je zonder haarwerk durven? En met haarwerk?

Hoe zou je het aanpakken bij sollicitaties en op je werk? Zou je over je alopecia vertellen?

Zou je durven te daten? Zou je over je alopecia vertellen op je date? Na hoeveel dates?

Hoe zou je het nu oplossen als je op vakantie gaat of gaat reizen (met nieuwe mensen)?

Hoe zou je het nu oplossen als je naar een pretpark zou gaan? Zou je in achtbanen gaan?

Zou je nog naar een zwembad gaan? Hoe zou je dit dan aanpakken?

Figure 6.5: Screens activities of 'Imagine... My activities'

KIES DE ONDERWERPEN VOOR MIJN ACTIVITEITEN:

☑ PRETPARKEN
☐ AANMELDEN VERENIGING
☐ OP STAP MET SLECHT WEER
☑ UITGAAN/FEESTJES
☑ VAKANTIE/REIZEN
☑ DATEN
☐ LOGEREN/SLAAPFEESTJES
☑ SOLLICITEREN
☑ ZWEMMEN

Figure 6.6: Choose subjects for activities.

Talk about alopecia:
- *Dating*
- *Tell friends / family / neighbors*
- *Join Alopecia Vereniging*

Sports & hobbies:
- *Swimming*
- *Mountain biking*
- *Helmet*
- *Dancing*

Wigs & PMU:
- *PMU or not*
- *What kind of wig*
- *New wigs*

Daily activities:
- *Going out the house with bad weather*
- *Biking*
- *Trying on clothes at home or store*
- *Children like to play with hair*

Work / school:
- *Class*
- *Colleagues*
- *Job interview*
- *Medical or wig related appointments*

pictures per participant with short descriptions of why they chose a specific picture was put in appendix 2-13. A lot of the chosen images contained activities or daily life aspects which they talked about.
These activities and daily life aspects served as a basis for a selection of activities that were put in the final design to give people an idea of what kind of activities they could choose to include in their 'Imagine… my activities'.
Moreover, the activities and daily life aspects the participants of the co-creative session mentioned were taken into account when creating this list (see the insights in chapter 5).

Other activities:
- *Travels / trips*
- *Theme parks*
- *Parties / festivals*
- *Sleepover (parties)*

Hair & Make-up filter

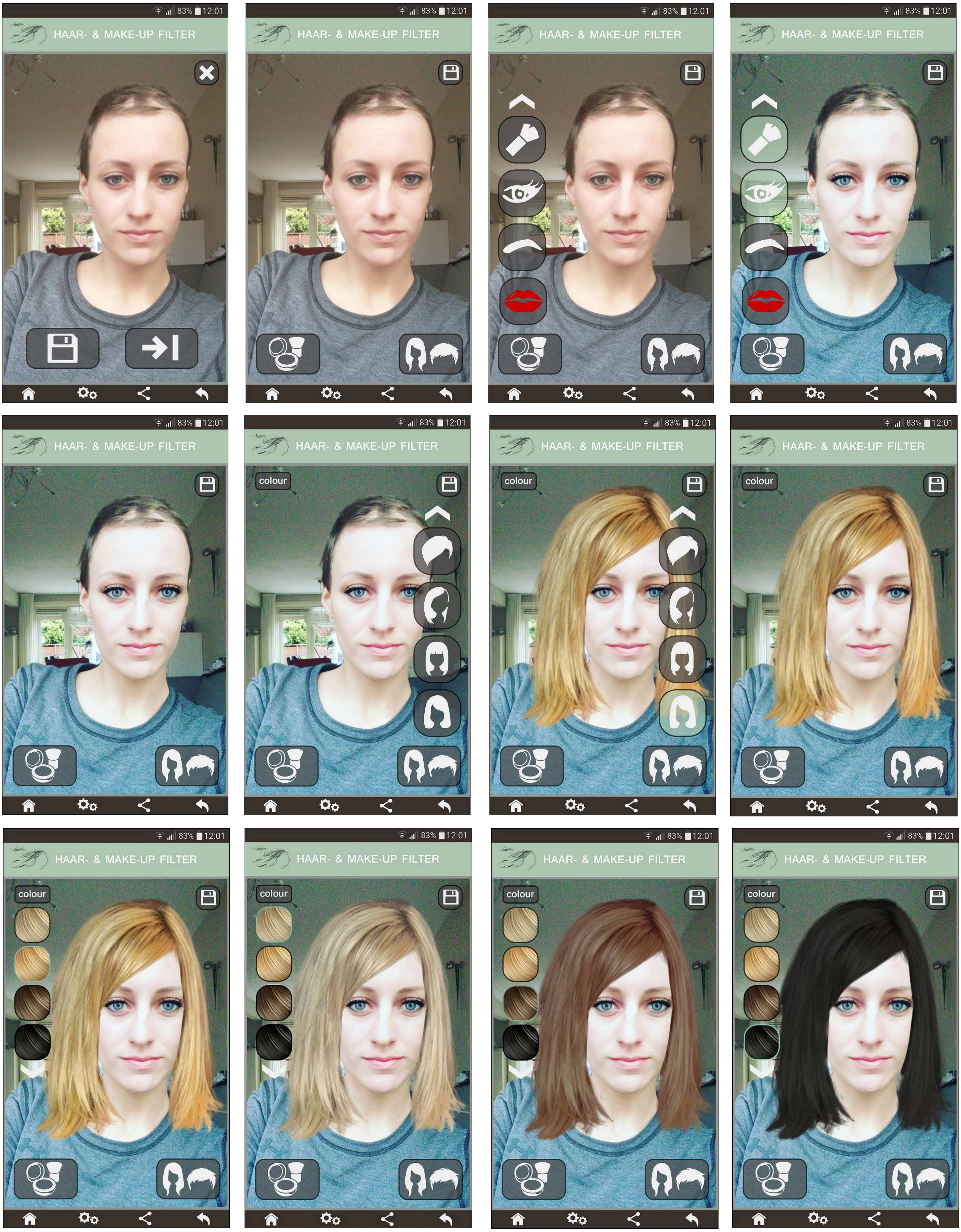


Figure 6.7: Screens 'Hair & Make-up filter'

HAIR & MAKE-UP FILTER

In the part ‘Hair & Make-up filter’ the person with alopecia can try on different wig and make-up filters to see what kind of wig or make-up would look good. Most of the screens of this part can be seen in figure 6.7, the other ones (hair filter without the make-up applied) can be found in appendix 2-23.
This function was clearly wished for by multiple participants of the concept evaluation as well as the participants of the co-creative session and so was included in the design, for example:
- *‘’I would design the filter app with wigs, in this way you can see what suits you.’’*
- *‘’The option to choose different wigs, also for yourself and friends, hair styles and colors.’’*
- *‘’That you can choose wigs as a filter. Apart from that the idea is great!’’*
- *‘’For example make-up advice.’’*

Unlike the two other parts of the application, this part is mainly used by the person with alopecia. On the other hand, the person with alopecia can try out different wigs and make-up with people close to him and ask advice about what looks good. Perhaps, also the other person without alopecia would like to use it to see what hair style would fit him and what he would choose when he would suffer of alopecia.

6.2 STAKEHOLDERS

As this final design had a clear target group and was designed with assistance of the Alopecia Vereniging, an association for which this final design might be useful to provide to her members, there are a few clear stakeholders:
- People who suffer of the alopecia conditon, as the people close to them will get a better understanding of the impact of their condition, will be better able to support them and the communication between both parties will be improved.
- People who are close to someone suffering of alopecia, as this group of people will get a better idea of how to provide the right support and gets a better understanding of the experiences of this person and the impact the condition has on him. This group of people usually do not know to provide the right support and when to provide it. Because the design stimulates communication, it requires less initiative of this group to start the communication.
- The Alopecia Vereniging, as the final design will be proposed and it could be further worked out and / or realized by her. The association could provide her members with the ability to download it.

6.3 CONLUSION & REFLECTION

The final design ‘Imagina alopecia’ combines elements of different developed concepts and implements insights from the different conducted studies like the interviews, concept evaluation study and co-creative session. In general, the mobile application gives people close to someone with alopecia a better understanding of the impact of the condition and stimulates the communication between them. The design contains three main functions:
- ‘Imagine... Your hair loss’;
- ‘Imagine... My activities’;
- ‘Hair & Make-up filter’;
- And additionally: ‘Choose subjects for activities’.

This final part serves to be able to choose the subjects and situations to include in ‘Imagine... My activities’. The first two function are intended to use together with someone close, which adds to understanding of the impact of alopecia and stimulates the communication by showing what alopecia would look like to him and letting the other party think about what he would do in different situations during hair loss and (daily) activities.

CHAPTER
07

DESIGN EVALUATION

CHAPTER SEVEN COVERS THE DESIGN EVALUATION STUDY WHICH WAS CONDUCTED AT THE NATIONAL ALOPECIA FAIR. IT DESCRIBES ITS SET-UP, RESULTS & ANALYSIS AND CONCLUSIONS AND DISCUSSES A FINAL ADJUSTMENT TO THE FINAL DESIGN 'IMAGINE ALOPECIA'.

The design evaluation was planned to obtain insight in the opinions of the target group on the final design after having them revised with the input of the co-create session. These insights served to be able to make final adjustments to the final design and write recommendations.

7.1 SET-UP

The final design was evaluated at the National Alopecia Fair organized by the Alopecia Vereniging. The fair was held on the 27th of May, 2017 at castle 'Kasteel van Rhoon' in Rhoon. The National Alopecia Fair is an information fair of three hours on which different companies present their products and/or services, like hats wigs, hair pieces, maintenance products, lashes, make-up, nutrition, psychological support, etc. The fair is free to enter for all members of the association.
It was possible for the companies to get a stand on the fair and the final design was also presented on such a stand.

The size of the table of the stand was 140 x 80 cm and on it the final design was presented by showing an A1 poster (see appendix 1-19) explaining the final design, smaller posters explaining the different parts of the design and pictures of people using the app together, two phones and tablet with a prototype. People got the chance to try the design on the phone and tablet.

The people who were told about the design, read into it and tried the prototype were asked to fill out a survey. Two different surveys were created, one for people with alopecia, one for people close to someone suffering of alopecia, see appendix 1-17 and 1-18. An English translation of the open questions can be found in appendix 1-16.

The surveys cover questions about the opinions of people on the final design in general, on the different parts of the design and on its logo.

Figure 7.1: Participants trying the prototype

During the design evaluation, no video was recorded as the design got evaluated in a sensitive setting. People who come to the fair are not always open about their alopecia and some might not like to get recorded. Pictures were taken of the stand and if possible of people using the prototype, see figure 7.1 and 7.2.

Figure 7.2: Set-up at alopecia fair.

7.2 ANALYSIS & RESULTS

In general people were enthusiastic about the design and were already asking where they could download it. They often mentioned that they liked it that something was developed for people with alopecia.

The participants filled out the surveys at the national alopecia fair organized by the Alopecia Vereniging. In total, nine people with alopecia and eight people close to people with alopecia participated. Of the nine participants with alopecia, eight were female. The ages of these participants with alopecia varied from 18 to 59. Three participants were aged between 20 and 34.
The ages of the participants of people close to a person with alopecia varied from 27 to 56.

SURVEY SCORES

For analysis of the results of the survey scores (see appendix 1-20), the participants were ordered according to the duration of suffering of alopecia. This was done to see if there are any differences in the way they perceive the aspects of the design. Also, the participants were ordered in such a way, that the person with alopecia could be easily compared with the person close to him, who also filled out the survey.
The scores participants gave to the different aspects of the final design were documented in two different tables, one with the participants with alopecia, one with participants close to someone with alopecia. The average scores were calculated per group per aspect of the design to be able to compare them. In this way, it was possible to see in what way the groups differed from each other when scoring the aspects. Of each part of the design, a graph was made to compare the average scores of the different participants groups, see figure 7.3 - 7.5.

The results of the scores:
When comparing the general scores of people with alopecia and their close ones, it can be seen that the hair loss process part is appreciated more by close ones. The activities part is almost equally scored but a bit higher by people with alopecia. The hair and make-up filter part was more appreciated by participants close to someone with alopecia.

Among participants with alopecia, at almost each aspect, part 2 scores higher than part one (hair loss). The participants with alopecia score high on 'adds to sympathy' for part one and two. The two aspects on which part one (hair loss) scores a bit better is the extent to which participants think it would help their friends and to what extent it is confronting. Part one could be improved on aspects like how much fun it is do and how much they think their family and friends would like to do this. Part two could also get improved on the aspects. These participants are the ones who have the initiate the use of the app.
For the Hair- and make-up filter, the participants think it is fun, convenient and it would help them. This part scores low on being confronting but also rather average on 'I would use it'. The participants consider this part more fun to use than the other parts but however think they would less use it. So the third part could be more focused on how to improve the chance that people with alopecia will use it, for example by adding the proposed function from the co-creative session and link wigs and make-up to information and tutorials. One participants scored the hair & make-up filter low because this was a male participant who does not wear wigs or make-up. Additional features could be added for this group within the target group.

Among participants close to someone with alopecia, all three aspects score equally on to what extent it would be helping. In contrary to the scores of the participants with alopecia, part one and two are both liked equally in general. It differs per aspect which part scores higher. The participants think that part 2 (activities) would stimulate providing support more than part 1 (hair loss) but part one adds more to their sympathy. The participants consider part 1 to be more confronting. The participants think part two would help the person with alopecia more and he would like it more to do that part.
All participants score rather low on whether it would help themselves. So part one (hair loss) could be improved on stimulating providing support and it can be made a bit less confronting, however, the open questions showed that this is not always considered a bad thing.

For the Hair- and make-up filter, the participants think it would help the person with alopecia and that it is convenient. It scores low on whether the person with alopecia would use it as also among these participants there was a mother of the male participant. This part scores lowest on whether the person with alopecia with use it and the support and fun aspects. So the third part could be less

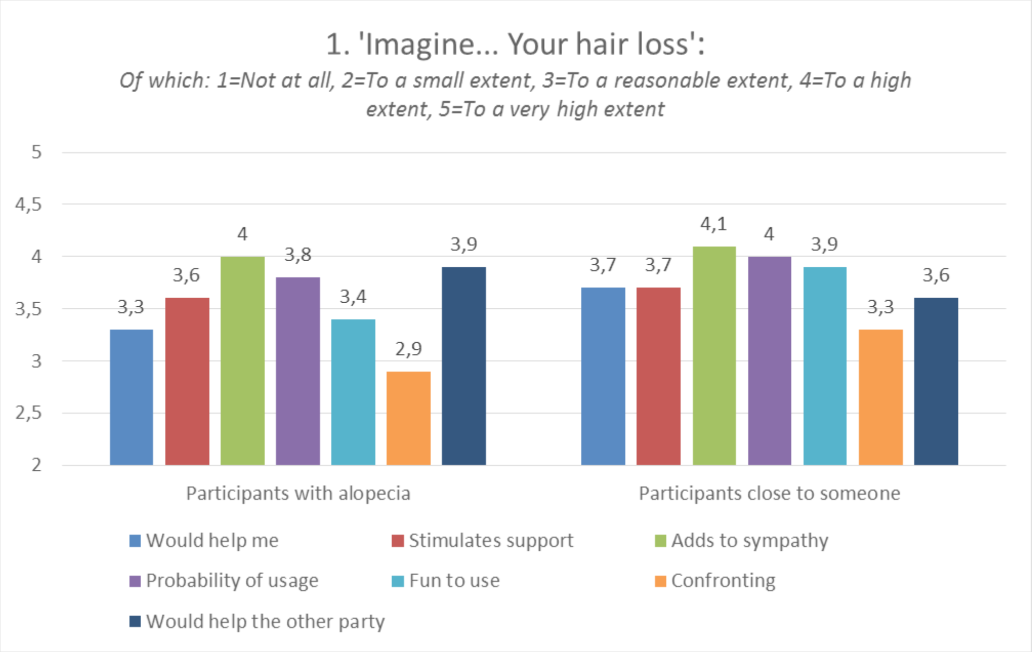


Figure 7.3

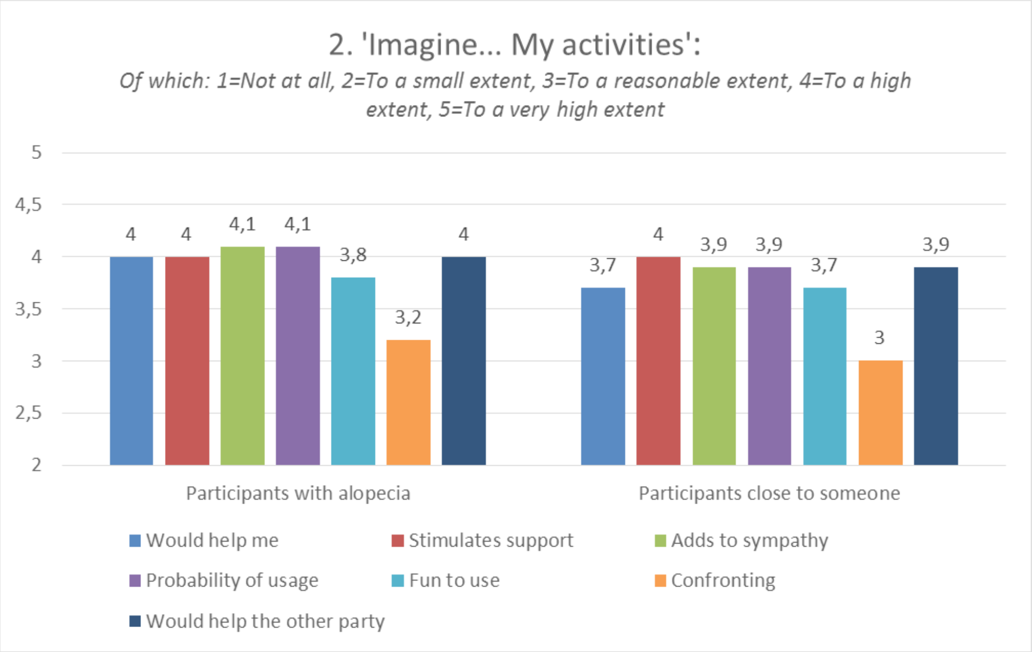


Figure 7.4

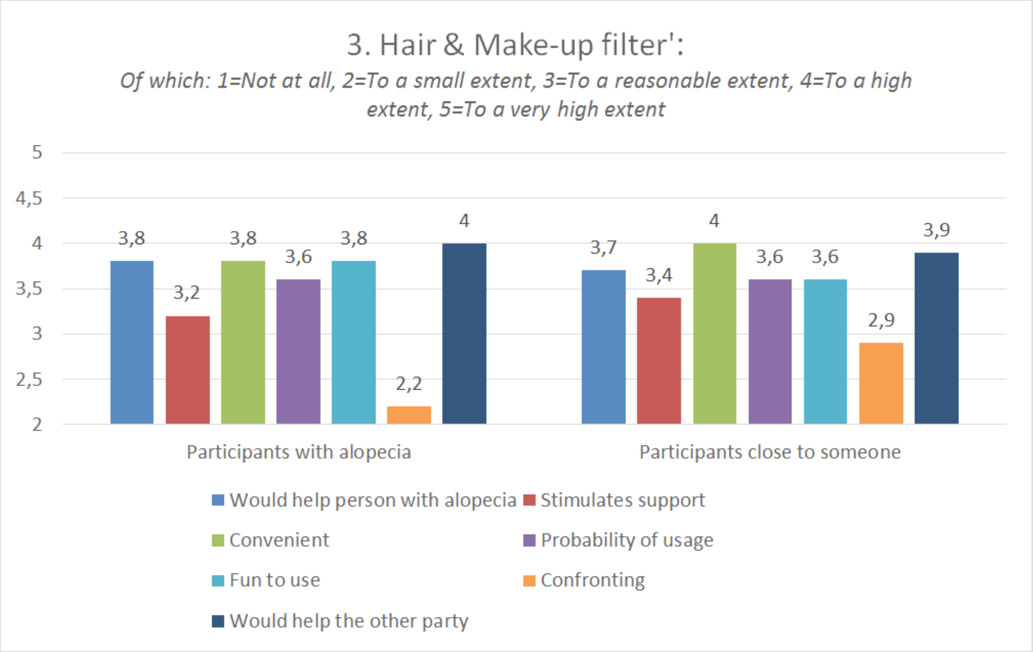


Figure 7.5

confronting and more fun and stimulating support for the person with alopecia.

In total there were five couples of people were close to eachother. Of these five people, their scores were put next to each other.

OPEN QUESTIONS

Apart from the survey scores, the participants answered open questions. The answers per question of all participants were put beneath each other for both groups to be able to compare them. The most important insights:

Participants with alopecia:
- All participants are positive and enthusiastic about the final design. They think it is good, original and innovative. One participant said it stimulates the communication.
- Five out of nine participants like that you can make things clear to other people and they can replace themselves. Two participants add to this that it adds to communication, which is especially hard in the beginning. Furthermore two participants like that it is very approachable and three participants think the app is very clear and simple to use and understand.
- One participant wondered when you would use the app. Another participant thinks there is a boundary to communicate it to other people.
- Most participant would use the app with their parents so they can better understand. One participant would not use it with her mother as her mother already feels so bad about it. Another participant said she believes the app would have added to the communication between her parents as she could not express her emotions with them. One participant doubts whether it would help his parents because he already discusses everything with them.
- All participants think the app would help their friends to better be able to replace themselves and understand the impact. For friends it is more often hard to understand. One participant said that it can make her communicate her emotions and fears and it adds to understanding, support and communication. She thinks people with alopecia often tend to not talk about it out of fear for hurting. One participant said it would help his friends to understand why he cannot do some activities.
- All participants would probably use the app. Six out of nine participants would use it especially with their friends. One participant added to this that she would only use it when someone is really willing to do this with her.
- Seven out of nine participants do not think the design is confronting. One participant thinks it is confronting, but so is alopecia. Another thinks it is a bit confronting, especially alopecia universalis, but soothed.
- Six out of nine participants do not prefer a cartoon version of the alopecia filter. One of those participants said realistic is better. Another participant suggests to use a cartoon version for young children in order to let them explain at school and to friends in a playful and educative way.

Participants close to someone with alopecia:
- All participants are positive about the final design 'Imagine alopecia'. They think it is good and beautiful. One participant said it can also make people more aware of what alopecia is and what the consequence of it is, one said it makes it better discussable and another participant said it gives her more insight into the condition.
- What participants like about the design is that it makes alopecia more discussable, adds to understanding for both people close to the person with alopecia as well as for people less close, the filters to imitate the process and the possibility to use your own picture and that it adds to understanding of daily obstacles. One participant said that because of her improved understanding she is able to better support her mother. It is also a very clear app.
- One participant wonders how many times you would use it.
- All participants said it would help them to go through the hair loss and activity parts, it would help them to better replace themselves in the situation and one participant said it would help to make it possible to talk about the subject without making it 'heavier'. One participant also said it can make her more aware of the small daily struggles and another said that thinking about it makes it possible to help think of solutions.
- All participants would like to go through the hair loss and activity parts, but one wondered how often you would use something like this and one said it would be confronting. One said thinking about solutions together gives her a feeling of being involved.
- Six out of eight participants would use it. One participant would only use it in the beginning but later on not anymore and for one it depends if she can use the information of the app as an addition to conversation with other people about it.
- Only one participant suggested a change, she would like to see more daily activities in the activities part of the app.

- Two out of eight participants think the design is confronting but not offending, four participants think it is not confronting of which one thinks it is respectful and one thinks like that the app makes it discussable.
- Three participants said they would not prefer a cartoon version, one suggested to leave both options open. One participant thinks a cartoon version would make it impersonal, while it is about people and another thinks that in some cases real images could maybe scare off some people.
- All participants are positive about the logo except for one who does not like it because of double line usage. One participant said it looks a bit like a shampoo logo but gets the idea when taking a better look at it. Another participant mentioned that a color distinction would make the losing hairs more clear.

FINAL ADJUSTMENT

The design evaluation showed that the menu to choose the activities for 'Imagine... My activities' should be improved. Participants wanted to see more different acticities and more daily activities. The menu was changed into two different screens instead of one, see examples in figure 7.6 and all added screen in appendix 1-21. When selecting the choose subjects for activities part, people first go to a menu to choose from a subject cluster and then go to the screen with subjects to choose from that cluster.
Also, the new screens visually better fit the rest of the app.

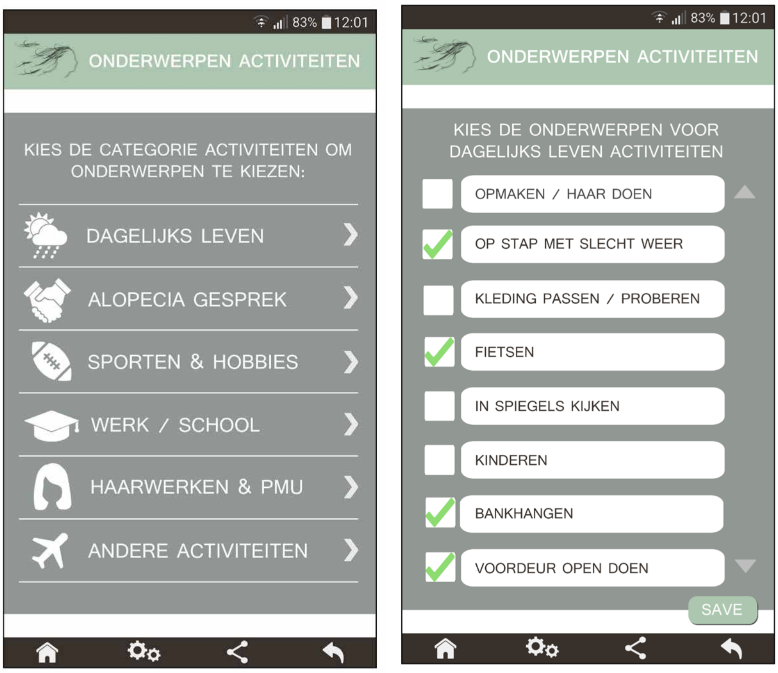


Figure 7.6: New adjusted screens.

7.2 CONCLUSION & REFLECTION

The design evaluation served to have a last moment of reflecting on the design 'Imagine alopecia'. In general people were enthusiastic about the design and were already asking where they could download it. They often mentioned that they liked it that something was developed for people with alopecia.

It can be concluded that the evaluation results in general showed that the target group and their close ones think the design adds to sympathy and understanding. Some points for reconsidering are the moment of use of the app, the long-term duration of usage, the boundary to communicate it to other people and the aspect of what to do when someone already communicates to his close ones?

Concerning the evaluation scores, although being postive about the design in general, the results showed that 'your hair loss' and 'my activities' parts had room for improvement on the aspects of how much the target group thinks their family and friends would like to do it.

The hair loss process part is appreciated more by close ones, the activities part was almost equally scored but a bit higher by people with alopecia. The hair and make-up filter part was more appreciated by participants close to someone with alopecia.
Af final improvement which was made to the final design is changing the menu for choosing the activities to include in the 'Imagine...My activities' part because people said they wished for more (daily) activities.

CHAPTER

08

DESIGN IMPLEMENTATION

THIS EIGHT CHAPTER DESCRIBES HOW THE FINAL DESIGN, IMAGINE ALOPECIA, WILL BE IMPEMENTED. IT DISCUSSES ITS IMPLEMENTATION, TECHNOLOGY, INTRODUCTION CHANNEL, THE COSTS AND POSSIBILITIES FOR ADJUSTED USAGE IN OTHER CONTEXTS.

8.1 IMPLEMENTATION

The design was made with the intention that it could be used by or proposed to people by the Alopecia Vereniging. Marion Kremer, former chair of the AV mentioned that the association has a wish for a tool, Marion mentioned for example a video, which explains alopecia to people who do not suffer of the condition (see chapter 3). The application 'Imagine alopecia' could be a tool for members or other interested people with alopecia to make other people understand the condition and its impact more.
Also research in the context showed that people have a need to explain or better let people who are close to them understand their alopecia and the impact this condition has. They would like to see the communication between them and their close ones improved. During the design evaluation, they mentioned this app can also help them to let close ones collaborate to think about possible solutions in different situations.
People can become aware of the existence of the mobile application by being a member of the Alopecia Vereniging or read publications of the association about this app.

Target group
Originally, the target group for the design was people with alopecia, aged between 16 and 35 (later 25) years old. However, the design was also evaluated with older people (aged till 59 years old) and this older group of people were interested in the product as well. First, people close to someone with alopecia were likely thought of to be parents, friends or siblings, but these can easily also be sons and / or daughters of the person with alopecia.

Long term usage
The novelty of the application's filters may wear off quickly so the application will have updates of filters every now and then. This way, people will stay interested to keep using the application as there will be different make-up and wigs available.

Interest of members
Board member and treasurer Josee Beets of the Alopecia Vereniging was contacted to get to know the amount of members the Alopecia Vereniging has. Currently there are 1380 members. The board member told that when the latest newsletter announced the new possibility to log into your own account on the website, around 60% of the people who received the email opened the link to check out this new function. So it can be stated that there is a percentage of 60% of the members of the association who are interested in digital developments and are curious for new functions and developments. So the estimated amount of people that would try or use the application is 60%, which means around 830 members.

International connections
For realizing the development of the app 'Imagine alopecia', international connections can be used in order to obtain the needed facilities and other alopecia associations can be contacted. The design of the app could be translated to English and so be made available to a lot of other countries.

8.2 TECHNOLOGY

Imagine alopecia is a mobile application. It can be made available for different mobile platforms like iOS, Android and / or Windows. A good option would be to make the app available for iOS and Android as the market share for these operating systems is 96,7% (Net application, 2017).

Filter technology
In the app, photo manipulation is used to show people how they look with the alopecia filter and hair and make-up filters. This photo manipulation can be done by computer vision techniques. Computer vision is a technology which creates clear descriptions of physical objects from analyzing images (Ballard & Brown, 1982).

Face detection algorithms & techniques are used to let the application understand where it should for example place the selected wig or where to create a bald spot. The filter is currently only applied statically but in the future making the filters dynamic could be a possible improvement for an update. Dynamic filters are much more time consuming to develop and considerably more expensive because the techniques are more difficult.
An example of a well-known application which uses computer vision technology is Snapchat (see figure 8.1). The app uses Looksery's computer vision technology which allows both for facial recognition as well as for modification in real time and so creates an augmented reality. So this makes it possible to have a dynamic filter. Figure 8.2 shows how Snapchat detects faces and creates a 3D mesh around the face from coordinate points (Fong & Lee, 2016).

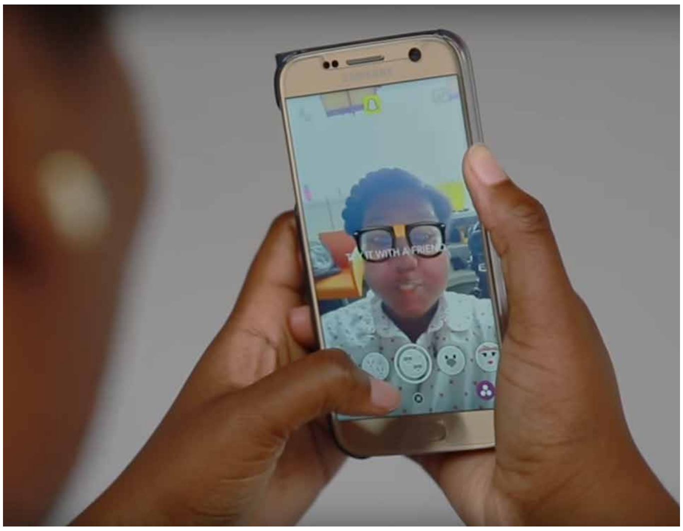


Figure 8.1: Snapchat application

Although Snapchat's filters are dynamic and so realistic, the hair loss process filters should be realistic in the sense of placing bald spots at the right position and adjusting the right skin color to the head. The app should also be able to well detect the hair line so it is advisable to provide the app with an explanation of how to best use the filter. The best result would for example be obtained when a blank background is used and when the hair is put backwards behind the ears or put in a ponytail. Applying wig filters is more easy and if necessary an adjustment to the design could help better position them. It would be a possibility to let the person be able to drag and locate the wig by swiping it slowly on the screen.

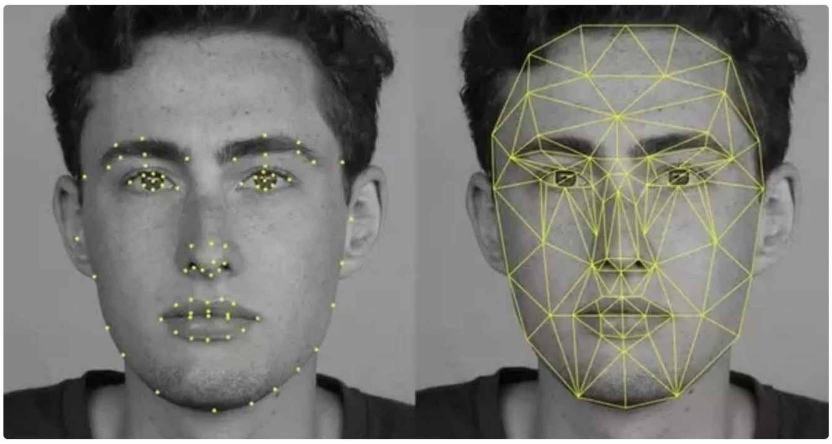


Figure 8.2: Face detection in Snapchat

8.3 INTRODUCTION CHANNEL

The final design is connected to the Alopecia Vereniging so the association can actively make publicity for the mobile application 'Imagine alopecia' on her different channels. It was already discussed that the alopecia magazine will include an article about the design of the app. Furthermore the association can mention it in her newsletter, post about the app on her website, on the public Facebook page and in the secret Facebook group and eventually it can also be put on the introduction flyer. It can also get advertised on days like the national alopecia conference and the national alopecia fair. On the last national alopecia fair, the design evaluation was conducted and people were already asking if it already existed and where they could download the app so on events like this people can be made enthusiastic and curious about it.
Furthermore, also doctors, psychologists, permanent make-up specialists and wigmakers can advise people about the application.

Media
Another way to introduce people with 'Imagine alopecia' is via media. The Alopecia Vereniging can send out press releases about the new service. When magazines, newspapers, other social media (apart from the Alopecia Vereniging Facebook page) or television can report about it, more and more people will know that they can download this application.

Explanation
The application will need some explanation so people understand in what context they can use it and how they are supposed to use it. This can be done with photos in which the interaction is made clear and by including videos about the app when publicizing about it. In publications, it should also be made clear that the application will have updates so users can try different wigs and make-up every now and then.

8.4 COSTS

The main costs of the design will be the development of the mobile application. Apart from those costs, publication or advertisements (to make people get known with the application) may cost money but that is relatively small in comparison to app development. An average custom made app costs around € 20.000. Highly sophisticated apps sometimes cost more than € 100.000, like when it has a high user friendliness or the app has to be able to connect with extensive databases (van der Loo, 2013).
For the development, the application includes a limited amount of different functions. There is no need to make an account and the app is not connected to external social media. The main functions of the app are:

- General application functions
- Usage of camera and gallery
- Image manipulation
- Save photos
- Share photos
- Image content

App-development is possible in native and hybrid form. Native development means that the development is platform dependent, so specially for Android and iOS devices; Hybrid development is web-based and applicable for multiple platforms. Native development is more expensive because the app will have to be developed for both platforms separately but does have a higher user experience. Hybrid development costs less because the app has to be developed once and the development is faster and simpler. The loading times of the app will be nearly similar to those of an app made with native development. For both forms it is possible to use the camera and use the gallery for photos (A. Blankestijn, personal communication, June 15, 2017 & Ziflaj, 2014).

Different app development companies were contacted to get an estimation of the costs to develop the app. The estimated amount of money per company for the development of the application:
-iOnline:
Native development: > € 50.000 excl. (total*)
Hybrid development: > € 30.000 excl. (total*).

- Share Force: € 10.000-20.000
- Fish on Fire: > € 30.000
- We Build Apps: - No sufficient skills or knowledge for computer vision part.

* These costs indicate the total needed investment.

The company iOnline gave a more detailed and trustworthy estimation of the costs as this company was personally contacted, read a description of the application and saw examples of screens. Email communication with iOnline can be found in appendix 2-24. The other companies gave their estimation based on a vocal explanation of the application and its functions.

So generally, it can be concluded that for the development of the app the investment will be around € 30.000.

App maintenance

Apart from these costs, the application will also require hosting costs, as the application needs to be maintained. The server needs to be hosted and the app will require updates every now and then.

Download for free

Because this app has a specific goal and it is connected to the Alopecia Vereniging, people may be more willing to pay a small amount of money for the app. The description of the app can make clear that this money is paid in order to get back the money from investments, finance updates and donate a part to the association. However, whether making people have to pay for the app is a good decision can be doubted as a large amount of people that will probably use the app are adults. Paying for an application is a big threshold when it comes to making the decision to download it. Usually paying for an app in an app store (like Google Play store) works with (prepaid) credit card or PayPal, paying methods not everyone has or is able to use. Another option is a google Play card but this requires people to take an extra step. Board member Josee Beets indicated that she thinks it is important that people have easy access to the app so making the app available to download for free would then be best. Financially, this means that the focus should lie on budgets of collaborating associations and / or donations.

Financing

Van der Loo (2013) describes different options for financing the development of an app:

- Loan from a bank (this has to be paid back while the app will probably not generate income).
- Investing person or organization (applicable if people will pay for the app).
- Family, friends and acquaintances
- Government subsidies
- Customers (in this case future users who are willing to donate).
- App-developer (this is applicable when the app generates income).
- Crowdfunding
- Self-financing (in this case budget of probably multiple organizations).

For financing the development of this application, a combination of different financing options would be possible. The association can look for subsidy possibilities of the government as this app will support people and provide them with information. Also crowdfunding would be a good option as people can get enthusiastic of becoming part of the realization of this design as it will help people. The same goes for family, friends and acquaintances and future users who are willing to donate. Finally, also letting multiple organizations collaborate will help realizing the financial aspect of realizing ‘Imagine alopecia’.

Graduation project

An alternative option would be to make the development of the application a graduation project. The quality of the developed app would perhaps not be as good as the one of a professional app-development company but it would limit the costs significantly. The disadvantage of this option is that it would probably cause the functions of the app design to get more simplified.

8.5 OTHER CONTEXTS

The final design is of course designed for people with alopecia and their close ones but it could very well get adjusted and used in other contexts. As this design is about the impact of losing hair, the application could well be used in the chemotherapy context but also in different contexts. Like the former chair of the Alopecia Vereniging said (see chapter 3), they represent a voice in the coming developments by Huidpatiënten Nederland. This is an association for people with skin and hair conditions which has individual members and also specific patient associations affiliated with the association. These developments are about psychosocial care and involving the group of people close to someone with alopecia.
The final design could for example also be developed in collaboration with Huidpatiënten Nederland. This association is for people with hair and skin disorders so she could collaborate to cover the hair aspect of her association. With adjustments the same design principle with an 'Imagine' filter could be applied to people who suffer of for example the vitiligo condition. Vitiligo is a condition in which people lose pigment on their skin so white patches develop. Then people can better understand what it is like to suffer of vitiligo and think about what they would do and what would become difficult when dealing with that condition. The final design has the name 'Imagine alopecia'. This name can easily be used in other contexts, like in the case of vitiligo: 'Imagine vitiligo.'

Figure 8.3: Vitiligo skin condition (Oakley, 1999)

Other contexts one can think of are contexts in which people have to deal with stigma. Contexts of other diseases or conditions are for example people with vascular malformations (like a port wine stain, see figure 8.3), atopic dermatitis, anorexia nervosa, obese, dwarfism and people with amputations, scars or skin burns.
These are all conditions in which people may have to deal with stigma because they cause a difference in appearance.

8.6 CONCLUSION & REFLECTION

'Imagine alopecia' will help members of the Alopecia Vereniging but perhaps also other people with alopecia and even people with alopecia at different places over the world to better make close ones understand the impact of their condition and stimulates communication between both parties. The AV can help promote the app by using her different channels and (media) connections.
There are possibilities to realize the development of the application. The app itself is simple, does not have a lot of different functions and so does not require very complicated development techniques. However, one of the main functions of the app involves computer vision and photo manipulation. The costs to develop an app with an advanced technique like computer vision can cause problems with financing the realization of this app. A problem with the computer vision part regarding the hair loss process is that it should be realistic. Detecting where the hair line starts and then creating bald spots in a realistic skin color is challenging. When the app would place something in a wrong way it would perhaps cause hilarity, which is not the intended goal. When collaborating with different associations for people with alopecia over the world, there are more possibilities.
The design of 'Imagine alopecia' can easily be adjusted to other conditions that are faced with stigma because of visual deviations. Expanding the design to be used in other contexts could also increase the chance of realizing the app because it would make it possible for many different association to collaborate.

CHAPTER

09


Stefanie Annique Photography

CONCLUSION

THIS CHAPTER COVERS THE CONLUSION OF THE WHOLE DESIGN REPORT. IT CONCLUDES THE FINDINGS OF THE RESEARCH AND LINKS THEM TO THE FINAL DESIGN AND CONCLUSIONS OF THE DESIGN EVALUATIONS.

This project was developed to investigate how to help people when disrupted life events occur and how to create strategies to empower them in coping with the situation. It is in connection with the research developed by PhD candidate Patrizia D'Olivo. It specifically addressed the context of people suffering of the disrupted life event alopecia and has a focus on using communication and optimism as means to foster self-cofidence and strengthen coping behaviors.

Literature research helped to define target group and people of 16 to 35 years old were chosen because they value physical appearance for which there are not a lot of specific solutions. From the in-depth interviews, it became clear that participants who just or recently got faced with hair loss, had a bad time coping with it and had a big need for comfort in their everyday life so the target group and research question got refined:

'How to make people, aged between 16 and 25 years old, who suffer of alopecia with a later age at onset in life, feel comfortable in their everyday lives?'

The interviews with the target group and expert showed that people with alopecia encounter a lot of problems in their lives. A socio-ecological perspective was applied and one of the bigger identified problems was a lack of good communication between them and the people they feel close with. The interview with the expert showed that this problem fitted well with the wishes of the AV as they want something to let people explain their alopecia and involve close ones in events. This problem also fitted with the focus of the project: 'communication and optimism as meaningful means to foster self-confidence and strengthen coping behaviors', so the refined design goal was:

To make people, aged 16-25 who suffer of alopecia with a later onset in life, feel comfortable in their everyday lives by designing coping strategies for the individual with alopecia and anyone this individual feels close with.

This addressed the interpersonal level of the socio-ecological framework discussed in chapter two. These close ones have to understand the impact of alopecia and what kind of support they should provide. This also meant to help the person with alopecia and the other party to start the communication about alopecia and make the communication more open between them.
After ideation, different concepts were created. Conducting and analyzing a concept evaluation showed that people liked to let people see themselves the way they see themselves daily and to share their story with close ones, to better make them understand what they go through.
An interactive storytelling website and an alopecia filter app were chosen to be worked out in more detail and got improved with the insights of the evaluation. Two of those insights already directed towards a mobile application version and an integrated version of both chosen concepts.
The two concepts were improved and with a combination shown to the target group in a co-creative session. This session gave a lot detailed insights into possibilities for adjusting and improving the design. This co-creative session was a unique chance to get clear and honest opinions of the target group because this group already knew each other. It was clear that the participants had a preference for the combination design and their comments and ideas helped to define the combination of the functions of both concepts.
It for example led to defining what to show in the story, define the order of showing cartoons or pictures in the story, gave insights into what activities and daily situations to include and gave insight into their preference for visual styles such as colors and cartoon styles.

After defining and improving the combined concept according to the insights of the co-creative session, the final design 'Imagine alopecia' was created. The design gives people close to someone with alopecia a better understanding of the impact of the condition and stimulates the communication between them. The design evaluation study showed that the target group feels that the design has the potential to improve the communication between them and their close ones. Also the cloes ones believe in the added value of the design.
All people at the national alopecia fair, were enthusiastic about the design and were already asking where they could download the application. Realizing the app can most likely be done with international contact of the Alopecia Vereniging and be introduced via the available platforms and connections of the association.

So when looking back at the set design goal, the coping strategies for the individual with alopecia and anyone this person feels close with are designed into a product which improves the communication between both parties. This gives more comfort in the lives of people with alopecia as they feel like they can talk about their condition to their close one and this last group can better provide support.

CHAPTER

10


Ode aan de Kale Vrouw door Herman van Gestel

DISCUSSION

IN THIS FINAL CHAPTER A CRITICAL LOOK IS GIVEN TO THE RESULTS AND CONCLUSIONS OF THE REPORT. ALSO RECOMMENDATIONS FOR THE ASSOCIATION AND THE DESIGN ARE GIVEN.

First of all, the goal of the final design was to improve the communication between the person with alopecia and people close to him. The parts ‘Imagine… Your hair loss’ and ‘Imagine… My activities’ add to this goal. The third part, ‘Hair & Make-up filter’ does not directly add to communication but a wish for this function was a clear outcome of both the concept evaluation as the co-creative session and may in some cases lead to communication and advice about wigs and make-up. However, this function may lead to confusion about the purpose of this design. A point for consideration is to either give the application a different name, adjust the function of the part to be more fitting the context of creating understanding, add also other functions or make the hair and make-up filter a separate application.

Recommendations
The evaluation of the final design at the Alopecia Vereniging fair confirmed that the target group feels that the design has the potential to improve the communication between them and the people they feel close with. They were enthusiastic about the design and were already asking where they could download it. Also people close to someone with alopecia believe in the added value of the design. However, the evaluation was conducted showing a poster and pictures of the design and letting people try out a prototype so drawing conclusions of what the design exactly does to the communication between both parties is hard to tell. The evaluation results showed that the target group and their close ones think the design adds to sympathy and understanding.
To validate the effect of the design on communication, it should be evaluated by letting people use the design in real life situations.
So it is recommended to evaluate the design with a full working version in real life situations.
Furthermore, although being postive about the design in general, the design evaluation score results showed that ‘your hair loss’ and ‘my activities’ parts had room for improvement on aspect of how much the target group thinks their family and friends would like to do it while they are the ones who have the initiate the use of the app so they should not be held back from doing so.

Moreover, the co-creative session gave multiple insights to further develop the design. Some insights, like including links to make-up tutorials and links to information about wigs were not included in the final design. Those insights can be considered if the app were to be further developed. However, including links could be conflicting with the wish of the Alopecia Vereniging to stay and independent association if linked to alternative websites than their own.

Another recommendation is to further detail the design in general. More activities and more wigs and make-up options can be added. Furthermore, men in the co-creative session mentioned they would like to have hats and caps in the wig filter part instead of wigs because they do not wear a wig.

Finally, when realizing the design for people with alopecia in general, it is recommended to also look into the prefered activities and situations to show and include of older people with alopecia. The design was targeted at young people and the included activities and situations were the result of insights obtained in research with the target group.

Recommendation for the Alopecia Vereniging
An insight from the co-creative session was that men would rather not have pink as a color for the application like the website of the Alopecia Vereniging. They prefer green or turquoise. When first visiting the website of the Alopecia Vereniging, men could get the feeling of an association for women with hair loss. The association could consider to make the website more appealing for men to join and for example add more photos of men with alopecia or switch to green or turquoise.

Another possibility to further work out the final design could be to collect data when people use the application. When starting the application, people can get an option to fill in their details about their alopecia, its duration and possible causes. When, as in chapter eight described, internationally applied, an enormous amount of data could be obtained of people with alopecia. Of course, this could also be done with a website but a mobile application probably has a smaller threshold to fill in the data as it requires little time. Data gathering makes it also more appealing for international organizations to join in the realization of this application and may add to more knowledge about the onset and causes of the alopecia condition.

Accuracy of study results
The research, concept evaluation, co-creative session and design evaluation were all conducted with people who are members of the Alopecia Vereniging, who come to organized events. This may have influenced the findings as the chair of the association mentioned that usually people who suffer of a severe case of alopecia feel the need to come to events. Because of this, the participants could generally have a worse way of coping with the condition. However, the design was targeted at people who need comfort in their daily lives so for this specific project, this influence was not necessarily bad.

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Most icons were created by Gregor Cresnar and got personally adjusted.

APPENDICES 1

1. PERSONAL REFLECTION YOUNGSTERS DAY

Before I went to the activity day, I already went to two other previously organized activities. Alopecia started 10 months before the activity day for youngsters. After 6 months I joined the HaarOm meetings. These were a couple of meetings organized by Alopecia Vereniging for people with alopecia to talk about their condition. For me these meetings were valuable because it was the first time I met other people with alopecia since my hair loss. There were around 7 women present to talk about subjects like alopecia and yourself and alopecia and your context. It was a good experience to share each other stories but for me this meeting and the way we talked about our condition felt forced and I really hoped there would be some women of my age. However, there were only women aged around 40, 50 and 60. I felt these women dealt with alopecia in such a different way so I felt the need to also talk to women or men of my age.

In august I went to a swimming evening organized by the association. I was a bit disappointed by the amount of other people of my age. There were a lot of children and it was more confronting for me than I expected to see the children. They of course did not use any make up so I recognized that from when I did not have the permanent make up yet. There was only one other girl of around my age. It was such a nice experience to talk to her on that day. After the swimming day I heard of the activity day for youngsters and I immediately signed up.

I had a really good experience during the activity day on the 12th of November. I had no idea how many young people would be coming and whether they would be girls or boys. We were with around 20 people of which three boys. At first I was a bit shocked to see the boys. Like the children on the swimming evening, they (nearly) had anything at all to hide their condition. It reminded me again of the most difficult period since the hair loss, seeing myself in the mirror without hair, eyebrows or eyelashes. It felt very good for me to experience that this confronting, shocking image disappeared because I spent time with the boys and had a good time during the laser game activity. Personalities were more important. This experience was good for me because I sometimes have the feeling that people cannot look through the alopecia part.

The atmosphere of the activity was really good. Everyone was enjoying themselves and everyone talked a lot to each other. The day felt a lot less forced than the HaarOm meeting. The youngsters did not have to talk to each other unless they wanted to but I noticed that most of the people really felt like talking about all their experiences regarding for example permanent make up, wearing wigs, discovering bald patches, dating, relationships, etc. There was even an atmosphere with black humor on the day. Jokes of black humor were for example: ‘no hair on my head which thinks of…’ or ‘he is no hair better than me’, which are Dutch sayings.

Some women also felt free to come to this activity day without a wig on and others felt free to take of the wig for some wilder activities. The division of the day was done very well. During the activities you did not directly need to talk a lot and could get to know everyone. After the activities during dinner it was possible to talk more to each other. I felt it was a pity though that during dinner everyone had set places so you just spoke a lot to the people that were sitting around the table with you. When half of the group left it was easier to switch positions and talk to people from the other table as well.

After the activity day I felt much better about having alopecia. It felt like I was not the only one suffering of this and that people should accept us for who we are because none of us chose for this condition. I also felt like my condition gave me something positive as well. I got to know so many kind people that activity day from all over the country. It sometimes also brings good things and it is good to focus on those positive sides.

2. WHATSAPP GROUP AFTER YOUNGSTERS DAY

The same colors are used when the same person wrote something in the group again.
The screenshots are numbered according to their sequence.

[redacted]
Ja! Was zeker leuk! Ook heel leuk om jullie allemaal te ontmoeten 😄 11:58

[redacted]
Hai🤗 tecilla hier. Was inderdaad super leuk om jullie allemaal te ontmoeten. Vind het een gezellige dag met iedereen! 12:00

[redacted]
Goed. Dus volgende week weer? 😂 12:00

[redacted]
Haha goed idee 😋 12:00

[redacted]
Was erg gezellig ja ☺️☺️ 12:25

1.

[redacted]
Hoop echt stiekem dat we dit vaker kunnen doen! Was zoo leuk en fijn 13:07

[redacted]
Jaa precies 😊 13:07

[redacted]
Zo'n gevoel van samen 1 🐵 13:08

[redacted]
Jaa precies 13:11
Jullie begrijpen het teminste :D 13:12

[redacted]
Het is ook helemaal niet ongemakkelijk met jullie, ook nu niet 13:12

[redacted]

2.

Het is wel moeilijk doordat iedereen in alle windstreken van het land woont 13:17

[redacted]
Ja dat klopt 13:17

[redacted]
Maar nu is t ook gelukt 13:18

[redacted]
Waarheid. Positief bekijken 😊 13:19

13 ONGELEZEN BERICHTEN

[redacted]
En anders slaap feestje 😋 13:20

[redacted]
Meteen al een wild idee 😂 13:20

3.

[redacted]
Het is ook helemaal niet ongemakkelijk met jullie, ook nu niet 13:12

[redacted]
Op zich zouden we zoiets ook zelf kunnen organiseren, als dit vanuit de vereniging niet mogelijk is, met groeps korting is dat best te doen... 13:13

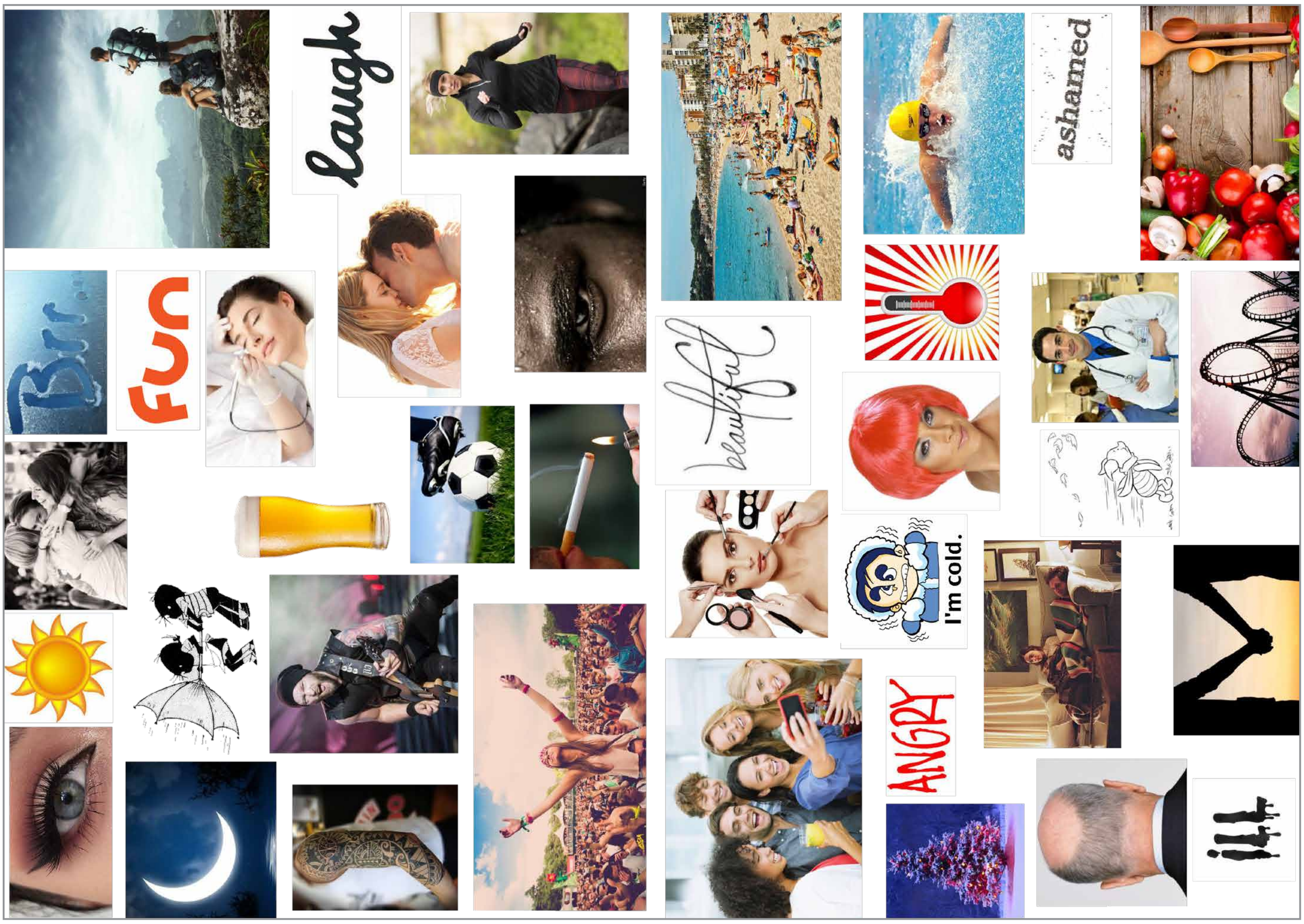
[redacted]
Ja, vind ik ook :) 13:14

[redacted]
Jaa 13:14

[redacted]
Jaa! 13:16
Of je haarwerk nou per ongeluk afschuift of niet🙈 13:16

4.

3. WORD & PICTURE SHEETS



4. IN-DEPTH INTERVIEW QUESTIONS

Introduction
Like I told you a while ago I do research about youngsters with alopecia for my graduation project of the study Industrial Design Engineering. I like to get to know how young people deal with alopecia. I have my own experiences but I am very curious about the experiences of other youngsters. The purpose of today is that we will do an interview with some small assignments. The interview exists of different questions about you and alopecia. I will give you some blank paper and pencils so that you can write or draw any time necessary for explaining something.
Apart from that there are two A3 sheets with different pictures. Every now and then you will be asked to point at some pictures that belong to or add to you answer to a question. You can always use them yourself whenever you want . You will also be asked sometimes to point to a mood on a pick-a-mood sheet. You can use this sheet yourself to while answering the questions whenever you need this.
Furthermore you will be asked after the interview to make a timeline of you and alopecia. I will first give you an informed consent sheet, which I ask you to sign. In this sheet it is for example explained that all data will stay anonymous and there will only be audio recording. Optionally I can take a picture of the setting and you but only if you feel okay with that.

Practicalities
1. At the activity day you told me you have [alopecia areata, totalis or universalis]. It started when you were [age], did your hair ever recur? How did or does that make you feel?
2. How did the diagnosis go? Did they offer you any treatments?
3. Did you do any treatments? Or did you try out things to make your hair grow again? Why (not)?
4. Do you believe there are or will be means to get your hair grow again? Why (not)?
5. Do you have any other conditions apart from your alopecia?
6. What in general changed for you between now and before the hair loss (except for wearing a hair piece or wig)?
7. What activities do you avoid which you participated in before? Why?
8. Does alopecia hinder you in your favorite activities (for example sports, parties, theme parks, motorbike with helmet)? How does that make you feel?
9. What kind of activities would you do when you would not have alopecia?
10. Are there situations when you stay at home because of your alopecia (for example weather, wig smells or does not look good, irritated skin)?
11. Do you wear something on your head at home (for men: outside)? Why (not)?
12. If wearing a wig: Do you wear different wigs in one period? Why (not)?
13. How does wearing a wig physically feel for you? Does your skin get irritated?

[Pictures: Can you select pictures that support your feeling regarding the impact of alopecia on your daily life?]

Emotions
14. Do you hope your hair will recur? Why (not)?
15. Do you see any advantages of having alopecia?
16. What is the biggest disadvantage of your condition for you? How does that make you feel? Why?
17. Do you feel the need to talk to people about your alopecia? Why (not)? If so, who do you talk to about it?
18. How do you feel about wearing a hair piece or wig?
19. How often per day are you aware of your alopecia? Do you sometimes forget about your alopecia (and wearing a wig or hair piece)?
20. Do you see your condition as a big burden in everyday life? Can you give some examples?
21. Do you feel like you are different than others because of your alopecia? Do feel like you are being treated differently than others?
22. Do you feel self-confident? Why (not)? Do you feel better when you wear your wig or hear piece?
23. Have you ever been asked about your condition by someone not close to you? How did you feel about this?
24. Do you always hide your condition? Why (not)? If not, when and why?
25. Did you ever have negative reactions to your condition? Why (not)? If so, what kind of reactions? How did they make you feel?
[Pictures: Can you select pictures that support your emotions regarding your alopecia?]

Social life
26. How do you get along with your family concerning alopecia? Does everyone know about it? Do you show yourself without your wig or hairpiece?
27. Does your relationship with your family and their support work well for you?
28. In what way does your family support you?
29. If siblings: How do your siblings deal with your condition? Do they treat you the same as before the hair loss? Are they scared they will get the same?
30. How do you get along with your friends concerning alopecia? Do they know about it? Do you show yourself without your wig or hairpiece? Why (not)?
31. Did your relationship with your friends change, if yes, in what way?
32. In what way do your friends support you?
33. Do your colleagues/co-students on work/study know about your condition? Do you always hide your condition for them? Why (not)?
34. How did your colleagues/co-students react to your condition?
35. Do your neighbors know about your condition? Why do or don't they?
36. To what extent does alopecia hinder your character, spontaneity and openness in a company that does not know about your condition? And in a company of people that do know about your condition?

[Pictures: Can you select pictures that support your feeling regarding your social life and alopecia?]

37. Why did you join Alopecia Vereniging?
38. Do you meet or talk to other people who also suffer of alopecia?
39. Apart from the activity day, what kind of events for people with alopecia did you visit? Why did you visit them? What did you think of them?
40. Does it help you to talk to people with alopecia? Why?

[Pictures: Can you select pictures that support your feeling regarding Alopecia Vereniging and her activities?]

Youngsters activity day
41. What did you think of the activity day on the 12th of November?
42. How was it for you to talk to other young people with alopecia?
43. Did you feel better about your condition after the activity day? Why (not)?
44. Was there anything you missed during the activity day?

If old enough:
45. Do you have a boyfriend/girlfriend? Since before or after the hair loss?
46. How did this boyfriend/girlfriend react to the hair loss or condition?
47. Do you consider your condition to be a critical factor for your relationship? Why (not)?
48. Do you go on dates? Why (not)?
49. Do you tell the person you're dating about your condition? Why (not)?
50. If you tell your date, after how many dates do you tell about the condition and why?
51. Do you consider your condition to be a critical factor for dating? Why (not)
52. Do you feel attractive without your wig or hair piece? Why (not)?

[Pictures: Can you select pictures that support your feeling regarding relationships and dating?]

General
53. Is there something you wish that would be there for people with alopecia (except for a cure or treatment) which does not exist yet?

The participant receives an A4 page with a blank timeline. After receiving this sheet, the following questions will be asked:
- Can you draw a timeline of an evaluation of yourself and your alopecia? For example, an event which made you lose your hair, recurrence of hair, losing hair again, choosing a new wig, more bald patches, telling colleagues about alopecia, etc.
- In the timeline, can you mention and draw some moments which were extreme in emotions? These can also be positive emotions.
- In the timeline, can you mention and draw some moments in which extremely hindered your daily life?
- In the timeline, can you mention and draw some moments in which your social life was extremely affected by your alopecia?

5. INTERVIEW QUESTIONS EXPERT

1. What are the obligations for the Alopecia Vereniging to stay an independent association? What does she need to provide the 'patient group'?

2. What tangible things and what services are currently available provided by the association? What kind of activities does she organize?

3. Does the association also organize mental support activities?

4. After about what time do people sign up for the Alopecia Vereniging?

5. What is the main way people get to find the Alopecia Vereniging?

6. What is the main reason for most people to become a member?

7. What kind of help does the Alopecia Vereniging provide when a person suddenly finds himself suffering of alopecia?

8. Does the association ever have de-registrations unrelated to the disappearance of alopecia? If yes, what is the reason for that?

9. What kind of difficulties or problems do people face with the website / Facebook page or activities?

10. Do you sometimes get in contact with people who are panicking? If yes, why and how? What do you do?

11. Does the association sometimes actively bring people together or bring people in contact with each other? If yes, why and how?

12. Does the association encounter difficulties or problems? If yes, what kind of difficulties or problems?

13. We spoke before of something which can bring people together. What kind of wishes does the Alopecia Vereniging have for this?

14. What if the association organized activities based on people that find themselves having the same problems or difficulties regarding specific subjects?

15. What if the association organized activities which brings together people who deal with their alopecia the same way?

16. What if the association organized activities which bring together people who deal with alopecia in a bad way with people who accepted their alopecia and are easy going about it?

6. FIRST EVALUATION IN-DEPTH INTERVIEWS

A first thing that appealed was that all participants dealt with their alopecia in a different way. However, there were also some commonalities among all participants:

- Age at onset
The age at onset of alopecia mattered in the way the participants dealt with their condition. Most often, when alopecia started in some of the first years of the participants' life, the participant was able to mentally cope more with the condition. They accepted their condition more than people with an older age at onset and were more used to live with it. However, this early age at onset sometimes also caused the person to have problems of bullying during primary or secondary school;

- Attitude towards others
The attitude of the person dealing with alopecia matters in the way other people also behave towards the person with alopecia. It seems the more the person accepted he has alopecia, the more people accept this condition too. Different participants with an early age at onset had different reactions on primary and secondary school because of their own attitude. The ones who were relaxed and had accepted their condition, got less bullied or were not bullied at all;

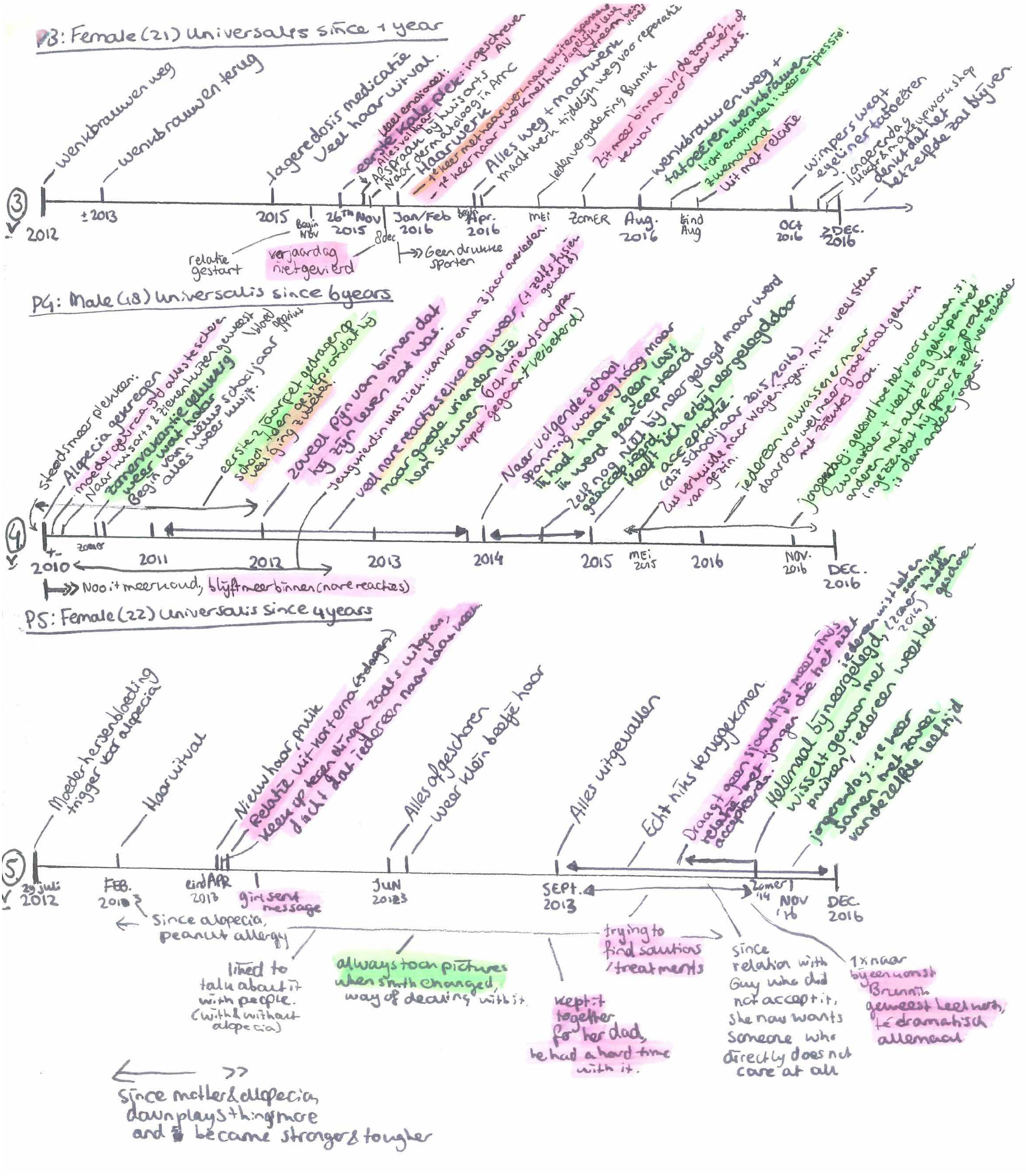
- Hope for recovery
Mostly the people with an early age at onset did not hope for recovery that much. These people were totally used to live with their condition and the hope for recovery was not as big as for people with a later age at onset. The latter still hope their hair will return and hair loss will not happen again;

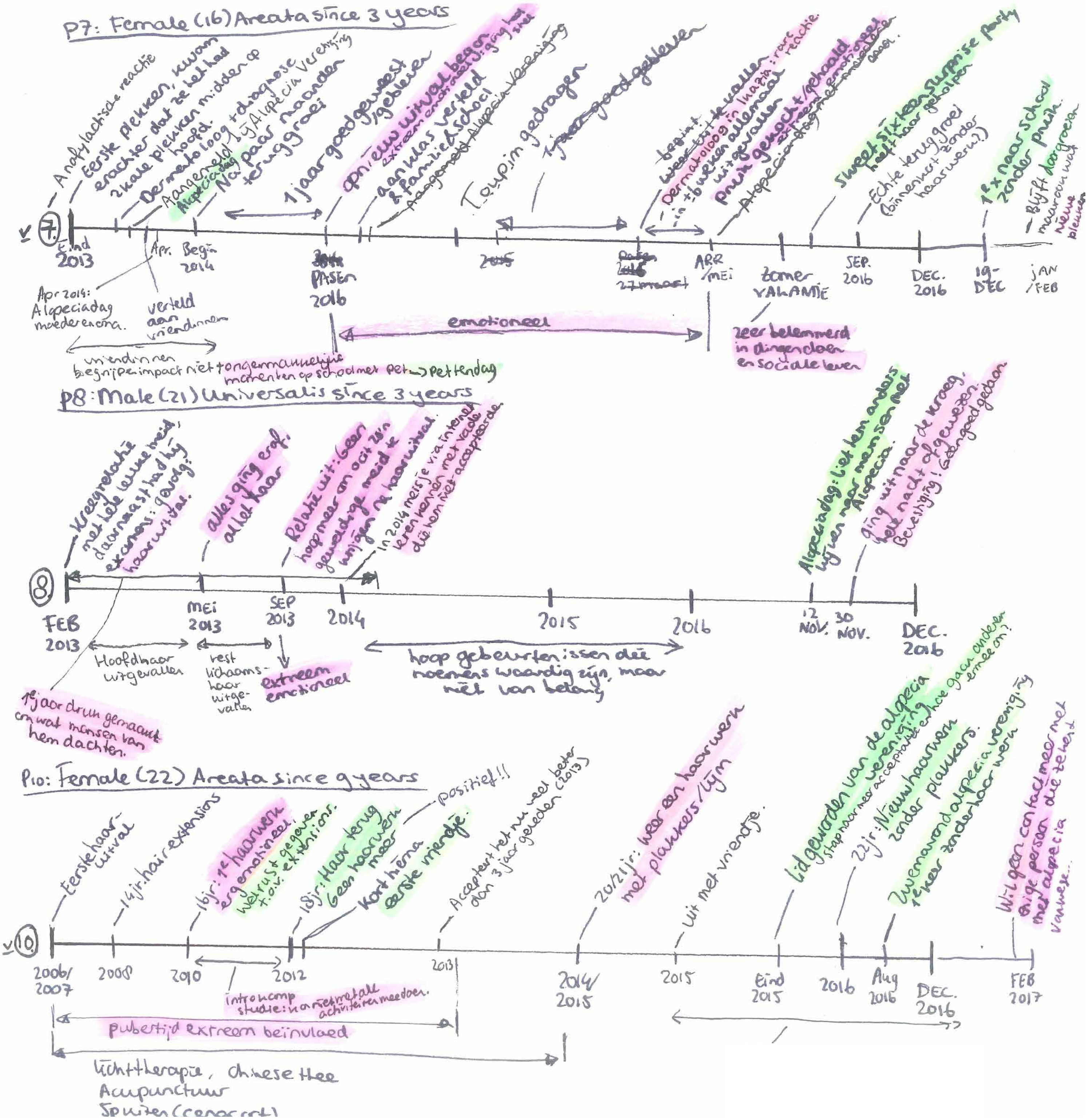
- Meeting fellow sufferers
Among all participants there was a need or wish to meet and speak with fellow sufferers of alopecia. However, they do not know how to get in contact with other sufferers and when they do, the fellow sufferer is not always of the same age group which makes it harder to relate and understand each other because the life styles are different. Also, there are some complains about the current ways of communicating and meeting other people with alopecia;

- Needs of parents
Although there were no questions for parents in the interview, still it was apparent that a lot of parents have a need for information and contact with other parents of sufferers or contact with sufferers themselves. Hair loss is not only a stressful event for the children, also their parents are stressed and insecure about the way they support their child;

- Need for information
When a person gets confronted with hair loss, this is a new experience most of the times. The sufferer is in a big need for information but he doesn't want to read or know all information. At the moment of the hair loss, the sufferer is experiencing a life changing even which already is stressful. When this person searches for information and for example reads or sees information he was not ready for, this can be confronting and stress causing.

7. TIMELINES: POSITIVE AND NEGATIVE EVENTS




P7: Female (16) Areata since 3 years
7.
Anafylactische reactie
Eerste plekken, kwam erachter dat ze het had
2 kale plekken midden op hoofd.
Dermatoloog + diagnose
Aangemeld bij Alopecia Vereniging
Alopeciadag
Na paar maanden teruggroei
1 jaar goed geweest / gebleven
opnieuw uitval begon
extreem emotioneel: ging het snel
aan klas verteld & familie & school
~~Aangemeld~~ Alopecia Vereniging
Toupim gedragen
~~1 jaar goed gebleven~~
~~begint weer tot~~ te vallen
Dermatoloog in Inazia: rare reactie.
in 6 weken allemaal uitgevallen
Pruik gekocht/gehaald
extreem emotioneel
Alopeciadag met [illegible]
Sweet Sixteen Surprise party
heeft haar geholpen
Echte teruggroei (binnenkort zonder haarwerk?)
1e x naar school zonder pruik.
Blijft doorgroeien maar ook wat nieuwe plekken
Eind 2013
Apr.
Begin 2014
~~2014~~
PASEN 2016
~~2015~~
~~Pasen 2016~~
27 maart
APR /MEI
Zomer VAKANTIE
SEP. 2016
DEC. 2016
19-DEC
JAN /FEB
Apr 2014: Alopeciadag moeder en oma.
verteld aan vriendinnen
vriendinnen begrijpen impact niet
ongemakkelijke momenten op school met pet → pettendag
emotioneel
zeer belemmerd in dingen doen en sociale leven
P8: Male (21) Universalis since 3 years
8
Kreeg relatie met hele leuke meid, daarnaast had hij examens: gevolg: haaruitval.
alles ging eraf, al het haar
Relatie uit: Geen hoop meer om ooit zo'n geweldige meid te krijgen na haaruitval.
In 2014 meisje via internet leren kennen met vader die hem niet accepteerde.
FEB 2013
MEI 2013
SEP 2013
2014
2015
2016
12 NOV.
30 NOV.
DEC. 2016
Hoofdhaar uitgevallen
rest lichaamshaar uitgevallen
extreem emotioneel
1e jaar druk gemaakt om wat mensen van hem dachten.
hoop gebeurtenissen die noemenswaardig zijn, maar niet van belang
Alopeciadag: Liet hem anders kijken naar mensen met Alopecia.
ging uit naar de kroeg, hele nacht op geweest. Bevestiging! Goed gedaan.
P10: Female (22) Areata since 9 years
10.
Eerste haaruitval
14jr: hair extensions
16jr: 1e haarwerk erg emotioneel.
Wel rust gegeven t.o.v. extensions.
18jr: Haar terug. Geen haarwerk meer
Kort hierna eerste vriendje.
positief!!
Accepteert het nu veel beter dan 3 jaar geleden (2013)
20/21jr: weer een haarwerk met plakkers/lijm
Uit met vriendje.
Lid geworden van de alopecia vereniging
Stap naar meer acceptatie en hoe gaan anderen ermee om?
22jr: Nieuw haarwerk zonder plakkers.
Zwemavond alopecia vereniging 1e keer zonder haarwerk
Wil geen contact meer met enige persoon met alopecia die te heftig vanwege...
2006/ 2007
2008
2010
2012
2013
2014/ 2015
2015
Eind 2015
2016
Aug 2016
DEC. 2016
FEB 2017
introkamp studie: kan niet met alle activiteiten meedoen.
pubertijd extreem beïnvloed
lichttherapie, Chinese thee
Acupunctuur
Spuiten (cenocort)

8. MOMENTS OF SHIFTS IN TIMELINES

1. First bald spots: The first bald spot(s) are very emotional and life changing.

2. Hair everywhere: Finding hair everywhere (pillow, bathroom, brush) during the hair loss period is very upsetting.

3. First wig: Getting a first wig is very emotional and confronting. It is the moment participants think it is for real.

4. First time among people with wig: The first time going outside the house, to work or school or going out with a wig is exciting and the participants can look up to it. They feel like everyone is watching them and able to see their hair is fake.

5. Summer more difficult: During the summer participants are suffering more of alopecia because it is too hot for a wig.

6. Permanent make up: Getting permanent make up can be emotional because it is painful and another 'necessary' consequence of alopecia. On the other hand it also makes them happy because it brings back expression to their face.

7. No relationship: When not in a relationship, participants are more aware of having alopecia, as they have to worry about dating and new relationships.

8. Support or extra stress by relationships: Relationships can be supportive when the boy- or girlfriend accepts the alopecia but can be extra stressful when not accepting it.

9. Swimming event: The swimming event of the Alopecia Vereniging was a relief to participants who like to swim but do not swim anymore since their hair loss.

10. Hair recurrence: Participants get a positive feeling when there is (some) hair recurring.

11. Stop wearing hat: One participant stopped wearing a hat at school when he started sweating too much and the hat was too hot and irritating.

12. Acceptance: One participant accepted her alopecia and started wearing different looking wigs when everyone knew about it and some friends shaved their heads.

13. Stop wearing scarves: One participant does not wear scarves ever since her ex-boyfriend did not accept her like that. It made her think differently about not wearing a wig, with hair you are 'bigger'.

14. Solutions seeking: Trying to find solutions and treatments are sometimes more bothersome than the condition itself. It takes a lot of time and it creates false hope as it mostly results into nothing.

15. Useless events: Going to events with people who are more emotional and dramatic about their alopecia does not improve anything for participants and creates a feeling of not being able to connect to anyone in by the Alopecia Vereniging.

16. Peace by wig: A wig can give peace to participants suffering of alopecia areata as they do not have to worry about hiding their bald spots anymore.

17. Non compassionate dermatologist: One participant had a bad experience with the dermatologist when she visited him while she was

quickly losing all hair. He did not show compassion and pretended everything would be fine soon.

18. Supportive surprise party: A surprise party organized by friends helped a participant a lot after she lost her hair.

19. Hat day at school: A ‘hat day’ was organized for a participant because she was allowed to wear a hat in school. For this day, she chose for an information email explaining her condition and the event. This event and informing email removed her awkward moments of actually not being allowed to wear a hat at school.

20. Youngsters day: The youngsters day was very valuable for the male participants because they learned how women deal with alopecia.

21. Talk with others: The youngsters day helped participants because they could talk to others with the condition.

22. Confidence back: One participant got a boyfriend directly after her hair returned for only a month. According to her this was clearly linked to each other.

23. Satisfied with wig: When participants find a wig which does not irritate and looks the way they want, they feel better and more confident.

24. Aware on holidays: Participants are more aware of their alopecia when on holiday. On holiday they are in a different context than home with different people, it is usually hot and they often have to or want to go swimming.

25. Acceptance by acceptance: One participant accepted his alopecia a year after his new class mates accepted him with it.

26. Suicidal thoughts: One participant had suicidal thoughts when he had to deal with bad comments every day and sometimes even physical violence.

27. No more worry about opinions: One participants stopped worrying about what other people think of him one year after his hair loss.

28. Banning alopecia: One participant stopped wanting any contact with the only person she knew with alopecia as that person has hair recurring. She could not handle that as she also wants her hair to recur and she wanted to make alopecia the smallest part of her life possible as she currently has more stress because of it.

29. Step towards acceptance: One participant became a member of the Alopecia Vereniging to make a step towards more acceptance and see how other deal with it.

30. Rejection confirmation: One participant went out to a pub to see how girls react to his looks. He was rejected the whole night which was a confirmation for him of his negative thoughts about his looks.

31. Support by friends: Good friends who support the participant in bad times can make a big difference.

32. Pictures for coping: One participant always took pictures of herself when something in her appearance changed (for example losing eyebrows). For her this was a way of dealing with it.

9. ANALYSIS INTERVIEW EXPERT

General aspects Alopecia Vereniging

Independence of the association
The Alopecia Vereniging (AV) made the decision to stay strictly independent. She wants to financially get organized only by the members and subsidy (and if applicable by other initiatives). They do not want to get financially supported by commercial institutions or companies and do not collaborate with or want to get financially supported by for example the pharmaceutical industry or wig makers.
This decision was made because the association looks from the perspective of the member and this condition is linked to a lot of wig makers, beauty specialists, etc. When the association says one is good, it would perhaps mean that the other is not. Furthermore, those companies or institutions would want something of the association because it is their perfect target group. ''The highest bidder would get the biggest stage.'' Also the chair notices there is a big need for an independent association among people with alopecia.

Subsidy
The association receives subsidy because it is a patient organization, to get this subsidy it has to have a minimal amount of members and it has to provide information and support to people with this specific condition. It is however not clear how long these subsidies will last so the association is dependent on her members.

Sources of information
For information the association has her website and a flyer. There is also the alopecia magazine for members and personal contact is very important for the Alopecia Vereniging. People can call or email the association.

Organized activities
Alopecia Vereniging annually organizes a swimming evening, a youngsters day, a children day, the national alopecia conference and twice a year HaarOm meetings and workshops about different subjects like hairstyle & make-up and mindfulness.

Products & services
The Alopecia Vereniging has a school package and a reading book for children. Apart from that she does not sell anything yet, however there are future plans and ideas for products and services. These should be things that really add value, things people need and cannot find elsewhere.
Personal contact by calling and email
Personal contact is very important for the association. It has a 48 hour response policy for emails and people can always call. For people calling, the association can advise people in what is best to and what can best support the person in his case, for example join the secret Facebook group or first go through a medical treatment program or someone is ready to buy a wig. So this is very personal and custom driven. The chair has the most contact with people calling on the phone who just got faced with alopecia and she can advise these people to go to the HaarOm meetings.

Advisory role wigs
The Alopecia Vereniging does not advice which wig maker to go to for example. Her boards think it is too personal because the personality of the wig maker also plays a role. Furthermore every wig maker is specialized in different types of wigs, for example synthetic, ready-made or custom made of real hair. They do advice people what to pay attention to and to go to a certified wig maker, for example ANKO or SEMH certified. The associated is involved in setting up the quality criteria.

Different options
Suffering of alopecia does not necessarily mean you have to wear a wig. The association communicates that this is only one option out of many possibilities so they like to show the options and provide advice for those options.

Stigmatization of a group
There is the problem of stigmatization of becoming a member of a group, especially in the past. ''At the moment you join a group, you actually say, I have this condition. And if you're not totally ready for that you also don't do it. But actually that moment will eventually come. And what we try to do is to show everything we publish the least negatively loaded. We try to project that positivity. And we try to avoid the word patient as much as possible because we don't feel like a patient in the end but just like an experience expert.'' The former name of the association was the Alopecia Areata Patiëntenvereniging (patient association).

Care procedures & familiarity of the association

Psycho-social aspect in care procedures
Behind the scenes, the association is involved in the care procedure. They talk to the association of dermatologists and doctors and are involved in the regulations. ''That part, those psycho-social

aspects, those have to be taken into account from the beginning of the whole treatment.''

AV mentioned during consult
The AV tries to let doctors and dermatologists directly mention the association because of information and for contact between fellow sufferers. The AV knows more of the condition than the dermatologist himself.
''At the consult, people hear something they do not want to hear. You start to have hair loss and you think there must be a reason for that and if we know that reason then I will get a medicine and then it's recovered again. But you get to hear a total different message and that message will cause you more anxiety. And then you just have the need for people with specialized knowledge, who know a lot about it. And when you search on the internet, well then you become totally crazy. So you approach a party of which you hope like, they can provide me with more information. And then you get that when you take that immediately serious, that it can be a huge shock and you take someone by the hand from your own experience already from the beginning. And then that point of acceptation or coping with will be there much faster instead of solely having the route of medical treatment.''

Overwhelming information at onset
It happens often that a person cannot see the forest for the trees when someone did not read into and thought of the possibilities of for example wearing a wig, a scarf or nothing when alopecia just started and he is going to a wig maker. It would be better when the person can first have contact with the association.

Connections for familiarity with the association
The AV sends her alopecia magazine with some flyers in it for free to dermatologists, wig makers, permanent make-up specialists, etc. to make them familiar with the association and up to date with the condition. The flyers can also be ordered by them and the quality criteria say that they should offer flyers of the Alopecia Vereniging. Furthermore AV has different other contacts, for example also with skin therapists.

Alopecia Awareness

(Social) media
Marion Kremer collaborates to many interviews and is being involved in a lot of things like representing the patient group at medical specialists congresses and many more networking activities. The AV is also present in the media a lot because it gets better known which also results in for example health insurance companies to recognize the condition.
Especially in the beginning, the chair also sent out a lot of press reports for the things they were working on or doing. She also used her own network which grew a lot. The last year, there are a lot of media requests to share the story. This results in the possibility for a lot of different people to share their story. In the beginning the chair shared her story which caused other people to wish to do the same. A couple of years ago, hardly anyone wanted to be public about the condition yet. The chair is proud of succeeding in letting people be more open about it.

Familiarity of the condition
''It really is that familiarity which causes you to have more peace of mind. It is especially that idea that people think you have cancer, that carries a heavy weight. You always have something to explain, that is just very annoying.''

Prejudices in the professional field
The chair had her own example of making a statement by putting a bald picture and a picture with wig on her CV because both show the way she is and the way she presents herself, depending on the time of the year. Then she knows people do not have wrong expectations and she does not want to feel like she has something to explain. A CV coach critically asked her about the pictures but Marion thinks she would not want to work somewhere where she does not get accepted for who she really is, it may also well evoke curiosity.
The (former) chair explained she became a successful online job interview expert which caused her to be open about her condition as she was advocating people to be themselves while she was not. This was the moment she began to make a statement against prejudices.
''I know that a lot of women have a difficult time with it at their work, that they want to tell it or don't dare to tell it or that they are being judged but also that they are not even allowed to show them like that because they have to be representative That is tough.''

Becoming a member

Membership fee
The money people pay for the membership of the Alopecia Vereniging will change from 25 euro per year to a free choice in 25, 50 or 75 euro per year, depending on what you like to pay the association. This is an option which members requested. With more money, more goals can be achieved.

Registrations
About nine out of ten people who first contact the association, via phone or email, directly register afterwards. These are mostly people with a new need; people who just got faced with alopecia but also people who have had it for a while and now get stuck. Or someone for who alopecia just recurred. About 70% of the registrations comes from people who directly had contact with people of the association. One will quickly find the Alopecia Vereniging when searching on the internet. Apart from that there is a big, growing group, who got directed to us via the dermatologist on their first consult.

Reason for registration
The main reason for people to become a member is the need for real information. People doubt the information they get from a doctor and seek for confirmation. ''They would rather hear something different but when they do get that confirmation, then it is more of a resignation.''
Secondly, people sign up for the contact with fellow sufferers. *''The feeling you are not alone.''*
Furthermore, they become a member for the practical part, what are different possibilities to do or go to. Also, you have something extra when you become a member. All days and activities the association organizes are free for members. You are welcome to join when you are not a member but then you pay 25 euro for each activity. Only the secret Facebook page is only for members.
And finally, there are a lot of people who become a member of the AV because they know that when there are developments in the medical field or treatments, the Alopecia Vereniging knows about them. She has the most contacts.

De-registrations
The association always emails people who deregister to confirm their de-registrations and ask if there is anything they can do for them or if there is a special reason they deregister. Most of the time the reason is that alopecia is no longer applicable because hair recurred. Sometimes people with recovery stay member. Sometimes people deregister because they live in further located area of the Netherlands and that the association does not organize enough activities there. However, the Alopecia Vereniging does try to organize them in different places, but the national days should stay central.

Contact between members

Facebook page and group
The association has a public Facebook page on which she posts everything she does and it is about publicity and alopecia in media. She also has a secret Facebook group, this is a closed of community for members. They see this group as a forum.

Secret Facebook group
The secret Facebook group is the most secret one you can have on Facebook, it is impossible to make it a private group later. It is only possible to click on someone's profile when someone posts something in the group. The Alopecia Vereniging is very strict with who they allow in the group. Around 10% of the members is also member of the secret Facebook group but not everyone knows about it yet. On the new website, people will get their own environment and they will get reminded of such things. But of course not everyone feels the need to join the group or has a Facebook account. Only members of the association who suffer or suffered of alopecia can join the group as also companies and wig makers are member of the AV. People who suffered of alopecia in the past are only present in the group at moments when someone needs something or has a question.
''You also see that people who eventually got their hair back, know how much it supported them, that they want to contribute to help other people.''

Facebook difficulties
Difficulties with the Facebook page and secret Facebook group are that someone constantly needs to monitor it. Sometimes people post links in the secret group and in any case when it contains too much of a commercial message, the person gets requested to delete it.
Furthermore, people need to be aware of social media rules. The secret group is secret and not visible to people but everything can get hacked or shared somewhere so people need to be careful with what they post in it.

Contact for close ones
The next years the AV wants to expand the HaarOm meetings and bring people who are close to someone with alopecia in contact with each other. There are possibilities for subsidies in the field of psychosocial care for chronic somatic conditions. The first developments in psychoscial care and involving close ones are coming from Huidpatiënten Nederland. These developments are part of a project proposal in collaboration with the patient federation and the AV represents a voice in this. Huidpatiënten Nederland is an association for people with skin and hair conditions which has individual members and also specific patient associations affiliated with the association. These developments can be specified for different target groups.

People for contacting
There are also people in the association who signed up to get contacted. They are the ones that can be directed to when someone is in need of a talk or advise. Marion does know these people personally so it is possible to direct people to the right person. These people to contact are also put on the back of the magazine.

Panicking people calling
When people are panicking because they just got faced with alopecia, they can call to the Alopecia Vereniging. Marion provides them a sympathetic ear and tries to really give all the information they need, provides them with realistic and clear information or explanations and listens to what needs the person has. She tries to ask them questions as well so they will think for themselves again. This experience of talking to her usually leads them to feel like they want to join the association.
Sometimes she tries to bring people together to let them talk to each other. When someone who is panicking calls or someone sends and email and she know people who were or are in a similar situation, she can bring them together. She also tries to bring people together who live in Belgium or who have the same kind of different type of alopecia. She matches these people according to their needs, stage in life, personality, experience with a specific (medical or psychological) treatment.

FFA and androgenetica groups
Within the Alopecia Vereniging, there are some separate smaller groups of people who suffer of the same, different types of alopecia, like the inflammation FFA or alopecia androgenetica. These were all women who were brought together.

Bringing people together with similar ways of coping
It is not necessary to bring together people who cope with alopecia in a similar way but it is good to keep it in mind. *''It does happen that I think of someone and then I think, well the personality does not really fit together. That has nothing to do with the type or experience but then I really look at the personality. And I also think like well better not. Suppose someone is very insecure and I know the other is quite dominant, then you should bring them together. There is a chance you will get the opposite effect then.''* But people should also have the possibility to pull each other up so they should not be too much the same when they are both closed.
'' I do think it is very important that you give everyone the space to cope with it the way they want or think they have to do. And there are people who are not good at that, who want to impose their own truth on someone.''

Bringing people together with different ways of coping
The chair notices that it happens that people who cope with alopecia in a different way already come together on activities. Only at the HaarOm meetings, people generally cope worse with the condition but even there you have some people who are more positive and some who are very negative. And they help each other.

Organized activities & meetings

Mental support activities
Alopecia Vereniging organizes HaarOm meetings for people for mental support. These are meetings in which people talk with each other about different subjects. The chair said: ''*Contact between fellow sufferers actually often already helps a lot, a lot more than most psychiatrists can do.''*
But when people need more support, the association refers them to for example a psychologist. They also always try to involve the subject of mental support in the workshops on the national conference. *''But you often already see that when we are in contact, that they can call and can ask their questions and possibly join the secret Facebook group, that it already helps and supports a lot.''*

Specified workshops
Sometimes the AV organizes workshops for a more specific group of people of the association, for example a hair workshop for people with alopecia who still have hair.

HaarOm meetings
The HaarOm meetings are more focused on people who have a hard time coping with alopecia. However, when people start to grow and cope better with the condition, they do not show up again. Each year the association proposes a follow-up HaarOm because everyone will be in a different stage but people do not feel the need for that or the need is smaller.

Youngsters day
On the youngsters day the AV tries to only organize nice things because the chair thinks that having deeper conversations is something that should come naturally on such a day.

Initiatives by youngsters
The AV would like young members to show initiatives in coming up with ideas about for example their own fora, meeting days, etc., according to their needs. The association would make those things possible then. The chair thinks that youngsters participate more in everything, more clearly have and express their voice and show their need and wishes.

Activities for people who cope well
There should also be activities for people who cope well with alopecia. For example the hair, style and make-up workshop attracts more people who cope well with the condition because they like to meet other people and get practical tips. This group of people also has a need to talk about for example daily frustrations and also for them there need to be advantages of being a member. The problem is that the need to go to meetings is less present.

Children day
The annual day for children is organized with fun activities for children. *''We take the parents separately, we try to do something for them too. And that is to split those two groups because parents of children with alopecia are more worried about what is happening and is my child able to do that? You would almost say overprotective. So by separating those group, you give the children space to be themselves. And those parents you take them away and try to support them in another way.''*

Needs of the association & future plans

Webmaster & communication manager
The AV would like to have more manpower and someone who is webmaster and a communication manager who can also analyze the online channels.

Volunteers
The association has a wish for a volunteer who is the contact person for and fully responsible for the volunteers.

Future plans
The new chair, Max, has a working group about research and works on the intentional contacts. This year the intention is to build contact with Columbia, where there is a medical examiner.

10. SUPPORT OR POSITIVE POINTS

The statement cards of the participants were investigated to see what things, activities or thoughts make the participants happy, positive or support them.

- Alternating between wigs is something other people are not able to. They have to go to the hair dresser each time they want to dye it. People with alopecia can just have different hair styles, but only if they have totally accepted it.

- No tangling hair on holiday is an advantage.

- For bald men, alopecia saves money, work and time as they do not have to go to the hair dresser, use gel or shampoo and fix their hair in the mirror.

- Not having to wash hair in the shower is an advantage.

- Already in the beginning of a relationship you find out how someone deals with problems like alopecia. If having no alopecia, you would only find out that someone is not handling those things well after some time.

- With alopecia you find out what is really important and you are less dependent on looks. Life is not only about cool hair and make-up.

- For men, when wearing a beanie, they would more easily make a chat with a stranger.

- One girl said she would feel more safe when dating someone who also has a psychological or physical problem

- When wearing a wig which is beautiful, the person also feels better and more beautiful.

- Some participants felt more free and more like themselves when not wearing a wig at home.

- Participant 5 likes to wear hat because it creates some differentiation in the way he looks.

- Some participants try to not avoid activities as much as possible because it would not help them.
- Having expression in your face because of permanent make up can make someone happy.

- Knowing that family and friends are there for support makes participant 7 less worry, no matter what happens, losing hair gain or not, they will be there.

- Participant 3 chose hair she could never have to take the positive side of her alopecia. She thinks this was a sort of self-protection.

- In the beginning participant 5 took pictures every time something changed as a way of processing it.

- A panicking mother was helped by calling another mother with a daughter in the same situation. It helped her get 'direction in the maze'.

- Alopecia can make participant 8 very happy when he knows someone really totally accepts it.

11. CONCEPT EVALUATION SURVEY FOR PERSON WITH ALOPECIA

Vragenlijst concepten afstudeerproject Tessa Majenburg

De antwoorden worden alleen gebruikt voor mijn afstudeerproject en alle antwoorden zijn en blijven anoniem.

☐ Ik ga akkoord met het gebruik van de antwoorden voor het afstudeerproject.

Man / Vrouw

Vorm alopecia:

Leeftijd:

Leeftijd start alopecia:

1. Welk concept (en/of welke variant ervan) heeft je voorkeur? Waarom?
1. Which concept (and/or which version of it) has your preference? Why?

2. Welk concept (en/of welke variant ervan) heeft je tweede voorkeur? Waarom?
2. Which concept (and/or which version of it) has your second preference? Why?

3. Met wie zou je de verschillende concepten gebruiken? Waarom?
3. With who would you like to use the concepts? Why?

4. Als je concept 1 zou gaan gebruiken, hoe zou jij het ontwerpen? Wat zou je eraan veranderen of wat zou je er anders aan willen?
4. If you were to use concept 1, how would you design it? What would you change about it or what would you like to see different about it?

5. Als je concept 2 zou gaan gebruiken, hoe zou jij het ontwerpen? Wat zou je eraan veranderen of wat zou je er anders aan willen?
5. If you were to use concept 2, how would you design it? What would you change about it or what would you like to see different about it?

6. Als je concept 3 zou gaan gebruiken, hoe zou jij het ontwerpen? Wat zou je eraan veranderen of wat zou je er anders aan willen?
6. If you were to use concept 3, how would you design it? What would you change about it or what would you like to see different about it?

7. Zijn één of meerdere concepten confronterend of kwetsend? Waarom (niet)?
7. Are one or more concepts confronting or offending? Why (not)?

8. Wat vind je leuk en/of goed aan de verschillende concepten?
8. What do you like about or think is good about the different concepts?

9. Kun je de verschillende varianten van de drie concepten beoordelen op de volgende aspecten op schaal van 1 tot 5 (met **1 heel weinig** en **5 heel veel**). Omcirkel:

Concept 1.1 – Activiteiten App

Dit zou mij helpen:

1 2 3 4 5

Stimuleert steun:

1 2 3 4 5

Draagt bij aan begrip:

1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5

Concept 1.2 – Activiteiten folder

Dit zou mij helpen:

1 2 3 4 5

Stimuleert steun:

1 2 3 4 5

Draagt bij aan begrip:

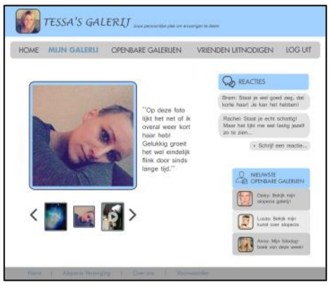
1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5



Concept 2.1 – Persoonlijke foto & video galerij website

Dit zou mij helpen:

1 2 3 4 5

Stimuleert steun:

1 2 3 4 5

Draagt bij aan begrip:

1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5

Concept 2.1 – Persoonlijke foto galerij folder uitbreiding

Dit zou mij helpen:

1 2 3 4 5

Stimuleert steun:

1 2 3 4 5

Draagt bij aan begrip:

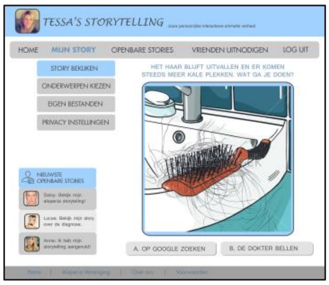
1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5



Concept 2.2 – Interactieve storytelling website

Dit zou mij helpen:

1 2 3 4 5

Stimuleert steun:

1 2 3 4 5

Draagt bij aan begrip:

1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5

Concept 3 – Alopecia filter app

Dit zou mij helpen:

1 2 3 4 5

Stimuleert steun:

1 2 3 4 5

Draagt bij aan begrip:

1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5

12. CONCEPT EVALUATION SURVEY CLOSE ONE

Vragenlijst concepten afstudeerproject Tessa Majenburg

De antwoorden worden alleen gebruikt voor mijn afstudeerproject en alle antwoorden zijn en blijven anoniem.

☐ Ik ga akkoord met het gebruik van de antwoorden voor het afstudeerproject.

Relatie tot persoon met alopecia:

Persoon met alopecia: Man / Vrouw

Leeftijd persoon met alopecia:

Vorm alopecia:

Leeftijd start alopecia:

1. Welk concept (en/of welke variant ervan) heeft je voorkeur? Waarom?
1. Which concept (and/or which version of it) has your preference? Why?

2. Welk concept (en/of welke variant ervan) heeft je tweede voorkeur? Waarom?
2. Which concept (and/or which version of it) has your second preference? Why?

3. Welke van de concepten zou je niet willen gebruiken? Waarom niet?
3. Which of the concepts would you not want to use? Why?

4. Als je concept 1 zou gaan gebruiken, hoe zou jij het ontwerpen? Wat zou je eraan veranderen of wat zou je er anders aan willen?
4. If you were to use concept 1, how would you design it? What would you change about it or what would you like to see different about it?

5. Als je concept 2 zou gaan gebruiken, hoe zou jij het ontwerpen? Wat zou je eraan veranderen of wat zou je er anders aan willen?
5. If you were to use concept 2, how would you design it? What would you change about it or what would you like to see different about it?

6. Als je concept 3 zou gaan gebruiken, hoe zou jij het ontwerpen? Wat zou je eraan veranderen of wat zou je er anders aan willen?
6. If you were to use concept 3, how would you design it? What would you change about it or what would you like to see different about it?

7. Zijn één of meerdere concepten confronterend of kwetsend? Waarom (niet)?
7. Are one or more concepts confronting or offending? Why (not)?

8. Wat vind je leuk en/of goed aan de verschillende concepten?
8. What do you like about or think is good about the different concepts?

9. Kun je de verschillende varianten van de drie concepten beoordelen op de volgende aspecten op schaal van 1 tot 5 (met **1 heel weinig** en **5 heel veel**). Omcirkel:

Concept 1.1 – Activiteiten App

Dit zou mij helpen:

1 2 3 4 5

Stimuleert steun:

1 2 3 4 5

Draagt bij aan begrip:

1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5

Concept 1.2 – Activiteiten folder

Dit zou mij helpen:

1 2 3 4 5

Stimuleert steun:

1 2 3 4 5

Draagt bij aan begrip:

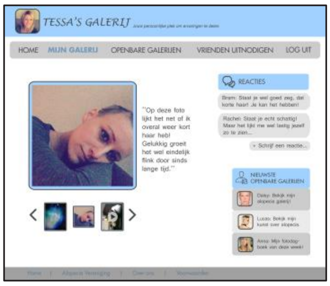
1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5



Concept 2.1 – Persoonlijke foto & video galerij website

Dit zou mij helpen:

1 2 3 4 5

Stimuleert steun:

1 2 3 4 5

Draagt bij aan begrip:

1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5

Concept 2.1 – Persoonlijke foto galerij folder uitbreiding

Dit zou mij helpen:

1 2 3 4 5

Stimuleert steun:

1 2 3 4 5

Draagt bij aan begrip:

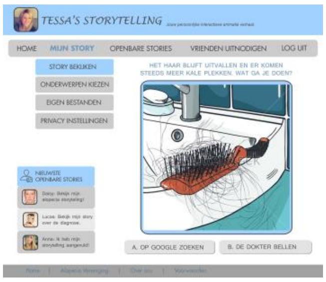
1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5



Concept 2.2 – Interactieve storytelling website

Dit zou mij helpen:

1 2 3 4 5

Stimuleert steun:

1 2 3 4 5

Draagt bij aan begrip:

1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5

Concept 3 – Alopecia filter app

Dit zou mij helpen:

1 2 3 4 5

Stimuleert steun:

1 2 3 4 5

Draagt bij aan begrip:

1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5

13. ANALYSIS CONCEPT EVALUATION

Participants concept evaluation:
AA = alopecia areata, AT = alopecia totalis, AU = alopecia universalis

Participants with alopecia:

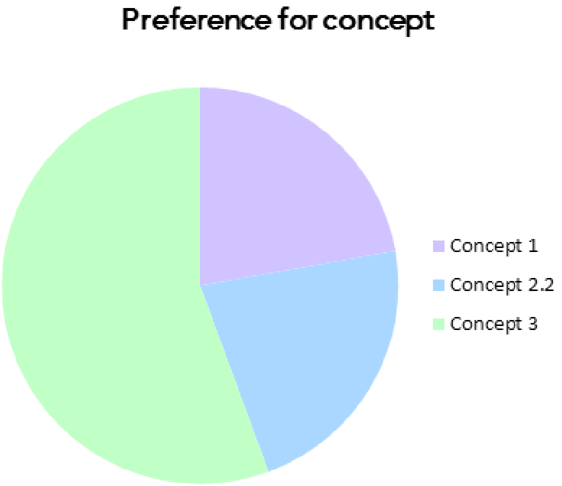
1. F, age 16, AA, start age 14
2. F, age 22, AT, start age 13
3. M, age 31, AU, start age 15
4. F, age 20, AU, start age 17
5. F, age 21, AU, start age 19
6. F, age 46, AT, start age 0
7. F, age 29, AA, start age 28
8. F, age 15, AT, start age 14
9. F, age 51, AT, start age 49

Participants people close to person with alopecia:
10. Mother of participant 1 (pediatric psychologist)
11. Grandmother of participant 1
12. Mother of participant 2
13. Father of a girl of 14 with alopecia areata (since age 12).
14. Sister of participant 4
15. Mother of participant 8 (has alopecia herself but answered as relative).

Questions answered by participants with alopecia:

1. Welk concept (en/of welke variant ervan) heeft je voorkeur? Waarom?
P1: Concept 3, omdat je dan ziet hoe je vriendinnen met situaties om zouden gaan. Het komt voor hen ook dichtbij > meer impact.
P2: Concept 3, mensen kunnen zien hoe het bij hun is, geeft ze meer besef / begrip. Met vrienden kan het grappig zijn wat het onderwerp luchtiger maakt.
P3: Concept 1, meest praktisch.
P4: De app met de alopecia filter.
P5: De app met alopecia filter. Zo zien anderen ook hoe het is om kaal te zijn.
P6: Concept 3, meest zichtbaar in voorstelling.
P7: Concept 2.2, andere in de positie stellen om het zichzelf af te vragen wat de volgende stap is. 2.1 is persoonlijk niets voor mij.
P8: Concept 2.2, interactieve storytelling website, omdat mensen zich zo kunnen inleven.
P9: Concept 1.1, goed voor je, zodat je niet achter de geraniums komt te zitten.

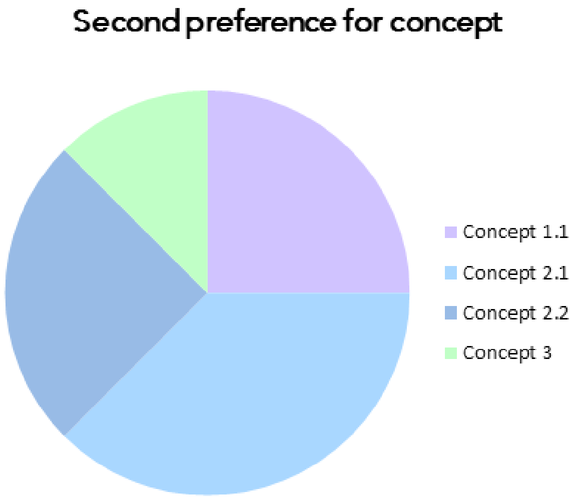
Conclusion: Concept 3 (5/9), because of the possibility to let friends put themselves in their place and to give them more sympathy. This concept is also best imaginable in use and it is makes the subject less heavy.



Concept 2.2 (2/9), because others can put themselves in their place and have the possibility to ask themselves what the next step is.
Concept 1 (2/9, 31 and 51 years old), because it is most practical and makes you do activities.

2. Welk concept (en/of welke variant ervan) heeft je tweede voorkeur? Waarom?
P1: Concept 2.2, omdat je dan ziet hoe anderen het zouden doen. Ze moeten er dan over na denken.
P2: Concept 1, handig gebruik door de app. Je kan het makkelijk aangeven ook al vind je het moeilijk om erover te praten.
P3: Concept 2, storytelling lijkt me een goede manier om het gesprek te openen.
P4: De activiteiten app.
P5: Soort mini dagboekje. Handig en fijn i.p.v. schrijven.
P6: Concept 2.
P7: Concept 3, nadenken + gevoel geven wat het met je doet.
P8: Alopecia filter app, vind het leuk hoe je jezelf kunt zien met de app.
P9: Concept 2.1, soort dagboek waardoor je het van je af schrijft.

Conclusion:
Concept 2.1 (3/9), because it makes you write about it and it is more convenient than writing.
Concept 2.2 (2/9), because it makes you see how others would deal in your situation and they have to think about it. It is also a good way to start a conversation.
Concept 3: (1/9), because it makes someone think about and feel what it does to you.
Concept 1.1 (2/9)



3. Met wie zou je de verschillende concepten gebruiken? Waarom?
P1: Vriendinnen, omdat die van mijn leeftijd zijn. Familie / ouders denken waarschijnlijk erg anders over bepaalde onderwerpen.
P2: Vriendinnen / vriendengroep en familie.
P3: Nu niet meer, op mijn 15e met vrienden / familie.
P4: Met vrienden, zo leven ze mee met het hebben van alopecia.
P5: Ouders, familie.
P6: Naaste familie / vrienden.
P7: Leerlingen in de klas > verschillen tussen mensen. En vrienden.
P8: Met mijn vrienden omdat ze actief bezig zijn met m'n aandoening.
P9: Met familie, vrienden en kennissen.

Conclusion: Most participants would use the concepts with friends or family. Three younger girls would only use them with their friends. One of the girls said she would use it with her friends because family probably think differently than her peers. One woman would show pupils at school to teach them about differences between people.

4. Als je concept 1 zou gaan gebruiken, hoe zou jij het ontwerpen? Wat zou je eraan veranderen of wat zou je er anders aan willen?
P1: Ik zou er niks aan veranderen.
P2: Kleurrijker + foto's.
P3: Geen idee.
P4: De filter app zal ik combineren met de activiteiten app.
P5: Veel invulling.
P6: Voor mij de minst aansprekende. Past minder bij mij en hoe ik met aa om ga.
P7: Concept 1.2 niet, maar dat is persoonlijke voorkeur. Wel belangrijk dat 't er is.
P8: Zou er niks aan veranderen!
P9: Ik zou het niet ontwerpen, dat kan ik niet. Ziet er mooi uit.

Conclusion: One girl would combine the alopecia filter app with the activities app. Another girl would add more colors and pictures to the concept. One older woman said this concept does not have her preference as it does not match with the way she deals with her alopecia. She does not want to be the center of attention for her friends and demand a lot of effort of them.

5. Als je concept 2 zou gaan gebruiken, hoe zou jij het ontwerpen? Wat zou je eraan veranderen of wat zou je er anders aan willen?
P1: Ik vind het helemaal goed zo.
P2: Optie om je 'story' te delen op bijvoorbeeld Facebook.
P3: Geen idee.
P4: Ik zou chatten met mede leden met alopecia en het afgeschermde is prima.
P5: In app vorm en een delen knop.
P6: Kan juist anderen ook helpen in het delen van ervaring. Daarin positief.
P7: Concept 2.2 niet, weer persoonlijke voorkeur. Wel belangrijk dat 't er is.
P8: Zou de site gebruiken om dingen te delen maar zou niks met de folder doen.
P9: Zie boven.

Conclusion: One girl would like to be able to chat with other member of the association in the app and likes that the app is private. Two girls of 21 and 22 years old like to have a possibility to share the story or diary. Two people said they prefer the website version over the booklet. One girl would prefer concept 2.1 to be as an app.

6. Als je concept 3 zou gaan gebruiken, hoe zou jij het ontwerpen? Wat zou je eraan veranderen of wat zou je er anders aan willen?
P1: Dat je pruiken kan kiezen als filter. Verder is het een top idee! :)
P2: Optie verschillende pruiken ook voor jezelf en vrienden, kapsels en kleuren.
P3: Geen idee.
P4: Ik zal de filter app ontwerpen met haarwerken, zo kan je zien wat bij je past.
P5: Alopecia filter misschien pruiken testen.
P6: Zoals je het concept toont, lijkt mij dit verder prima.
P7: Als alle vormen erin staan is 't perfect!
P8: Zou er veel foto's mee maken, en er niks aan veranderen.
P9: Zie boven.

Conclusion: Four out of nine participants said they would like to also have the possibility to try on different wigs (different hair styles, different colors) with the alopecia filter app. These girls were all aged 16, 20, 21 and 22.
7. Zijn één of meerdere concepten confronterend

of kwetsend? Waarom (niet)?
P1: Nee, alles is gewoon erg persoonlijk en zou voor mij niet confronterend / kwetsend zijn.
P2: Confronterend voor jezelf als je nog niet helemaal hebt geaccepteerd, niet kwetsend.
P3: Concept 3 lijkt me het meest kwetsend: hilariteit ligt op de loer.
P4: Ik vind het juist goed ontworpen. Hoe opener je erover bent hoe beter.
P5: Nee, eerder confronterend voor anderen om te zien hoe zij eruit zien zonder haar.
P6: De eerste vind ik wel confronterend en kwetsend!
P7: Allemaal confronterend maar nodig!
P8: Nee.
P9: Nee.

Conclusion: Five out of nine participants do not think the concepts to be confronting or offending. One girl said it could be confronting for yourself only if you have not yet totally accepted it, but not offending. One man said concept 3 looks most offending because the possibility of hilarity is present. One older woman said concept 1 is confronting and offending. One woman of 29 said all concepts are confronting but said that is necessary.

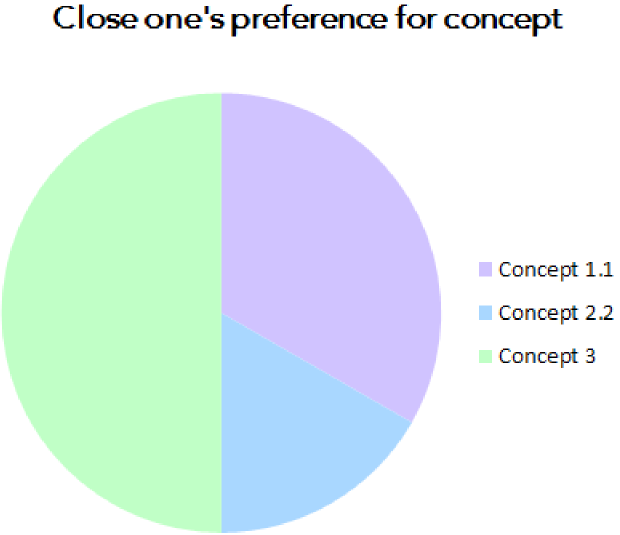
8. Wat vind je leuk en/of goed aan de verschillende concepten?
P1: Dat je kennissen aan het denken zet en laten inleven in jouw situatie, zoals concept 3 / 2.2. En je hun acties op situaties kan zien.
P2: Actueel, leuk om te doen!
P3: Digitale tools voor bespreekbaar maken van alopecia = goed.
P4: Dat mensen hetzelfde als jij kan ervaren.
P5: Dat het van deze tijd is en iedereen het kan gebruiken.
P6: Concept 3 is heel tastbaar.
P7: Meer opties, iedereen vindt iets anders belangrijk.
P8: Dat je zo je verhaal kunt delen vind ik erg leuk.
P9: Vrijblijvend en op deze manier kan je het goed ventileren.

Conclusion: Participants said they like that people can experience the same as you. Also, they like that the concepts are up-to-date, everyone can use it and they are fun to do. It is noncommittal and digital tools to address alopecia is good. One participant likes that there or more options, as everyone thinks something else is important. One participant likes that it provides the possibility to share your story. Finally, one participant said concept 3 is very tactile.

Questions answered by participants close to person with alopecia:

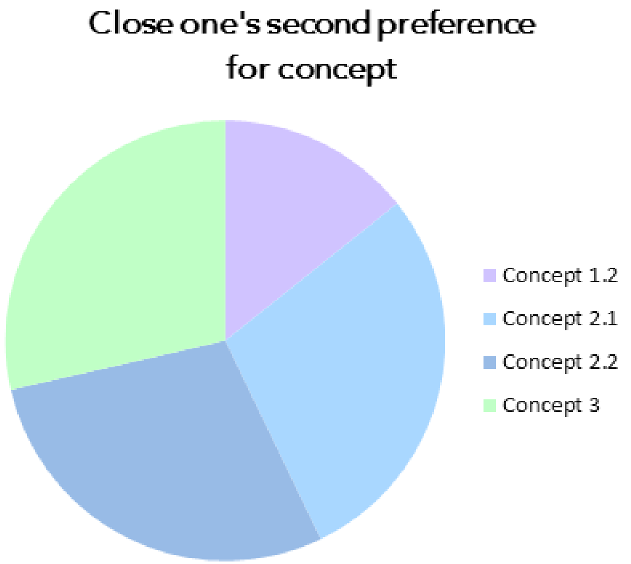
1. Welk concept (en/of welke variant ervan) heeft je voorkeur? Waarom?
- P10: Concept 3, alopecia filter app. Leuk, laagdrempelig, soort 'snapchat', achter mobiel te doen, groot beroep op inlevingsvermogen. Letterlijk verplaatsen in situatie!
- P11: Concept 3 – empathisch vermogen.
- P12: Concept 2.2 geeft duidelijkheid zonder persoonlijk te worden.
- P13: Concept 1.1
- P14: Activiteiten app
- P15: Concept 3.

Conclusion (see figure):
Concept 3 (3/6), because it is nice, accessible, possible to use with a phone and requires empathy.
Concept 2.2 (2/6), gives clarity without getting personal.
Concept 1.1 (2/6)



2. Welk concept (en/of welke variant ervan) heeft je tweede voorkeur? Waarom?
- P10: 2.1 & 2.2. Achter mobiel te doen en persoonlijk.
- P11: Concept 2.2 – empathisch vermogen.
- P12: Concept 3 zeker voor jongeren/kinderen om 't 'luchtig' te maken.
- P13: Concept 1.2
- P14: Alopecia filter app
- P15: Concept 2.1

Conclusion (see figure):
Concept 2.2 (2/6): Because is possible with a mobile phone and is personal.
Concept 2.1 (2/6): Because is possible with a mobile phone, is personal and requires empathy.
Concept 3 (2/6): because is especially for younger people and makes it 'light'
Concept 1.2 (1/6).



3. Welke van de concepten zou je niet willen gebruiken? Waarom niet?
- P10: -
- P11: Concept 1.1 Te heftig.
- P12: Concept 2.1 Te persoonlijk (misschien alleen voor familie en vrienden).
- P13: -
- P14: De chats, bestaan er al een aantal van. Is niet perse vernieuwend.
- P15: Met wie zou je het gebruiken: Met mijn dochter.

Conclusion: Concept 1.1 is too intense, concept 2.1 is too personal (but perhaps possible only with friends or family) and for the concept with chats, there are already a lot of them out there.

4. Als je concept 1 zou gaan gebruiken, hoe zou jij het ontwerpen? Wat zou je eraan veranderen of wat zou je er anders aan willen?
- P10: Leuk zo! Goed voor met vrienden enzo.
- P11: N.v.t.
- P12: -
- P13: -
- P14: Ik zou de activiteiten app gebruiken en dan de filter app als onderdeel daarvan gebruiken.
- P15: Ik zou er niets aan veranderen.

Conclusion: One participant would make the alopecia filter app a part of the activities app.

5. Als je concept 2 zou gaan gebruiken, hoe zou jij het ontwerpen? Wat zou je eraan veranderen of wat zou je er anders aan willen?
- P10: Het woord storytelling associatie met sprookje, is juist reality: 'Walk in my shoes.'
- P11: Act-folder; story bekijken. Verder ok!
- P12: Zo 'luchtig' mogelijk. Niet te zwaar.
- P13: -
- P14: Ik zou er iets vernieuwends bij doen zodat het zich onderscheidt van de andere chats.
- P15: Niets veranderen.

Conclusion: One participant said she associates the word 'storytelling' with a fairytale and would rather use the name 'walk in my shoes'. One older participant said she would like the storytelling to also be available as a booklet. One participant said it should be designed as 'light' as possible and one said she would like something innovative to make it different from other chats.

6. Als je concept 3 zou gaan gebruiken, hoe zou jij het ontwerpen? Wat zou je eraan veranderen of wat zou je er anders aan willen?
- P10: Goed voor alopecia vereniging jongeren app. Linken met Snapchat (in aa-awareness maand) en link naar aa. AA filter erop.
- P11: N.v.t.
- P12: Ik zou 't niet doen.
- P13: -
- P14: Zie vraag 4.
- P15: Bijv. make-up advies + zichtbaar.

Conclusion: One participant said she would like the concept to be linked to Snapchat, the alopecia association and maybe the alopecia-awareness month. One participant would combine the filter with the activities app and one participant would like the alopecia filter app to also have make-up advice.

7. Zijn één of meerdere concepten confronterend of kwetsend? Waarom (niet)?
- P10: Nee, zet aan het denken!
- P11: N.v.t.
- P12: Confronterend, 2.1.
- P13: Concept 3, confronterend. Je wordt als familielid, vriend, etc. met je neus op de feiten gedrukt. Helpt wellicht acceptatie.
- P14: Nee, leuke manier van omgaan met alopecia.
- P15: Niet voor mij totaal niet.

Conclusion: One participant said concept 2.1 is confronting. One participant said concept 3 is confronting as you get confronted with the facts as a family member or friend, but this concept might add to acceptance. Two participants said the concepts are not confronting but a nice way of dealing with alopecia and they make people think.

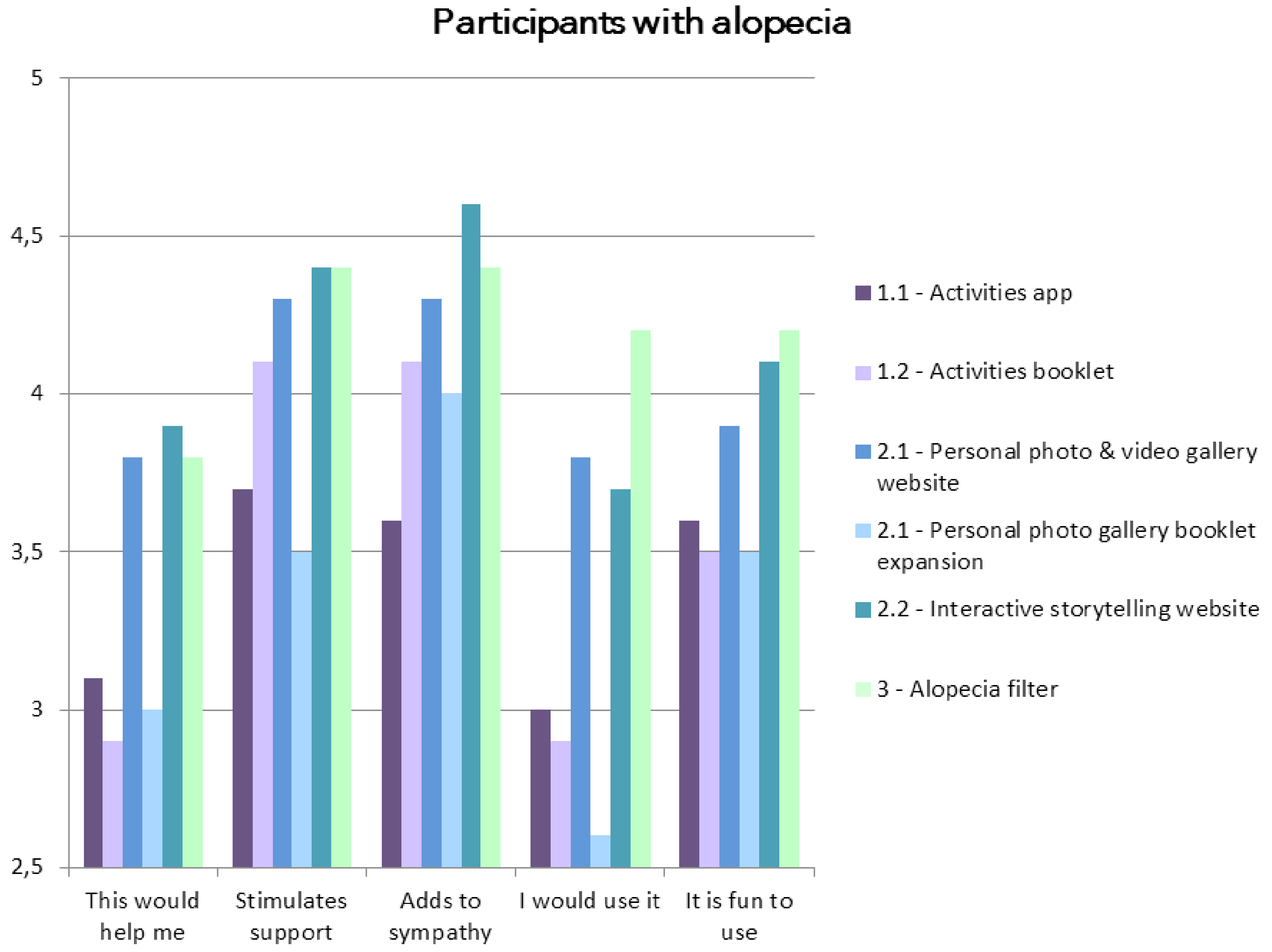
8. Wat vind je leuk en/of goed aan de verschillende concepten?
- P10: Twee meer op denkniveau, inleven (1+2) > Meer voor vrienden / familie.
Eén meer op activiteiten doen (3) > Meer voor interne vereniging.
Allebei goed, beeldend aansluitend bij jongeren! Knap gedaan.
- P11: Weet ik niet.

- P12: Voor verschillende leeftijden geschikt.
- P13: Alle drie wel goed hulpmiddel voor eigen acceptatie en acceptatie door omgeving.
- P14: Concept 1 + 3 zijn vernieuwend en van deze tijd.
- P15: 2.1, 2.2, 3. zijn erg leuk. Vooral v.a. jonge leeftijd.

Conclusion: One participant likes that the concepts are suitable for different ages, one likes that the concept are visually well corresponding to youngsters. One participant said all three concepts are good means for self-acceptance and acceptance by the environment and one participant said concept 1 and 3 are innovative and up-to-date. Finally, one participant said concept 2.1, 2.2 and 3 are fun, especially, from a young age.

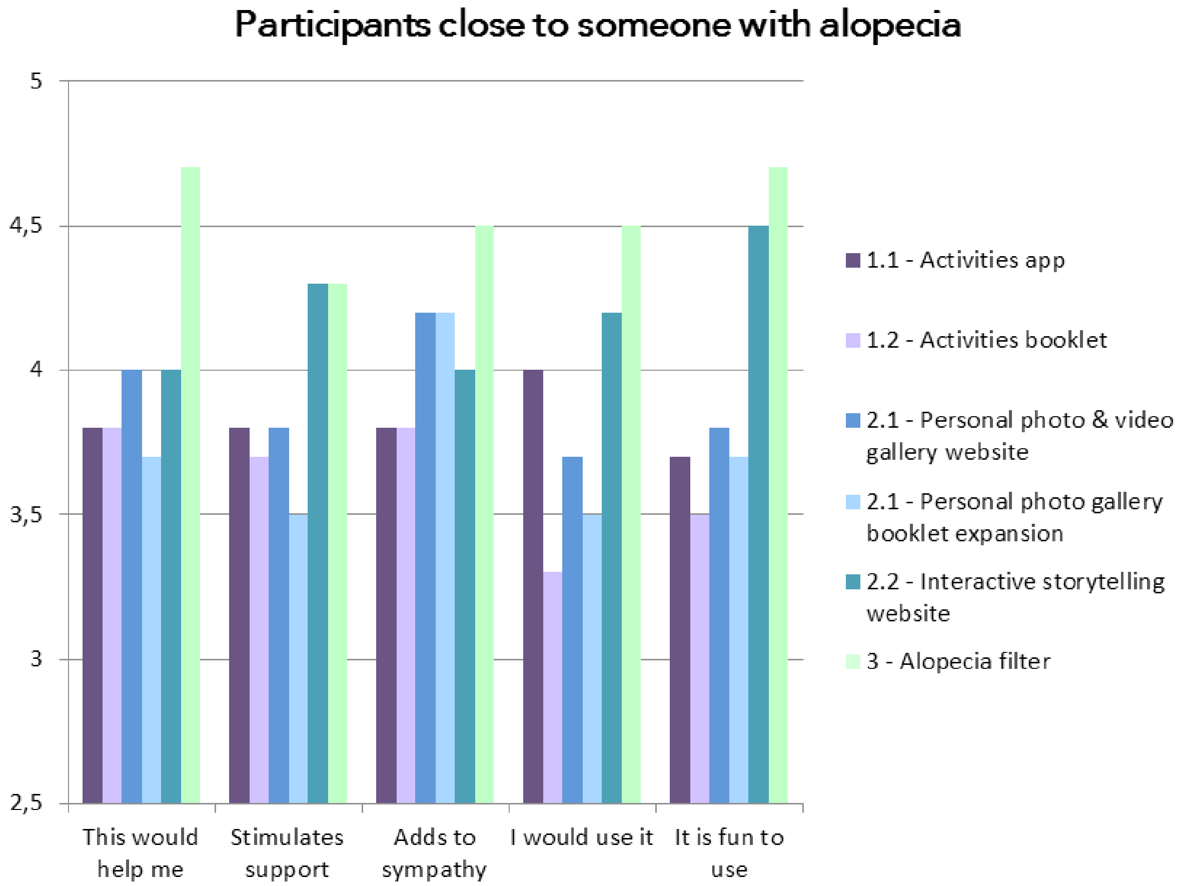
Scores participants with alopecia:
The scores are the average scores of people with alopecia. The highest and lowest scored are colored green and red respectively. The average scores were never lower than 2,5 so all graphs start with a score of 2,5 on the vertical scale.

	Concept 1.1 – Activities app	Concept 1.2 – Activities booklet	Concept 2.1 – Personal photo & video gallery website	Concept 2.1 – Personal photo gallery booklet expansion	Concept 2.2 - Interactive storytelling website	Concept 3. – Alopecia filter app
This would help me.	4, 3, 1, 5, 5, 5 = **3,8**	3, 4, 3, 5, 4, 4 = **3,8**	5, 4, 3, 4, 3, 5 = **4**	5, 4, 3, 4, 1,5 = **3,7**	5, 3, 4, 4, 3, 5 = **4**	5, 5, 4, 4, 5, 5 = **4,7**
Stimulates support.	4, 4, 2, 3, 5, 5 = **3,8**	4, 3, 3, 3, 5, 4 = **3,7**	5, 4, 3, 3, 3, 5 = **3,8**	5, 4, 3, 3, 1, 5 = **3,5**	5, 4, 4, 4, 4, 5 = **4,3**	5, 5, 3, 3, 5, 5 = **4,3**
Adds to sympathy.	3, 5, 2, 3, 5, 5 = **3,8**	3, 4, 3, 3, 5, 5 = **3,8**	5, 5, 4, 3, 3, 5 = **4,2**	5, 4, 4, 3, 4, 5 = **4,2**	5, 4, 5, 2, 3, 5 = **4**	5!, 5, 3, 4, 5, 5 = **4,5**
I would use it.	4, 4, 2, 4, 5, 5 = **4**	2, 3, 3, 4, 3, 5 = **3,3**	5, 4, 3, 4, 1, 5 = **3,7**	5, 4, 3, 4, 1, 4 = **3,5**	5, 4, 5, 4, 2, 5 = **4,2**	5, 5, 4, 3, 5, 5 = **4,5**
It is fun to use.	4, 3, 2, 3, 5, 5 = **3,7**	3, 4, 3, 3, 3, 5 = **3,5**	5, 4, 3, 3, 3, 5 = **3,8**	5, 3, 3, 3, 3, 5 = **3,7**	5, 4, 5, 4, 4, 5 = **4,5**	5, 5, 5, 3, 5, 5 = **4,7**



Scores participants people close to person with alopecia:
The scores are the average scores of people close to the person with alopecia. The highest and lowest scored are coloured green and red respectively.

	Concept 1.1 – Activities app	Concept 1.2 – Activities booklet	Concept 2.1 – Personal photo & video gallery website	Concept 2.1 – Personal photo gallery booklet expansion	Concept 2.2 - Interactive storytelling website	Concept 3. – Alopecia filter app
This would help me.	2, 4, 1, 5, 5, 1, 3, 3, 4 = **3,1**	2, 3, 1, 4, 4, 4, -, 2, 3 = **2,9**	3, 4, 1, 5, 4, 4, -, 4, 5 = **3,8**	1, 4, 1, 5, 4, 3, -, 2, 4 = **3**	2, 5, 1, 5, 5, 2, 5, 5, 5 = **3,9**	4, 5, 1, 5, 4, 4, 1, 5, 5 = **3,8**
Stimulates support.	4, 4, 5, 5, 4, 1, 3, 3, 4 = **3,7**	4, 4, 5, 5, 5, 4,-, 3, 3 = **4,1**	3, 4, 4, 5, 4, 5, -, 4, 5 = **4,3**	2, 3, 3, 5, 4, 4, -, 3, 4 = **3,5**	3, 4, 5, 5, 5, 3, 5, 5, 5 = **4,4**	4, 5, 2, 5, 5, 4, 5, 5, 5 = **4,4**
Adds to sympathy.	3, 4, 5, 5, 3- 4, 2, 3, 3, 4 = **3,6**	3, 4, 5, 5, 5, 5, -, 3, 3 = **4,1**	3, 4, 3, 5, 5, 5, -, 4, 5 = **4,3**	3, 4, 4, 5, 5, 4, -, 3, 4 = **4**	4, 5, 5, 5, 5, 2, 5, 5, 5 = **4,6**	5, 5, 1, 5, 4, 5, 5, 5, 5 = **4,4**
I would use it.	2, 5, 1, 4, 4, 1, 4, 2, 4 = **3**	2, 3, 1, 4, 4, 5, -, 1, 3 = **2,9**	3, 4, 1, 5, 4, 4, -, 4, 5 = **3,8**	1, 3, 1, 5, 4, 2, -, 1, 4 = **2,6**	2, 4, 1, 5, 5, 1, 5, 5, 5 = **3,7**	5, 5, 1, 5, 4, 4, 4, 5, 5 = **4,2**
It is fun to use.	4, 4, 4, 4, 4, 1, 4, 3, 4 = **3,6**	4, 2, 4, 5, 4, 4, -, 2, 3 = **3,5**	3, 4, 3, 5, 5, 2, -, 4, 5 = **3,9**	3, 3, 4, 5, 5, 2, -, 2, 4 = **3,5**	3, 4, 4, 5, 5, 1, 5, 5, 5 = **4,1**	5, 5, 2, 5, 4, 3, 4, 5, 5 = **4,2**



Conclusion:
Among both the participants with alopecia as well as participants close to people with alopecia, concepts 3, 2.2 and 2.1 (website) scored best. Among this last group, concept 3 scored best in every aspect. Among participants with alopecia, concept 2.2 and 3 both scored best, followed by concept 2.1.

14. CO-CREATIVE SESSION PLANNING

1. Explain ideas

2. Show sketch concepts.
- What do you like about it?
- Would you use it?
- What do you not like about it / what would you like to see different?
- How would you have designed it yourself? Can you draw this?
- Which functions would you like to see?
- Which situations would you like to convey?
- Would you prefer the situation sketches in cartoon style or as realistic pictures?

3. Could you integrate the two different concepts to one design? What would the app look like if both these functions were in it?

4. Show own integration design.
- What do you think of this integration?
- What do you think is good about it?
- What can be improved or better?

5. Show high fidelity integrated concept.
- What do you think of the visual style?
- Would you like it if the app was in the same style as the website of the Alopecia Vereniging?
- Could you act out with these concept prototypes how you would use it? Act like the other is your friend or friends.
- Do you notice things that can be improved when you use it like this?

15. CO-CREATIVE SESSION INSIGHTS

There were six participants during the co-create session and later a seventh one joined:
Participant 1: Male, 18 universalis since age 12.
Participant 2: Female, 16, totalis since age 14.
Participant 3: Female, 21, areata since age 3 (studies communication).
Participant 4: Male, 22, universalis since age 17.
Participant 5: Female, 16, universalis since age 3.
Participant 6: Female, 18, areata since age 13.
Participant 7: Female, 16, universalis since age 3.

1. Preference for cartoon style
All participants agreed that a cartoon style would be best for the situation story. They thought that they would get really confronted when real people would be involved. Cartoon is more calm. Participant 3: 'If you're gonna use real people, you can think like, hey it's not like that for me, personally. This happens less with a cartoon style because you can better give an interpretation to it.'

2. Realistic cartoon style
All participants prefer a realistic cartoon style. They do not want a 'Donald Duck' or 'weird puppets', they want real people, 'with five fingers and so on'.

3. Positive but serious cartoon style
The participants do not want a depressive cartoon style, not like alopecia is the end of the world, but something more positive. However, it should not be too happy and should not seem like it is fun. ''It should stay serious, not depressed but also not happy because then you lose part of your message. You do not all understand what I struggle with, that's why I have this story, but this is all very happy so what are you struggling with then?'' Furthermore, they want bright and happy colors.

4. Make-up filter with links to tutorials
For participant three and five, the link between the intention of the design and the make-up filter was not directly clear. When participant two explained she started using fake lashes after only taking selfies with the make-up filter on Snapchat, they understood. Participant three said ''Maybe it is a nice addition to that, that you can see different make-up looks with it and that you link those to a Youtube movie of how you can make that look yourself. Otherwise, it looks really nice on the app, but how can I do that myself? Here you have a beauty vlogger who does that like that too.'' Participant six added to that: ''Like that, you have for example this Masha of Beautyworld, she made a video of how you can cover bald spots. You could link something like that.''

5. Wigs information
- Possibility of wigs filter with links to brands or stores?
The participants would like this possibility but for example also to just get more information about different kind of wigs because there are so many different ones. They proposed to link it to the wig information part of the Alopecia Vereniging website, so you do not have to go to random websites.

6. Link to Alopecia Vereniging
The participants think it is convenient to link the app or website to the Alopecia Vereniging website because there is a lot of information there. ''When you think this seems interesting, I want to know more about that. And perhaps it is possible to make such a make-up tutorial yourself in collaboration with the Alopecia Vereniging.''

7. Link to Youtube
The participants do not care if the app had the tutorial information or links you to an external website. They think it is more important that is has the links and when you get directed to Youtube it is also nice that you see some related or recommended videos on the side.

8. Usage of designs
Participant one said he would not use the make-up filter but would use the story and alopecia filter. He said: ''I would use that alopecia filter, purely to see my class mates bald for once and to say, well that's how that feels!'' Participant six: ''I think you can make people very conscious with that.''

9. Permanent make-up
Participant six said the make-up filter would be good for people to try different eyebrows because a lot of people do not dare to get the permanent make-up because they are scared the shape of the eyebrows will not look nice on them. You cannot just stick them on like you can with lashes. With the filter, they can just easily try different shapes. Participant one agreed to this.

10. Awareness
Participant three says people can find the alopecia filter design very personal and maybe hard to face. She does not think that is a bad thing. She mentioned videos in which people for one day get make-up to look bald. Those people are shocked as well. She thinks it creates that sort of awareness.

People will think about it very differently then. She said the other interactive app is very personal, your own story which can be nice for people too. Participant two agreed: ''Then they can see what we go through.''

11. Switch order in integrated design: see the result of your choices.
Without mentioning the existence of an integrated version, participant four started explaining P3 that the idea is to first see the picture and that go through the story. Then, participant six said she would like to see it the other way around because people would easily say they would wait to see what happens. Participant three agreed and added: ''Maybe you can have different stages in that filter app, half bald till totally bald. And then when people wait in the interactive app, they will see a picture of that. You take a picture beforehand of who will go through the story and then you see the result of your choices. Then you really go through it yourself and it becomes a lot more personal as well.''
Participant one: ''That is indeed nice. That when opening the app, you have to take a picture of yourself, now you have hair. And then you will answer questions and you start to lose hair and you'll see your head with some bald spots.''

12. Link with Snapchat is dangerous
Some participants warned that linking the app to Snapchat can be dangerous. Participant six: ''With snapchat people make fun of it quite easily. You also have that witch look and then like 'O look I'm bald!' People who do not realize that it is a disease will think it is funny to see it for once.'' Participant 6 suggested to link the app to the Facebook page or website of the Alopecia Vereniging.

13. Issue of asking people to use the app and solutions
P5: ''A lot of people with alopecia don't dare to tell their friends or family so I don't know… Some people have to find a lot of courage to for example fill this in and share it with everyone. A few years ago I was also at a youngsters day with totally different people and almost everyone wore a wig and friends and family of most of them didn't know about it.''
P3: ''Good point, share something is a big step.''
P6: ''Maybe it's a good idea when you don't need to invite friends but you have the app on your phone and you can approach someone. Then he doesn't need to download it. Imagine we would just meet for fun and like, o look you should try this for once. How would you do it? And then you also get into a conversation with each other.''
P3: ''Additionally, you also have friends who live far away. Maybe in the app you can, when you create your story, that you get a code there which you can send to your friends. If they download the app they can enter the code and they can also…''
P6: ''Only watch out that it's the correct code, that you cannot enter something random and find someone. Or maybe a sort of QR code just like Snapchat.''
P3: ''Or a difficult long code, or a code of two parts.''
P6: ''First a code and then a name. You don't just guess that. Then you don't have think all the time like, o I have to accept, have to accept.''

14. Side-line updates unnecessary
P4: ''Something substantive, I don't think you have the need to see this on the side-line at the moment you go through the timeline.''

15. Experience situations to show people
P4: ''Your first bald spot, that you discover it or believing you have a bald spot when someone tell you about that.''
P6: ''Yes I thought I probably became stuck with it somewhere, it will just come back.''
P5: ''Or for people who suffer of it for longer, what it's like to live with it, that you don't have hair. How many things you cannot do then. I cannot remember the first spot. How much you have to think about it, how many problems you have because of it.''
P3: ''Yes things you normally don't think about but you have think about now.''
P6: ''For example a boy who did not understand how annoying a wig is, he said, that is not so different right? I said, imagine you are wearing a hat the whole day. During gymnastics I'm not going to hang upside down. Only then he realised you have think about it with everything. When you get on a bike and there is a strong wind, sh*t a strong wind. People don't think about that.''
P3: ''Yes everyday situations. Because it's mainly those small things you…''
P5: ''Yes exercising or biking in the wind, such daily small things.''
P1: ''Theme parks.''
P3: ''Imagine it starts to rain.''
P4: ''The moment of the decision, there are so many spots now that you cannot hide it anymore.''
P1: ''Yes, you have so many bald spots, isn't it

more wise to shave it off? That was the toughest moment, but also the best decision I made.''

16. Question about self-image
Participant 6 came up with the idea of questioning someone about their self-image after showing a picture without hair. ''When you ask someone to shave it or not and he chose yes, then you have a bald picture. Then you could say: Do you think you are still good looking? Because then you make them realize, he sh*t.'' Participant one: '' That is really a diehard question!''
P4: ''Yes that is really bold.'' P6: ''Yes it is a hard question but with that you make people aware of what it does to you.''
P3: ''But it is also very hard for some people. It is not easy.'' Participant four: '' No it is not fun and easy but I don't we should scare away people with it. That is too negative.'' Participant six said she would think it to be ingenious when someone would react positive to a picture with hair loss.''

17. Preference for app over website
All participants agreed that they prefer an app over a website for the design. P1: ''You'll get much more views and users on the app than on the website.''
P3: ''I also think that if you're going to combine them and during the story you will show the person who's going through it pictures of him, it's gonna be difficult on the computer because not everyone has a webcam. To what extent is a website needed and to what extent is it adding something? Nowadays everyone has a smartphone. I think the app suggests you can use it everywhere.''
P5: '' I would rather go to an app than go to a website.''
P6: ''I think an app will be used much more nowadays. I only use the Facebook app, never the website.''

18. More personal by using own phone
Participant 4 said it is more personal to invite someone to use the app on his own phone: '' I would rather use it with my own phone. That I approach someone and say: hey you should check this out. Personally you can share it better and it is also more personal to the other when you approach someone with it yourself.''

19. Order of showing picture/cartoon depends on situation
Participants think differently about the order of showing a picture or a cartoon situation first. They concluded that it depends on the situation whether you first see a picture or a cartoon.
P3: ''Yes. For some first the cartoon and when you made a choice, then the picture. Because that shows more what it is about.''
P5: ''When you first answer the question and then see the picture, then you don't know what is going on.''
P6: ''But then you do see the result of it.''
P5: ''You should see that first when you ask what you would do after you see the first bald spot.''
P3: ''I don't know. Do you see the result of the choice to do nothing or to go to the doctor?''
P5: ''But those bald spots, those you see. Then you have to make a choice.''
P6: ''It just depends on which one. You first see your bald spots, then you first need your own picture. Then you go to the doctor and you cannot see the result of that up front. So for some you have a picture beforehand and for some afterwards.''

20. Hats or caps instead of wigs for men
Participant 1 said that for men you can ask about hats or caps instead of wigs.

21. Choose form of alopecia at the start
Participant 5 mentioned she would like to be able to choose what form of alopecia she has at the beginning of the app.

22. No preference for Alopecia Vereniging style
The participants said they prefer a green or grey style over the Alopecia Vereniging style. P6: ''Turquoise, women like it and men are also ok with it, but pink is very girly.'' P4: ''Yes and very cliché!''

23.Different ways of approaching people with design
P1: ''Hey mate, you should try this out! See how you feel. Take a picture with this.''
Participant one would only use the alopecia filter, he would show the other filters to female friends to let them try it.
P7: ''My friends know that I don't feel bad about it, so they would be more interested like, hey how would it look on me?''
P2: ''I actually don't know. I always ask myself how I will say something before I go somewhere. And then I get there, and it is all different.''
P5: ''I would not dare to ask that at all. I never talk about it with anyone, one person who is around 40 years old. But apart from him I talk about it with nobody. It directly becomes awkward when I start talking about it so I try to avoid that.''

16. ENGLISH DESIGN EVALUATION SURVEY

Participant with alopecia:

1. What in general do you think of the final design 'Imagine alopecia'?
2. What do you think is nice and/or good about the design?
3. Are there negative aspects about the design? If so, which?
4. Suppose you would go through the story with your parents, would this help you? Why?
5. Suppose you would go through the story with one or more friends, would this help you? Why?
6. Do you think you would use it? Why (not)?
7. Are there things you would like to see differently in the design? If so, what?
8. Do you think the design is confronting or offensive? Why (not)?
9. Do you have a preference for a cartoon version of the alopecia filter? If so, why?
10. What do you think of the logo of the design?

Participant close to someone with alopecia:

1. What in general do you think of the final design 'Imagine alopecia'?
2. What do you think is nice and/or good about the design?
3. Are there negative aspects about the design? If so, which?
4. Suppose you would go through the story, would this help you? Why?
5. Would you like it to go through the story?
6. Do you think you would use it? Why (not)?
7. Are there things you would like to see differently in the design? If so, what?
8. Do you think the design is confronting or offensive? Why (not)?
8. Are there things you would like to see differently in the design? If so, what?
9. Do you have a preference for a cartoon version of the alopecia filter? If so, why?
10. What do you think of the logo of the design?

17. DESIGN EVALUATION SURVEY ALOPECIA

Vragenlijst eindontwerp afstudeerproject Industrieel Ontwerpen Tessa Majenburg
Voor persoon met alopecia

De antwoorden worden alleen gebruikt voor mijn afstudeerproject en alle antwoorden zijn en blijven anoniem.

☐ Ik ga akkoord met het gebruik van de antwoorden voor het afstudeerproject.

Geslacht: Man / Vrouw

Leeftijd:

Vorm alopecia:

Leeftijd start alopecia:

De app 'Imagine alopecia' laat personen die dichtbij iemand met alopecia staan, de impact van alopecia beter inzien en triggert/stimuleert de communicatie tussen beiden.

1. Wat vind je in het algemeen van het eindontwerp 'Imagine alopecia'?

2. Wat vind je leuk en/of goed aan het ontwerp?

3. Zijn er ook negatieve aspecten aan het ontwerp? Zo ja, welke?

4. Stel je voor dat je 'Imagine… Jouw haarverlies' of 'Imagine… Mijn activiteiten' met je ouders zou doorlopen, zou dit je helpen? Waarom?

5. Stel je voor dat je 'Imagine… Jouw haarverlies' of 'Imagine… Mijn activiteiten' met één of meerdere vrienden zou doorlopen, zou dit je helpen? Waarom?

6. Zou je het denk je gebruiken? Waarom (niet)?

7. Zijn er dingen die je anders zou willen zien in het ontwerp? Zo ja, wat?

8. Vind je het ontwerp confronterend of kwetsend? Waarom (niet)?

9. Heb je voorkeur voor een cartoon versie van de alopecia filter (zie afbeelding hiernaast)? Zo ja, waarom?

10. Wat vind je van het logo van het ontwerp?

z.o.z.

Kun je de verschillende onderdelen van het eindontwerp beoordelen op de volgende aspecten door te omcirkelen op schaal van 1 tot 5 met:

1=Helemaal niet, 2=Nauwelijks, 3=In redelijke mate, 4=In hoge mate, 5=In zeer hoge mate

De kale plek is groter geworden. Wat zou je er denk je mee doen?

Hoe zou je het nu oplossen als je op vakantie gaat of gaat reizen (met nieuwe mensen)?

Onderdeel 1 – Imagine… Jouw haarverlies

Dit zou mij helpen:

1 2 3 4 5

Stimuleert steun:

1 2 3 4 5

Draagt bij aan begrip:

1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5

Dit is confronterend:

1 2 3 4 5

Dit zou mijn familie leuk vinden te doen:

1 2 3 4 5

Dit zou mijn familie helpen:

1 2 3 4 5

Dit zouden mijn vrienden leuk vinden te doen:

1 2 3 4 5

Dit zou mijn vrienden helpen:

1 2 3 4 5

Onderdeel 2 – Imagine… Mijn activiteiten

Dit zou mij helpen:

1 2 3 4 5

Stimuleert steun:

1 2 3 4 5

Draagt bij aan begrip:

1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5

Dit is confronterend:

1 2 3 4 5

Dit zou mijn familie leuk vinden te doen:

1 2 3 4 5

Dit zou mijn familie helpen:

1 2 3 4 5

Dit zouden mijn vrienden leuk vinden te doen:

1 2 3 4 5

Dit zou mijn vrienden helpen:

1 2 3 4 5

Onderdeel 3 – Haar- & make-up filter

Dit zou mij helpen:

1 2 3 4 5

Stimuleert steun:

1 2 3 4 5

Dit is handig:

1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5

Dit is confronterend:

1 2 3 4 5

18. DESIGN EVALUATION SURVEY CLOSE ONE

Vragenlijst eindontwerp afstudeerproject Industrieel Ontwerpen Tessa Majenburg
Voor familie/vrienden van persoon met alopecia

De antwoorden worden alleen gebruikt voor mijn afstudeerproject en alle antwoorden zijn en blijven anoniem.

☐ Ik ga akkoord met het gebruik van de antwoorden voor het afstudeerproject.

Leeftijd:

Relatie tot persoon met alopecia:

Leeftijd persoon met alopecia:

Vorm alopecia:

Leeftijd start alopecia:

De app 'Imagine alopecia' laat personen die dichtbij iemand met alopecia staan, de impact van alopecia beter inzien en triggert/stimuleert de communicatie tussen beiden.

1. Wat vind je in het algemeen van het eindontwerp 'Imagine alopecia'?

2. Wat vind je leuk en/of goed aan het ontwerp?

3. Zijn er ook negatieve aspecten aan het ontwerp? Zo ja, welke?

4. Stel je voor dat je 'Imagine… Jouw haarverlies' of 'Imagine… Mijn activiteiten' zou doorlopen, zou dit je helpen? Waarom?

5. Zou je het leuk vinden om 'Imagine… Jouw haarverlies' of 'Imagine… Mijn activiteiten' te doorlopen?

6. Zou je het denk je gebruiken? Waarom (niet)?

7. Zijn er dingen die je anders zou willen zien in het ontwerp? Zo ja, wat?

8. Vind je het ontwerp confronterend of kwetsend? Waarom (niet)?

9. Heb je voorkeur voor een cartoon versie van de alopecia filter (zie afbeelding hiernaast)? Zo ja, waarom?

10. Wat vind je van het logo van het ontwerp?

z.o.z.

Kun je de verschillende onderdelen van het eindontwerp beoordelen op de volgende aspecten door te omcirkelen op schaal van 1 tot 5 met:

1=Helemaal niet, 2=Nauwelijks, 3=In redelijke mate, 4=In hoge mate, 5=In zeer hoge mate

De kale plek is groter geworden. Wat zou je er denk je mee doen?

Onderdeel 1 – Imagine… Jouw haarverlies

Dit zou mij helpen:

1 2 3 4 5

Stimuleert het geven van steun:

1 2 3 4 5

Draagt bij aan mijn begrip:

1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5

Dit is confronterend:

1 2 3 4 5

Dit zou hij/zij leuk vinden te doen:

1 2 3 4 5

Dit zou hem/haar helpen:

1 2 3 4 5

Hoe zou je het nu oplossen als je op vakantie gaat of gaat reizen (met nieuwe mensen)?

Onderdeel 2 – Imagine… Mijn activiteiten

Dit zou mij helpen:

1 2 3 4 5

Stimuleert het geven van steun:

1 2 3 4 5

Draagt bij aan mijn begrip:

1 2 3 4 5

Zou ik wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5

Dit is confronterend:

1 2 3 4 5

Dit zou hij/zij leuk vinden te doen:

1 2 3 4 5

Dit zou hem/haar helpen:

1 2 3 4 5

Onderdeel 3 – Haar- & make-up filter

Dit zou hem/haar helpen:

1 2 3 4 5

Stimuleert steun voor hem/haar:

1 2 3 4 5

Dit is handig:

1 2 3 4 5

Zou hij/zij wel gebruiken:

1 2 3 4 5

Het is leuk te gebruiken:

1 2 3 4 5

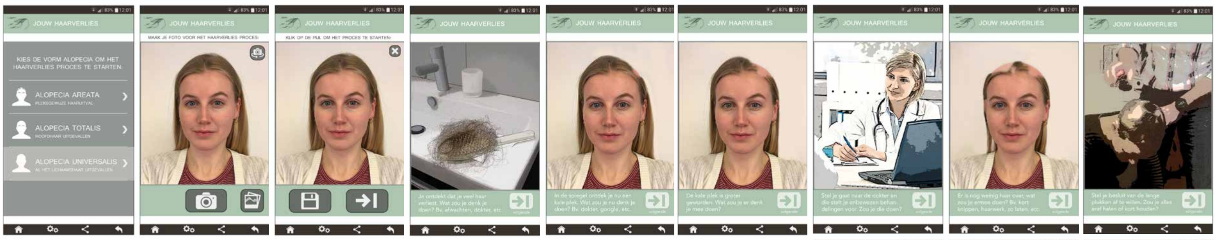
Dit is confronterend:

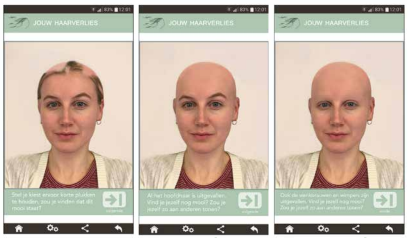
1 2 3 4 5

19. A1 POSTER DESIGN EVALUATION

IMAGINE alopecia

*De app **'Imagine alopecia'** laat personen die dichtbij iemand met alopecia staan, de **impact** van de alopecia beter inzien en triggert/ stimuleert de **communicatie** tussen beiden.*





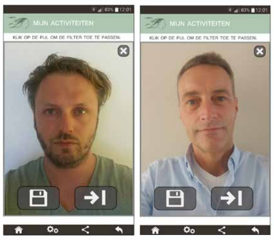
areata **totalis** **universalis**

IMAGINE... JOUW HAARVERLIES

In 'Imagine... Jouw haarverlies' doorloopt de persoon die dichtbij iemand met alopecia staat een haarverlies proces. De persoon met alopecia kan kiezen voor een proces tot alopecia areata, totalis of universalis.

IMAGINE... MIJN ACTIVITEITEN

In 'Imagine... Mijn activiteiten' krijgt de persoon die dichtbij iemand met alopecia staat een alopecia filter en vervolgens vragen over activiteiten van de de persoon met alopecia.

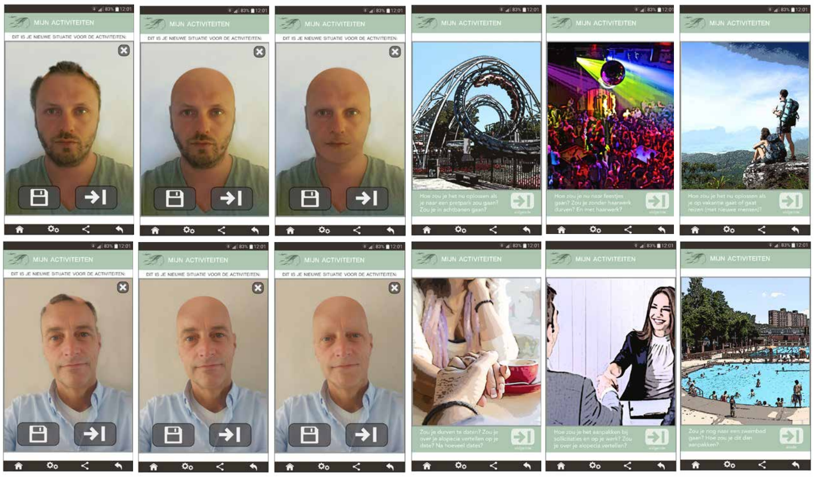


ONDERWERPEN ACTIVITEITEN

KIES DE ONDERWERPEN VOOR MIJN ACTIVITEITEN:

- ☑ PRETPARKEN
- ☐ AANMELDEN VERENIGING
- ☐ OP STAP MET SLECHT WEER
- ☑ UITGAAN/FEESTJES
- ☑ VAKANTIE/REIZEN
- ☑ DATEN
- ☐ LOGEREN/SLAAPFEESTJES
- ☑ SOLLICITEREN
- ☑ ZWEMMEN

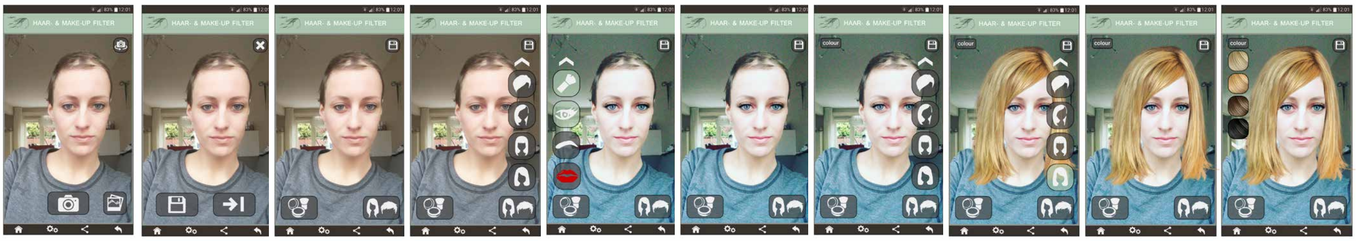
SAVE



areata **totalis** **universalis**

HAAR- & MAKE-UP FILTER

In 'Haar- & Make-up filter' kan de persoon met alopecia haar- en make-up filters toepassen om te kijken wat voor haarwerk en make-up leuk of goed zou staan.



Afstudeerproject van Tessa Majenburg voor de studie Industrieel Ontwerpen aan de TU Delft.

TU Delft

20. ANALYSIS DESIGN EVALUATION SURVEYS

The participants filled out the surveys at the national alopecia fair organized by the Alopecia Vereniging. In total, nine people with alopecia and eight people close to people with alopecia participated. Of the nine participants with alopecia, eight were female. The ages of these participants with alopecia varied from 18 to 59. Three participants were aged between 20 and 34.
The ages of the participants of people close to a person with alopecia varied from 27 to 56.
The participants with alopecia are ordered according to the duration of suffering of alopecia, with the first participants shortest duration.

Participants with alopecia:
1. F, age 47, FFA, start age 46
2. F, age 47, AT/AU, start AA around age 20, start AT/AU at age 46.
3. F, age 30, AA, start age 6, severe at age 28
4. F, age 59, Pseudopelade van Brocq, start age 56.
5. M, age 18, AU, start age 12.

6. F, age 51, AU, start age 41
7. F, age 20, AU, start age 9
8. F, age 34, AA, start age 12
9. F, age 46, AU, start age 4

Participants people close to a person with alopecia:
1. Husband of participant 1, age 45.
2. Sister of participant 2, age 52.
3. Friend of participant 3, age 27.
4. Daughter participant 4, age 33.
5. Mother participant 5, age 48.

6. Father of a girl of 14 with alopecia universalis, age 51.
7. Mother participant 7, age 56.
8. Mother of participant 8.

Questions answered by participants with alopecia:

1. Wat vind je in het algemeen van het eindontwerp 'Imagine alopecia'?
P1: Ziet er goed uit.
P2: Door zaken zichtbaar te maken komt juist het gesprek goed op gang om aan te geven wat het haarverlies zeker op emotioneel gebied teweeg brengt bij iemand met Alopecia. Maar ook de activiteiten om aan te geven aan de ander zonder Alopecia wat de gevolgen zijn om de meest simpele activiteiten waar iemand met bijvoorbeeld een haarwerk wel over na moet denken.
P3: Heel gaaf idee, origineel, zou ik zeker gebruiken.
P4: Mooie tool voor mensen met alopecia.
P5: Ik vind het een erg mooi ontwerp.
P6: Baanbrekend.
P7: Goed idee.
P8: Origineel!
P9: Goed initiatief.

Conclusion: All participants are positive and enthusiastic about the final design. They think it is good, original and innovative. One participant said it stimulates the communication.

2. Wat vind je leuk en/of goed aan het ontwerp?
P1: Dat anderen zich kunnen inleven in jouw situatie.
P2: De opzet van je app is eenvoudig van aard zoals ik het op de poster kan zien, dus zeer toegankelijk voor een ieder. Dat vind ik persoonlijk fijn. De stappen zijn eenvoudig te doorlopen. Alopecia in de breedste zin komt aan bod waaronder dus ook activiteiten waar iemand met Alopecia mee te dealen heeft. Mooie aan je ontwerp is juist dat iemand zonder Alopecia kan ervaren wat er gebeurd. Wat dus zeker bijdraagt aan de communicatie! Top, gesprek is nu eenmaal moeilijk zeker in het begin. Knap dat je jezelf kwetsbaar opstelt door zelf op de poster te staan, wilde ik even kwijt ;)
P3: Mooie, duidelijke app. Gelijk logisch hoe het werkt.
P4: Het zet je aan tot praten met je omgeving.
P5: Duidelijke plaatjes, mooie kleuren.
P6: Dat omstanders / naasten er meer van komen te weten / inzicht.
P7: Situaties aangeven die voor mensen met alopecia lastig zijn.
P8: Haarwerken passen + 'omstanders': Wat zou je doen in pretparken enz.?
P9: ++ Laag drempelig.

Conclusion: Five out of nine participants like that you can make things clear to other people and they can replace themselves. Two participants add to this that it adds to communication, which is especially hard in the beginning. Furthermore two participants like that it is very approachable and three participants think the app is very clear and simple to use and understand.

3. Zijn er ook negatieve aspecten aan het ontwerp? Zo ja, welke?
P1: -
P2: Ik zie ze niet eerlijk gezegd.

P3: -
P4: Nee.
P5: Nee ik vind het erg mooi ontworpen
P6: -
P7: Wanneer gebruik je de app?
P8: Drempel om het te communiceren naar omstanders.
P9: Geen idee.

Conclusion: One participant wondered when you would use the app. Another participant thinks there is a boundary to communicate it to other people.

4. Stel je voor dat je 'Imagine… Jouw haarverlies' of 'Imagine… Mijn activiteiten' met je ouders zou doorlopen, zou dit je helpen? Waarom?
P1: -
P2: Ja mijn ouders zijn geen praters en er is mij in het haarverlies proces meer malen gezegd "Jij zit er maar hele dagen op te letten of je plekken groter worden. Je bent er veel te veel mee bezig". Dus had ik het idee dat ik mijn emoties over het haarverlies en de angst om helemaal kaal te worden (wat dus gebeurd is) niet bij hen kwijt kon. Dat was moeilijk om te ervaren. Inderdaad geloof ik dat jouw app een bijdrage had kunnen leveren aan de communicatie.
P3: Ja, denk met name mannen het niet zo kunnen voorstellen :)
P4: Ja dat zou ze zeker helpen. Het geeft inzichten naar de andere personen wat en waarmee je te maken krijgt in het leven.
P5: Ik zou het wel kunnen doen, ik zou niet precies weten of het gaat helpen want ik zeg alles tegen hun waar ik mee zit dus weten hun al aardig veel.
P6: Ze zouden het niet meer 'for granted' nemen.
P7: Op dit moment niet, maar toen ik 9 jaar was, denk ik wel.
P8: Niet denk ik, mijn moeder vindt het al zo erg.
P9: N.v.t.

Conclusion: Most participant would use the app with their parents so they can better understand. One participant would not use it with her mother as her mother already feels so bad about it. Another participant said she believes the app would have added to the communication between her parents as she could not express her emotions with them. One participant doubts whether it would help his parents because he already discusses everything with them.

5. Stel je voor dat je 'Imagine… Jouw haarverlies' of 'Imagine… Mijn activiteiten' met één of meerdere vrienden zou doorlopen, zou dit je helpen? Waarom?
P1: Begrip.
P2: Ja juist om mijn emotionele gevoelens die bij het haarverlies horen naar voren te kunnen brengen. Maar ook de angsten die je hebt bij bepaalde activiteiten en waarom je ze nu mogelijk niet meer uitvoert. Kweken van begrip, ondersteuning en communicatie. Men is juist vaak meer geneigd om er niet over te willen praten uit angst voor kwetsing.
P3: Jazeker, meer begrip te verkrijgen erdoor.
P4: De andere partijen begrijpen dan meer wat het voor je betekent.
P5: Ja dat denk ik wel dan zouden ze meer begrijpen waarom je dingen wel kunt doen of niet.
P6: Ze zouden zich meer in mijn dagelijkse gedoe met alopecia kunnen verplaatsen.
P7: Ja, zij hebben meer moeite met bedenken hoe het zou zijn.
P8: Met vrienden/omstanders die ongenuanceerd reageren naar verwijzen ter bewustwording.
P9: Uitwisseling van ervaring, steun, inspiratie / krachtbon.

Conclusion: All participants think the app would help their friends to better be able to replace themselves and understand the impact. For friends it is more often hard to understand. One participant said that it can make her communicate her emotions and fears and it adds to understanding, support and communication. She thinks people with alopecia often tend to not talk about it out of fear for hurting. One participant said it would help his friends to understand why he cannot do some activities.

6. Zou je het denk je gebruiken? Waarom (niet)?
P1: Misschien om toch bepaalde keuzes te maken.
P2: Ja, maar alleen als men bereid is dit met mij te doen. Ik zou mensen niet zomaar voor het blok zetten. Iedereen zegt het te begrijpen maar het gevoel wat het haarverlies je geeft is moeilijk over te brengen.
P3: Ja, zie 5.
P4: Ja, om het gesprek positief te kunnen voeren.
P5: Ja zou graag aan mijn vrienden willen laten zien hoe het is om alopecia hebben dan zouden ze mij beter begrijpen.
P6: Ik zou het bij vrienden adviseren.
P7: Ja, voor mijn vrienden.
P8: Zelf, omdat ik een haarwerk zoek + antwoord vraag 5.
P9: Denk het wel.

Conclusion: All participants would probably use the app. Six out of nine participants would use it especially with their friends. One participant added to this that she would only use it when someone is really willing to do this with her. One participant said it would stimulate communication positively.

7. Zijn er dingen die je anders zou willen zien in het ontwerp? Zo ja, wat?
P1: -
P2: Nou nee, vind je ontwerp goed gekozen en toegankelijk.
P3: Eigen foto van iemand kunnen gebruiken.
P4: Nee.
P5: Nee vind het erg mooi.
P6: -
P7: Meer herkenbare situaties.
P8: Dat het er echt komt :)
P9: ?

Conclusion: There are no real things people would like to see differently.

8. Vind je het ontwerp confronterend of kwetsend? Waarom (niet)?
P1: Nee.
P2: Voor mijzelf vindt ik het niet confronterend en ook niet kwetsend. Het is zoals het is en verstoppen hoeft niet. Het is goed dat er op deze wijze aandacht aan wordt besteed en een ander kan "ervaren" wat iemand met Alopecia doormaakt.
P3: Beetje, vooral de universalis, maar wel verzacht (?).
P4: Nee.
P5: Nee ik heb er niet veel last van alleen de opmerkingen die je krijgt.
P6: Ik vind het bijna ontroerend dat er zoiets komt waarmee openheid binnen alo. komt.
P7: Nee, het is een goed ontwerp voor herkenbaarheid.
P8: Ja, maar dat is alopecia ook.
P9: Nee.

Conclusion: Seven out of nine participants do not think the design is confronting. Participant three thinks it is confronting, but so is alopecia. One participant thinks it is a bit confronting, especially alopecia universalis, but soothed.

9. Heb je voorkeur voor een cartoon versie van de alopecia filter (zie afbeelding hiernaast)? Zo ja, waarom?
P1: Nee.
P2: Een cartoon versie zou wel jonge kinderen die Alopecia hebben kunnen helpen met het uitleggen op school en aan vrienden. Maakt er voor hun een speelse aangelegenheid van die gelijk educatief is.
P3: Nee, niet nodig lijkt me.
P4: Foto 1 laat zien wat er gebeurt! Foto 2 is milder.
P5: Ik vind het mooier zonder filter ziet er echter uit.
P6: Hoeft niet zo van mij.
P7: Nee, realistisch is beter.
P8: Weet ik niet.
P9: Wellicht, minder direct.

Conclusion: Six out of nine participants do not prefer a cartoon version of the alopecia filter. One of those participants said realistic is better. One participant does not know and one might prefer a cartoon version as it is less direct. Another participant suggests to use a cartoon version for young children in order to let them explain at school and to friends in a playful and educative way.

10. Wat vind je van het logo van het ontwerp?
P1: Mooi.
P2: Beetje afhankelijk of je doelgroep alleen degene met Alopecia en zijn omgeving is, dan dekt het logo de lading. Zij leggen de link met het uitvallen van het haar wel in het logo. Dus is je app snel herkenbaar. Ik denk dat een buitenstaander geheel ontwetend van Alopecia in je logo niet het haar als uitvallend zal herkennen.
P3: Mooi!
P4: Mooi.
P5: Super mooi.
P6: Mooi, wel vrij lief / zacht.
P7: Artistiek.
P8: Goed.
P9: -

Conclusion: All participants like the logo of the final design. One of the participants likes it, but does think it is rather sweet and soft. Another thinks that people who do not know of alopecia would not recognize the hair loss in the logo.

Questions answered by participants close to person with alopecia:

1. Wat vind je in het algemeen van het eindontwerp 'Imagine alopecia'?
P1: Mooi initiatief om impact te laten ervaren.
P2: Vind het een goed ontwerp. Het kan helpen duidelijk maken wat Alopecia is voor diegene die niet precies weet wat het is of inhoudt voor het dagelijks bestaan van personen met Alopecia. In alles wat mijn zus meemaakt is me vaak opgevallen dat het voor de meeste mensen nog zo onbekend is.
P3: Mooi vormgegeven en overzichtelijk. Makkelijk in gebruik.
P4: Het geeft mij meer inzicht in de aandoening van mijn moeder
P5: Ik vind dat het er erg mooi uit ziet. Op deze manier kun je het goed bespreekbaar maken en actief bezig zijn met de situatie waarin iemand zich onvrijwillig in bevind.
P6: Erg goed.
P7: Leuk idee.
P8: Ja ik kan het me wel voorstellen, maar nooit

helemaal voelen wat mijn dochter áltijd voelt.

Conclusion: All participants are positive about the final design 'Imagine alopecia'. They think it is good and beautiful. One participant said it can also make people more aware of what alopecia is and what the consequence of it is, one said it makes it better discussable and another participant said it gives her more insight into the condition.

2. Wat vind je leuk en/of goed aan het ontwerp?
P1: Maakt alopecia beter bespreekbaar.
P2: Goed is dat het veel duidelijkheid kan geven in gevoel, dagelijkse 'obstakels' en het gesprekken op gang kan brengen die anders achterwege blijven. Dit vaak omdat de mensen erom heem niet willen kwetsen of degene die alopecia heeft het niet onder woorden kan brengen.
P3: De filters waarmee je het proces nabootst en de mogelijkheid je eigen foto te gebruiken.
P4: Ik begrijp door de uitleg meer van het proces waardoor ik haar kan ondersteunen.
P5: Het is begrijpelijk en je ziet gelijk waar het over gaat.
P6: Goed voor begripsvorming bij derden.
P7: Goed om andere mensen op een nette manier hiermee bekend te maken / confronterend maar op een goede manier.
P8: Ontwikkeling goed.

Conclusion: What participants like about the design is that it makes alopecia more discussable, adds to understanding for both people close to the person with alopecia as well as for people less close, the filters to imitate the process and the possibility to use your own picture and that it adds to understanding of daily obstacles. One participant said that because of her improved understanding she is able to better support her mother. It is also a very clear app.

3. Zijn er ook negatieve aspecten aan het ontwerp? Zo ja, welke?
P1: Nee.
P2: Nee.
P3: Areata kwam volledig overeen met totalis.
P4: Niet dat ik me kan bedenken.
P5: Ik kan niet goed zien wat de activiteiten gedeelte inhoudt. Kan iemand aangeven wat hij/zij leuk vindt om te doen en hier misschien moeite mee heeft?
P6: -
P7: Wanneer en hoe vaak vraag ik me af.
P8: -

Conclusion: Five out of eight participants do not think there are negative aspects about the design. One participant wonders how many times you would use it. Another participant thinks areata is very similar to totalis. One participant was not sure if she understood the activity part.

4. Stel je voor dat je 'Imagine… Jouw haarverlies' of 'Imagine… Mijn activiteiten' zou doorlopen, zou dit je helpen? Waarom?
P1: Helpt om hierover te praten, zonder het onderwerp 'zwaarder' te maken.
P2: Het zou me misschien nog meer inzicht kunnen geven in de praktische dingen waar mijn zus tegenaan loopt als het gaat om de gevoelens en activiteiten. Qua gevoel heb ik haar het proces van dichtbij zien doorlopen en ben met alles mee geweest; haarwerk, laatste haar verwijderen, bijeenkomsten, enz., maar er blijven door het houden van toch altijd dingetjes die je net even mist en je zo kunt leren inzien.
P3: Ja het maakt het inzichtelijker omdat het letterlijk gevisualiseerd wordt en je over je eigen situatie / keuzes gaat nadenken.
P4: Door er over na te denken kan je meedenken ik oplossingen.
P5: Ik denk dat het heel goed is om informatie te weten over hoe je een sollicitatie gesprek moet aan pakken. Ga je meteen vertellen wat er aan de hand is? Hoe maak je het bespreekbaar? Een eerste indruk is het halve gesprek.
P6: Te zien en voelen wat mijn dochter voelt.
P7: Zeker om me zo goed mogelijk in te leven en eventueel te helpen.
P8: -

Conclusion: All participants said it would help them to go through the hair loss and activity parts, it would help them to better replace themselves in the situation and one participant said it would help to make it possible to talk about the subject without making it 'heavier'. One participant also said it can make her more aware of the small daily struggles and another said that thinking about it makes it possible to help think of solutions.

5. Zou je het leuk vinden om 'Imagine… Jouw haarverlies' of 'Imagine… Mijn activiteiten' te doorlopen?
P1: Ja.
P2: Ja.
P3: Ja, wel confronterend.
P4: Ja de oplossingen samen kunnen bedenken geeft mij een betrokken gevoel.
P5: Het lijkt me leuk om de app te bekijken en ermee aan de slag te gaan en anderen er ook naar te laten kijken.
P6: Ja.
P7: Ja, maar vraag me wel af hoe vaak je zoiets gebruikt.
P8: -

Conclusion: All participants would like to go through the hair loss and activity parts, but one wondered how often you would use something like this and one said it would be confronting. One said thinking about solutions together gives her a feeling of being involved.

6. Zou je het denk je gebruiken? Waarom (niet)?
P1: Ja.
P2: Ik zou het gebruiken om nog beter inzicht te krijgen.
P3: Ja, voor meer begrip en inzicht.
P4: Ja.
P5: Het hangt er van af of de informatie die ik lees, kan gebruiken als aanvulling op de gesprekken die ik voer met mensen.
P6: Ja.
P7: In het begin maar later niet meer.
P8: -

Conclusion: Six out of eight participants would use it, one participant did not answer the question. Another participant would only use it in the beginning but later on not anymore and for one it depends if she can use the information of the app as an addition to conversation with other people about it.

7. Zijn er dingen die je anders zou willen zien in het ontwerp? Zo ja, wat?
P1: Nee.
P2: Bij activiteiten meer algemene dagelijkse activiteiten.
P3: Nee.
P4: -
P5: Zo ver ik nu kan zien niet.
P6: Nee, ok.
P7: -
P8: -

Conclusion: Only one participant suggested a change, she would like to see more daily activities in the activities part of the app.

8. Vind je het ontwerp confronterend of kwetsend? Waarom (niet)?
P1: Nee, is respectvol, er wordt in oplossingen / mogelijkheden gecommuniceerd.
P2: Vind het niet confronterend of kwetsend, maar ben er dan ook bekend mee. Voor mensen die een drempel hebben of niet precies weten wat alopecia inhoudt zou het confronterend kunnen zijn.
P3: Niet kwetsend, wel confronterend omdat je beseft wat iemand meemaakt in dagelijkse situaties.
P4: Nee ben er al aan gewent.
P5: Omdat ik een zoon heb met alopecia, schrik ik niet van de beelden. Ik vind het alleen maar mooi dat het bespreekbaar wordt gemaakt.
P6: Heb het nog niet doorlopen.
P7: Nee, we zijn eraan gewend, inmiddels 11 jaar.
P8: Wel confronterend, niet kwetsend.

Conclusion: Two out of eight participants think the design is confronting but not offending, four participants think it is not confronting of which one thinks it is respectful and one thinks like that the app makes it discussable.

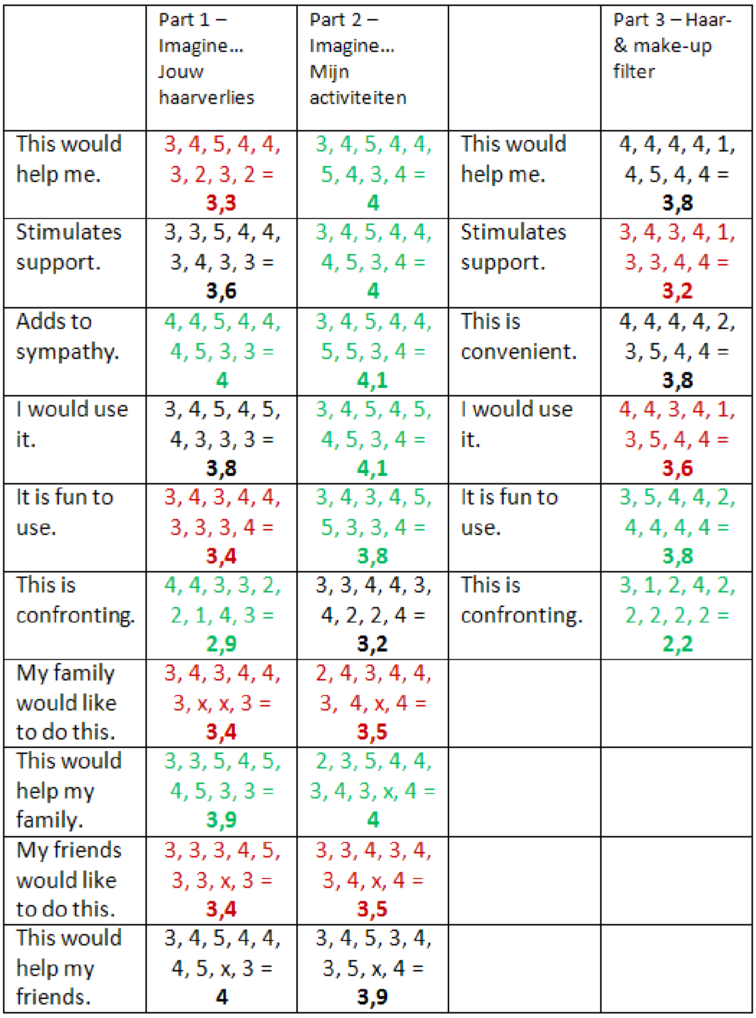
9. Heb je voorkeur voor een cartoon versie van de alopecia filter? Zo ja, waarom?
P1: Nee, werkelijke beelden spreken meer.
P2: Nee, het wordt er weer zo 'onpersoonlijk' van. Het treft mensen en vindt dan ook dat je hiervoor geen cartoons moet gebruiken.
P3: Nee.
P4: Ik vind het logo niet mooi.
P5: Het zou misschien in sommige gevallen beter zijn. De originele beelden kunnen afschrikken bij sommige mensen.
P6: Laat beide opties open.
P7: -
P8: -

Conclusion: Three participants said they would not prefer a cartoon version, one suggested to leave both options open. One participant thinks a cartoon version would make it impersonal, while it is about people and another thinks that in some cases real images could maybe scare off some people.

10. Wat vind je van het logo van het ontwerp?
P1: Mooi.
P2: Mooi logo, maar zou gaan voor iets van kleur om de scheiding tussen het profiel en het verliezende haar duidelijker te maken.
P3: Lijkt een beetje op een shampoo logo maar bij beter kijken zie ik het idee. Dat is wel mooi gedaan.
P4: Lijnen zijn dubbel. Niet mooi!!!
P5: -
P6: Top.
P7: Vriendelijk.
P8: -

Conclusion: All participants are positive about the logo except for one who does not like it because of double line usage. One participant said it looks a bit like a shampoo logo but gets the idea when taking a better look at it. Another participant mentioned that a color distinction would make the losing hairs more clear.

Scores participants with alopecia:
The scores are the average scores of people with alopecia. The high and low scores are colored green and red respectively.

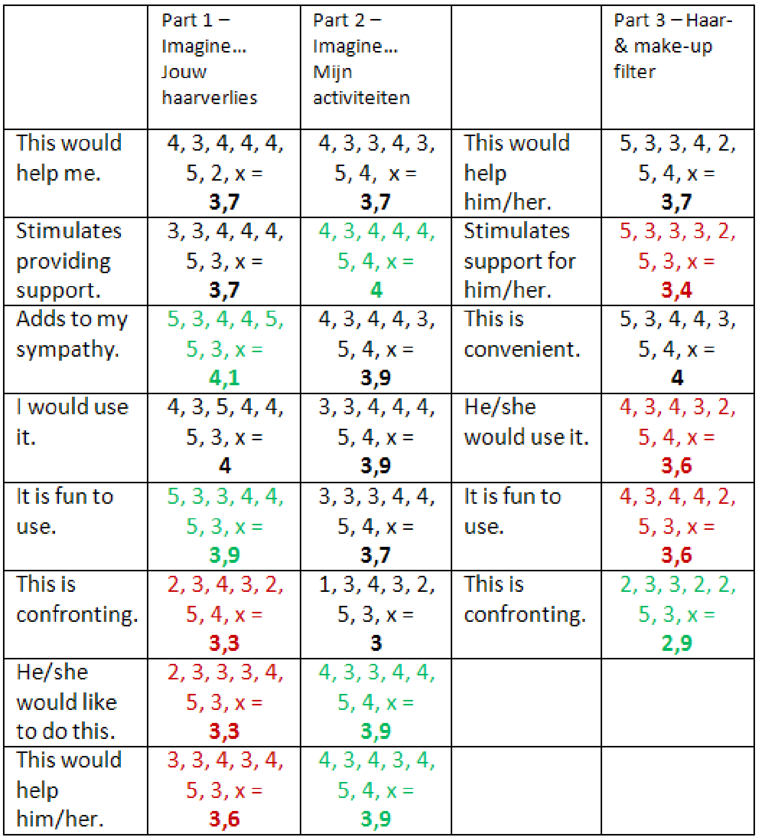


	Part 1 – Imagine… Jouw haarverlies	Part 2 – Imagine… Mijn activiteiten		Part 3 – Haar- & make-up filter
This would help me.	3, 4, 5, 4, 4, 3, 2, 3, 2 = **3,3**	3, 4, 5, 4, 4, 5, 4, 3, 4 = **4**	This would help me.	4, 4, 4, 4, 1, 4, 5, 4, 4 = **3,8**
Stimulates support.	3, 3, 5, 4, 4, 3, 4, 3, 3 = **3,6**	3, 4, 5, 4, 4, 4, 5, 3, 4 = **4**	Stimulates support.	3, 4, 3, 4, 1, 3, 3, 4, 4 = **3,2**
Adds to sympathy.	4, 4, 5, 4, 4, 4, 5, 3, 3 = **4**	3, 4, 5, 4, 4, 5, 5, 3, 4 = **4,1**	This is convenient.	4, 4, 4, 4, 2, 3, 5, 4, 4 = **3,8**
I would use it.	3, 4, 5, 4, 5, 4, 3, 3, 3 = **3,8**	3, 4, 5, 4, 5, 4, 5, 3, 4 = **4,1**	I would use it.	4, 4, 3, 4, 1, 3, 5, 4, 4 = **3,6**
It is fun to use.	3, 4, 3, 4, 4, 3, 3, 3, 4 = **3,4**	3, 4, 3, 4, 5, 5, 3, 3, 4 = **3,8**	It is fun to use.	3, 5, 4, 4, 2, 4, 4, 4, 4 = **3,8**
This is confronting.	4, 4, 3, 3, 2, 2, 1, 4, 3 = **2,9**	3, 3, 4, 4, 3, 4, 2, 2, 4 = **3,2**	This is confronting.	3, 1, 2, 4, 2, 2, 2, 2, 2 = **2,2**
My family would like to do this.	3, 4, 3, 4, 4, 3, x, x, 3 = **3,4**	2, 4, 3, 4, 4, 3, 4, x, 4 = **3,5**		
This would help my family.	3, 3, 5, 4, 5, 4, 5, 3, 3 = **3,9**	2, 3, 5, 4, 4, 3, 4, 3, x, 4 = **4**		
My friends would like to do this.	3, 3, 3, 4, 5, 3, 3, x, 3 = **3,4**	3, 3, 4, 3, 4, 3, 4, x, 4 = **3,5**		
This would help my friends.	3, 4, 5, 4, 4, 4, 5, x, 3 = **4**	3, 4, 5, 3, 4, 3, 5, x, 4 = **3,9**		

In general, at almost each aspect, part two (activities) scores higher than part one (hair loss). The participants with alopecia score high on 'adds to sympathy' for part one and two. The two aspects on which part one (hair loss) scores a bit better is the extent to which participants think it would help their friends and to what extent it is confronting.
Part one could be improved on aspects like how much fun it is do and how much they think their family and friends would like to do this. Part two could also get improved on the aspects. These participants are the ones who have the initiate the use of the app.
For the Hair- and make-up filter, the participants think it is fun, convenient and it would help them. This part scores low on being confronting but also rather average on 'I would use it'. The participants consider this part more fun to use than the other parts but however think they would less use it.
So the third part could be more focused on how to improve the chance that people with alopecia will use it, for example by adding the proposed function from the co-creative session and link wigs and make-up to information and tutorials. One participants scored the hair & make-up filter low because this was a male participant who does not wear wigs or make-up. Additional features could be added for this group within the target group.

Scores participants close to someone with alopecia:

All three aspects score equally on to what extent it would be helping.
In contrary to the scores of the participants with alopecia, part one and two are both liked equally in general. It differs per aspect which part scores higher. The participants think that part 2 (activities) would stimulate providing support more than part 1 (hair loss) but part one adds more to their sympathy. The participants consider part 1 to be more confronting. The participants think part two would help the person with alopecia more and he would like it more to do that part. All participants score rather low on whether it would help themselves. So part one (hair loss) could be improved on stimulating providing support and it can be made a bit less confronting, however, the open questions showed that this is not always considered a bad thing. For the Hair- and make-up filter, the participants think it would help the person with alopecia and that it is convenient. It scores low on whether the person with alopecia would use it as also among these participants there was a mother of the male participant. This part scores lowest on whether the person with alopecia with use it and the support and fun aspects. So the third part could be less confronting and more fun and stimulating support for the person with alopecia.



	Part 1 – Imagine… Jouw haarverlies	Part 2 – Imagine… Mijn activiteiten		Part 3 – Haar- & make-up filter
This would help me.	4, 3, 4, 4, 4, 5, 2, x = **3,7**	4, 3, 3, 4, 3, 5, 4, x = **3,7**	This would help him/her.	5, 3, 3, 4, 2, 5, 4, x = **3,7**
Stimulates providing support.	3, 3, 4, 4, 4, 5, 3, x = **3,7**	4, 3, 4, 4, 4, 5, 4, x = **4**	Stimulates support for him/her.	5, 3, 3, 3, 2, 5, 3, x = **3,4**
Adds to my sympathy.	5, 3, 4, 4, 5, 5, 3, x = **4,1**	4, 3, 4, 4, 3, 5, 4, x = **3,9**	This is convenient.	5, 3, 4, 4, 3, 5, 4, x = **4**
I would use it.	4, 3, 5, 4, 4, 5, 3, x = **4**	3, 3, 4, 4, 4, 5, 4, x = **3,9**	He/she would use it.	4, 3, 4, 3, 2, 5, 4, x = **3,6**
It is fun to use.	5, 3, 3, 4, 4, 5, 3, x = **3,9**	3, 3, 3, 4, 4, 5, 4, x = **3,7**	It is fun to use.	4, 3, 4, 4, 2, 5, 3, x = **3,6**
This is confronting.	2, 3, 4, 3, 2, 5, 4, x = **3,3**	1, 3, 4, 3, 2, 5, 3, x = **3**	This is confronting.	2, 3, 3, 2, 2, 5, 3, x = **2,9**
He/she would like to do this.	2, 3, 3, 3, 4, 5, 3, x = **3,3**	4, 3, 3, 4, 4, 5, 4, x = **3,9**		
This would help him/her.	3, 3, 4, 3, 4, 5, 3, x = **3,6**	4, 3, 4, 3, 4, 5, 4, x = **3,9**		

21. FINAL ADJUSTMENT DESIGN

ONDERWERPEN ACTIVITEITEN

KIES DE CATEGORIE ACTIVITEITEN OM ONDERWERPEN TE KIEZEN:

- DAGELIJKS LEVEN ❯
- ALOPECIA GESPREK ❯
- SPORTEN & HOBBIES ❯
- WERK / SCHOOL ❯
- HAARWERKEN & PMU ❯
- ANDERE ACTIVITEITEN ❯

ONDERWERPEN ACTIVITEITEN

KIES DE ONDERWERPEN VOOR ANDERE ACTIVITEITEN

- ☑ REIZEN
- ☑ VAKANTIES
- ☑ UITGAAN / FEESTJES
- ☐ CONCERTEN
- ☐ FESTIVALS
- ☑ PRETPARKEN
- ☐ LOGEREN / SLAAPFEESTJE
- ☐ NAAR HET STRAND

ONDERWERPEN ACTIVITEITEN

KIES DE ONDERWERPEN VOOR DAGELIJKS LEVEN ACTIVITEITEN

- ☐ OPMAKEN / HAAR DOEN
- ☑ OP STAP MET SLECHT WEER
- ☐ KLEDING PASSEN / PROBEREN
- ☑ FIETSEN
- ☐ IN SPIEGELS KIJKEN
- ☐ KINDEREN
- ☑ BANKHANGEN
- ☑ VOORDEUR OPEN DOEN

ONDERWERPEN ACTIVITEITEN

KIES DE ONDERWERPEN VOOR ALOPECIA GESPREK ACTIVITEITEN

- ☐ GESPREK MET VRIENDEN
- ☐ GESPREK MET FAMILIE
- ☑ GESPREK MET BUREN
- ☐ GESPREK MET COLLEGA'S
- ☐ GESPREK MET MEDESTUDENTEN
- ☑ GESPREK MET ONBEKENDEN
- ☑ ALOPECIA VERENIGING
- ☑ GESPREK TIJDENS DATE

ONDERWERPEN ACTIVITEITEN

KIES DE ONDERWERPEN VOOR HAARWERKEN & PMU ACTIVITEITEN

- ☑ EERSTE HAARWERK KIEZEN
- ☐ VERSCHILLENDE HAARWERKEN
- ☑ SYNTHETISCH OF ECHT HAAR
- ☐ NIEUW HAARWERK KIEZEN
- ☐ VERSCHILLENDE HAARKLEUREN
- ☑ NEPWIMPERS PLAKKEN
- ☑ PERMANENTE MAKE-UP NEMEN
- ☐ PMU IS NIET NAAR WENS

ONDERWERPEN ACTIVITEITEN

KIES DE ONDERWERPEN VOOR SPORTEN & HOBBIES ACTIVITEITEN

- ☑ DANSEN
- ☐ MOUNTAINBIKEN
- ☑ ZWEMMEN
- ☐ TENNIS
- ☐ VOETBAL
- ☑ GITAAR SPELEN
- ☐ PIANO SPELEN
- ☑ MOTORRIJDEN

KIES DE ONDERWERPEN VOOR HAARWERKEN & PMU ACTIVITEITEN

- ☑ EERSTE HAARWERK KIEZEN
- ☐ VERSCHILLENDE HAARWERKEN
- ☑ SYNTHETISCH OF ECHT HAAR
- ☐ NIEUW HAARWERK KIEZEN
- ☐ VERSCHILLENDE HAARKLEUREN
- ☑ NEPWIMPERS PLAKKEN
- ☑ PERMANENTE MAKE-UP NEMEN
- ☐ PMU IS NIET NAAR WENS

KIES DE ONDERWERPEN VOOR WERK / SCHOOL ACTIVITEITEN

- ☑ SOLLICITATIEGESPREK
- ☐ COLLEGA'S VERTELLEN
- ☑ BAAS / MANAGER VERTELLEN
- ☐ MEDESTUDENTEN VERTELLEN
- ☐ MEDISCHE VERPLICHTINGEN
- ☑ HAARWERK VERPLICHTINGEN
- ☐ SCHOOLKLAS INLICHTEN
- ☑ HELE SCHOOL INLICHTEN

Designing comfort for people with alopecia

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2017