

Supporting Healthy Eating through Technology

Supporting those with eating disorders in times
of crisis, such as the COVID-19 pandemic

Bachelor Thesis Creative Technology

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Abstract

Eating disorders are very dangerous illnesses that negatively affect all sorts of life aspects. Still, the vast majority of eating disorder sufferers does not receive any treatment at all. While day to day tasks could already be a struggle for this group of people, the problems experienced have only gotten more and worse with the COVID-19 pandemic. In an attempt to reach a struggling underserved population, smartphone applications, partly due to their accessibility, are considered to have the potential for providing support or help.

This research aims to firstly explore this target group and analyse the problems experienced (in normal times and times of the current pandemic), by using not just existing literature, but mainly forums, blog posts, and YouTube videos from members of this target group themselves. Besides, a state of the art research was held on the underserved population, smartphone applications in eating disorder treatment, and other self-help tools.

Next, the research focuses on designing a smartphone application to support eating disorder sufferers through times of COVID-19. Using the previously obtained knowledge and with a focus on empathy in design, through ideation, specification, and realisation phases, a prototype of an application was created that aims to help to calm down, to uplift and motivate, to inform, to communicate and reach out, and to separate the individual from their eating disorder voice.

Lastly, this prototype was evaluated. This was done by non-target group participants and two eating disorder experts. It was well received by the non-target group participants, where the focus of the corresponding test mainly lied on usability. The experts did believe the prototype to be valuable and promising, but also gave enough suggestions and comments on what could and sometimes needed to be worked on for it to be more beneficial to potential users. The necessary next step, not included yet, is the evaluation by the target group itself, in order to assess and conclude the core of this research.

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Chapter 1: Introduction

Eating disorders are mental illnesses characterized by abnormal thoughts, obsessions, or habits surrounding food or eating, that negatively impact an individual's life psychologically, physically, and socially. Having the second-highest mortality rate of all mental health disorders [1], these disorders that affect anyone indiscriminately, are intensely dangerous. They severely impact diverse areas of an individual's daily life, making regular life in itself a draining task on top of all problems more directly caused by the illness.

Despite all of this, many eating disorder sufferers do not reach out and receive treatment for several reasons [2]. For those who do receive treatment, relapse rates are high. Regarding anorexia nervosa, reported relapse rates were found to be ranging from 9 to even 52% [3]. This calls for extra support for both those not receiving treatment (anymore) and those in treatment. Self-help tools can be used to provide just that when designed right. Technology as a means to support traditional treatment in the form of mobile health apps in eating disorders can help those currently underserved [4].

At the time of conducting this research, the world is in the grip of the COVID-19 pandemic. This crisis and its accompanying necessary measures bring a wave of uncertainties, and as Yao et al. found they “caused a parallel epidemic of fear, anxiety, and depression” that those with pre-existing mental health conditions or issues are even more impacted by [5, p. e21]. Those with eating disorders and their day to day problems are affected to a great extent as aspects of or activities in their lives that were already difficult became more problematic.

1.1 Aim

This graduation project aims to research how exactly this group of people can best receive much-needed support to cope with the new daily life this crisis has brought on top of their pre-existing problems through the medium of an app as self-help tool. This requires background research on eating disorders themselves and the complications they bring with. The effect the COVID-19 pandemic has had on the mental health of the population shall be addressed and what parts of this have impacted eating disorder sufferers in specific and how. Research on already existing self-help tools and ways of coping in relation to eating disorders shall be included. The project aims to collect results on all of these points to design a contextually appropriate self-help app. As this target group and the current crisis are both complex and sensitive, the ethical side of the graduation project is also of great importance. The focus is to provide help with coping with an eating disorder in times like these, and not to attempt to cure these illnesses nor provide a full treatment or recovery programme.

1.2 Research question

All the previously mentioned leads to the following main research question:

“How could a self-help tool, such as an app, help people suffering from an eating disorder or recovering from an eating disorder, get through a crisis situation, such as the COVID-19 pandemic?”

Chapter 2: Background research

In this chapter, first, the target group is explored and more specifically defined, and its physical and non-physical complications are presented. Then the research is presented on how the COVID-19 situation has influenced these problems and added new ones. It ends with a state of the art research on the underserved population of the target group and how smartphone applications and other non-technology self-help tools are used for eating disorder treatment.

2.1 The target group

There are different types of eating disorders, and even within the same type, the disorder expresses itself differently among individuals. The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) categorises the following eight diagnoses: Anorexia Nervosa (AN), Bulimia Nervosa, Binge Eating Disorder (BED), Pica, Rumination Disorder (RD), Avoidant/Restrictive Food Intake Disorder (ARFID), Other Specified Feeding or Eating Disorder (OSFED) and Unspecified Feeding or Eating Disorder (UFED). In Appendix A, an overview of these disorders and their DSM-V diagnostic criteria can be found.¹

Though all of these disorders have in common that they contain abnormal eating habits, some are more similar in nature to each other than others. Both Anorexia Nervosa and Bulimia Nervosa have a criterium in common that describes how their body weight or shape unduly influences their self-evaluation, and feelings of guilt and shame surrounding their eating-related habits play a big part in these disorders. In Binge Eating Disorder, criteria contain that individuals can feel embarrassed, disgusted, depressed, or guilty after their disordered behaviour. The distress around the eating behaviours and the extent to which this affects AN, BN and BED sufferers' self-worth, highlights their similarity. In addition, for all these disorders, additive genetic factors account for approximately 40 to 60% of the risk for development [6]. Pica, RD, and ARFID do not have any diagnostic criteria associated with self-worth or self-evaluation. That difference between the first and latter three can be quite influential when it comes to forming a target group for product design. The mentioned factors uniting AN, BN, and BED influence the type of problems experienced in daily life and a specific area of negative self-worth that needs treatment. OSFED can be linked to this group of eating disorders as well, as it includes those who are just short of meeting the full criteria for AN, BN, and BED but very similar, such as atypical anorexia nervosa, bulimia Nervosa of low

¹ https://bodymatters.com.au/wp-content/uploads/2015/01/DSM_V_Diagnostic_Criteria_for_Eating_Disorders.pdf

frequency and/or limited duration, binge eating disorder of low frequency and/or limited duration, and purging disorder. UFED was not considered in the same group due to by criteria missing specification of what this disorder contains.

When this report mentions eating disorders and the target group for the research, here it means this includes AN, BN, BED, and OSFED. Despite the myths and stereotypes surrounding eating disorders and white, underweight, anorexic, financially well off teenage girl, these disorders do not discriminate and affect all races, sexes, genders, social classes, and ages [7], [8], [9]. Rather than those factors, personality is of bigger importance for eating disorders. As found in [10, Sec. 1], “Personality traits commonly associated with eating disorder (ED) are high perfectionism, impulsivity, harm avoidance, reward dependence, sensation seeking, neuroticism, and obsessive-compulsiveness in combination with low self-directedness, assertiveness, and cooperativeness”.

These personality traits can be linked to the coping strategies commonly used or lacking in those with eating disorders, as compared to those without. An example of a dysfunctional coping strategy found is rumination when something negative is experienced. The sufferer can then hold onto this negative thought and go over and over it, and find it difficult to control the behaviour and stop doing that [11]. This seems in line with the mentioned obsessive-compulsiveness and low self-directedness. Those fully recovered from an eating disorder and healthy controls both commonly used task-oriented coping and uncommonly used emotion-oriented coping [12], fitting with for example the mentioned impulsivity, reward dependence, and sensation seeking. However, this does not match for all. Harm avoidance mentioned as a personality trait, would fit with avoidance-oriented coping as a strategy. Here not all literature seems to agree, as discussed in [12, p. 692] “although avoidance has been associated with eating disorder symptoms, some studies have found results of the contrary”.

The personality traits and coping strategies can also be masked or caused by a co-occurring disorder. It is unfortunately very common for those with eating disorders to have additional (mental) health problems or disorders. Examples of these commonly co-occurring are post-traumatic stress disorder, trauma, anxiety in general, obsessive-compulsive disorder, bipolar disorder, depression, and substance disorders [13]–[17]. This can make and the life of the sufferer harder, and make the eating disorder harder to treat.

2.2 Problems experienced

2.2.1 Physical complications

Despite eating disorders being mental illnesses, they come with many physical health consequences as well, adding to the danger of these diseases. Some of these consequences will be discussed in the coming paragraphs. These are the consequences that are part of eating disorders themselves, and not specific to the current pandemic.

Overall weakness and fatigue

Fatigue, dizziness, and low energy can be considered symptoms of eating disorders [18]. Feeling weak or exhausted is common amongst sufferers, and many factors can contribute to this. Eating disorders often come with issues concerning sleep and rest. Menculini et al. [19] confirmed that circadian disruptions are common. In a study with 400 female anorexia nervosa or bulimia nervosa patients, sleep disturbance seemed present in 50.3% [20]. In anorexia nervosa, weight loss, starvation, and malnutrition, for example, affect the sleep quantity and quality of patients [21]. When a lot of fat and/or muscle is lost, and a patient is (severely) underweight, falling asleep can be hard as each position can be painful. As for eating disorders that include binge eating, an investigation by Trace et al. [22, p. 1] offered empirical support “for an independent association between sleep problems and binge eating, which is likely due to complex psychological, biological, neuroendocrine, and metabolic factors”. While eating disorder sufferers more often suffer from disrupted sleep, it is also interesting to note that those with poor sleep seem to have an increased risk for eating disorders [23].

Many with eating disorders burn more calories than they consume on a day to day basis. This can be the case with or without purging behaviours. Though it differs per individual how much exactly, a body needs a certain amount of calories as fuel for everyday activities. Not consuming enough food can lead to low blood sugar levels, adding to fatigue throughout the day. Though more common in anorexia nervosa, patients of several different types of eating disorders are also predisposed to osteopenia and osteoporosis [24]. The bone mass reduction causes weakness and pain in bones and increases their likelihood of getting fractured.

When a body cannot get enough fuel to get through the day from calories consumed, it will start to use its own muscle for it. Muscle reduction anywhere in the body will reduce an individual's strength, but this gets especially dangerous when it gets to the heart. Cardiovascular complications can be part of all eating disorders, and in anorexia nervosa, it has been reported even up to 80% of patients suffer from this [25]. Hypotension (low blood pressure), arrhythmia (irregular heartbeat), and bradycardia (low heart rate) contribute to the high mortality rate in

eating disorders [26]. In addition to that, in bulimia, as found in [27, p. 91] “Electrolyte disturbances and associated arrhythmias are a major cause of death”. Excessive vomiting and laxative abuse can cause these disturbances.

Vomiting and laxative abuse

Of all types of purging, self-induced vomiting causes the most medical complications. Alarming, as this is also the most common method of purging in eating disorder patients, with a prevalence ranging from 56.6% to 86.4%. Self-induced vomiting can cause health complications such as dental complications (sometimes also caused by poor nutrition or dehydration), parotid glands swelling and enlargement of minor salivary glands, oral bleeding, oesophagus damage, and gastrointestinal tract problems. Apart from electrolyte imbalances, laxative and diuretic abuse can cause damage to for example the colon motility, kidney, and gastrointestinal. In addition, rhabdomyolysis and osteomalacia can occur [28].

Binging specific

Lastly, bingeing in eating disorder patients can lead to health-threatening complications such as acute gastric dilatation and gastric perforation [29]. Those with eating disorders consisting of bingeing without purging or compensating, have a higher chance of becoming obese. For these individuals, physical health consequences can be similar to those of clinical obesity, such as high blood pressure, high cholesterol, heart disease, and type 2 diabetes mellitus.²

All these physical complications can be especially problematic if eating disorders are left untreated. Apart from these health problems based on literature research, it is important to look at what the other issues are in the daily lives of people with eating disorders– from the sufferers’ perspective. While the physical complications are results of the eating disorder and are to be treated only clinically, the latter issues mentioned are of importance for how an individual copes with their disorder to get through the day. As this project aims to help with coping, these are more thoroughly explored in the next sections. Firstly in a general, pre-pandemic setting (2.2.2), and afterwards specific to the current pandemic (2.3).

2.2.2 Non-physical complications

Method

To find out what problems eating disorder sufferers face in their day to day lives, information was gathered from different media, and analysed with the use of emergent coding. A list of

² <https://www.eatingrecoverycenter.com/conditions/binge-eating/health-risks>

problems was created by going through each source and adding to it each time a new issue came to surface. No distinguishment between the severity of issues that occurred was made, as all problems were treated as equally important. When a certain problem kept reoccurring this was noted, as well as if a problem occurred more in a certain group.

The following three types of sources were used:

1. **Forums and blogs**

The use of forums and blogs, especially anonymous, is popular among those with eating disorders. As this target group can feel misunderstood and isolated, the use of anonymous forums or blogs can help a person to feel less alone by sharing their story, experiences, and opinions to those who understand what they are going through. The posts in these places can be very valuable for understanding the target group because of the openness and the details sufferers are willing to share. There were no particular keywords used to find threads that would be fit for this analysis, instead the sites used were excessively explored to find which threads belonged to discussing day to day problems. Two of the forum websites contained subcategories for ‘peer’ discussions which facilitated the inclusion of different genders, sex, ages, and ethnicities in the problems analysed.

2. **YouTube videos**

Despite YouTube being significantly less anonymous than the forums and blogs, there seemed to be a lot of personal content coming from this target group. Those who posted videos ranged from being in the depth of their disorder and sharing their struggles to (almost) fully recovered and sharing their journey. Initial videos that were used were found through the search terms “eating disorder”, “anorexia”, “bulimia”, “binge eating disorder”, “osfed”, and “ednos” in combination with the terms “my” and/or “story” to make it easier to find videos from the perspective of the sufferer. The types of videos included were recovery stories, day in the life videos, diary-style vlogs, what I eat in a day videos (including thoughts about what was eaten), life stories, documenting of symptoms, ‘update’ videos (updates on the struggles but also updates on recovery), and even videos of (recovered) sufferers reading from their diaries from when they were very ill in general, or specifically from when in treatment centres. Though sometimes it was not possible to determine someone’s age, gender or ethnicity from the video, an effort was made to find and include videos of a variety of people regarding those aspects.

3. Documentaries

A few documentaries were also included, but only the problems mentioned by (interviewed) sufferers themselves were taken into account. These were the following:

- a. Love, Chantal: Diary of an Eating Disorder (Feature Documentary) ³
- b. Desperately Hungry Housewives (Full Documentary) | Only Human ⁴
- c. Living with Anorexia ⁵
- d. BBC Documentary 2017 - Battle with ANOREXIA NERVOSA - Full Documentary ⁶
- e. Millstone - Documentary about Eating Disorders in Men – 2015 ⁷

Analysis

The problems from the list mentioned in the method were put into groups of similar nature that show different aspects of life in which the individuals can struggle to cope with their eating disorder. These categories, discussed in the paragraphs to come, are meant to make it easier to present the different issues and do not imply that these are not interconnected.

Family and home

Many people with eating disorders want to (or have to) hide their behaviours, which can be difficult. Those living with their parents or parental figure(s) often have to adhere to rules out of their control. The feeling or fear of losing control was a theme in many problems read or heard, but when it concerned living in a parental situation, explicitly mentioning not having control seemed the most prevalent. This could be because it is most clear to whom the control is shifted in this case. Restrictive eating disorders often work with food rules that are made up by the disorder and differ per individual, that can clash with parental rules. An example was having to leave at least a certain amount food left on the plate or only being allowed a certain amount of bites, clashing with a parental rule of having to finish all that is served on the plate.

Those with disorders including bingeing and/or purging often took extreme measures to hide this. Examples of what was mentioned are having bags of old vomit underneath beds, or spitting out food into an opaque cup after chewing it during mealtime. Depending on the

³ Love, Chantal: Diary of an Eating Disorder (Feature Documentary):

https://www.youtube.com/watch?v=LFAP2_i02no

⁴ Desperately Hungry Housewives (Full Documentary) | Only Human:

https://www.youtube.com/watch?v=Y_NS6IcTma8

⁵ Living with Anorexia: <https://www.youtube.com/watch?v=sJMNpHoJ7Kg>

⁶ BBC Documentary 2017 - Battle with ANOREXIA NERVOSA - Full Documentary:

<https://www.youtube.com/watch?v=fbskMrF0NE4>

⁷ Millstone - Documentary about Eating Disorders in Men:

<https://www.youtube.com/watch?v=iRim224xFjE>

household dynamic, this caused a lot of tension and strains on relationships. Secrecy and the difficulties coming with it was commonly brought up, as the accompanying guilt was something these individuals had to deal with daily, sometimes to the extent that the thoughts of this troubled their sleep.

Those being a parental figure themselves carried an especially high level of guilt and shame around their eating disorder. Often reported was the feeling of being a bad parent, or not being fit to be a parent, even when the children did not know about their disorder and they had hidden everything successfully. Many struggled with being extra conscious of how they would eat or not eat around (especially young) children in fear of unintentionally passing on damaging behaviours and presenting an unhealthy relationship with food and one's body as normal.

Friends and dating

Just like with family, a lot of (daily) struggles came up with maintaining good friendships and not getting lost in the guilt and shame of secrecy and lying. Eating in front of others can be challenging for those with eating disorders, but food and drinks are commonly used as ways to socialize. Feeling isolated was a key problem in this category. As hiding discomfort around food can be exhausting, many cancel events or decline invites, and isolation can come as a consequence quickly. An often brought up problem was not having a social circle in university or college, when from the beginning all social activities were avoided.

Though fearing the problems around food was one reason for self-isolating, another was non-eating related. There were cases of individuals purely disliking themselves too much to 'allow' themselves to leave the house. A common case was when they did not let themselves leave the house until they had lost a certain amount of weight, with the common comment followed that actually even when they were at that goal weight they would still not let themselves. There were many people saying they felt they were too fat, ugly, uninteresting, annoying etc. to be around others, and self-isolated as a form of not bothering someone else with their presence, or as a form of self-punishment. The common theme around this was 'not feeling like they are enough'.

Next, some felt left out with or behind on friends or peers as they were not able to do what was expected to be typical for their age group. An example of this is when teenagers or young adults were in a social context where they were expected to drive and want a car, but because of the physical state their eating disorder had left them in, they were medically not allowed to take driving lessons. Others mentioned they were not able to relate to their peers as much as they wanted to on everyday topics, as they were consumed by their disorder and disordered thoughts occupied their brains.

Dating and romantic relationships were considered hard to pursue and maintain in many stories. Just like with peers, there is a pressure to impress the other in this context, and the

individuals looking for partners had a tendency to find themselves not interesting, pretty, or fun enough by default. Putting a lot of effort into being perceived that way regardless, added to feelings of shame, of 'living in a lie' and 'faking it'. This added stress and anxiety in each reencounter with this person as they felt they had to live up to an image of themselves that they had created. In maintaining relationships, it was said self-doubt was what caused trouble, for example, portrayed in difficulties with accepting compliments. Some said it turned them very cynical, even when this was normally not a part of their personality.

Eating out

Eating out in public spaces often was said to come with an increase in anxiety and self-consciousness. This could be due to uncertainty about how a food is made, what exactly is in it, the way it is served, and what is on the menu to begin with, as well as the fear of feeling judged in the way an individual is eating or taking up space even when showing no disordered behaviours.

Doing groceries

Going out for groceries seemed problematic whether done alone or in a group, for different reasons. Most eating disorders work with safe foods, how many and which foods qualify as a safe food differs greatly. There can be a lot of anticipatory anxiety surrounding whether or not the safe foods will be in stock, or how many other people will be in that same aisle the type of food is in. Going to new supermarkets or stores for the first time could be stressful as individuals experienced anxiety around uncertainties such as where the foods are located in the store, whether or not there are self-scan/self-checkout options available, how close the aisles are to each other, and how easy it is for other shoppers to pay attention to what you are grabbing or whether you are reading the food labels.

Lastly, for many being around large quantities was a general trigger for their disordered thoughts to get louder, and think more about their eating disorder.

Work and education

As eating disorders cause more or exaggerate existing feelings of self-doubt and a negative self-image, many reported having problems with feeling worthy of their position in work or education. Feeling like an imposter was mentioned. There were worries that if their eating disorder would get worse, they would immediately drop out of their education or get fired at their job. Many also struggled with focusing due to physical issues such as being cold (even in a warm room with proper clothing), being hungry, having throat or stomach pain from purging, being tired, and being dizzy or lightheaded; but also due to obsessive thoughts about food, their body, or general self-loathing. A regular day of work or class could be followed by exhaustion.

Haunting thoughts

The target group mostly spoke and wrote very negative about themselves, sometimes parts seemed related to co-occurring disorders. The cruel constant negative self-talk was what fuelled the disordered behaviours and thought patterns. As sufferers often end up isolating themselves, this is when this negative self-talk was the most dangerous. The lack of distraction from other people or work/study obligations enabled harmful patterns. Many discussed how when alone, the 'eating disorder voice' would be louder, and emphasize how there were no more excuses left not to act on it. This eating disorder voice was present in many stories, some had given it a name and personality and referred to it as such. This was a way for them to separate their rational self and original personality, from thoughts from the eating disorder and the ways of acting because of it.

Most people seemed fully aware of what part of them was the disorder and what their original self, and managed to discuss this in a very rational manner. Shame and emotion came up in those talking about how the eating disorder voice can become so loud and prominent that they end up giving in while they know they should not listen. Identifying the 'other' voice helps, some even actively talk back to it as if it was another person, but in moments of crisis this can get very difficult. Some described not feeling in control of their own body while for example exercising excessively or self-induced vomiting, actively disagreeing with their actions in the moment but not quitting. Struggling with grounding themselves to the present moment and gaining back control was mentioned, along with feeling powerless. The negative self-talk could make looking in the mirror or reflections in windows either something to be avoided at all costs, or something to pursue compulsively. Both can be distracting in daily life.

When being stuck with an eating disorder voice, it can be difficult to try to eat normally. Some mentioned that getting themselves to try was the greatest challenge, others mentioned it was knowing what 'normal' implied. Even when trying to recover, it seemed hard to find a good reference as to what to try to eat and how much of it if it was not for a strict meal plan. They might compare with what peers or family eat, but then it was easy to feel down when eating even a little bit more. What a normal relationship with food is seemed difficult to know, and hard to ask.

Feelings of isolation and loneliness in the fight against their eating disorder left many feeling hopeless or helpless about the future. Feeling alone would still happen even when knowing there are many others struggling with the same issues. Reaching out could be hard when not knowing how others would react, and some considered reaching out to people they knew personally off-limits after some bad experiences. Even when willing to reach out, a problem came up that it was hard to find the words to describe what they were feeling or what was happening to them, and it was hard to think of how to bring it up. Some who had no

previous bad experiences did not feel comfortable reaching out because of how they had heard others talk about eating disorders or the people suffering from them, in real life or the media. There was a fear of not being taken seriously.

Stigma and the media

Part of the fear of opening up was the stigma surrounding eating disorders, and the way it is represented in the media. People reported feeling too ashamed to ask for help because they did not feel like they were sick enough. Though this is partly because of the eating disorder voice, this was also influenced by the awareness of eating disorder stereotypes going around. People who were aware they had a disorder still struggled with feeling that they ‘did not really have an actual eating disorder’ because they were not underweight (enough), or because ‘they could be doing worse’. The myth that eating disorder sufferers are teenage, white, financially well-off girls did not only hurt those who did not fit into that box, but also those who did.

Summing up findings

In short, the information surveyed and reviewed led to the conclusion of the following possible issues: shame; guilt; need to hide the behaviours; (fear of) lack of control; difficulties in relationships; self-isolation; not feeling enough; (fearing) feeling left out; self-doubt; triggers when out in public; anxieties from multiple sources; obsessive thoughts; self-loathing; work-life disturbances; eating disorder voice; stigmatization; among many other not specified issues. This extensive list of issues shows the destructive and personal nature of these diseases, and how complex life as part of this target group can be. This is crucial to understand before starting to ideate a product for this group.

2.3 COVID-19 and daily life

The COVID-19 pandemic affects the daily life of people in a number of ways, worldwide. Measures keep changing and can differ per country, state, or even city. Anyone can start experiencing increased levels of anxiety, panic, or fear as a result of the constant changes, new worries, and the spreading of the virus itself. Stankovska et al. [30] stressed the importance of psychological support during these times. They broke down into the phases before, during, and after, and for each phase listed the main psychosocial manifestations in the population, and corresponding mental health actions. They provided a useful overview of this in the form of a table, presented below as figure 1.

Phases/psychosocial manifestations in the population	Mental health actions
Before: - Sense of inevitability, with a high level of tension in the population, - Maximization of preexisting characteristics (positive or negative); - Worry, fear, tension, anxiety, depression, insomnia...	- Communicate risk to the population, with emphasis on vulnerable groups (children, adolescents, old persons, persons who contracted the disease and survived, persons with chronic physical illness). - Locate personnel trained in mental health. - Establish psychosocial support and counseling groups. - Detect psychosocial risk factors. - Encourage collective spirit and support community participation. - Organize mental health services for an adequate emergency response (mobile teams, crisis intervention units and services in general hospitals).
During: - Loss of initiative. - Feelings of fear, worry, vulnerability. - Adaptation to changes in the usual patterns of life (restricted movement, wearing masks, reduction in direct physical contact, closure of schools or universities, closure of shops....). - Anxiety, depression, stress, panic attacks, agitation, somatic disorder of psychological origin.	- Evaluation of the psychosocial needs of the population. - Support of the core actions of early detection, reporting, care and containment. - Mass communication, information and guidance on: what is happening, what is being done, and what the people should do. - Provide psychosocial care and support (individual and group-based) for affected people, families, and communities. - Create opportunities for mutual support in the community. - Create a menu of personal self-care activities that the person enjoys, such as spending time with family, exercising or reading a book. - Take a break from media coverage of COVID-19. - Support everyone to be connected with others. - Promote work rotation and organize working hours appropriately. - Take time to talk with children or teens about the COVID-19 in a way that they can understand. - Protect human rights (migrants, refugees, prisoners, people with disabilities). - Specialized services for pandemic settings.
After: - Fear of a new epidemic. - Social and mental health conditions: depression, posttraumatic stress, violence, depression, alcohol or drug abuse. - A slow, progressive recovery process begins.	- Maintain a mass communication strategy to facilitate recovery. - Implement individual and group-based mental health care for the affected persons, families and communities. - Support that new life projects should be fostered and encouraged.

Figure 1: Table overview phases and mental health actions in times of COVID-19 [30, p. 42]

Those already struggling with mental health issues to begin with, were impacted even more severely by the new fear, anxiety, and depression this pandemic brought with [5].

2.3.1 Method

To find out more about how those who already had to fight daily against their eating disorders have been affected by the current pandemic, desk research was conducted. This time, an a priori coding approach was followed. The pre-defined categories that came to be in chapter 2.2.2 through emerging coding were used as categories from the start, with the addition of one extra category: “Other COVID-19 specific”. The sources were analysed in such a way that each time problems with one of these categories were amplified because of the situation surrounding the pandemic, this amplification was noted in the fitting category. If a new day to day struggle came up that did not properly fit in any of these categories but was related to COVID-19, this was added to the new category.

For this part of the research, YouTube videos and forums were analysed. To find COVID-19 specific forum posts and reactions, the following keywords were used to search within forums: “pandemic”, “covid-19”, “corona”, “rona”, “lockdown”, “isolation”, “quarantine”, “virus”, “measures”, as well as taking into consideration the dates of posting. When the theme of a thread had to do with this pandemic, the entire thread was read and analysed, not just the posts containing keywords. This provided a thorough amount of information.

The YouTube videos were found either by going to some of the channels found in chapter 2.2.2 and looking at their more recent uploads to see if there was an update video, and by searching for the same keywords as in chapter 2.2.2 but now using YouTube’s filter feature, and setting the ‘Upload Date’ to solely include ‘This month’.

2.3.2 Analysis

Family and home

Some people, especially students who had already moved out, came back to living in their family home during this time, while others now spend full days with their housemates that they usually only might see during evenings. In both cases, this meant spending more time with people they were not used to being around as much. The usual problems of family, that turned out also relevant concerning housemates, seemed amplified as for example hiding behaviours got much harder because people are home more often. There was also, in case of unhealthy relationships with family or housemates, more room for triggering comments to be made – many mentioned their family commenting on their food behaviour being very triggering and

that this happened way more often now. The secrecy and therefore the shame and guilt for not being able to eat 'normal' increased. Some actually said that they automatically compared themselves (body and food intake) with those they lived with now, often followed by a disclaimer that they know they should not. Seeing how much/little housemates ate made them either question whether they really had an eating disorder because 'their housemate also ate this little/much' or, when trying to recover, they will see someone who eats less than them as 'this is a normal amount of food'. Not being able to engage in (as much) eating disorder behaviour because of others being home or even due to active supervision in these times, could cause weight gain, which many mentioned was harmful to their self-esteem.

On the other hand, there are also those who suddenly spend entire days all alone because of the situation. Sometimes they already lived alone and now all their activities and obligations are cancelled or at home, sometimes they lived with housemates that went back to their families for this time. They were now left alone with their thoughts and had no distractions to keep them from thinking about food. Because of the lack of other people, they got complete freedom to engage in eating disorder behaviours as it was hard to find a reason not to, or to remember a reason not to. Those in recovery mentioned fear of relapse because of this.

Friends and dating

At first, it seemed the mentions were mostly positive about this, as because people felt they had less need to lie now. Events and activities were mostly being cancelled for them now, they did not feel the pressure to go or the need to make excuses not to go. Then the downside of this became clear, as many put great value on social connection for their mental health. Some had certain friendships in which they felt more comfortable eating than alone, that they relied on a bit for part of their recovery. There seemed more isolation from social circles than before.

Sufferers found it harder to reach out to friends as they felt more like a burden, thinking how the world situation had affected their friends too. They did not want to add stress or negativity and did not know how to let them know they were struggling.

Eating out

Some of those in recovery had been going alone to eat out in public spaces as part of their treatment plan or as something they challenged themselves to do. This was to slowly get rid of fears by exposure to eating foods the individual did not prepare, or going somewhere where the individual had not seen the menu beforehand. This is difficult now, and people mentioned this to be demotivating to them for recovery, as their progress was put on hold.

Doing groceries

As many of the regular population around the world had suddenly started panic buying and stocking up on all kinds of foods, the fear of safe foods running out is much bigger now. In supermarkets emptied by these panic buyers, seeing empty shelves even when it is not about safe foods in specific, could cause higher anxiety or even panic in those with eating disorders. The general atmosphere in a lot of supermarkets had changed to a much higher tension than normal. The everyday shoppers who usually do not have any anxieties or fear relating to doing groceries might do now because of the virus. Those with eating disorders tend to be very sensitive, and sensing this increased general anxiety fuels their own.

The new and increased amount of rules in supermarkets because of the pandemic clash with some individuals' food rules. An example mentioned was the eating disorder food rule "you cannot pass by the bread and candy aisle" clashing with a new rule in the supermarket of one-way traffic, causing a forced path, past these aisles too. The rules could also clash with ways of coping sufferers use to ease their shopping anxieties. An example here is someone who struggles with binge eating and wants to avoid having larger quantities at home. For this, using shopping carts was avoided as this incentivises buying more binge food. This clashes with the new rule in many supermarkets of carts being mandatory to maintain proper distancing between customers. Being triggered by being surrounded by more food at home has become a larger issue now due to avoidance of leaving the house unnecessarily, and buying more food at once.

Some people who have been dependent on doing groceries online and having them delivered because of their anxiety around going to a supermarket or other reasons, suddenly suffered from changes in how often and what they can buy. This is because of the pandemic now people who before never ordered groceries online suddenly do it too, and those who already did sometimes might do it more now, so the home delivery services get overwhelmed with orders.

Work and education

Work and education becoming mostly online caused more sadness. For some who were isolated to the point of not having another social circle, especially those living alone, the place where they worked or followed education could serve as the only place they had social interaction with others. In addition, the physical work or study place helped to keep distracted from the eating disorder voice, as they had to work/pay attention and used that as their response. Now there is another 'no excuses' possibility for the eating disorder to use against the sufferer. Lunch breaks at school or work were sometimes used as help for recovery to feel pressured to eat lunch and not engage in behaviours.

Haunting thoughts

Despite guilt already being prominent before this, it seemed to have increased now. The guilt in those who struggled with feeling they were not very sick to begin with or like their problems were not valid or ‘real’ problems, as ‘there are much worse problems in the world’, seemed to have significantly increased with a pandemic worrying the world. It got harder to feel validated. Some mentioned feeling guilty for the thoughts they had surrounding the virus that were essentially part of the eating disorder voice. Examples of these thoughts were thinking about ‘wanting’ to catch the virus to lose appetite and for it to be easier to lose weight, and thinking about ‘wanting’ to catch the virus and die from it to be able to die without having to commit suicide. This made these individuals feel like bad people for thinking this, even when knowing it was only part of their disorder.

The loss of control over life aspects and the uncertainty the COVID-19 situation was mentioned to create general feelings of anxiety in daily life. Those with co-occurring disorders such as depression, OCD, and PTSD, mentioned this made it harder to not engage in disordered behaviours. The compulsion to purge, restrict, or binge seemed stronger as it felt like there were even less excuses not to engage in this compared to the days before the pandemic. Routine disappearing and a sudden lack of structure in days was also a factor influencing the increased struggling. People mentioned finding it very hard to either set up or stick to a new self-created routine as them being fully in control of their time meant them having to full-time force themselves to ignore disordered tendencies and distract themselves from it.

Some mentioned feeling like they needed to restrict more than usual in a way to compensate for the gyms being closed, even when they worked out from home as a replacement. Some of those with obsessive thoughts about losing weight said the uncertainty of not knowing when ‘normal life’ would open up again, felt more pressured to lose weight now as that meant they could ‘return to normal life’ skinnier.

Stigma and the media

On social media a lot was shared with regards to the pandemic that could be seen as harmless, but to those with eating disorders could be quite triggering. Many memes went around about how people would come out fat after lockdown or quarantine was over, from not moving or exercising enough. These came together with supposed motivational posts to inspire people to move more and not just stay inside and sit still, now that there was time. To someone who is trying to fight a disorder forcing them to restrict and purge, this can cause damage.

In addition, it was common to find productivity posts online, that would tell individuals this is the time to get everything done and pick up all sorts of new hobbies or courses that had been put off before. Again, though likely not the intention of the post, this made some sufferers

who already also suffered from low self-esteem and fatigue, and could find doing tasks like getting out of bed and taking very energy consuming, feel much worse about themselves.

Other: COVID-19 specific

There were concerns from people with eating disorders fearing getting infected with the virus itself. Many stories mentioned being scared of catching the virus, and worrying about whether their eating disorder and the damage it had caused to their bodies made them more vulnerable for the health consequences of COVID-19. Some started fearing for not recognizing the symptoms or not knowing when they would need to go to the hospital or call a doctor. This was because they felt used to health complaints and feeling unwell. Some symptoms for COVID-19 were similar to what they felt on regular bad days of their eating disorders, that they feared not being able to recognize the difference. Examples mentioned were chest pains and pressures, sore throat, tiredness and overall body pain, headaches, and loss of taste. It was noted that feeling anxious about these symptom uncertainties was brought up by those who engaged in self-induced vomiting in particular.

Some who (now) lived with their parental figures who were aware of their eating disorder mentioned their parental figures were very worried about them being at greater risk from the virus. Their parental figures would for example not allow them to do groceries or go outside for a walk out of fear. This extra loss of control and freedom led those individuals to feel worse and sometimes like they needed to compensate by controlling what they ate or how they purged at home even stricter, as well as adding guilt for worrying those who cared about them.

Treatment changes

Many who were receiving some sort of treatment before the pandemic, mentioned having difficulties with the changes brought by the lockdown. Face to face treatment most often switched to treatment through phone- or video calling, though in some cases treatment had to be put on hold completely. Some mentioned that the financial difficulties that the pandemic brought, had left them having to cancel their treatment in order to save up. Stories also occurred of being supposed to start an inpatient treatment around these times after a long wait and it being postponed, or even of having to leave an inpatient treatment unexpectedly due to a change in the maximum amount of patients allowed. Some without treatment mentioned it now felt even more inaccessible, with all the rest going on.

Those who continued their therapy sentence over phone-or video called faced a few problems. One was not having the privacy in their house to open up about their feelings to their therapist the way they could in a therapist's office. Some have not told their family or friends they receive therapy and cannot call discretely while sharing a house. Another was patients

fearing to be a burden now, and not wanting to further worry their therapist by bringing negativity and stress into a session. Patients could tell their therapist was more stressed than usual, and felt guilty for taking up time even when paid for. Finally, there are many things a video or phone call cannot pick up on that can be of major importance in therapy, such as body language. Depending on the disorder, it can be an important part of therapy for the therapist to notice the changes in a patient's body composition, which are now hard to tell. All of these things can make treatment feel less effective, and disrupt the motivation to get better.

Positive aspects found

Though not part of the problem analysis, there were also some positive aspects for some to this situation with regards to their eating disorder. Some had mentioned that they were forced time off from their job or education because of the circumstances, and that they had managed to take the time to work on themselves and their recovery. The ability to take it slow physically, was of help to those struggling with fatigue and weakness. This was even the case when education and work still continued, but the commute to campus or office was not necessary anymore which provided for some more opportunity to rest. Some who had good relationships with their family or housemates now had time to nourish that relationship, as everybody is together for at least nearly the entire day.

Summing up findings

YouTube videos and forums were surveyed through a priori coding, to study the direct consequences for eating disorder sufferers' daily life of the COVID-19 pandemic. Adding and updating the previous anecdotal findings, it was concluded that there was an increase or intensification in: difficulty and therefore effort in hiding behaviours; difficulty to do groceries; difficulty to move towards or get to know a normal relationship with food; difficulty in reaching out; difficulty in accessing or making the most use out of treatment; non-eating disorder related reasons to worry; general anxiety; triggers; triggered anxiety; feelings of invalidation, shame, and guilt; compulsive comparison; media pressure; isolation; and the presence and power of the eating disorder voice. It is important that these intensified problems are taken seriously.

There have however been a few positive aspects too, that are also worth noting. For some, there was more time to work on themselves, their mental or physical recovery, and their relationships with those they lived with. This should also be kept in mind when designing further for this target group.

2.4 State of the Art

2.4.1 and 2.4.2 both are part of the literature review written and handed in for the subject Academic Writing from Module 11 of Creative Technology.

2.4.1 Reaching an underserved population

There is a big underserved population among eating disorder sufferers. Though it is hard to find exact statistics on the untreated, Kazdin et al. mention a treatment gap of about 80%. The treatment gap is defined as "the large number of people in need of clinical care but who are not receiving services" [31, p. 170]. Treatment delays contribute to the size of the underserved population. There is a gap of on average 3.6 years between the onset of an eating disorder and patients acknowledging said disorder, and an average of 4.2 to 6.3 years between the onset and treatment-seeking [32]. This seems alarming considering how dangerous these illnesses are. The treatment gap is hard to narrow as many factors play a part in its preservation.

The multiple barriers contributing to the size of the underserved population reflect the need for more accessible support. Lack of available services and systematic disparities in service accessibility call for ways of reaching those without treatment. From identifying that what is experienced are symptoms, to seeking out, getting in, and remaining in treatment: there are many steps involved in obtaining mental health care, each having corresponding complications for those who are ill [31]. Ali et al. [33, p. 9] suggest "stigma and shame, denial of and failure to perceive the severity of the illness, practical barriers (e.g., cost of treatment), low motivation to change, negative attitudes towards seeking help, lack of encouragement from others to seek help and lack of knowledge about help resources" as the main perceived barriers. These findings are in line with the four main barrier categories for initial treatment-seeking of Regan, Cachelin, and Minnick [34], as all previously mentioned barriers fit into at least one of the following: personal feelings of shame/fear, ED-related beliefs/perceptions, lack of access/availability, and aspects of the treatment process. These are many problems to tackle, indicating the importance of a lower barrier version of treatment for eating disorders.

Smartphone applications have the potential to make treatment more accessible. A proposed model to address the treatment gap and reach underserved sufferers, is the use of disruptive technology. The accessibility of mobile applications suggests the potential for an app to enhance intervention delivery as a new medium [31]. Despite seeing the advantages, not much certainty can be placed on the effectiveness of the medium yet. As Aardoom, Dingemans, and Van Furth [35, p. 42] stated: "the effectiveness, validity, and clinical utility of these apps have not yet been established and warrant further investigation". Because this is a relatively new field, not that many apps that are designed for this purpose are yet available in app stores. This seems likely to change with the increasing popularity of using apps in mental health care.

2.4.2 Types of apps in use for eating disorder treatment and their qualities

The few apps specifically designed for eating disorder sufferers and/or their care providers that exist vary in functionalities, though all lack evidence. Fairburn and Rothwell [36] and Juarascio et al. [37] reviewed existing eating disorder apps at the time of research. In order of prevalence, the four main functions categorized are provision of advice, self-assessment tools, self-monitoring, and information transfer between patient and clinician. Of all apps reviewed, the clinical utility is not clear [36]. The apps use strategies not yet empirically tested, contain little integration of evidence-based treatment for eating disorders, and do not take advantage of all the possibilities a smartphone brings as a new medium [37]. In agreement with the previous authors mentioned, the applications do have the potential for bringing positive support as an extension of a traditional treatment method and as a way of increasing access to care for those untreated, despite evidence for effectiveness lacking for now.

The apps that focus on advice provision and self-assessment are assessed poorly. The advice provided can be unsatisfactory and sometimes even harmful. This is concerning considering the prevalence of this category and the sensitivity of the target group. The majority of the self-assessment apps do not use methods deemed reliable, and though the accuracy of the provided information depends on the app, few were up to standard [36]. The risk of potentially harmful advice in ED apps can also occur in apps that contain social forums to communicate with other users, as ill individuals might give each other detrimental advice [37].

Self-monitoring apps seem promising as treatment support, though experiences differ per individual. Self-monitoring is a crucial part of cognitive behavioural interventions often used in traditional eating disorder treatment. Reminder features used by some self-monitoring apps are valuable for potentially enhancing motivation and compliance [37]. Using an app instead of traditional methods seems to be an advantage for self-monitoring for psychopathology tracking, though a disadvantage for psychopathology analysis [36]. An app in this category, targeting eating disorder recovery, called “Recovery Record” appeared a popular choice with over 108000 downloads reported in 2015. A majority of users still monitoring their meals at 30 days of use shows great acceptability. The iterative, user-centred design and development approach may have contributed to its successful utilization [38]. A 2018 study on outpatient patients’ experiences with the app shows experiences with specific features differ greatly between patients. Causes for not logging meals or finding features more obstructive than helpful differ, and so, cooperation between patients and clinicians for how the patient could best use the app is recommended before use [39]. Ideally, the apps would become more customisable, facilitating this process. This way, the app is used in addition to traditional treatment.

Apps can be used in blended treatment for eating disorders, though clinicians' needs need to be taken into consideration. Previously mentioned Recovery Record self-monitoring app also has a clinician interface. The interface lets clinicians access the patient's data and use it for their face-to-face treatment, forming a system of blended care and allowing for information transfer between patient and clinician in between sessions. The change of treatment conditions (for example the possibility for a patient to now be continuously monitored) comes with many challenges that have a stressful, negative impact on clinicians [40].

Health care providers found various, including similar, barriers with the use of TCAApp. TCAApp is described by Anastasiadou et al. [41, Sec. 2.2] as “an mHealth tool specifically designed to bidirectionally connect patients with EDs and their therapists in the periods between medical consultations”. The discovered barriers were most often external factors relating to the human or organisational environment, but for instance also health care providers not feeling sufficiently comfortable or confident to use the technology fully [41]. App usage in the form of blended treatment or enabling communication between patient and clinician should be approached carefully as clinicians remain hesitant to use these even when seeing the possible advantages.

2.4.3 Non-eating disorder specific apps

Apart from the potential for eating disorder specific apps being used, there are also apps that were not primarily targeted to eating disorder sufferers that can still be helpful. BodyMatters Australasia, an eating disorder clinic, keeps up a website with an extensive overview of information and resources. Psychologist Madalyn Olivier listed eight apps in an article on it, about apps to support eating disorder recovery⁸. Of her list, only two were eating disorder specific. Of the other apps, one is focused on help with falling asleep and returning to sleep, another on daily mindfulness meditation, and one on reducing and managing anxiety through focused breathing exercises. The remaining apps were all derived from Cognitive Behavioural Therapy (CBT) techniques, the first providing online CBT through the app, the second using CBT based tools to help control anxiety, and the third using CBT technique ‘stimulus control training’ with main focus on managing one’s worrying.

It is not surprising that CBT based apps are recommended for eating disorder patients given the evident efficacy that this type of treatment has for BED without additional pathology [42]. On top of that, CBT has shown to improve treatment adherence and minimizes dropout in patients with AN, not to mention that it is also the currently leading evidence-based treatment for BN [43], [44].

⁸ Article “BodyMatters recommends: Apps to support your eating disorder recovery”: <https://bodymatters.com.au/bodymatters-recommends-apps-support-eating-disorder-recovery/>

2.4.4 Non-technology self-help tools

The use of self-help tools is, of course, not limited to technology. In a study with 22 women that were recovered from an eating disorder for example [45, p. 222], “participants reported that journaling helped develop personal awareness of their eating disorder and an understanding of their emotions, such as anger and sadness.”

Kati Morton, a licensed marriage and family therapist, and eating disorder specialist, commonly stresses the benefits of journaling on her public mental health video channel on YouTube. Apart from the playlist of journal topic videos ⁹, she has created a free eating disorder recovery workbook with corresponding videos that has received very positive feedback. This workbook interestingly starts off with the task for a sufferer to write down the things the eating disorder tells them, and next to it how they could respond with recovery in mind. As so many had mentioned the eating disorder voice in the problems found in 2.2.2 and 2.3, this seemed like an appropriate way of separating oneself from the disorder.

Another popular eating disorder workbook for self-help, is “8 Keys to Recovery from an Eating Disorder Workbook”, written by Carolyn Costin and Gwen Schubert Grabb, both Certified Eating Disorder Specialists.¹⁰ The workbook contains assignments and activities, stories from others’ recovery journey including from the authors who have also overcome their eating disorders, journal entries to finish, and resources and information for each aspect of recovery.¹¹

⁹ Kati Morton, YouTube Journal Topics playlist link:

https://www.youtube.com/playlist?list=PL_loxoCVsWqxzfoO3zr6AGRZtB8PFC604

¹⁰ Overview of books by Carolyn Costin, including “8 Keys to Recovery from an Eating Disorder Workbook”: <https://www.carolyn-costin.com/books>

¹¹ Book review of “8 Keys to Recovery from an Eating Disorder Workbook”:

<https://psychcentralreviews.com/2017/book-review-8-keys-to-recovery-from-an-eating-disorder-workbook/>

Chapter 3: Methods and Techniques

This chapter provides an overview of the different steps and phases of this graduation project, and touches upon the different methods and techniques used throughout the process. In addition, it states the order in which different phases of the research are discussed in this report.

3.1 Design Plan

The background research laid the foundation for the project, and now what was left was moving towards a working prototype. In an attempt to obtain more overview over this big step, in a linear fashion within this process different smaller steps were distinguished. These steps make up the design plan, and a flowchart of these can be seen in figure 2 below.

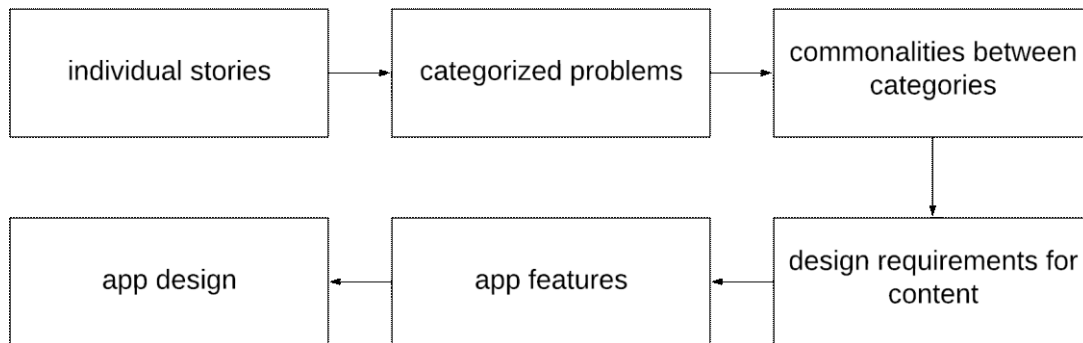


Figure 2: Design plan flowchart

The first two chart entries are part of what was done during the background research, as the problem scenarios extracted from the individual stories that were listened to and read, were already divided into different categories by the end of it. For all remaining entries, several actions had to be taken before being able to move from one to the other. This is a very surface-level overview, but helped with keeping on track with what had to be done. After having gone through all these steps, a final prototype should be ready to be built and tested.

3.2 Empathic Design

As this project's focus lies on people and their experiences, using empathy is important throughout the entire process, similar to the mindset of the Design Thinking Bootleg from Hasso Plattner Institute of Design at Stanford ¹². In A framework for empathy in design:

¹² Design Thinking Bootleg: <https://dschool.stanford.edu/resources/design-thinking-bootleg>

stepping into and out of the user's life, Kouprie and Sleeswijk Visser divide the process of using empathy in design practice into four distinct phases [46]. By making potentially seemingly obvious steps explicit, the framework aims to support empathic approaches. The four phases and their descriptions can be found in figure 3.

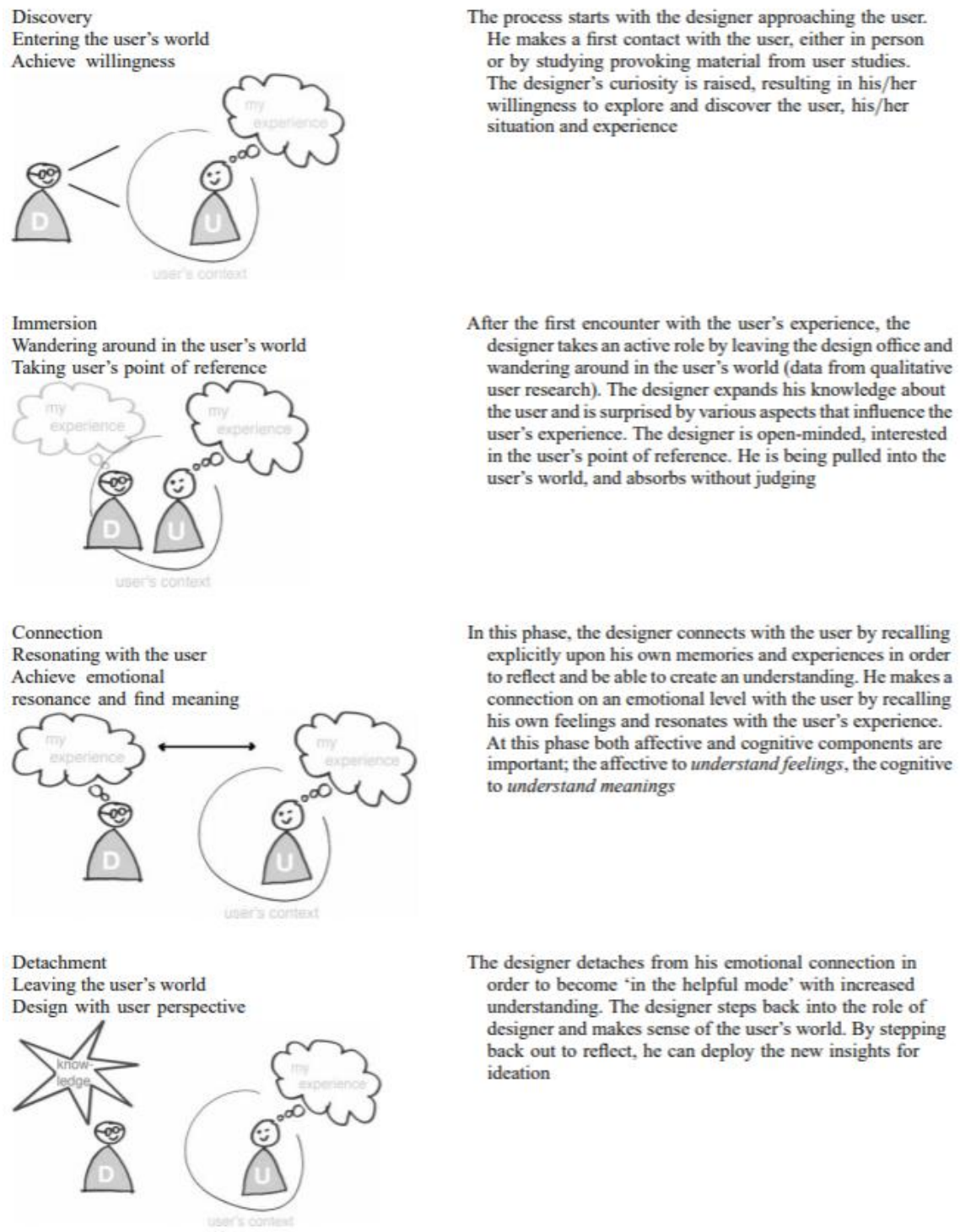


Figure 3: The four phases of empathy [46, p. 445]

The last three phases, Immersion, Connection, and Detachment, apply to the execution of this graduation project. The Immersion phase mostly took place in the process of the methods described in chapter 2.2.2 and 2.3. These methods describe how individual stories coming from members of the target group themselves were listened to and read, which was an effective way of being pulled into the target user's world. This experience formed the foundation for the rest of the project, as it helped to keep in mind who this research was about in the form of individuals rather than a theoretical target group description.

The Connection phase is most prominent when going from the design plan step categorized problems to commonalities between problems. In this step the problems categorized need to be understood and given meaning to get to the underlying factors, often in shape of feelings. For this, usage of own knowledge on feelings and emotions in experiences is beneficial for the analysis, making for the need of both affective and cognitive components of empathy.

Anything after this step can be seen as a result of phase four, Detachment. The remaining steps are more related to product design and building a prototype, where the focus lies on designing as a designer, but using all the insights gathered from the previous phases.

3.3 The Creative Technology Design Process

The Creative Technology Design Process (CTDP) is a design process for the bachelor programme Creative Technology at the University of Twente [47]. This iterative design process describes four main phases: ideation, specification, realisation, and evaluation. See figure 4 for an overview of the full CTDP. The CTDP was used in the design process of this project. What happened in each phase was the following:

1. Ideation phase

For this project, the starting point of the process was the problem summarised in chapter 1, with the fixed technology of designing a smartphone application. Chapter 2 can be seen as the start of the ideation phase, as context and problem analyses took place then. For the rest of the ideation phase, commonalities were found between the categories of problems that were converged and then translated to design requirements. This was followed by two mind mapping sessions, one on user scenarios and one on possible application features.

2. Specification phase

In this phase, the results of the ideation phase converge into a list of features to include in a prototype, through an ethical filtering process. A preliminary taxonomy is then set up by using open card sorting.

3. Realisation phase

The realisation phase is split in two. The first is the realisation of the mock-up, in which a mock-up was created and tested by ten participants. The second is the realisation of the prototype, where based on the results of the first realisation, the final prototype was built and explained screen by screen.

4. Evaluation phase

The final prototype was to be tested with a focus on functionality, usability, utility, and visual appeal. The evaluation phase was split up into three separate, individually discussed parts. Each with different participants and a different focus. Originally, it was split into four, as it contained a test with the target group. Due to limitations out of this project's control to do with speed in ethical approval, this could not be executed.

Therefore now the evaluation phase is left with: function testing and pilot testing in one for usability testing, an evaluation with non-target group participants focused on usability, and an expert review.

These phases shape the structure of the rest of this report, each phase discussed in its own chapter.

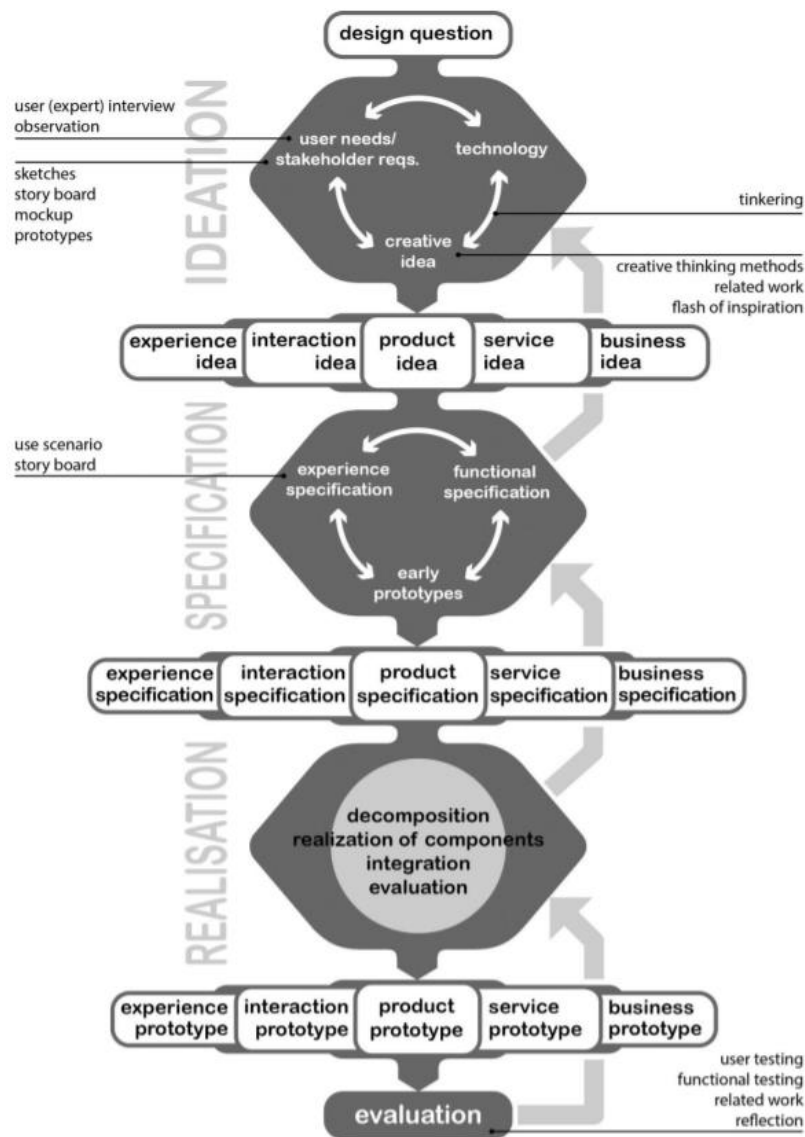


Figure 4: The Creative Technology Design Process [47]

3.4 The Ethical Toolkit

Designing something with the intention of it being used by real people comes with great responsibility. Vallor et al. [48] proposed an ethical toolkit that helps with implementing ethical reflection, deliberation, and judgement in many types of design projects, in line with what is being done. This toolkit explains and provides implementation cases on the following seven tools:

- Tool 1: Ethical risk sweeping
- Tool 2: Ethical pre-mortems and post-mortems
- Tool 3: Expanding the ethical circle
- Tool 4: Case-based analysis
- Tool 5: Remembering the ethical benefits of creative work

Tool 6: Think about the terrible people

Tool 7: Closing the loop: ethical feedback and iteration

The application of the toolkit on this graduation project was fully worked out for the final report for the course Reflection from Module 12 of Creative Technology, and was consulted multiple times during this research. Since ethical design was considered a key heuristic throughout the design of this product, the ethical toolkit was consulted on all phases of the research. For demonstrating how it was applied, explicit use of the first two tools is shown when converging in the specification phase.

Chapter 4: Ideation

In the ideation phase, the first steps were taken to go from broad research to a final prototype. Part of the background research, especially chapters 2.2.2 and 2.3, can already be seen as part of the ideation, as hearing individual stories and extracting all different kinds of problem scenarios is in itself a form of establishing user needs. This formed the first part of divergence in the ideation phase that helped to obtain a broad perspective on the problems the target group experiences.

4.1 Finding commonalities

To go from the categorized problems from chapter 2.2.2 and 2.3 to the commonalities between categories, following the design plan, the problems explained in the individual stories needed to be taken out of their original context to see what underlying issues or feelings remained. As the product to be designed is a support tool, the problems occurring in context from the stories are not to be solved by the tool, but rather guide the search for what the individual will benefit from having support for.

All problems from the different categories were re-analysed and each underlying factor found was written out. This was done from the perspective of the individual with the eating disorder as the final prototype is designed for them and not the other people in their lives. In the situation that for example a family member makes a comment that causes an individual to feel anxious, the problem the prototype aims to tackle is not the family member's comment, but the anxiety the individual is now dealing with. After each category was re-analysed for this purpose, all factors were added to a list where they were merged if they were identical or nearly identical. All that occurred in at least three out of nine categories were considered commonalities, forming the final list. To better illustrate how these commonalities were present throughout the different categories, figure 5 shows a stem-leaf diagram with the sorted data. It is important to note that what is shown in figure 5 does not mean that it is not possible to experience any of the commonalities in categories that are not marked with their occurrence. The results presented are merely based on the stories and problems analysed in this research.

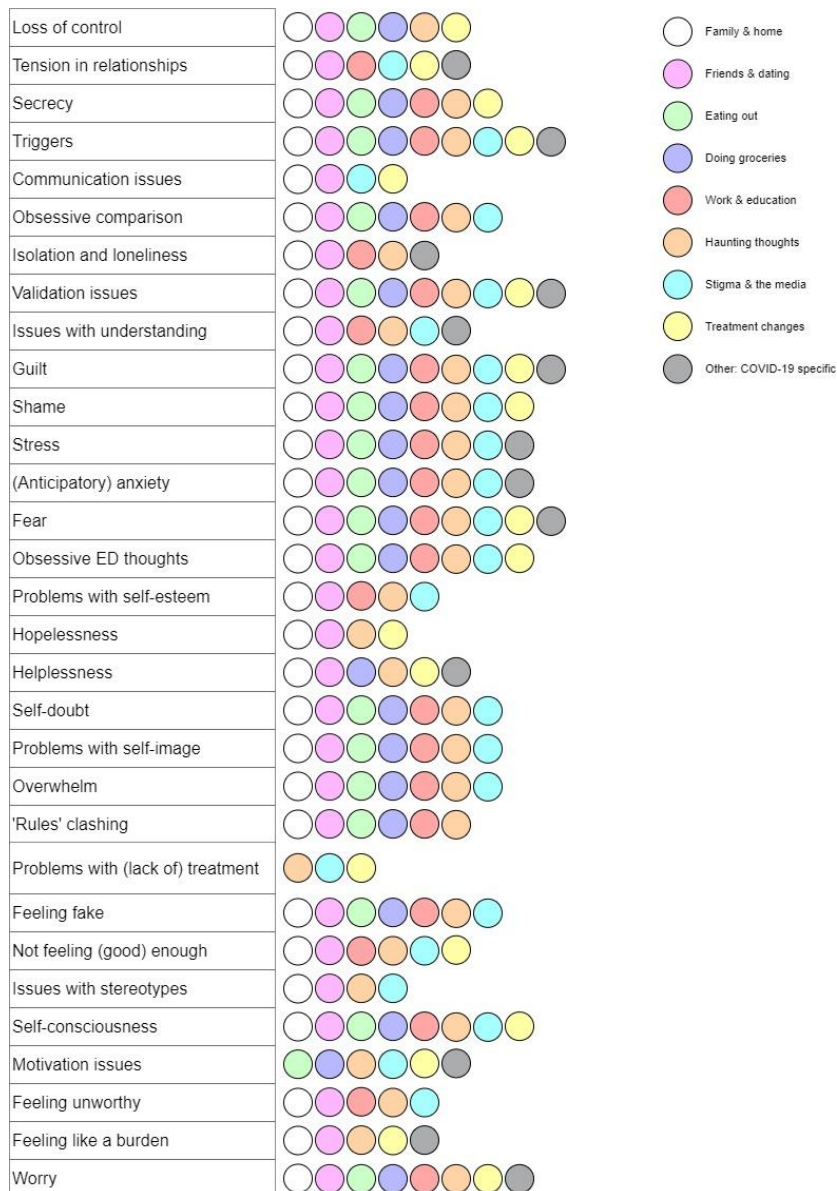


Figure 5: Stem-leaf diagram with the sorted data of finding commonalities

4.2 Converging the commonalities

The list of commonalities formed a more solid foundation than the individual experiences and categorized problems, but still left too broad of a design space for designing the final prototype. Therefore, instead of getting straight into the design requirements, first, some main points that the final prototype should focus on were concluded from the list of commonalities. The following five points are believed to encapsulate the found commonalities:

1. Anxiety and panic
2. Negative feelings towards oneself or one's life
3. Issues with understanding and validation
4. Communication issues (towards others or oneself)
5. The eating disorder voice

All found commonalities belong to at least one of these points, the vast majority to multiple. As many of them are closer to feelings and thoughts, and common throughout many different issues, formulating the points was not meant to separate or dissect the commonalities. Their presence is subjective and fluid, and so, overlap between the different points with regard to the commonalities was expected (figure 6).

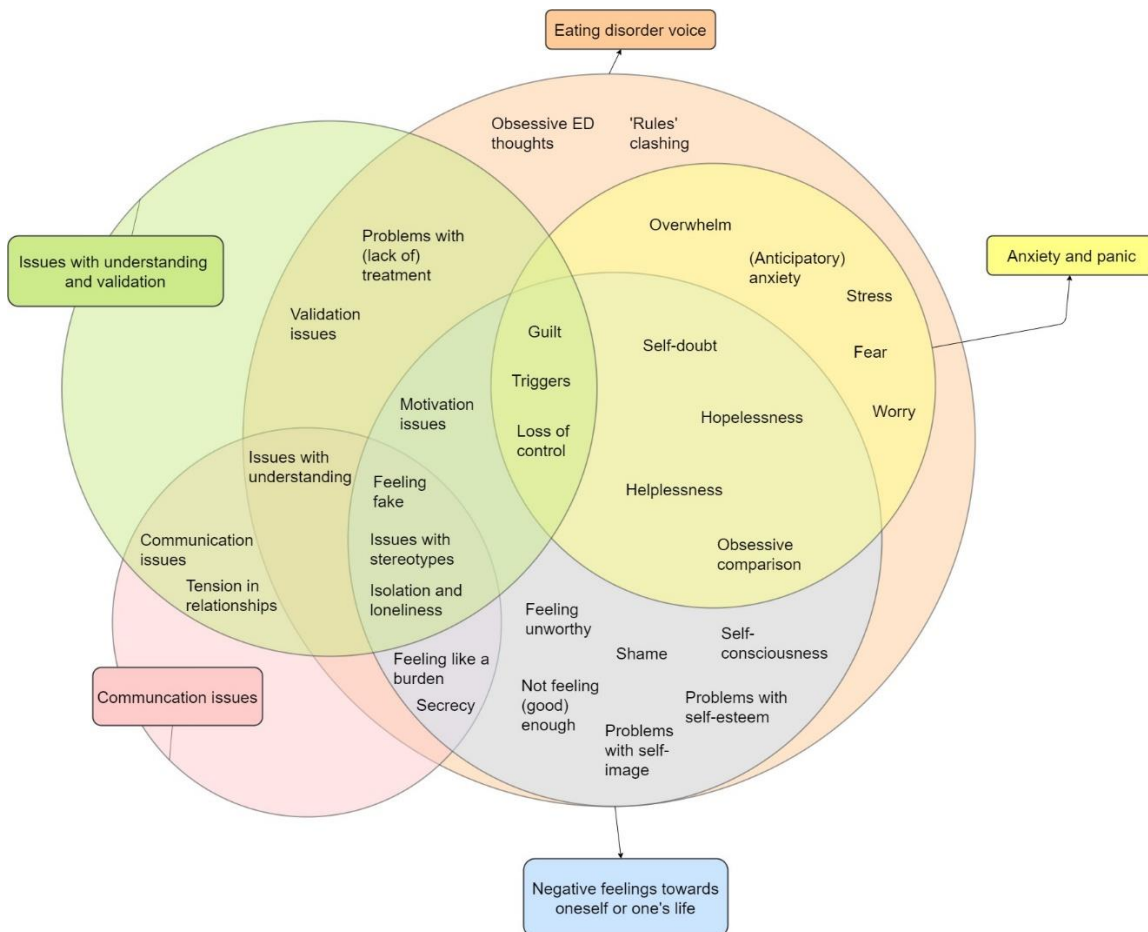


Figure 6: Venn diagram on the found commonalities

4.3 Design requirements

The five points were one-on-one translated to the following five design requirements for the content of the final prototype.

The smartphone application aims to help to:

1. Calm down

The counter state of anxiety and panic is one of calm and relaxation, hence the aim here is to help calm down.

2. Uplift and motivate

To counterbalance negative feelings and make space for more positive ones, the aim here is to help uplift, and motivate the user to get better.

3. Inform

As knowing more about a struggle and that one is not alone in it can help with understanding oneself and feeling more valid in one's position, the aim here is to help inform¹³.

4. Communicate and reach out

To diminish barriers experienced in and problems with interpersonal and intrapersonal communication, the aim here is to help to communicate and reach out.

5. Separate the individual from their eating disorder voice

As the eating disorder voice can overwhelm the individual, making it hard to distance themselves from it and not give in to it, the aim here is to help separate the individual from their eating disorder voice.

These requirements served as clearer design goals to work towards for the final prototype. The creation of these goals was nearly equally important as design heuristics in the form of avoiding doing any of the opposites of these points. For the next, more targeted design steps, the approach taken was to first come up with scenarios for each content requirement, of when this part of the product would be used (mind mapping #1). The results of these mind maps of scenarios then served as the starting point for a constrained but not yet filtered mind mapping session on possible app features (mind mapping #2).

4.4 Mind mapping #1: User scenarios

A session was held to come up with several user scenarios that could lead to using the final prototype, based on each of the content design requirements. The scenarios did not include the user actually using the product, but instead ended with the target user reaching for their smartphone. The mind mapping was based on the background research, and excluded scenarios where the target user would be in a directly life-threatening situation.

The full result of the mind mapping can be seen in figure 7.

¹³ Self-Validation, Psychology Today: <https://www.psychologytoday.com/us/blog/pieces-mind/201407/self-validation>

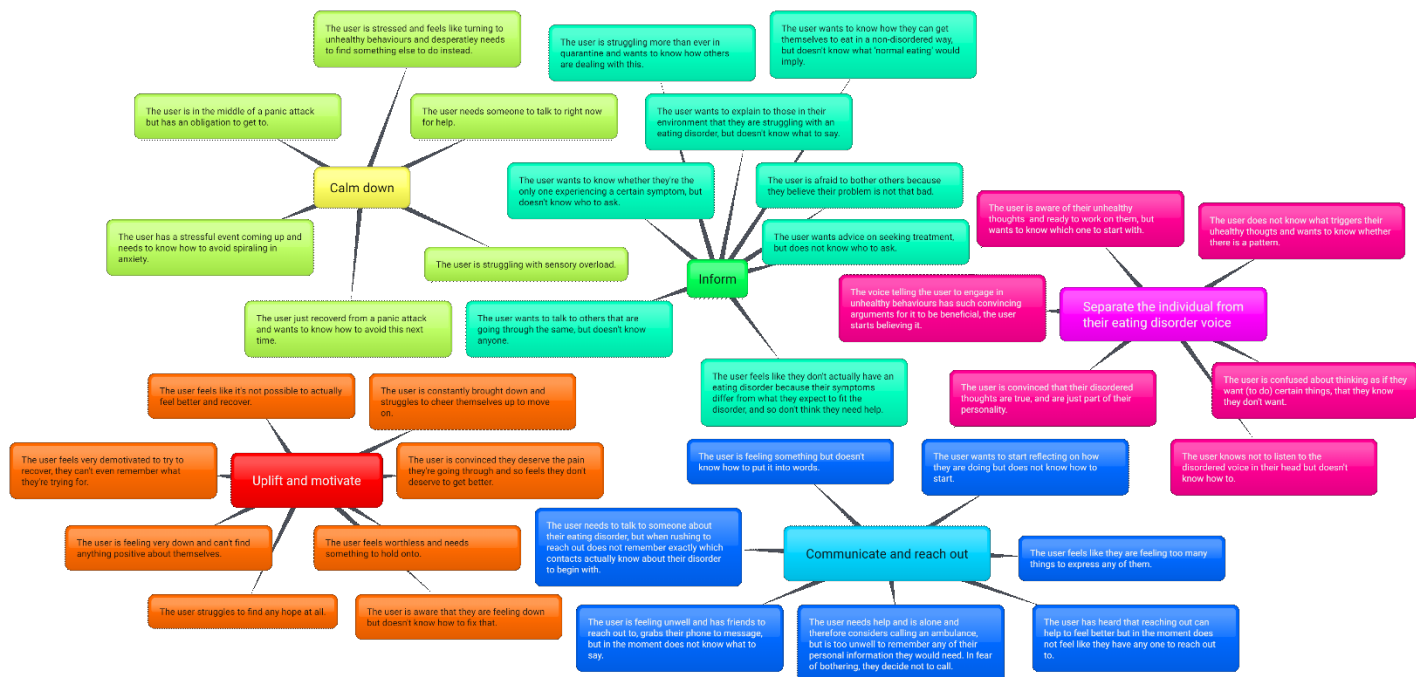


Figure 7: Mind mapping #1 results, user scenarios

4.5 Mind mapping #2: App features

The result of mind mapping #1 formed the base for the session on possible features of the final prototype. There were a few constraints put in place for this session:

1. Given that the aim is to create a smartphone application, no other technologies should be considered during the session.
2. Each feature idea must relate to at least one of the content design requirements that were formulated.
3. Each feature idea must be for target user use only, and should not be aimed to influence the behaviours of others involved or other external factors.

The full result can be seen in figure 8.

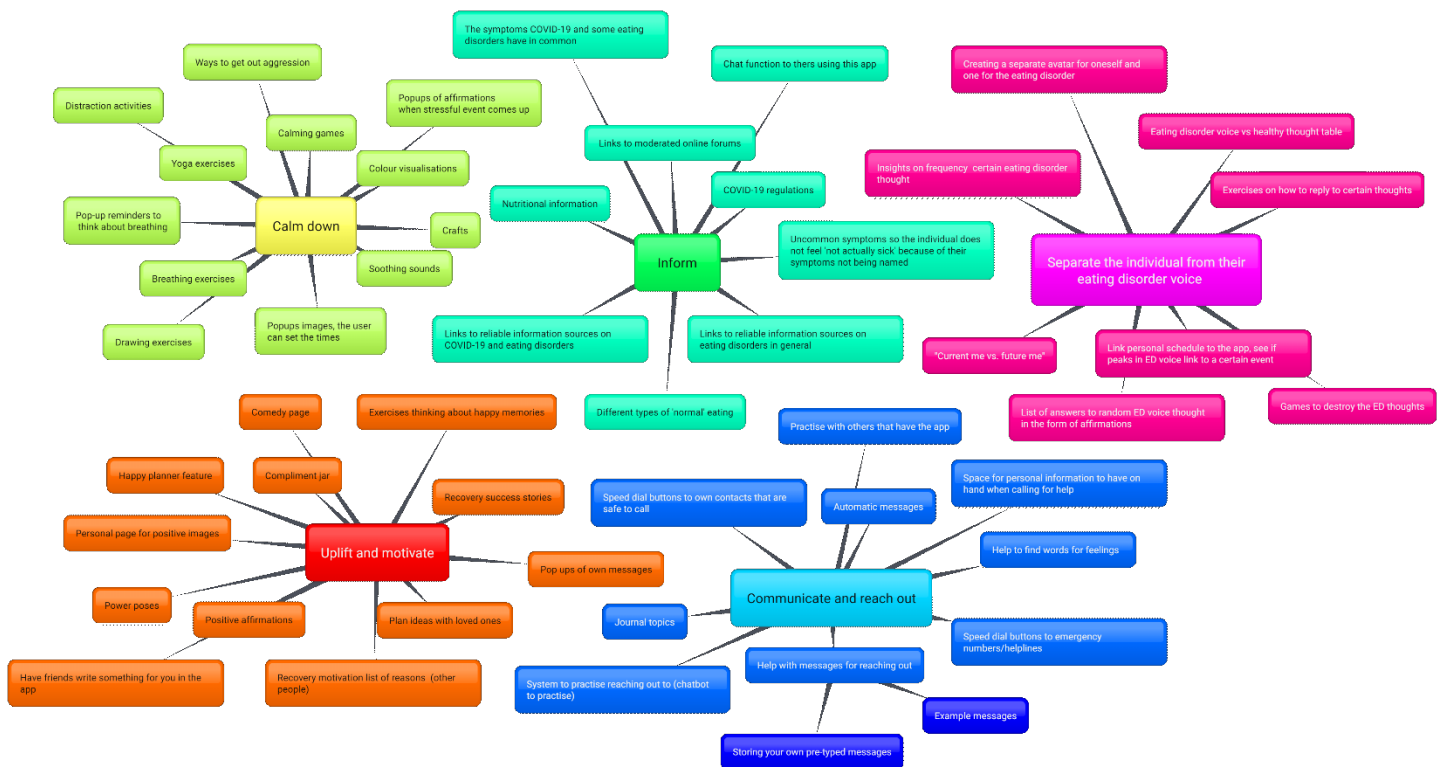


Figure 8: Mind mapping #2 results, app feature ideas

Chapter 5: Specification

The result of the ideation phase consisted of a variety of ideas that were yet to be converged. While the ideas for features were based on the background research, the same research had shown how individual and sensitive tackling problems within this target group can be. The main goal for the features to include is to be helpful to individuals, but this should not come at the cost of being potentially harmful or triggering to other target users. Therefore the potential app features were to be filtered by the following question: Is this feature valuable without causing any harm?

To be able to come up with an as accurate as possible answer to this question for each feature idea, the ethical toolkit, discussed in chapter 3, was consulted. The first two tools of this toolkit focus on ethical risk sweeping and exploring ethical pre-mortems, and seemed most fitting for this part of the design process. 5.1 and 5.2 are both adapted versions of parts of the final report submitted for the course Reflection from Module 12 of Creative Technology.

5.1 Ethical risk sweeping

The first tool of the ethical toolkit is *Ethical risk sweeping*. The term *ethical negligence* is used to describe not having taken enough action to make sure avoidable harms are indeed avoided [48]. To make sure ethical negligence is not an issue, first the potential ethical risks identified were laid out and put into different categories of failed accurate assessment due to not understanding well enough.

These were the following:

1. Not accurately assessing who belongs to the target group
 - a. Falling for stereotypes
 - b. Not understanding what eating disorders are thorough enough
2. Not accurately assessing the target user as an individual, complete person
 - a. Only thinking of the target user in the context of using the product
 - b. Not taking into consideration possible co-occurring disorders
3. Not accurately assessing the problems the target group experiences
 - a. Failing to see the seriousness of the health consequences of eating disorders.
 - b. Only focusing on the physical problems and neglecting the mental pains.
 - c. Only focusing on the pain of the sufferer, and not looking deeper into how being in pain makes the sufferer feel.
 - d. Missing out on too many problems due to incomplete or low effort research.
4. Not accurately assessing for what problems to design
 - a. Assuming which problem would be 'more severe' than the other.

- b. Neglecting the importance of discomforts that come with larger problems.
- 5. Not accurately assessing for what problems not to design
 - a. Failing to understand the sensitivity of the target group with regards to triggers.
 - b. Failing to identify and stay away from providing any service through the product that should require the designer to have a certain qualification that they do not have.
- 6. Not accurately assessing how to approach a target user
 - a. Failing to identify and assess potential discomforts when approaching disorder sufferers in certain ways.
- 7. Not accurately assessing who, apart from the target user, will be affected by the product
- 8. Not accurately assessing how to put the product out in the world.
 - a. Advertising the product in a way that does not reflect the product accurately
 - b. Not thinking through how the way the product is presented in, for example, the app store, can affect a potential user.

Revisiting the list in this phase in particular was important as the main decisions of what to include and exclude in the final prototype happened here. The same is the case for revisiting the pre-mortems explored.

5.2 Pre-mortems

Ethical pre-mortems and post-mortems is the second tool of the ethical toolkit, but for this project only pre-mortems are applicable. Going through the categories of ethical risks, examples of scenarios applying the pre-mortems protocol from the ethical toolkit are given below.

1. Not accurately assessing who belongs to the target group:

By, for example, falling for the stereotype, the app might become targeted towards individuals who are severely underweight. By trying to include a positive affirmation, the app might say that putting on weight by eating more will only make them stronger. For someone with an eating disorder where their unhealthy habits are aimed towards gaining weight in order to become more and more heavy, this affirmation becomes a justification for the unhealthy obsession. The app will then not help those with eating disorders, but encourage some eating disorders.
2. Not accurately assessing the target user as an individual, complete person:

If in the design process the user is always imagined in only the context of using the app, a well-intentioned idea could be to include anxiety-reducing exercises sporadically throughout the day to help the user feel calmer. While participating in exercises meant to calm down, it could be nice if the app temporarily blocks all other activities on the

phone to help focus. While this could be relaxing and helpful when these pop up during at home time, failing to understand the user could have a job or other responsibilities, could result in them, for example, missing an important meeting as their phone is blocked and telling them to do calming exercises - costing them their job.

3. Not accurately assessing the problems the target group experiences:

If it is discovered that some eating disorder sufferers struggle with feeling very cold from for example not eating enough, in an attempt to help with this a decision might be contemplated to dedicate a part of the app to provide information on different (creative) ways that warm up the body (fast). By not looking for further problems from these same individuals, it might get overlooked that many sufferers struggle with urges to want to feel cold, to burn more calories. These users might then never use these tips, or worse, look at this information to make sure what to avoid and make their bodies colder.

4. Not accurately assessing for what problems to design:

By not conducting complete research, someone might pick up that mealtimes are difficult for sufferers, and decide this is the main problem. The app, designed to help support with eating disorders, could then solely consist of support for getting through meals and being around food. In this case, it was failed to see the problems in all other aspects of life, apart from the obsession with food and eating when it is time for food and eating. This design could then for many only amplify the unhealthy obsession with food that can perpetuate the disorder.

5. Not accurately assessing for what problems not to design:

In an attempt to provide support for the problem that some malnourished eating disorder sufferers find it difficult to nourish themselves due to not knowing what to eat to be healthy or eat 'normal', a feature could be included that provides help with nutrition. Based on what is commonly considered healthy, this feature is filled with tips, but without consulting a nutritionist and going straight into designing for this problem, it could be failed to realise how personal proper nutrition can be. Considering the target group, the feature could turn out life-threatening.

6. Not accurately assessing how to approach a target user:

To broaden understanding of the potential user, contacting eating disorder patients that then allow an interview could be done. In an attempt to find out more about possible causes of eating disorders, in this scenario, it is asked directly to the interviewees to explain the first time they remember engaging in an unhealthy eating habit. Even while

being aware of direct questions being asked about experience, asking this in an uncaring manner could throw the patient straight into a traumatic memory and cause a hurtful situation or panic attack.

7. Not accurately assessing who, apart from the target user, will be affected by the product:

If the product will, for example, include a quick way to access the suicide hotline to provide the user with proper resources, the user might be the only one thought of. If the hotline workers and other users of the hotline are not considered, in a user test someone might call the hotline just to test the feature. This could contribute to causing a hotline to get oversaturated or make someone in need be put on hold whereas they could have gotten direct access to the hotline as a direct consequence.

8. Not accurately assessing how to put the product out in the world:

When the app is ready to be put in the app store, by incorrectly assessing the app might be named something along the lines of 'eating disorder help'. If this name also appears under the icon when a user has it on their phone, it could cause problems to those who would want to download the app but are not (yet) open about suffering from an eating disorder and do not want a name of an app on their screen to give this away.

These pre-mortems are examples to help smoothen the process of assessing each decision keeping in mind the worst possible consequence.

5.3 COVID-19 considerations

Apart from what had to be avoided based on the different triggers and sensitivity of this target group, such as naming calories, weight, movement, etc., in a regular world state, the effect of the current pandemic as explored in chapter 2.3 had to be considered.

This concerned extra considerations such as:

- Being careful with suggesting to contact others. While reaching out is definitely of importance, the problem of feeling like a burden when contacting others has increased during the pandemic, as individuals indicated how those around them were dealing with more struggles than usual too. While it should not be avoided, it should not be encouraged as the very first option when not feeling well, but not in a dire emergency state either.
- Not suggesting activities that would be conspicuously loud or obvious, as many have less access to privacy now than in the pre-pandemic state, causing more issues.

- Not pushing too hard towards recovery or getting further in recovery. While encouragement is good to some extent, many reasons were found for how this pandemic has negatively affected the recovery process of some, and the product should not add to the shame or guilt of not moving forward.
- Avoiding referring to and encouraging to do what someone ‘normally does when they feel like this’, as it is quite probable that this is not possible due to current measures.
- Not suggesting going outside or visiting friends or family in a feature. While activities like these can be very beneficial, it can be irresponsible or even not allowed at all during the pandemic depending on where the individual is, and being reminded of how this is not possible anymore can be harmful.
- Not including links within the product that direct to social media platforms, even when it is to accounts focusing on general encouragement and motivation, as it was found that, even when well-intentioned, these posts could make individuals feel worse.
- Not pushing towards seeking treatment, as many had issues with treatment being even less accessible than before due to consequences of the pandemic.
- Avoiding including tips or activities of which the execution depends on spaces other than an individual’s home. As measures can change constantly and are highly dependent on location, anything concerning, for example, sports clubs, stores, even parks, is a risk to include with regards to potentially detrimental advice.
- Being more careful to not add any extra pressure to the individual who uses the product, as their state can be more vulnerable than normal. As the product is not an active intervention but is meant for support, it already has a nature of suggesting and not pushing or making someone use the features. Still, it is good to keep in mind that given the situation it can be extra hard for individuals to make changes and they should not feel guilty for not doing enough.

5.4 Converging feature ideas

After revisiting these tools and considering the current pandemic, the filtering question (Is this feature valuable without causing any harm?) could be answered more accurately for each potential feature.

The filtered list of app features is the following:

1. Breathing exercises
2. Examples of distraction activities
3. Soothing sounds
4. Journal topics
5. Recovery motivation list of reasons

6. Recovery success stories
7. Positive affirmations
8. Personal page for positive images
9. Links to reliable information sources on COVID-19 and eating disorders
10. Links to reliable information sources on eating disorders in general
11. Links to moderated online forums
12. Speed dial buttons to emergency numbers/helplines
13. Speed dial buttons to own contacts that are safe to call
14. Help to find words for feelings
15. Help with messages for reaching out
16. Space for personal information to have on hand when calling for help
17. Eating disorder voice vs healthy thought table
18. Insights on frequency certain eating disorder thought

5.5 Organising the mock-up

Once the list of features for the prototype was established, card sorting was used for their initial organisation. In card sorting, The testing participants organise ideas, features, or objects into whatever categories they prefer and think make the most sense. The participants may also choose to label the groupings¹⁴. In this design process, the inclusion of participants for organising did not happen until later, as testing the organisation would be part of the same procedure as testing the visual design to fit the time window available to this research better. By the time card sorting happened with participants, a mock-up version of the smartphone application should therefore already have been created. Therefore for the organisation of the features for this mock-up, an open card sorting session as a designer took place. An open card sorting session means that there are no pre-defined labels for the categories, but that the cards with features will first be grouped together and later labelled accordingly. The result of this session can be found in figure 9. The different groupings represent the content of the different screens in which the smartphone application would be divided and their labels the screen titles to be used for navigating.

¹⁴ Card Sorting: <https://www.usability.gov/how-to-and-tools/methods/card-sorting.html>

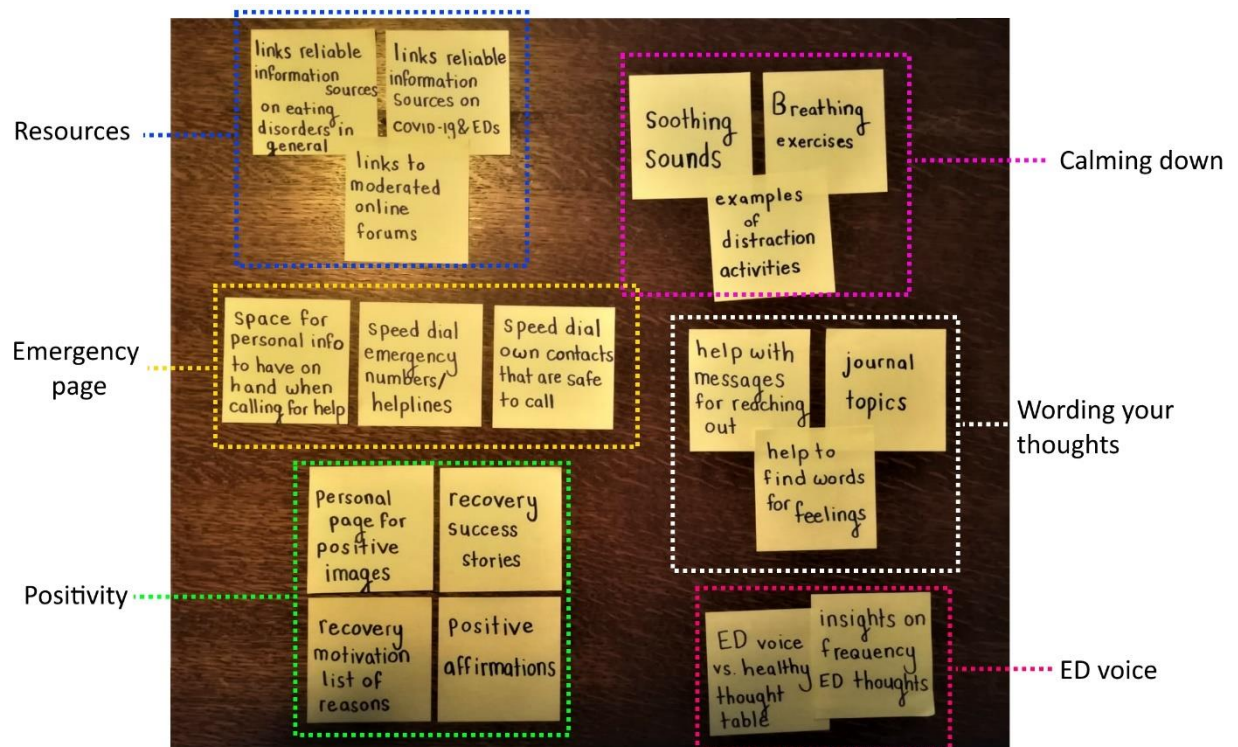


Figure 9: Open card sorting results

Most of the grouping can be mapped back directly to the different design requirements: the cards of *Calming down* to Calm down, of *Positivity* to Uplift and motivate, of *Resources* to Inform, of *Wording your thoughts* to Communicate and reach out, and of *ED voice* (*eating disorder voice*) to Separate the individual from their eating disorder voice. During the card sorting, three cards seemed to have more to do with immediate necessity rather than any of the specific design requirements. They came close to the design requirement of Help to communicate and reach out, but their sense of urgency led to the creation of a separate category, *Emergency page*.

The labels that were given to the categories now would be serving as titles for the application screens. While based on the content and design requirements of the cards, the titles were formulated to be read from a user instead of a designer standpoint and to indicate what could be found in the screen.

5.6 Visual layout

The visual layout of the user interface was designed with an atmosphere in mind based on the content design requirements. Feelings of calm and tranquillity were to be evoked, while at the same time the design should reflect feelings of empowerment and hope. The design should not overwhelm the user, and so no screaming colours should be used. Lastly, while some variation should take place between different screen designs, the design should be coherent and flow

nicely together using just one colour scheme. Based on this, a colour swatch, see figure 10, was created to be used for the mock-up and to be evaluated later.



Figure 10: Colour swatch for mock-up prototype

Chapter 6: Realisation mock-up

After sketching some primitive versions of user interfaces, the mock-up was created using Figma. Figma is a browser-based free interface design tool that among other things lets users create prototypes for (web) applications ¹⁵. The mock-up created in this phase did not include individual features and was, besides navigation and button clicking, not functional, but contained a home screen and a screen for each category of grouped app features to show what the final prototype was meant to look like (see figure 11). Figma's presentation view feature allows for navigation as if it was happening on a smartphone, and was used to create a screen recording of the complete mock-up.



Figure 11: Mock-up prototype overview created with Figma

¹⁵ Figma official website: <https://help.figma.com/hc/en-us>

A user test was set up to evaluate the taxonomy and desirability of the mock-up. For this test, it was expected that the participants did not need to be target users, because it aimed to find out whether the organisation and visual layout of the application features followed a logical structure and were desirable, disregarding whether these or the prototype as a whole fulfilled its purpose. With the exception of possibly the *Eating disorder voice*, the terms used should be familiar. As the content of this mock-up was unreviewed, it was decided to actively only recruit participants without eating disorders or disordered eating problems, to avoid any harm by unintentional exposure to potentially triggering content. This test, further elaborated in the method, was approved by the ethical committee with RP 2020-93.

6.1 Method

The test was an unmoderated, remote test conducted with 10 participants. These participants were all adults (above 18 years old) with a healthy relationship with food, and were located in Brazil, Germany, Norway, The Netherlands, and the United States of America. Each participant received an information brochure on the research beforehand (see Appendix B) and signed a corresponding consent form (see Appendix C).

The user test consisted of three different parts, each made up of a different type of test that took place on a different website. Google Forms was used for the setup of the user test. The Google Form did not contain any questions, but was used to provide an introduction to the user test and give an overview of its three parts. It introduced each part and provided its corresponding link. There was no time limit assigned to any of the parts, but the time a participant took to complete each part was automatically measured by the different tools used.

These three parts were Hybrid card sorting, Tree testing, and the AttrakDiff questionnaire, in said order. Tree testing can only be done with a pre-determined organisation of what is being tested in place, in this case the organisation was the result of chapter 5.5 (Organising the mock-up). The Hybrid card sorting took place before the Tree testing, to avoid having said organisation influence the participants' choices there. The screen recording video of the mock-up was not shown until the AttrakDiff questionnaire part, as again the participants should not be influenced by the existing organisation in the mock-up, and to appropriately separate visual design from taxonomy testing [49]. Each test part is individually discussed below.

6.1.1: Hybrid card sorting

While the card sorting done for organising the mock-up was open card sorting, the participants were given a hybrid card sorting test. In hybrid card sorting the participant is given existing categories, but (as opposed to closed card sorting) is also able to create their own. OptimalSort (from Optimal Workshop) was used for this ¹⁶, an online tool designed specifically for card sorting. A total of 20 cards was used, the 18 from chapter 5.4 (Converging feature ideas) of which two were split into two cards as a result of reflection on the open card sorting done. ‘Breathing exercises’ was split into ‘Different breathing exercises’ and ‘Breathing exercise for when in panic’ and ‘Speed dial buttons to emergency numbers/helplines’ was split into ‘Helplines’ and ‘Speed dial of emergency numbers’. Some names of the cards, where possible, were slightly changed to avoid keyword matching ¹⁷, the practice of sorting cards based on similar keywords on them rather than the meaning of those words. The categories used were the ones that came out of the open card sorting for the organisation.

6.1.2: Tree testing

Tree testing is often used in combination with card sorting and sometimes referred to as reverse card sorting ¹⁸. A small version of tree testing was done, consisting of only three tasks. These tasks asked were:

1. You have been logging your unhealthy thoughts with regard to your eating disorder. You are curious as to what thoughts have been most common lately. Where in the app would you find this information?
2. You want to find ways to connect with others who have similar struggles. Where on this app would you go to find more on this matter?
3. You are not in a crisis, but are also not feel particularly well. You think it would help to chat about it with a friend, but you're not sure how to bring it up or how to describe it in a message. Where on the app would you go for help?

For this, also from Optimal Workshop, the tool Treejack was used ¹⁹. The navigation was to be tested more thoroughly in the Evaluation phase (in the form of usability) when the final prototype has been created and participants can physically navigate through the application on their own device.

¹⁶ Optimal Workshop’s OptimalSort: <https://www.optimalworkshop.com/optimalsort/>

¹⁷ Card Sorting: Pushing Users Beyond Terminology Matches: <https://www.nngroup.com/articles/card-sorting-terminology-matches/>

¹⁸ Tree testing: <https://www.userfountain.com/tree-testing>

¹⁹ Optimal Workshop’s Treejack: <https://www.optimalworkshop.com/treejack/>

6.1.3: AttrakDiff questionnaire

The last part of the user test was an AttrakDiff questionnaire ²⁰. The AttrakDiff questionnaire was used for testing the desirability of the visual design of the mock-up through the means of contrasting the perceived pragmatic quality and the perceived hedonic quality. Before sending out the user test to the participants, the same questionnaire was filled out based on the ideal level of pragmatic usability and hedonic usability from a designer's perspective. This was done for comparison, to be able to better assess the results after the user test was done.

After user testing, the participants' results were used to calculate four distinct constructs: Pragmatic usability; Hedonic identification; Hedonic stimulation; Attractiveness. Additionally, the two hedonic qualities were merged and contrasted to the pragmatic quality providing the desirability graph. Desirability is lastly compared to the attractiveness [50].

6.2 Results

6.2.1 Hybrid card sorting analysis

While participants were able to create their own categories, or rename existing ones, only 1 out of the 10 made use of this possibility. This person created a "Help!" category, in which three cards were sorted: (1) *Personal information to have on hand when calling for help*, (2) *Speed dial of emergency numbers*, (3) *Help with messages that can be used for reaching out to personal contacts*. This created category seemed almost like a subsection of the *Emergency page*. Of the three cards, two were sorted the most into the category *Emergency page* by the other participants, and the third was a card that was commonly classified as an *Emergency page* card as well (discussed more later on). The nature of the category name, "Help!", is also very similar to that of *Emergency page*. For these reasons, the "Help!" category was merged into the *Emergency page* category, leaving just the name *Emergency page*. After this, as the rest of the participants only used predefined categories, the results more so resembled that of closed card sorting than that of hybrid card sorting. After the standardisation was done within OptimalSort itself, the standardisation grid was updated for the analysis. In figure 12 an 'expected' column is added to the standardisation grid containing the category names from the open card sorting. The card names are grouped and ordered based on these open card sorting results. The findings will be discussed per category.

²⁰ AttrakDiff: <http://www.attrakdiff.de/index-en.html>

Expected	Name	Calming down	ED voice	Emergency Page	Positivity	Resources	Wording your thoughts
Calming down	Different breathing exercises	9				1	
Calming down	Distraction activities	7	1		2		
Calming down	Soothing sounds	7	2				1
ED voice	A two-column table, to separate eating disorder thoughts and what your rational/healthy mind is thinking	1	2			1	6
ED voice	Insights on how often you have a certain eating disorder thought		3	1		1	5
Emergency Page	Breathing exercise for when in panic	8		2			
Emergency Page	Personal information to have on hand when calling for help			8		2	
Emergency Page	Personal page to fill with own uplifting pictures/quotes	1			9		
Emergency Page	Speed dial of 3 personal contacts			9		1	
Emergency Page	Speed dial of emergency numbers			9		1	
Positivity	Affirmations	1	2		4		3
Positivity	Recovery motivation				9	1	
Positivity	Recovery stories	2			6	2	
Resources	Covid-19 and eating disorders information		1	1		8	
Resources	Helplines			6		4	
Resources	Online support resources			2		8	
Resources	Resources for information on eating disorders					10	
Wording your thoughts	Help putting feelings into words	1	1				8
Wording your thoughts	Help with messages that can be used for reaching out to personal contacts	2		6	1		1
Wording your thoughts	Journal topics	1				6	3

Figure 12: Standardisation grid after merging “Help!” into “Emergency page”

Calming down

All cards that were placed in this category in the open card sorting were also sorted mostly in this category by the participants: *Different breathing exercises* by 9 out of 10 participants, *Soothing sounds* by 7 out of 10, and *Distraction activities* by 7 out of 10.

The card *Breathing exercise for when in panic* was surprisingly placed in this category by 8 out of 10. This card was intended to be part of the *Emergency page* as a single exercise, however, only two participants placed it there. Given these numbers, it seems that those in a state of panic might be more likely to find help for their breathing in *Calming down* than to consider this part of the concept of emergency. It would be considered the responsible choice to add the guiding animation for this simple breathing exercise (in a slightly smaller format) to the main *Calming down* screen as well. The same exercise will nevertheless still also be part of the *Emergency page*.

Positivity

The cards that were placed in this category in the open card sorting, all had *Positivity* as the most chosen category in this test. *Recovery motivation* (9 out of 10) and *Personal page to fill*

with own uplifting pictures/quotes (9 out of 10) more convincingly than *Recovery stories* (6 out of 10) and *Affirmations* (4 out of 10).

The *Affirmations* card was quite spread out over categories. This could be because of the subjectivity on to what extent and in what way affirmations could be useful to someone, but it also sparked doubt about the name chosen for this feature. While not exclusively practised by believers, the word has religious and spiritual weight to it. For the next phase of the project, *Affirmations* will remain categorized under *Positivity*, the name could be changed to something more descriptive and clear, such as '*Empowering statements*', or '*Positive thinking*'.

Emergency page

With the two cards regarding *Speed dial* and the card *Personal information to have on hand when calling for help* put in this category by 9 out of 10, 9 out of 10, and 8 out of 10 respectively, the core of the *Emergency page* made for the mockup can remain the same. Both *Help with messages that can be used for reaching out to personal contacts* (in the mockup categorized in *Wording your thoughts*) and *Helplines* (in the mockup categorised in *Resources*) were sorted into the *Emergency page* by a majority of participants (both 6 out of 10).

Incorporating (direct access to) these two features into the *Emergency page* seemed beneficial, without being harmful. Once users enter the *Emergency page*, it could happen that they come to realise that they are not in a state of emergency as to call a suicide hotline or national emergency number, but do feel the need to reach out to a non-emergency helpline as fast as possible. Similarly, once they enter the *Speed dial of personal contacts* screen they might feel the need to reach out to a loved one but not necessarily to call (perhaps they even prefer not to call). Having the pre-written messages as part of that same feature in the *Emergency page* could be useful in those situations.

Resources

That it is useful to avoid using the same terms for both a card and category, and rather aim for synonyms, showed its relevance as the slip up in card *Resources for information on eating disorders* was the only one that was assigned to the same category by all the 10 participants (the category being *Resources*). It is surprising in this category that 6 out of 10 participants put the card *Journal topics* in it. A possible theory on why this could be is the ambiguity of the term 'journal'. The naming could indicate it being about eating disorder related topics addressed in academic journals for example, which would fit well in this category. In order to avoid confusion, *Journal topics* shall be renamed as *Journaling prompts* in the next prototype.

Despite the previously mentioned card *Helplines* being more commonly categorized under *Emergency page* (6 out of 10) than *Resources* (4 out of 10), there did not seem to be a

reason to remove the feature from where it was initially intended to be. It will not harm the application or user by having this particular feature in both categories it was sorted into, given that there is physical space for this without requiring the elimination of any other feature. The similarity matrix obtained, see figure 13, shows how, for example, *Resources for information on eating disorders*, a key feature of this category, and *Helplines* were grouped together 60% of the time.

Similarity matrix

Resources for information on eating disorders																		
80	Online support resources																	
80	60	Covid-19 and eating disorders information																
60	50	40	Journal topics															
10	10	20	40	A two-column table, to separate eating disorder thoughts and what your rational/healthy mind is thinking														
10	10	30	40	70	Insights on how often you have a certain eating disorder thought													
0	0	0	0	10	30	Affirmations												
0	0	0	0	10	0	40	Personal page to fill with own uplifting pictures/quotes											
10	10	10	0	0	0	30	80	Recovery motivation										
20	10	20	0	0	0	30	50	70	Recovery stories									
10	0	10	20	0	0	10	0	0	20	Different breathing exercises								
0	10	0	0	10	0	10	10	0	20	70	Breathing exercise for when in panic							
0	0	0	10	10	0	10	30	20	20	60	50	Distraction activities						
0	0	0	10	20	0	0	10	0	10	60	50	70	Soothing sounds					
0	0	0	0	10	0	10	20	10	20	10	20	30	10	Help with messages that can be used for reaching out to personal contacts				
10	20	20	0	0	10	0	0	10	10	0	10	0	0	50	Speed dial of emergency numbers			
20	30	10	20	0	0	0	0	0	0	0	10	0	0	50	70	Personal information to have on hand when calling for help		
10	30	20	10	0	10	0	0	0	0	0	20	0	0	40	70	60	Speed dial of 3 personal contacts	
40	60	20	30	10	10	0	0	10	10	0	20	0	0	30	60	50	50	Helplines
0	0	0	10	40	30	30	0	0	0	10	10	0	10	10	0	0	0	Help putting feelings into words

Figure 13: Similarity matrix, obtained through the use of result analysis on ‘OptimalSort’ from ‘OptimalWorkshop’, used for this test (<https://www.optimalworkshop.com/>)

ED voice

This category had the lowest agreement score, only 29%. Of the seven different cards placed within it, the most often the card was placed there was only three. This was, however, expected to be the least clear category to those without eating disorders, as the term ‘eating disorder voice’ could be unknown to them. As for ethical reasons the participants in this stage of testing were all healthy adults without eating disorders, a decision had to be made to either explain this category further with the risk of influencing the card sorting, or leave the name for what it was. It was decided not to add an explanation, as an explanation on one of the categories could also influence how participants would see the remaining categories or could stop them from making an own extra category they would have otherwise created.

While neither of the two cards making up this category in the open card sorting, was also placed in here by the majority of participants, the two were grouped together 70% of the time. Both cards were most prominent in the category *Wording your thoughts*. Considering that the eating disorder voice is a specific form of describing thoughts, this did make sense as a category. As the target group likely differentiates the *ED Voice* from *Wording your thoughts* and in the next phase adding an explanation to a page does not become obstructive, in combination with the fact that the features belonging to *ED Voice* were grouped together at such a high rate, for the next prototype there does not seem to be a major reason to change the organisation of the application for this category. This assumption should, however, be tested with the target group in a later stage.

Wording your thoughts

Help putting feelings into words was placed in this category by 8 out of 10 participants. The other two cards expected to be part of this category were *Journal topics* and *Help with messages that can be used for reaching out to personal contacts* - both of which were discussed earlier to be most popular in other categories. By renaming *Journal topics* to *Journaling prompts*, it can be imagined to be seen as more likely that this feature would belong to a screen such as *Wording your thoughts*, though this cannot be said to be true without testing. While content-wise *Help with messages that can be used for reaching out to personal contacts* seems to belong here, only one participant placed it in this category.

Subjectivity

While the sorted cards did tend to indicate what the most popular category for that card was, out of twenty every card but one was placed into multiple categories. When looking at each category separately and how the total number of cards was sorted, the lowest agreement score on a category was 29%, and the highest only 52%. This could be due to the subjectivity of the categories. The application aims to support individuals, but what one might consider supporting the other might find useless. It is different for everyone. *Calming down* is a good example of this, as what makes one calm is very personal. Apart from what was discussed previously on the category, there were still seven different cards remaining that were sorted into it, but only by 1 or 2 participants each. Some overlapped with *Positivity*, like *Recovery stories*. These stories are meant to help uplift and help keep sufferers optimistic and hopeful, but someone might find it useful to read through those as reassurance in order to calm down in a state of distress.

Concrete changes to make

1. Add *Breathing exercise when in panic* to *Calming down* as well [as discussed in **calming down**].
2. Change the name of *Affirmations* into something more descriptive and clear, such as '*Empowering statements*', or '*Positive thinking*' [as discussed in **positivity**].
3. Add *Help with messages that can be used for reaching out to personal contacts* to *Emergency page* as well [as discussed in **emergency page**].
4. Add *Helplines* to *Emergency page* as well [as discussed in **emergency page**].
5. Change the name of *Journal topics* into *Journaling prompts* [as discussed in **resources**].

6.2.2 Tree testing analysis

Task 1

It became clear that the task of the first scenario (see figure 14) had problems. The task describes a scenario that with the current navigation, if it is working as intended, should end up in *Insights of Eating disorder voice*. While in the card sorting it seemed like the right decision to not explain the eating disorder voice further, this same decision might have needed a different approach here. While the goal was to test tasks in which the navigation through the app could be considered more challenging, task 1 might have not been an accurate task to include when testing with participants not representative of the target group.

It was interesting to see that the success rate of 30% (see figure 14), was fully made up of direct success. These were likely the people who could imagine the meaning of the term or knew of it, as no other paths were explored. The majority of others ended up clicking *Wording your thoughts*, which as discussed similarly in the card sorting, makes sense as a response for scenarios related to the eating disorder voice if unfamiliar with the term. The reason the term was not used in the task description was to avoid telling the participants what to do in the task instead of presenting them with a scenario and letting them navigate naturally. This conflict resulting in deciding on not explaining the term, might have still given useful results for the type of testing of card sorting, but not for testing navigation paths in the application.

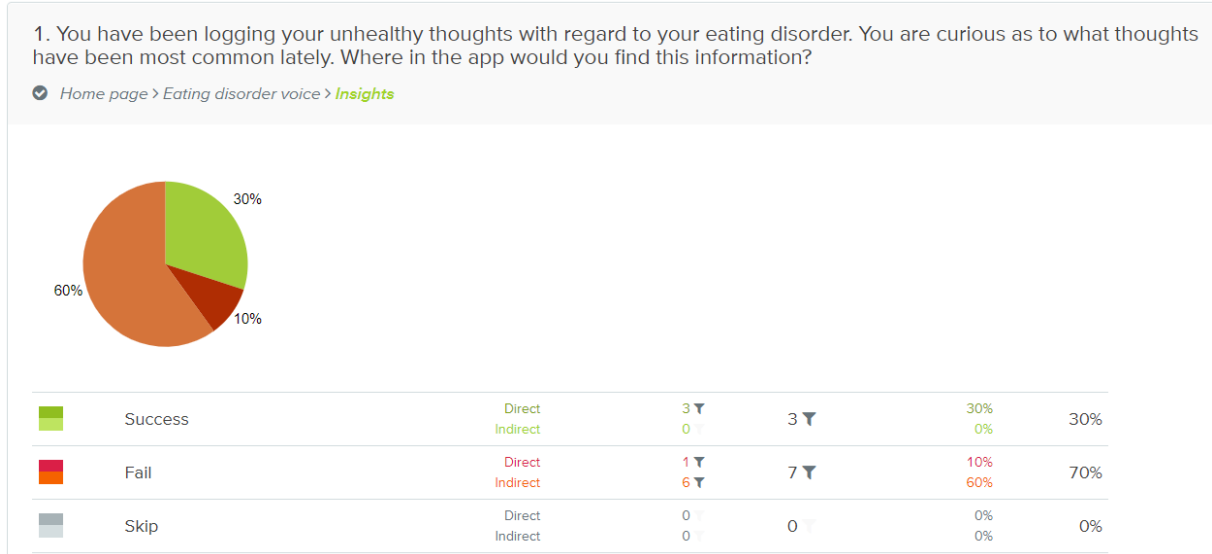


Figure 14: Task 1 results from Tree Testing, obtained through the use of result analysis on ‘Treejack’ from ‘OptimalWorkshop’, used for this test (<https://www.optimalworkshop.com/>)

Task 2

The second task (see figure 15) had a very low success rate, namely of 20% (10% direct and 10% indirect). This could, for example, mean that *Online support* does not properly describe in its name that the page will contain links to among other things forums to connect to others. This should be taken into consideration in the next phase of the design process.

Also interesting to note is that 20% ended up in *Helplines* (see figure 16). It would actually be a good idea to add links to connect to others, e.g. a link to a recovery forum, in *Helplines* as well - instead of only linking to professional help.

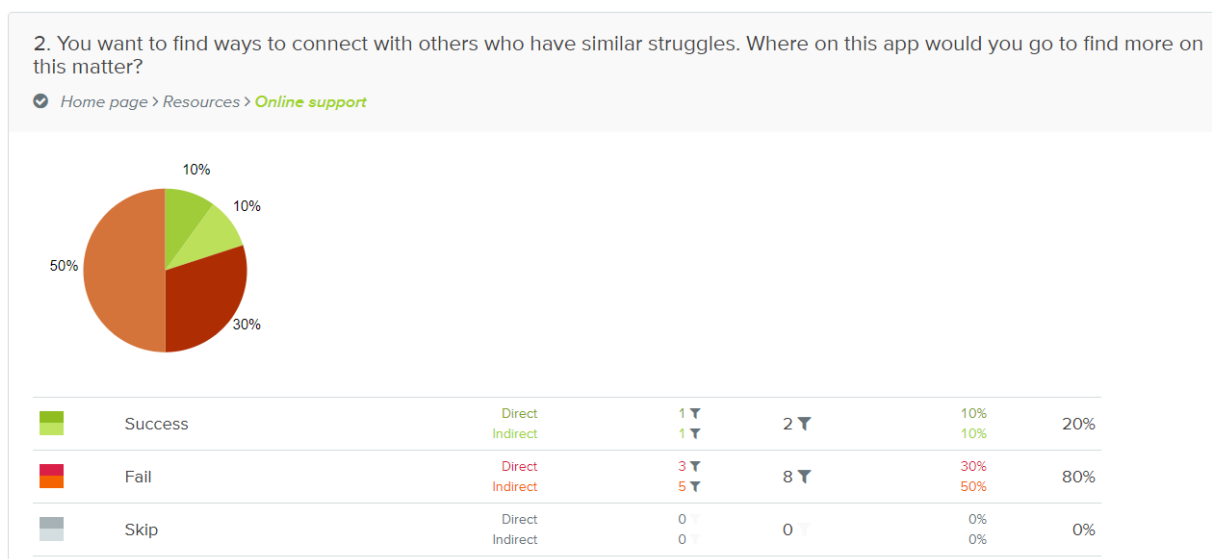


Figure 15: Task 2 results from Tree Testing, obtained through the use of result analysis on ‘Treejack’ from ‘OptimalWorkshop’, used for this test (<https://www.optimalworkshop.com/>)

Participant destinations

■ Correct
 ■ Incorrect (< 10% of responses)
 ■ Incorrect (10% - 20% of responses)
 ■ Incorrect (> 20% of responses)



Figure 16: Participant destinations from Tree Testing, obtained through the use of result analysis on ‘Treejack’ from ‘OptimalWorkshop’, used for this test (<https://www.optimalworkshop.com/>)

Task 3:

The results of this task (see figure 17) showed that interestingly 90% of the participants chose a destination within *Wording your thoughts*, which means nearly all were in the right direction (see figure 16). The success rate was 40% (see figure 17), but 50% chose for *Putting feelings in words*. This seems very reasonable, as not knowing how to describe something in a message is part of the task. While *Reaching out* belongs to *Wording your thoughts*, initially, this was meant to imply that *Reaching out* will contain help on wording thoughts specifically meant for reaching out. This will likely need a more explicit name for the next prototype, based on these results.

Based on the names of these features, it makes sense to feel like going to *Putting feelings in words* for help with wording first, like the 50% of participants did, and thinking that afterwards one should go to reaching out.

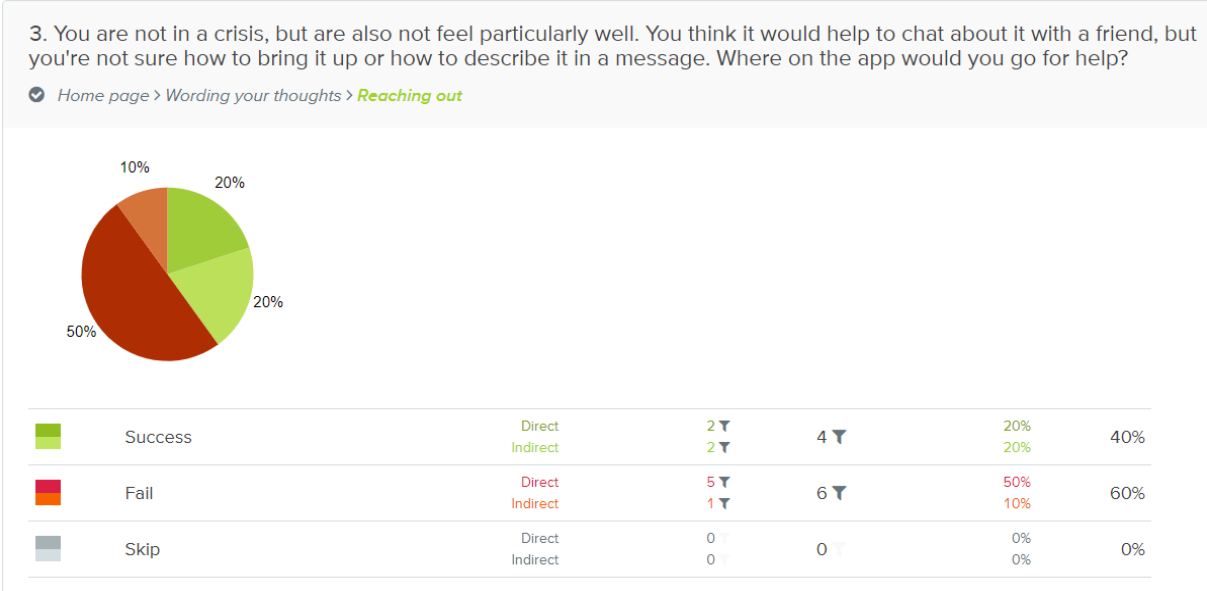


Figure 17: Task 3 results from Tree Testing, obtained through the use of result analysis on ‘Treejack’ from ‘OptimalWorkshop’, used for this test (<https://www.optimalworkshop.com/>)

6.2.3 AttrakDiff analysis

As opposed to the Hybrid card sorting and the Tree testing, the AttrakDiff test only was done by nine participants out of the original ten. Since this was the last of the three, it could be because the overall test was rather long, and the one dropped out participant ran out of time, concentration, or motivation. All AttrakDiff results discussed come from nine participants instead of ten.

As can be seen in figure 18, between pragmatic and hedonic, pragmatic quality scored highest insinuating a product that is easy and expected to be effective at doing the tasks that it attempts to do. Hedonic stimulation can be seen to have scored close to neutral in the same figure, highlighting that the product gives the feeling that it is passive and well known. This is a good place to be since it makes the user not aggravated by the app, even in times of high stress. The positive score in the hedonic identification value presents a confirmation of how the product creates a sense of personal care/attachment between the user and the product. These results match with the intentions for the visual design of the prototype. Figure 19 shows how these same results are expressed in descriptive word-pairs.

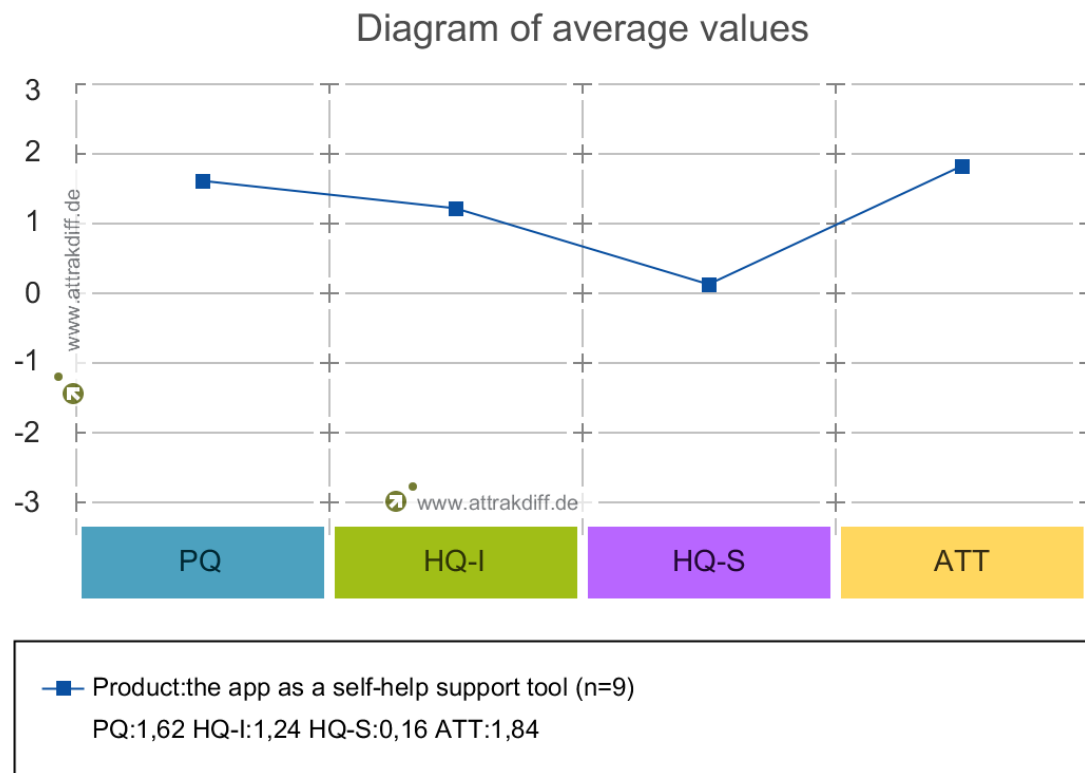


Figure 18: Diagram of average values obtained through the use of AttrakDiff (<http://www.attrakdiff.de/science-en.html>)

Description of word - pairs

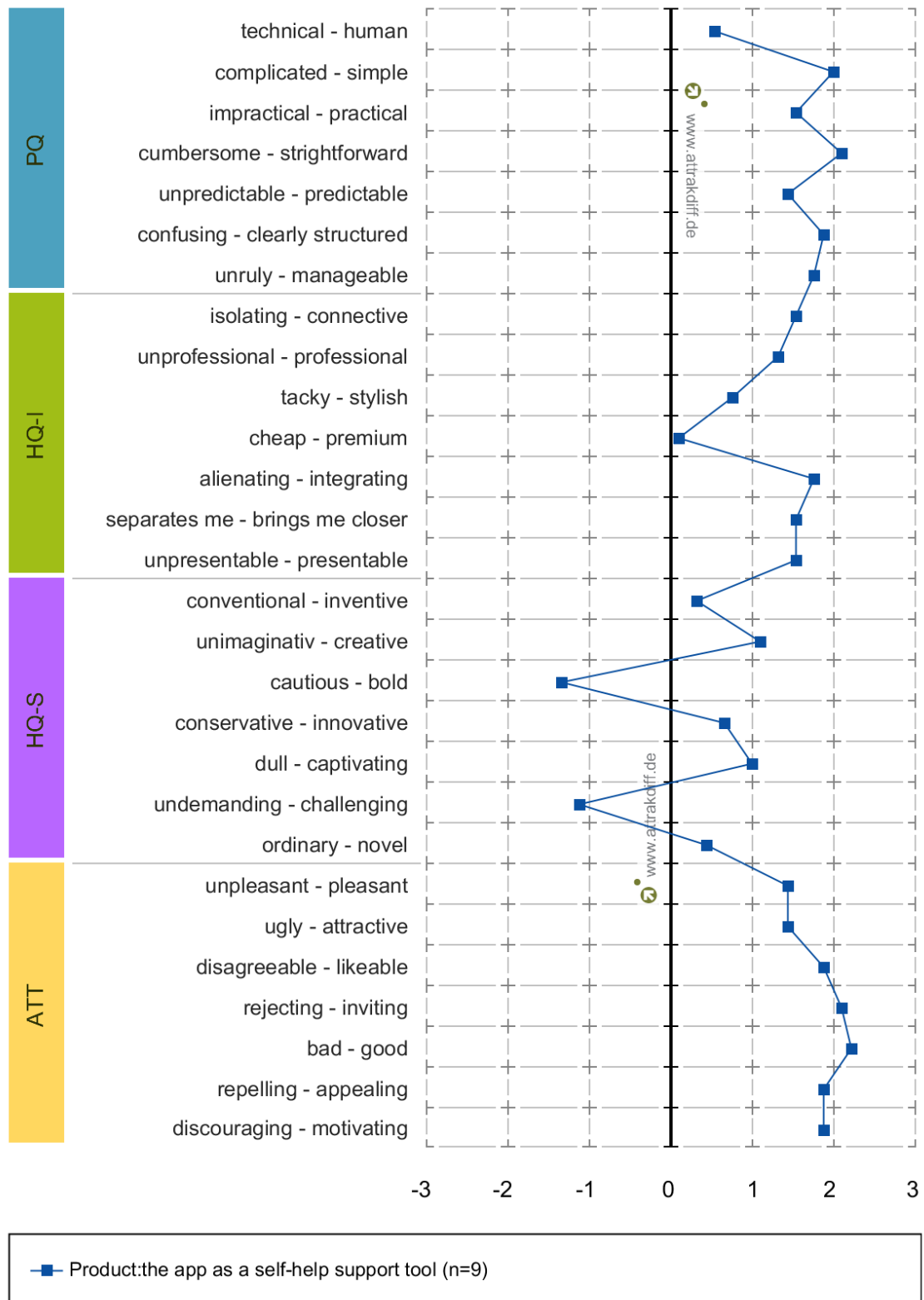


Figure 19: Description of word-pairs results obtained through the use of AttrakDiff
<http://www.attrakdiff.de/science-en.html>

As can be seen in figure 20, the assorted values of the hedonic quality and pragmatic quality lead to an interpretation that the app is quite desirable, though marginally more task-oriented. This, however, is not a problem, since the app does, in the end, attempt to provide features that should be able to be quickly and simply used. As can be seen in both figure 18 and 19, the attractiveness and its corresponding words scored high and showed that, despite the inclination towards a more pragmatic product, it is still likely to be quite desired by most users.

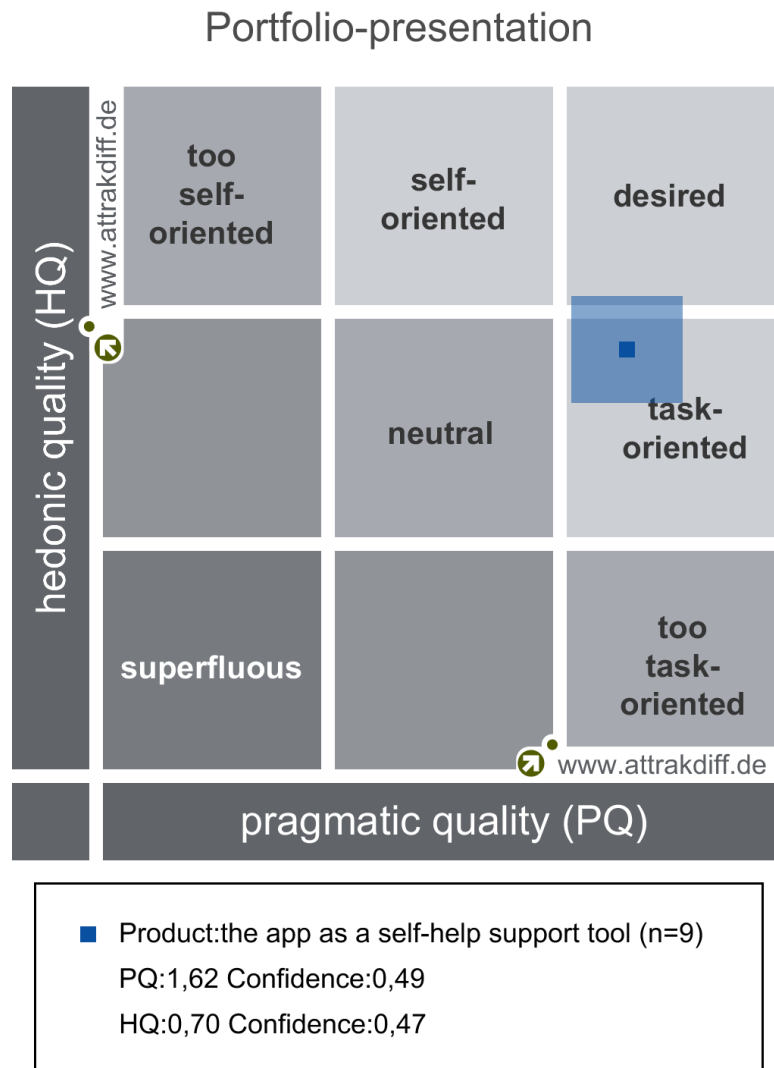


Figure 20: Portfolio-presentation obtained through the use of AttrakDiff (<http://www.attrakdiff.de/science-en.html>)

Chapter 7: Realisation prototype

In the realisation phase, the final prototype was created based on the outcomes of the previous phases, with the ethical toolkit still kept in mind. Based on the card sorting and tree testing analysis the organisation and naming was slightly changed, and based on the AttrakDiff results the visual design was kept as similar as possible to the mock-up design. This was done using the program Unity, version 2019.3.15f1.

7.1 Building the application

The Unity project is in 2D, and the platform in Build settings was set to Android. For each screen for the application an empty GameObject was created, containing a canvas and camera. The canvas has reference dimensions of a smartphone in portrait mode, and the camera a full view over this specific canvas. All elements placed on each canvas were anchored to the centre for them to scale accordingly independent of the screen size of the user's phone. A Screen Manager script was created, controlling the turning on and off of each screen's empty GameObject. This script is called on each button click that is meant to take the user to another screen, making up for the navigation through the application. A total of 23 screens were needed for the application, each briefly discussed below. An overview of these screens and how they are linked to each other, can be found in figure 21. By making use of PlayerPrefs in the Unity scripts, all that is personalised by the user in a screen is saved and will still be there after the application closes and opens again.

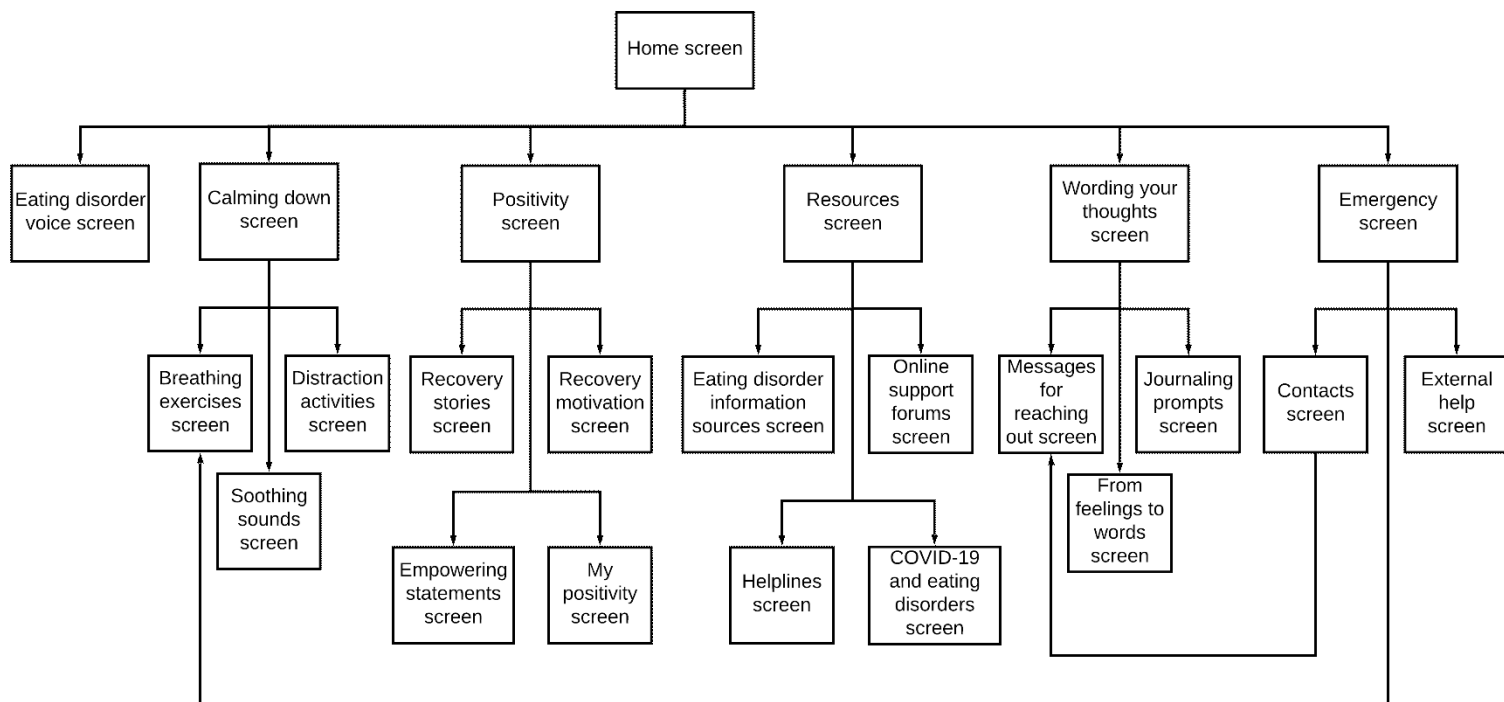


Figure 21: Overview of the different screens in the prototype

7.1.1 Home screen

This is the first screen the user sees when opening the application, and serves as a hub to go straight to different sections. It has buttons that allow navigation to the *Eating disorder voice screen*, the *Calming down screen*, the *Positivity screen*, the *Resources screen*, the *Wording your thoughts screen*, and the *Emergency screen*.

While all other screens, with the exception of the *Emergency screen*, have a rectangular banner on top with the name of the current screen, the *Home screen* simply has a coloured wave banner without text on top instead. This makes it stand out as a specific point of interest for better navigation.

7.1.2 Eating disorder voice screen

This screen contains the feature meant to help the individual to separate the thoughts that belong to their eating disorder voice from their rational, healthy thoughts. Findings from A systematic review of the ‘eating disorder voice’ experience by Aya et al. suggest “that the existence of an ‘ED voice’ is often recognized by patients with eating disorders and that this voice has a powerful, negative and omnipotent nature” [51, p. 347]. A two-column table makes up this screen, to be used for an exercise based on Kati Morton’s eating disorder recovery workbook discussed in chapter 2.4.4. The table is meant to be filled by the user with: on the left side what their eating disorder voice tells them, and on the right side their healthy counterthoughts. The user can add a new entry by pressing ‘Add new’, and change an existing entry by pressing the

corresponding 'Edit entry' button. When either of those is pressed, a popup overlay appears with corresponding text input fields. The screen has a short explanation of this table, and for the prototype version of the application there is a maximum of ten entries. The table does not contain an example entry as these entries can be personal to the individual and their type of eating disorder, and there is a risk of providing an example that might trigger a user. As it also makes sense that an example could be very helpful for some, this decision was brought up during the expert review in the evaluation phase. For now, it was left out.

Originally this screen was also meant to contain a section with insights on what the most common entries were and how often the user had indicated these to occur. This feature ended up being taken out, as it felt as if it could be more demotivating for the user to see their most common eating disorder voice thoughts than it would be helpful for the overview. This feature idea could be more useful for users that also have a coach or therapist, as the insights could be helpful to discuss in session. As this application is designed for the underserved population, and even part of the population who did receive treatment now faces problems with treatment changes due to the pandemic, this prototype the feature was taken out.

7.1.3 Calming down screen

This screen contains buttons that allow for navigation to the *Breathing exercises screen*, the *Soothing sounds screen*, and the *Distraction activities screen*. As a result of mock-up testing, a breathing exercise from the *Breathing exercises screen* was placed on this screen as well. When entering the screen it starts playing automatically, as to be the first thing to be seen when clicking *Calming down*.

Breathing exercises screen

In this prototype, the user can choose between two breathing exercises: 4-7-8 breathing and box breathing. 4-7-8 breathing is a technique based on the Pranayama yogic technique ²¹. In this exercise, the user breaths in for 4 seconds, holds their breath calmly for 7 seconds, and forcefully exhales for 8 seconds. The use of pranayamic breathing exercises can improve cognition, anxiety and general well being [52]. Box breathing is a simple, paced breathing technique that follows a set rhythm of breathing in, holding breath, and breathing out for 4 seconds each ²². Potential benefits of the box breathing technique are: reduction in physical

²¹ What Is the 4-7-8 Breathing Technique?: <https://www.healthline.com/health/4-7-8-breathing#1>

²² Box Breathing Techniques and Benefits: <https://www.verywellmind.com/the-benefits-and-steps-of-box-breathing-4159900>

stress symptoms in the body, positive effect on emotions and mental well-being, increase of mental clarity, energy, and focus, and improvement in future reactions to stress ²³.

For both exercises, Figma ²⁴, an animation tool plugin in Figma, was used to create a GIF with instructions. The GIF included a visualisation of inhaling and exhaling in the form of a circle slowly becoming darker or lighter, fitting within the colour scheme of the application. The gifs were then converted to MP4 videos, and turned into a render texture to be used in Unity.

Soothing sounds screen

There are four audio files that can be played on this screen, that loop automatically when activated, and all four are nature sounds. Sounds that can be found in nature can help with stress recovery [53] and relaxation [54]. The sounds for this prototype were downloaded from Sound Jay ²⁵ and used in accordance with their terms of use. It concerns the following sounds: Rain Sound Effect 07, Stream Sound Effect 2, Stream Sound Effect 3, and Windy Forest Ambience 01. These sounds were selected considering two separate aspects. The first was that the sound bites listened to when choosing had to have minimal low and mid bass (frequency ranges below 100Hz) given the fact that these ranges are known to increase stress [55]. The sound bites should also avoid soundscapes that featured too many sounds in the treble range since geophonic acoustic resources tend to not produce them. The second was that it was important that the sounds chosen matched the criteria of natural (non-urban) sounds as much as an artificial sound sample can. An additional benefit of having acoustic environments with sounds in the midrange and high midrange is that higher frequency tones, especially around the peak sensitivity of human hearing (4000Hz), have shown to decrease stress [56].

Distraction activities screen

In this screen, examples of activities or exercises that help the user to re-ground and calm down are presented, between which can be switched using a button. For this prototype, only two activities are available. The first is the 5-4-3-2-1 method activity, where an individual starts observing their environment and tries to identify 5 things they can see, 4 they can touch, 3 they can hear, 2 they can smell, and 1 they can taste. This grounding technique, encouraging the use of all five senses, is mostly used by those struggling with anxiety ²⁶, but also common in for

²³ What is box breathing?: <https://www.medicalnewstoday.com/articles/321805#benefits>

²⁴ Figma Figma animation tooling: <https://www.figma.com/community/plugin/733025261168520714/Figma>

²⁵ Sound Jay: <https://www.soundjay.com/>

²⁶ 5-4-3-2-1 Coping Technique for Anxiety: <https://www.urmc.rochester.edu/behavioral-health-partners/bhp-blog/april-2018/5-4-3-2-1-coping-technique-for-anxiety.aspx>

example addiction recovery²⁷. The second is a progressive muscle relaxation (PMR) exercise, PMR being proven to be beneficial for coping with stress [57]. In PMR exercises, an individual works with creating tension in a muscle, to then release that same created tension, making it easier to relax the muscles than if one starts directly with trying to relax. For this PMR exercise, one was chosen that only uses the hands, as these exercises require a lot of connecting to one's body, especially if performed with multiple muscles groups, which in itself can be a trigger to this target group. The instruction steps for this exercise come from an article by The Hope Line, on grounding techniques for panic attacks²⁸. The exercise in specific shall be brought up in the expert review in the evaluation phase, to check whether just using the hands is safe enough to leave in the application.

7.1.4 Positivity screen

This screen contains buttons that allow for navigation to the *Recovery stories screen*, *Recovery motivation screen*, *Empowering statements screen*, and *My positivity screen*.

Recovery stories screen

An overview of stories from others who have lived with an eating disorder is given with the aim to inspire. The screen contains excerpts from four different stories, with a link to each full story that will open the webpage in the default browser when clicked. All are from the *Featured Stories of Hope* collection from National Eating Disorders Association (NEDA)²⁹, and this is made clear on the application screen as well.

Recovery motivation screen

At the top of this screen, a ribbon-shaped banner is positioned meant to display a reason to recover entered by the user. The user can tap a button to make use of a popup overlay that allows users to input text. The text is saved and displayed in the banner. The rest of this screen contains a vertical scroll view filled with a list of reasons that motivate other eating disorder sufferers on their path to recovery. A list of seventeen reasons was created by going through the same forums that were used for chapter 2.2.2 and 2.3, searching for 'recovery reasons' and 'recovery motivation'. The reasons chosen all came directly from sufferers trying to motivate

²⁷ A Guide to Grounding Techniques in Addiction Recovery:

<https://www.rehab4addiction.co.uk/guides/grounding-techniques-addiction-recovery#3> Point Header

²⁸ 25 Grounding Techniques for Panic Attacks: <https://www.thehopeline.com/25-grounding-techniques-panic-attacks/>

²⁹ Featured stories of hope, NEDA Feeding hope.: <https://www.nationaleatingdisorders.org/stories-of-hope/featured-stories-of-hope>

themselves and others by sharing their reasons, but were filtered to not have a high risk of triggering someone else suffering. This could happen if a reason contained terms or numbers that could be triggering to the target group as a whole, or if the reason to recover was too directly tied to the specifics of what ‘recovery’ means to a certain eating disorder, which could be the direct opposite of another (e.g. The reason found “To feel less heavy to be able to run with my children” coming from someone with binge eating disorder who was overweight seemed valuable for others in a similar position, but could be very harmful to those struggling with restriction and the urge to lose weight using the same application). The list of the reasons included for this prototype can be seen in Appendix D.

Empowering statements screen

The middle foreground of this screen contains a rectangle resembling an open card displaying an empowering statement in text, the background rectangles resembling closed cards. There is a shuffle button that lets the user shuffle through thirty different eating disorder recovery specific statements for self-affirmation. The thirty affirmations used are from the page Recovery Warriors. The *30 Positive affirmations to empower yourself in recovery* were written by Anastasia Amour, body image educator and self-esteem coach ³⁰. There is a button that opens this webpage when clicked, with text on it referencing this source.

My positivity screen

Users can upload images that bring them joy and store them on this screen for quick access. The prototype application is designed for eight images, but in a future version the application aims to have space for more as well as include spaces for text. The asset *Native Gallery for Android & iOS* from Süleyman Yasir Kula on the Unity Asset Store was used for this feature ³¹.

7.1.5 Resources screen

This screen contains buttons that allow for navigation to the *Eating disorder information sources screen*, the *Online support forums screen*, the *Helplines screen*, and the *COVID-19 and eating disorders screen*.

³⁰ 30 positive affirmations to empower yourself in recovery:

<https://www.recoverywarriors.com/30-positive-affirmations-to-empower-yourself-in-recovery/>

³¹ Native Gallery for Android & iOS:

<https://assetstore.unity.com/packages/tools/integration/native-gallery-for-android-ios-112630>

Eating disorder information sources screen

This screen, the *Online support forums screen*, and the *COVID-19 and eating disorders screen*, all have an identical, simple layout, as they all only provide an overview of links to other resources. The resources this particular screen provides are the following:

1. Learn – What are eating disorders? ³² (National Eating Disorders Association (NEDA))
2. Eating disorders explained ³³ (Butterfly Foundation, national eating disorder charity Australia)
3. Learn More About Eating Disorders ³⁴ (Academy for Eating Disorders (AED))
4. DSM-V Diagnostic Criteria for Eating Disorders ³⁵ (BodyMatters Australasia)
5. Signs and Symptoms of Eating Disorders ³⁶ (BodyMatters Australasia)
6. Dutch: Wat is een eetstoornis? ³⁷ (Human Concern – Centrum voor eetstoornissen)

Online support forums screen

The forums linked are free to use and create an account for:

1. Eating Disorder Recovery Forum WMDN ³⁸ (WhatMiaDidNext, administrator: Mia Findlay (Recovery Coach at Beyond Body Coaching))
2. NEDA – Feeding Hope. Eating Disorder Forums ³⁹ (National Eating Disorders Association (NEDA))
3. Dutch: Proud2BMe Forum Eetstoornissen ⁴⁰ (Proud2BMe, largest online eating disorder help website for The Netherlands and Belgium)

These forums are meant for support and understanding, and purposefully are all moderated, filtering out harmful content. As was discovered in the background research, it is common for eating disorder sufferers to (anonymously) turn to the internet for expression and understanding. There exist many eating disorder related forums that are not moderated, of which some can contain seriously harmful content [58].

³² What are eating disorders?: <https://www.nationaleatingdisorders.org/what-are-eating-disorders>

³³ Eating disorders explained: <https://butterfly.org.au/eating-disorders/eating-disorders-explained/>

³⁴ Learn more about eating disorders: <https://www.aedweb.org/resources/about-eating-disorders>

³⁵ DSM-V diagnostic criteria for eating disorders: https://bodymatters.com.au/wp-content/uploads/2015/01/DSM_V_Diagnostic_Criteria_for_Eating_Disorders.pdf

³⁶ Signs and symptoms of eating disorders: <https://bodymatters.com.au/wp-content/uploads/2010/11/signssymptoms2.pdf>

³⁷ Wat is een eetstoornis?: <https://humanconcern.nl/wat-is-een-eetstoornis/>

³⁸ Eating disorder recovery forum WMDN: <https://whatmiadidnext.discussion.community/>

³⁹ NEDA Feeding hope. Eating disorder forums: <https://www.nationaleatingdisorders.org/forum>

⁴⁰ Proud2BMe Forum: <https://forum.proud2bme.nl/>

Helplines screen

This screen provides resources in the form of telephone contact numbers to call, for help with the eating disorder or mental health. When the number is clicked, the smartphone's number dialler is opened with the corresponding number already filled in. For this feature, the asset *Android Native Goodies PRO*⁴¹ from Nineva Studios in the Unity Asset Store was used.

As this prototype is created for evaluation first, and will not be directly used for its design purpose, it was decided to disable the helplines and their on click call function for now. This is because it was not considered responsible to facilitate calling helplines that need to be available to those in need, in case someone would decide to click a number just to test this feature. The helplines included but disabled were all numbers from the Netherlands for this prototype. As helplines differ per country the top of the screen contains a dropdown menu to select the appropriate one, but due to the time limitations of the creation of this prototype just this one country was used for now. The following four helplines with information were included:

1. WEET hulplijn⁴²

A helpline of the Dutch patient association for eating disorders WEET, to talk anonymously to volunteers who are all either personally experience experts or have been very close to someone with an eating disorder and know its impact in that way.

2. MIND Korrelatie⁴³

A national organisation that also deals with eating disorders of which their helpline provides anonymous contact with a professional.

3. de luisterlijn⁴⁴

This is an organisation that allows people to call anonymously at any time of the day or night, any day of the year, to talk to one of their volunteers about how they are feeling or what they are struggling with.

4. 113 Zelfmoord preventie⁴⁵

This is the Dutch suicide hotline, also open for calls 24/7.

⁴¹ Android Native Goodies PRO: <https://assetstore.unity.com/packages/tools/integration/android-native-goodies-pro-67473>

⁴² WEET hulplijn: <https://www.weet.info/hulplijn/>

⁴³ MIND Korrelatie: https://mindkorrelatie.nl/?gclid=EAIaIQobChMlpIvxhYX56gIVVe3tCh0COwPjEAAYASABEgLDs_D_BwE

⁴⁴ de luisterlijn: <https://www.deluisterlijn.nl/>

⁴⁵ 113 Zelfmoord preventie: <https://www.113.nl/>

COVID-19 and eating disorders screen

The following resources were provided for information on COVID-19 and eating disorders, and tips for managing:

1. Managing Eating Disorders during COVID-19 ⁴⁶ (Michigan Psychiatry Resources for COVID-19)
2. 10 tips for coping during the coronavirus crisis ⁴⁷ (Beat (eating disorder charity, UK) Ambassador Summer)
3. Coping with Covid-19 ⁴⁸ (Beat (eating disorder charity, UK) Ambassador Issy)
4. Eating disorders and COVID-19: Tips for coping and more ⁴⁹ (Medically reviewed by Jillian Kubala, MS, RD — Written by Amanda Barrell)
5. 7 ways I'll keep working towards recovery during the pandemic ⁵⁰ (Beat (eating disorder charity, UK) contributed by Rachel)
7. COVID-19: Tips & Advice for people with an eating disorder ⁵¹ (Butterfly Foundation (eating disorder charity, Australia))

7.1.6 Wording your thoughts screen

This screen contains buttons that allow for navigation to the *Messages for reaching out screen*, the *Journaling prompts screen*, and the *From feelings to words screen*.

Messages for reaching out screen

This screen contains 10 boxes in which users can store messages they would like to use when reaching out to their contacts. As it was found that some sufferers do have the support system to reach out to, but in moments of distress or panic have a hard time formulating or typing the message, this screen aims to provide a way for them to pre-write these messages and access them easily when those moments come. Each box has an edit button, which again makes a

⁴⁶ Managing Eating Disorders during COVID-19: <https://medicine.umich.edu/dept/psychiatry/michigan-psychiatry-resources-covid-19/specific-mental-health-conditions/managing-eating-disorders-during-covid-19>

⁴⁷ 10 tips for coping during the coronavirus crisis: <https://www.beateatingdisorders.org.uk/your-stories/recovery/tips-coping-during-coronavirus>

⁴⁸ Coping with Covid-19: <https://www.beateatingdisorders.org.uk/your-stories/recovery/coping-with-covid-19>

⁴⁹ Eating disorders and COVID-19: Tips for coping and more: <https://www.medicalnewstoday.com/articles/eating-disorders-and-covid-19#eating-disorders>

⁵⁰ 7 ways I'll keep working towards recovery during the pandemic: <https://www.beateatingdisorders.org.uk/your-stories/7-ways-keep-working-recovery-during-pandemic>

⁵¹ COVID-19: Tips & Advice for people with an eating disorder: <https://butterfly.org.au/covid-19-tips-advice-for-people-with-an-eating-disorder/>

popup overlay appear for text input, but it also has a copy to clipboard button so the user can easily copy and send the messages. For the copy to clipboard feature, the asset *Android Native Goodies PRO*⁵² from Nineva Studios in the Unity Asset Store was used. Originally, this screen was going to contain a few example messages, to help the user with reaching out more easily. During the building of the application, after some contemplation this feature was scratched as since everyone's contacts and support system situation is different, it did not feel responsible to provide an example message to be sent out. It was not possible to assess accurately how a pre-formulated message would be received in any scenario, by any type of person, and so it did not feel safe enough to include for now.

Journaling prompts screen

As was found in the background research, journaling can be helpful to eating disorder sufferers. This screen provides journaling prompts from a list put together by Margarita Tartakovsky, M.S. (writer, and associate editor and contributor at PsychCentral.com, with a master's degree in clinical psychology, according to PsychCentral), published in the blog post *30 Journaling Prompts for Self-Reflection and Self-Discovery*⁵³. This is mentioned on the top of the screen and a button to go directly to the blog post is provided, next to a button that will show an overlay which displays the entire list of 30. The screen is mainly occupied by a rectangle in the middle that displays one journal prompt at the time, (example: "Name a compassionate way you've supported a friend recently. Then write down how you can do the same for yourself") that can be changed by pressing the button 'Show new prompt' below. This will pick another prompt from the list randomly.

From feelings to words screen

When overwhelmed with feelings or emotions, putting feelings into words, also known as affect labelling, can help [59]. However, eating disorder sufferers can struggle with this. This was touched upon in the individual stories from the background research, but also later found to be confirmed by literature [60].

This screen provides a tool created to help with affect labelling. The user first chooses whether a tone, feeling, or emotion is going to be described, and then whether it is positive, negative, or something other. For each final node, fifteen example words appear on the screen. The user can use the words provided to perform affect labelling, or can use them as inspiration

⁵² Android Native Goodies PRO: <https://assetstore.unity.com/packages/tools/integration/android-native-goodies-pro-67473>

⁵³ 30 Journaling Prompts for Self-Reflection and Self-Discovery: <https://psychcentral.com/blog/30-journaling-prompts-for-self-reflection-and-self-discovery/>

for the word they are looking for. The words used for creating this tool were taken from YourDictionary, from the page *List of Adjectives to Describe Tone, Feelings, and Emotions* ⁵⁴. A button to go to this page, displaying the source, is present. The words are automatically copied to the phone's clipboard when they are tapped, and for this, the asset *Android Native Goodies PRO* ⁵⁵ from Nineva Studios in the Unity Asset Store was used.

7.1.7 Emergency screen

This screen contains buttons that allow for navigation to the *Breathing exercises screen* (button name: 'Help Breathing'), the *Contacts screen* (button name: 'I need to contact someone I know') and the *External help screen* (button name: 'I need to call for external help'). The buttons here have a slightly different name than the screens themselves, as there has been taken into consideration that the user is likely in an emergency or panic state when entering this screen. This tone seemed more accurate as it directly speaks to the individual, instead of merely providing a description. The screen has a dedicated space in the middle for the user to put their own text or quote, so this will be the first thing they see when they might be in distress when entering the screen. Also, there is an empty rectangle space on the bottom to fill with any information that might be good to have on hand when reaching out in an emergency state, such as insurance information, address, date of birth, etc. Both text spaces work with a tap to edit button, that will make the popup overlay with text input field appear.

Contacts screen

This screen has three shapes with phone icons, for the user to store three contacts that are safe for them to reach out to in a state of emergency. Each has an edit button next to it, that will show the popup overlay where the user can fill in a name and phone number. Each shape when pressed, will automatically open the smartphone's number dialler with the contact's number filled in. Again, for this feature, the asset *Android Native Goodies PRO* ⁵⁶ from Nineva Studios in the Unity Asset Store was used. The screen also links straight to *the Messages for reaching out screen*.

⁵⁴ List of Adjectives to Describe Tone, Feelings, and Emotions:

<https://grammar.yourdictionary.com/parts-of-speech/adjectives/list-of-adjectives-to-describe-tone-feelings-emotions.html>

⁵⁵ Android Native Goodies PRO: <https://assetstore.unity.com/packages/tools/integration/android-native-goodies-pro-67473>

⁵⁶ Android Native Goodies PRO: <https://assetstore.unity.com/packages/tools/integration/android-native-goodies-pro-67473>

External help screen

This screen is very similar to the *Helplines screen*, except it contains emergency numbers to call rather than general helplines. The screen also contains a drop-down menu for choosing a country, for it to display the correct emergency numbers. In this prototype, the only country available is the Netherlands. For the same reasons as in the *Helplines screen*, if not more relevant here, the calling features were disabled for the testing done in the evaluation phase.

7.2 Prototype limitations

Due to limited time, the prototype does not equal a finalised application yet. For one, the *Eating disorder voice screen*, the *Messages for reaching out screen*, and the *My positivity screen*, all handle an input maximum. In a final version, the user would be less constrained. The screens *Breathing exercises* and *Distraction activities* only contain two content items each for prototype purposes, but in a finalised version the user could have many more techniques to choose from. Screens like the *Soothing sounds screen*, could allow for an option to upload own content too for example. The prototype also only has the option to pick the Netherlands as country for now, which makes certain resources provided country-specific, while in a finalised version it would be customisable for many different countries. A last major limitation is that the prototype can only be used with Android smartphones, for the reason that constant testing took place with a smartphone to see whether features worked during the building process and for this no iPhone was available.

Chapter 8: Evaluation prototype

After the final prototype was built, it was ready to be evaluated. The goal was to have a functioning prototype that was nice and easy to use, of value to and useful for the target group (mainly referring to the fulfilling of the design requirements), and pleasant to look at. To be able to test to what extent this goal had been achieved, the following four different aspects should be focused on in this evaluation phase:

- Functionality
- Usability
- Utility
- Visual appeal

While the target group is the centre of this research, not all aspects need to be exclusively tested by its members. As mentioned in the user test that took place for the mock-up, for unreviewed versions it could be good to test specifically with users that are not in the target group.

However, as learned from that same test, when using terms specific to the target group these should be explained. In this evaluation, when the eating disorder voice comes up in the test, it contains a description of what this name implies for those with eating disorders.

The evaluation phase was set up to consist of different parts, each with an own test focusing on the different aspects. The final part was going to be a target user test, but as mentioned in Chapter 3 this, unfortunately, had to be cancelled. Instead of four, there are now three different evaluation parts to be discussed: A function testing + pilot testing focused on functionality with one non-target group participant, a non-target group test focused on usability with a bit of visual appeal, and an expert review with two experts in the field of eating disorders. The expert review originally aimed to mostly focus on reviewing whether the prototype was safe enough to be evaluated by the target group, but because of the cancellation of the fourth part now focuses on the expected utility for the target group from an expert standpoint.

8.1 Evaluation #1: Function testing + pilot testing

Method

The first test was a function test for evaluation #2 and a pilot test in one, and therefore the main focus was functionality. It was of extra importance as evaluation #2 was going to be remote and unmoderated. Besides, so far the prototype had only been displayed on one personal phone during building, which was a HUAWEI P8 lite with a screen resolution of 1080x1920, and it had not been tested on another phone yet. This test was done by just one participant who did not

belong to the target group, an adult with a healthy relationship with food. It was a remote test where the participant had to download the application to their device, in this case, a Samsung Galaxy A8 with a screen resolution of 1080x2220. The test was moderated, and this was done by having the participant broadcast their phone to their laptop screen while sharing their laptop screen with the moderator through a video call. The participant was familiar with this setup and used an AirDroid⁵⁷ app for this that they already had installed. The participant was instructed to go through each screen of the prototype, and press each button on each screen, testing out all features, while thinking out loud. The participant interacted with all that was interactable, using all text input boxes, uploading images, testing the call button, etc. If something stood out to the moderator, the participant would be asked to perform a certain task again or perform a specific action. After this was done and after a short break, the Google Form that was created for evaluation #2 was opened, and the participant was asked to go through each question, again thinking out loud.

Results

This test was done as a semi-structured walkthrough of the full prototype. To present the results a list is given below, consisting of the changes made based on the error discoveries.

- For the most part, the layout of the prototype application was not different on the participant's phone. This was with the exception of very few but specific images seemingly unrelated to each other, that were stretched out. It turned out this was due to mismatching anchor points in only these images, as they were anchored to the top while all else was anchored to the centre.
- In the *Emergency screen*, the button to go to the *Breathing exercises screen* was not working. As this was discovered at the very start of the test, this was fixed during the test. All the other buttons worked correctly.
- In the *Eating disorder voice screen*, a user can edit an existing entry by pressing the 'edit entry' button next to each entry space, and add a new entry by pressing the 'add new' button. The participant was slightly confused about having two buttons, and then added their first entry by pressing 'edit entry' next to the first empty space. This confused the script that kept track of the number of entries in. Based on this observation, the change was made to have the 'edit entry' buttons next to each entry space only appear once that specific entry had already been added.
- As described in Chapter 7 (Realisation prototype), features in the *Helpline screen* and *External help screen* were disabled for the evaluation phase. In the Google Form, the

⁵⁷ AirDroid: <https://www.airdroid.com/en/>

participant is asked to navigate freely through the prototype before answering certain questions. When the participant came to this section, it was confusing to them why these screens did not contain the phone numbers. Therefore a note was added to the instruction in the final Google Form, explaining the situation.

- It also became clear that five scenario-based tasks (further explained in evaluation #2) had to remain the maximum included, and that to keep the concentration of the participant no extra one should be added (which was an initial contemplation). This was because at the fourth task the participant started saying they thought these tasks were a bit much, and after the fifth stated that it was good that it was the last one else they would not have done another one of the same question styles.

8.2 Evaluation #2: Non-target group test

Method

This part of the evaluation consisted of an unmoderated, remote test with 5 participants located in Brazil, Germany and The Netherlands. These participants were all not part of the target group, and different from those who took part in Chapter 6 (Realisation mock-up). This test focused on usability, but also briefly touched upon utility and visual appeal. Each participant read an information brochure (Appendix B) and returned a signed consent form (Appendix C) on the research. This test was approved by the ethical committee with reference number RP 2020-93. Then participants were sent the prototype application to be downloaded on their own device, and a link to a Google Form in which the research took place. Screenshots of the application at this stage of the design process can be found in Appendix E.

The first part of the test consisted of tasks based on hypothetical scenarios. The participant was asked to imagine they were an eating disorder sufferer and found themselves in the presented situation, then they were asked to perform a task on the prototype application. In the Google Form, they were asked to indicate whether they managed to complete the task or not. If the task was completed successfully, the participant would answer the Single Ease Question (SEQ) to indicate how easy or difficult the completion was on a scale of one to seven [61], and give the motivation for their SEQ answer. If the task was not completed successfully, the participant answered two questions on why they thought this could be the case. This was done for a total of five scenario-based tasks.

Before starting the second part of the test, the participants were asked to freely navigate and click around through the whole prototype application. They were asked to make use of the customisable features and get a general feel of the application as a whole before moving on to the remaining questions. They were then asked:

- To answer the SEQ but for navigating through the application as a whole.
- Whether anything, in particular, stood out positively and negatively.
- On a seven-point scale from “I believe this app would be useless as a support tool.” to “I believe this app would be very useful as a support tool.” whether keeping in mind that it was designed for people suffering from eating disorders they believed it could serve as a support tool. This question aimed to derive the level of utility imagined or expected by a non-targeted group of people.
- Which five words from a list of 14 adjectives were believed to be most fitting to this application prototype. This was based on the Microsoft Desirability Toolkit to Test Visual Appeal ⁵⁸, and aimed to see whether the response to the visual appeal was in line with the results from the AttrakDiff test in the specification phase. The 14 adjectives chosen were the word pairs from the Attractiveness construct of AttrakDiff. It was chosen not to include the full AttrakDiff questionnaire again, as the design of the mock-up (that was tested with the AttrakDiff) was closely followed in the realisation - and while testing the mock-up there was already one participant who left the test just before filling in the AttrakDiff, potentially because the test was too long. As this test was even longer and the question on visual appeal was mostly meant to confirm that it is still liked, it was left out here.
- The 10 questions from the System Usability Scale (SUS) ⁵⁹ [62], the wording adapted to fit this application prototype and the participants not pertaining to the target group. For example, wherein the SUS the first question was “I think that I would like to use this system frequently.”, this was adapted here to “If I were to belong to the target group for this app, I think I would like to use this app frequently.”

Results

The full results can be found in Appendix F, below conclusions for each question type are presented.

Scenario-based tasks

All participants managed to complete the scenario-based tasks successfully. With a single exception of one 2 given, on the seven-point scale all SEQ scores were between 5 and 7. For each task, the averages of all participants were, in order, 5.8, 6.2, 6.6, 6.2, and 6.4. These

⁵⁸ Using the Microsoft Desirability Toolkit to Test Visual Appeal:

<https://www.nngroup.com/articles/microsoft-desirability-toolkit/>

⁵⁹ System Usability Scale (SUS): <https://www.usability.gov/how-to-and-tools/methods/system-usability-scale.html>

averages lie very close to each other, and so a total average was calculated to be 6.24, which reflects a high ease of task completion. The task that scored a 2 on the SEQ by one participant, was the task aimed to log a new eating disorder thought and counter thought in the Eating disorder voice screen. The participant who gave this score explained this was because “I couldn't find a log option. I tried first "Wording your thoughts".” This confusion could be due to the usage of the word ‘log’ in the task, and the button to perform the task being “+ Add new”.

After free navigation and full exploration

Overall navigation SEQ

The average of the answers to the SEQ on the full navigation on the application was a 6.8. This score was compared to the total average SEQ score of the scenario-based tasks. This was because there were many more possible tasks that were not asked as this would have made the test too long. If the average of the overall navigation SEQ would have been much lower than the average on the scenario-based tasks SEQ, it could have been the case that the tasks chosen for the scenario-based tasks were relatively easy as compared to the non-tested tasks. In this case, the score for the overall navigation SEQ was slightly higher, and so the tasks asked were considered not a poor representation of the total amount of tasks possible.

Positives and negatives

The answers to what stood out positively in the prototype touched upon the visual design, the prototype being comforting, a clear text and flow, ease of personalisation. In addition, the *Positivity* section, in particular, seemed to stand out to two out of five participants. The negatives touched upon needing to memorise where some of the things were, the size of some text not being uniform, and that some items required previous work. One participant stated nothing stood out negatively, and one only mentioned ‘soothing sounds was odd’ but did not explain in what way.

Imagined utility

On a seven-point scale, the non-target group participants believed this application could serve as a support tool, keeping in mind that this was designed for people with eating disorders, by an average of 6.8 out of 7. This aims to measure the imagined utility: when coming from the target group the utility measured is of more value, but this can still help indicate how the prototype was perceived.

Best fitting adjectives

All adjectives chosen by participants to be most fitting for this prototype, see Appendix F, were in line with the AttrakDiff results on attractiveness.

System Usability Scale

The system usability scale scores calculated per participant based on their answers to the ten questions were 95, 100, 97.5, 92.5, and 75. This gave a total average score of 92 out of the maximum attainable score of 100. This meant the obtained SUS score is a high score, above average (which is considered to be 68) ⁶⁰.

8.3 Evaluation #3: Expert review

For this part, two experts in the eating disorder field that actively work with patients participated in a moderated test. Both experts have had an eating disorder in the past and have recovered from it. This test aimed to find out mostly whether, from an expert point of view, the different features included in the prototype would be considered useful to have for this target group. Again, it is about something being valuable for target users but not at the cost of being potentially harmful towards some of those users. The expert reviews did not have a rigid structure, but in both first the project was explained, and then each screen was visited on the application to open a discussion to find out what they thought of it and ask questions. The five design requirements were revisited while going through the application with the experts, and were also used to structure the outcomes of what was discussed below.

8.3.1 Design requirement 1: the app aims to help to calm down

Both experts thought overall the features from *Calming down* of the prototype would likely be helpful to eating disorder sufferers, and did not seem triggering. While on the *Soothing sounds screen* not much was said aside from it being good to include nature sounds and taking into consideration the frequencies, more comments were made on the other two screens to do with calming down.

In the *Breathing exercises screen*, one expert mentioned the techniques should always include a longer exhale than inhale, which *Box breathing* does not do. The explanation was mostly about doing these exercises every day consistently, and how when practised daily the techniques with longer exhales can be highly beneficial. While the prototype currently does not place focus on building a habit of doing these exercises, it could be interesting to add a section, when more breathing exercises are added for a later version, of breathing exercises that

⁶⁰ Measuring usability with the System Usability Scale (SUS): <https://measuringu.com/sus/>

specifically would be beneficial to practice every day. This way there are still the exercises meant to help clam down in the moment, while a willing individual could without pushing be informed and hinted to use some more habitually.

The other expert commented that it was good that the current breathing exercises only focused on breathing itself and did not include other body parts like the stomach or even full-body breathing exercises. The bodyscan was brought up as an example of a mindfulness exercise that focused on breathing and that is very beneficial to many, but that could be uncomfortable and harmful for this specific target group because of how connected it requires someone to be with their whole body. They suggested to keep paying attention to these aspects when adding more breathing techniques.

One expert commented the visualisation of the exercises needed to be more clear and interesting in addition to needing a video walking the user through the exercise for it to be more effective, while the other liked the current colours and thought the design and animations like this brought tranquillity with them.

While both experts agreed on finding the exercises from the *Distraction activities screen* to be useful, one found the name of the screen to be problematic. The name would give the impression that it is good to look for distraction and that would mean it is okay to run away from your problems. This expert said that the person using the application should not just distract themselves from the issue, but take the opportunity to tackle it. The section could be renamed to for example ‘Grounding techniques’ or ‘Awareness activities’, so the user first uses it to ground themselves and then works on the actual problem.

The other expert, however, believed that for this target group it made sense to specifically keep distraction activities in to help calm down. They explained how an eating disorder in itself is a distraction from an underlying, bigger issue, and that it could be good to show that in the moment there are also other, healthier ways to distract yourself and get back to the present. They found it to be about finding a balance between when to distract yourself to be able to get through and when to look for the problem to deal with it, and that the latter is mostly for therapy. It could benefit from a name such as ‘Alternative distraction’ to make it more clear that these are healthier distractions. For the adding of more activities, this expert proposed looking into what is used for dealing with addictions, as it would likely be similarly helpful for eating disorders.

Both experts did agree that this section would benefit greatly from some additional instruction in the form of video or audio, at least for the slightly longer exercises. It was also verified here that the current PMR exercise in the prototype is very likely not triggering to eating disorder sufferers, and that including exercises including muscles in just the hands should be fine.

8.3.2 Design requirement 2: the app aims to help to uplift and motivate

The *Recovery stories screen* was said to be very good for motivation, especially when individuals feel hopeless it can be hard to imagine that it can get better. It would be good to add more, to have enough representation of the different disorders and the variety of people who have suffered from an eating disorder, to cover all the different types of potential users. Similarly, the *Recovery motivation screen* could use more, different types of reasons. While discussing this screen, one of the experts came to an idea of a full new feature, explained further in Other suggestions (chapter 8.3.6).

The *Empowering statements screen* was seen as a good way to bring positivity to a user, but only as long as they remain relatively short statements and properly avoid triggers. The ones in the prototype were seen as appropriate, especially since these were written for eating disorder recovery in specific, but if more are added later they should be assessed carefully. It was suggested by one expert to adapt this feature such that it includes popup notifications of the empowering statements, so the user would not have to go through several clicks to read one statement. The expert suggested there for example to be 365 statements saved, and have the user pick a time to receive a daily empowering statement at the chosen moment.

When opening the *My positivity screen*, both experts referred to the feature as a mood board. One expert that was quite positive about this feature suggested having the option for a user to upload chosen music as a key part in this. They explained how sometimes patients they work with have a particular song from their childhood, for example from before their eating disorder, that can fill them with joy or help them calm down right when they need it when hearing it, which could be particularly helpful when combined with images of happier memories.

They did mention that calling it *My positivity* would be a difficult name to deal with for those at the very beginning of their journey in recovery or managing their disorder, and that this is likely a large part of the application's target group. They said that for this group the other screens within *Positivity* likely made them feel better easier, as those are reasons and stories coming from other people that they might be able to identify with. Someone at the worst of their disorder, or at the very beginning, can be very uncomfortable associating the 'my' of themselves with something positive, despite being comfortable with the positive of somebody else. The name of *My positivity* could be enough for them to not click the feature to begin with, and to include this group in the use of this feature just calling it 'Mood board' instead could already make the difference.

8.3.3 Design requirement 3: the app aims to help to inform

The discussion on the *Resources screen* and related screen was shorter, as it was seen that as long as they were carefully selected and trustworthy sites, having links to resources could always be beneficial. One expert did come with a suggestion for an addition: to have a similar screen to the other resources, but to fill this with links to information and support groups for family or friends of someone struggling. This, not despite but because of the prototype being targeted to the ones with the eating disorder, could help them feel less alone.

They explained how this could serve as a subtle hint towards the user that an eating disorder is not something you should have to fight on your own, that asking for help is good, and that others care and are interested in your struggles. It could be what brings them to share their issue with others and talk about it, as they could, for example, show their family these resources without feeling pressured to. This was a valuable insight as it was something missed in the design process. When it was decided to design the prototype for it to be used by only the individual with the eating disorder, this fully ruled out adding features aimed towards their surroundings, which it should not have.

8.3.4 Design requirement 4: the app aims to help to communicate and reach out

With regards to communicating towards oneself, the *Journaling prompts screen* was seen as useful as, while someone could find these prompts also by just searching online, it takes away the effort of having to look for something like this and the energy can be spent the actual reflecting and writing.

On the *From feelings to words screen*, the experts were more divided. One believed this feature would not work as they said it did not do anything. According to them, it would need to tell what to do with those feelings of emotions, as now it just helps come to a word but does not tell what it could mean. They said to include examples underneath of what desire or need a certain emotion is linked to, to include more words as these did not cover all.

However, the other expert told that for some, especially people who have not yet gotten treatment or are very deep into their eating disorder, it can already be very helpful to have guidance towards figuring out whether they are feeling something happy or sad. They said that it is often not about the exact word or description, but about a general direction, and that adding more tools or words to this screen could be too overwhelming. This expert suggested to focus on checking if some words in it are very specific now, and to turn those into words that are a bit more general, to maintain a helpful overview and leave it as such.

With regards to help to communicate with others, both found it valuable to have a screen like *Messages to reaching out*. After asking about whether adding examples would be beneficial or more harmful, one expert said all of the message spaces could already be filled with a standard message directed to different sorts of people that could be in the life of the user. They would then have a blank space for the name so the user would only make very small adjustments. The other suggested having two distinct but very general examples in it as a guideline for someone who does not know how to start, and then leave the others empty as it is personal.

In the *Emergency screen*, both the section of emergency numbers and of personal contacts were seen as helpful for reaching out. However, while one of the experts was positive about leaving space on the screen to store personal information to have on hand, the other was quite sceptical on whether people would use it and in the moment remember they wrote something there.

Specifically for the *I need to contact someone I know screen*, one expert pointed out that it would be important to add some sort of text encouraging the user to communicate to the contact they are saving on this screen. They should tell them that they put their name and number in their emergency screen for reaching out and why. They then proceeded to find similarities with a prevention plan that people suffering from mental health issues can be advised to set up, and that having this plan in the app could be a more useful alternative over the paper or document version. They suggested looking into these prevention plans and some basic setups of the different ones, to see if it could be integrated into the application.

8.3.5 Design requirement 5: the app aims to help to separate the individual from their eating disorder voice

According to one expert, having a table with an eating disorder thought and corresponding counter thought is helpful for the separation between the two. They mentioned how they are usually key thoughts that keep coming back, so once one has a proper counterthought, having them in an overview could be used a lot. They did however also mention that while the target group most likely knows the ‘eating disorder voice’ in practice as well as the term, it can be harder to know that there is also a healthy voice or thought that is their own. They suggested providing a link at the top to somewhere where this distinction is explained, perhaps that has tips on how to find a healthy voice, so the table can be used more effectively. They also suggested providing just one very general example in the table.

When asked whether it would be useful or not to include an insights section, where the user could track which thoughts are most common and look for patterns on when certain thoughts occur the most, they said they would not recommend this to this target group.

They said this would be more for those already in therapy or further in therapy, and that having a table like this, with one example and the link to a further explanation, would be work enough for those coping with their disorder without any professional help.

The other expert thought the table itself and the idea of it was helpful but not the way the two columns were labelled. They believed ‘My thought’ not to have success as the user would not know what ‘my’ means. Instead, they suggested changing it to for example ‘My hero thought’ or ‘My warrior thought’, for it to be easier to imagine for the user. While discussing this screen, they started touching upon the idea to stray from the ‘eating disorder voice’ and making the table about general negative thoughts. They said to change the ‘my ED thought’ to ‘my inner critic’ or ‘my unhealthy thought’ for it to be broader in use.

8.3.6 Other suggestions

One of the experts recommended including a step by step instructional video in nearly all of the screens. They said that the user would need to be guided through the application for them to use the included features. The other expert, however, only mentioned believing an instructional video to be helpful in the *Distraction activities screen*.

The full new feature one expert suggested, mentioned in chapter 8.3.2, was a screen consisting of a table similar to the *Eating disorder voice screen* but concerning the positive and the negative aspects of an eating disorder for the individual. They explained how for those looking from the outside it likely looks like an eating disorder only brings negatives and it can be hard to understand why someone suffering from one would not feel like they want to pursue recovery immediately. However, to a sufferer the eating disorder can bring a lot of comforts or a sense of security, and there are aspects of the eating disorder that seem positive to them. Choosing to try to recover means letting go of those positives, and the expert mentioned that this goes with a process of acceptance and grief. They said they would believe it to be very valuable to have a section in the application where individuals could store and keep working on a pros and cons list, so they can have an overview of what they are dealing with and what they have to give up to get better, but also why getting better would be worth it.

Lastly, one of the experts suggested incorporating the circle of motivation in the application, as in several separate screens of the prototype they mentioned it fit into a certain phase of this circle. They said having easy access to this circle can already help someone to assess how they are doing concerning their disorder, and that based on the different phases, certain sections of the application would be more useful than others. It would be interesting to see whether there is a way to incorporate this and have the user be redirected to different sections of the application based on the phase they are in at that moment.

Chapter 9: Conclusion

This research aimed to explore the research question “How could a self-help tool, such as an app, help people suffering from an eating disorder or recovering from an eating disorder, get through a crisis situation, such as the COVID-19 pandemic?”. For this, first, the target group and the different problems experienced by its individuals, as well as which issues were amplified or were newly added as a direct consequence of the COVID-19 pandemic, were analysed through existing literature and the use of forums, blog posts, and YouTube videos coming from the target group. After this, the underserved population of eating disorder sufferers was studied and a state of the art research was held on applications and self-help tools in eating disorder treatment. With the knowledge gathered on the problem context, the target group, and the potential of smartphone applications to reach an underserved population, the rest of the project consisted of using this knowledge to design and build a smartphone application prototype for the use described in the research question, and evaluating it.

With features such as breathing exercises, recovery stories, resources, journaling prompts, helplines, and an eating disorder thought vs. counterthought table, the created prototype attempts to fulfil its design requirements of helping to calm down, to uplift and motivate, to inform, to communicate and reach out, and to separate the individual from their eating disorder voice. The prototype was first evaluated by test participants that did not belong to the target group by making use of methods such as scenario-based tasks and single ease questions, and the system usability scale. The prototype was well received by this group, including high scores on the single ease questions and system usability scale, and agreement on that it could serve well as a support tool.

After this, it was presented to two experts in the field of eating disorders. While based on the expert reviews nearly all features could be seen as helpful to those with eating disorders, often it was seen as helpful to a certain extent. For many features, their design requirement was mostly fulfilled as they were seen as beneficial, but many suggestions were given on how these features could be improved. Interestingly, the opinion of the two experts seemed to clash on multiple aspects where they gave suggestions and recommendations. One seemed to base most suggestions on what to include to encourage the user to use it more, while the other based suggestions rather on not overwhelming the user and helping to take it slow. Both did consider the prototype to have the potential to become a valuable support tool for those suffering from eating disorders.

The main limitation here is that the prototype has not been tested with the target group, those who would be best in assessing its utility, and whose opinion is most valuable on this. The experts did not consider the prototype to be triggering or harmful to the target group, and so

while answers could partly be gathered through non-target testers and expert reviews, letting the target group assess the (next iteration of) the prototype is the logical and necessary next step to accurately assess this project and more properly answer the research question.

Chapter 10: Discussion

9.1 Contributions

The problem of not being able to conduct in-person interviews with people from the target group during the COVID-19 pandemic that was initially seen as a limitation, led to one of the contributions of this research. While in-person interviews have many benefits, this restriction sparked the research on problems experienced by the target group to take place online. This led to the interesting method of exploring YouTube videos and forums as main media, to find a certain rawness and honesty in some stories, sometimes anonymous, that would likely not have come to light if a question was asked in an interview setting. By listening and reading to stories, likely many more individuals' experiences could be part of the research than would have been possible within this same time frame if in-person interviews would have taken place.

Listening to many individuals express themselves freely was also beneficial for the use of empathy in the design process. Watching the videos felt like they had an added value as compared to the stories read, as emotion could be heard in the voices. As empathy was a major point in this design process, this way of observing the target group facilitated the use of the Framework for empathy in design and the Ethical toolkit (both discussed in chapter 3). This makes it likely that it would also facilitate the use of other models based around empathy that despite not having been used would have fit the project, such as the Design Thinking Bootleg from Hasso Plattner Institute of Design at Stanford ⁶¹ in which empathy is seen as the foundation of human-centred design.

While there are certainly other applications on the market that contain similar features to the developed prototype, such as the Rootd app ⁶² (focused on panic and anxiety relief), Rise Up + Recover ⁶³ (focused on eating disorder monitoring), and the VGZ Mindfulness coach ⁶⁴, the prototype does not only aim to create a collection of all these different types of exercises to be useful for eating disorder sufferers, but also actively avoids including any potentially triggering content. A contribution of this project would be the constant reflection on whether each aspect can be considered valuable *without being harmful* in designing for a sensitive target group in a sensitive world state. The prototype avoids triggers based on the regular problems of the target group but also based on the current pandemic by listening to people's stories. This process will make clear that the question of what not to include is equally important as what to

⁶¹ Design Thinking Bootleg: <https://dschool.stanford.edu/resources/design-thinking-bootleg>

⁶² Rootd: <https://www.rootd.io/>

⁶³ Rise Up + Recover from Recovery Warriors: <https://www.recoverywarriors.com/app/>

⁶⁴ VGZ Mindfulness coach: <https://www.vgz.nl/mindfulness-coach-app>

include. When designing a new app for a sensitive target group based around specific circumstances, a similar approach can be taken to make sure that something well-intentioned would not accidentally end up doing more harm than good.

The prototype of this application could, for example, also be seen as an application for use in a regular world state, without the pandemic going on. It would not make too much of a difference, as the pandemic mostly influenced potential features being taken out. However, if the pandemic and its effects had not been considered in the design process, the prototype would only be safe to use in normal times and could be harmful to use in times of COVID-19.

9.2 Limitations

A large part of the foundation of this project consists of the analysed problems of the target group. While using forums and videos for this has its strengths, in this also lie some limitations. Firstly, in contrast to in an interview with a target user where the participant communicates to contribute to the research, the stories read and heard online could be expressed with any purpose in mind. If a participant is asked to name their struggles for participation in research, it would not be uncommon for them to start naming struggles that are straightforward to them but that they know the researcher might not know. While taking stories from an eating disorder forum can provide information that would be less likely to come up during a research interview, it also comes with the risk that in such research the for the target group seemingly obvious problems are omitted – they are after all expressing themselves to others likely struggling with the same.

Secondly, by basing analysing problems of eating disorder sufferers on these stories, one is already looking at a group with a certain base level of awareness or acceptance, and certain expressional skills for them to be able to speak or write about it online. This can exclude the problems of the group that might be equally struggling with specific issues but is not able to verbalise those (yet). Terms such as the eating disorder voice, or eating disorder thoughts (as opposed to talking about own voice and thoughts) for example seemed like a concept known and used by near everyone in the desk research conducted. The problems were commonly about it being hard to differentiate the eating disorder from oneself or not listening to the eating disorder in the moment, but all individuals mentioning this had to be at least to some extent aware that separating themselves from their eating disorder is possible. This came back in the expert review, when an expert recommended adding a link to an explanation of the concept in the *Eating disorder voice screen* before getting straight into the table aimed to help, in case someone might not know. Those who might not know, might be the ones overlooked in the desk research because of this.

During this research, no evaluation took place with the target group due to limitations in the speed of ethical approval. This was a critical limitation as the main aim of the way of conducting this research was to keep the target user centre throughout the process. To make up at least partly for this, the expert evaluation was changed to be shaped towards how helpful they imagined the prototype to be for the target user instead of focusing mainly on whether the prototype was safe to be tested by the target group. In this expert evaluation, it would have been useful to then involve more than two experts. As the two experts clashed in opinion on some aspects, it is hard to conclude on what to adapt or not adapt in certain evaluated features.

Not testing with the target group also showed a brief problem when testing the mock-up. It affected the execution of one of the task-based scenarios as the term ‘eating disorder voice’, likely known to those from the target group, caused trouble navigating for those not in the target group. For the evaluation of the prototype, it was made sure that that time the term would be explained within the same task. However, while this was thought to be caused by participants not belonging to the target group, based on the discussion with one of the experts, as mentioned above, even when working with the target group it is good to explain.

Another limitation of this research was the design process of the visual layout of the application, as this could have been done in a more structured manner. While the application was considered appealing by research participants, in the expert evaluation one expert thought the colours were very fitting and the other thought they should change. Both comments of the experts are opinions and they clash with each other. As the decisions made in the designing of the visual layout and choosing of the colours were not based on deeper evidence or theory, there is no foundation to justify leaning more towards the opinion of one or the other expert now.

The function testing done together with the pilot test could also have been more extensive and should be more extensive when a next iteration of the prototype would be tested. The function testing in this research included making sure that everything worked well enough for the usability test to be able to be executed smoothly. However, since the usability test followed a set list of tasks and some free navigation just to explore, it was unlikely that a participant would try to do something greatly unexpected or overuse certain features. Before sending a prototype out to be tested for a longer period or without a questionnaire to follow, and of course when sending out a final application, much more thorough function testing needs to be done.

Lastly, another evaluation limitation was that since the prototype is designed for support and does not have a clear, active intervention as its goal, it is harder to properly evaluate how successful or unsuccessful it turned out. In this research, participants evaluated the prototype during their first time using it, and potential excitement of a first time user could have influenced the results of the evaluation to be more positive. Besides, the context in which the

final application would be used also includes states of panic and distress, and one should consider the possibility of the user's hands shaking or eyes tearing up. This could influence the smoothness of the navigation and usability, and the conducted usability test did not test on this type of user context.

9.3 Future recommendations

Continuing with the last point of the limitations, a long-term study where people have access to such a self-help tool would be interesting for finding out whether it can be proven to be beneficial on long term use, or whether participants would even use it at all after some time has gone by. Perhaps in such research, the participants, ideally from the target group, would be able to identify and come forward themselves with what they would like to see in a support application. Apart from regular evaluation from the target group, more extensive collaboration with these individuals would be the only way to get to an optimal product. Involving target users earlier on, could for example help with the first-mentioned limitation. A target user could go over the list of problems researched, and help check if anything would have been missed out on or whether there is some selection bias that is easier to identify by the target group themselves.

Involving experts earlier in the process could also be beneficial. Having an eating disorder expert within the design team could help with the constant reflection on whether a decision made could be potentially harmful to the target group. For evaluations done with non-target groups, an expert could help with pointing out what parts of the evaluation set up would likely differ greatly if it was being tested with the target group, and perhaps help find ways to minimise these differences and get the most out of each evaluation.

In a next evaluation with experts where the experts also once belonged to the target group (like was the case in the expert review in this research), asking questions about what type of eating disorder they used to have and possibly about how they dealt with it themselves, could be of value. While this cannot be concluded from just these two expert reviews, it would be possible that the opposing opinions from the expert reviews would be influenced by their eating disorder type or past treatment, as both occasionally touched upon their past struggle during the review. As a future recommendation as well it would be better to consult a larger number of experts, to be able to speak of a majority or minority agreeing or disagreeing, instead of having two opinions opposing.

Apart from this, a topic that would be interesting to explore in future research would be the problems that individuals with eating disorders experience in situations where food needs to be bought, even if it is not eaten in public. The experience of doing groceries for someone with an

eating disorder can be very intense, even worse with the pandemic. While this project did seriously consider the pandemic, it mostly left features out based on it. Creating a research and prototype specifically targeted towards getting the target user to go to those places that they need to go to but that are especially triggering in a crisis situation, and creating something to help in such specific context, would be very challenging but interesting and worth exploring.

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Appendix A:



DSM-V DIAGNOSTIC CRITERIA FOR EATING DISORDERS

Pica

- A. *Persistent eating of nonnutritive, nonfood substances over the period of at least 1 month.*
- B. *The eating of nonnutritive, nonfood substances the inappropriate to the developmental level of the individual.*
- C. *The eating behaviour is not part of a culturally supported or socially normative practice.*
- D. *If the eating behaviour occurs in the context of another mental disorder (e.g. intellectual disability, autism spectrum disorder) or medical condition (e.g. pregnancy), it is sufficiently severe to warrant additional clinical attention.*

Rumination Disorder

- A. *Repeated regurgitation of food over the period of at least one month. Regurgitated food may be re-chewed, re-swallowed, or spit out.*
- B. *Not attributable to an associated gastrointestinal or other medical condition (e.g. reflux).*
- C. *Does not occur exclusively during the course of anorexia nervosa, bulimia nervosa, binge-eating disorder, or avoidant/restrictive food intake disorder.*
- D. *If symptoms occur in the context of another mental disorder (e.g. intellectual disability), they are sufficiently severe to warrant additional clinical attention.*

Avoidant/Restrictive Food Intake Disorder

- A. *A feeding or eating disturbance (e.g. lack of apparent interest in eating food; avoidance based on the sensory characteristics of food; concern about aversive consequences of eating) as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following:*
 - 1. *Significant weight loss (or failure to achieve expected weight gain or faltering growth in children).*
 - 2. *Significant nutritional deficiency.*
 - 3. *Dependence on enteral feeding or oral nutritional supplements.*
 - 4. *Marked interference with psychosocial functioning.*

- B. *The disturbance is not better explained by lack of available food or by an associated culturally sanctioned practice.*
- C. *The eating disturbance does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way in which one's body weight or shape is experienced.*
- D. *The eating disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder. When the eating disturbance occurs in the context of another condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention.*

Anorexia Nervosa

- A. *Restriction of energy intake relative to requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health. Significantly low weight is defined as a weight that is less than minimally normal or, for children and adolescents, less than minimally expected.*
- B. *Intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain, even though at a significantly low weight.*
- C. *Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.*

Specify whether:

Restricting type: *During the last three months, the individual has not engaged in recurrent episodes of binge eating or purging behaviour (i.e. self-induced vomiting, or the misuse of laxatives, diuretics, or enemas). This subtype describes presentations in which weight loss is accomplished primarily through dieting, fasting and/or excessive exercise.*

Binge-eating/purging type: *During the last three months the individual has engaged in recurrent episodes of binge eating or purging behaviour (i.e. self-induced vomiting, or the misuse of laxatives, diuretics, or enemas).*

Specify current severity:

Mild: BMI more than 17

Moderate: BMI 16- 16.99

Severe: BMI 15-15.99

Extreme: BMI less than 15

Bulimia Nervosa

- A. *Recurrent episodes of binge eating. An episode of binge eating is characterized by both:*

1. *Eating in a discrete period of time (e.g. within any 2 hour period), an amount of food that is definitely larger than what most individuals would eat in a similar period of time under similar circumstances;*
 2. *A sense of lack of control over eating during the episodes (e.g. a feeling that one cannot stop eating or control what or how much one is eating).*
- B. *Recurrent inappropriate compensatory behaviors to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, or other medications; fasting; or excessive exercise.*
- C. *The binge eating and inappropriate compensatory behaviors both occur, on average, at least once a week for 3 months.*
- D. *Self-evaluation is unduly influenced by body shape and weight.*
- E. *The disturbance does not occur exclusively during episodes of anorexia nervosa.*

Specify current severity:

Mild: *An average of 1-3 episodes of inappropriate compensatory behaviours per week.*

Moderate: *An average of 4-7 episodes of inappropriate compensatory behaviours per week.*

Severe: *An average of 8-13 episodes of inappropriate compensatory behaviours per week.*

Extreme: *An average of 14 or more episodes of inappropriate compensatory behaviours per week.*

Binge-Eating Disorder

- A. *Recurrent episodes of binge eating. An episode of binge eating is characterized by both:*
1. *Eating in a discrete period of time (e.g. within any 2 hour period), an amount of food that is definitely larger than what most individuals would eat in a similar period of time under similar circumstances;*
 2. *A sense of lack of control over eating during the episodes (e.g. a feeling that one cannot stop eating or control what or how much one is eating).*
- B. *Binge eating episodes are associated with three or more of the following:*
1. *Eating much more rapidly than normal.*
 2. *Eating until feeling uncomfortably full.*
 3. *Eating large amounts of food when not feeling physically hungry.*
 4. *Eating alone because of feeling embarrassed by how much one is eating.*
 5. *Feeling disgusted with oneself, depressed, or very guilty afterwards.*
- C. *Marked distress regarding binge eating is present.*
- D. *The binge eating occurs, on average, at least once a week for 3 months.*
- E. *The binge eating is not associated with the recurrent use of inappropriate compensatory behavior as in bulimia nervosa and does not occur exclusively during the course of bulimia nervosa or anorexia nervosa.*

Specify current severity:

Mild: *1-3 binge eating episodes per week.*

Moderate: 4-7 binge eating episodes per week.

Severe: 8-13 binge eating episodes per week.

Extreme: 14 or more binge eating episodes per week.

Other Specified Feeding or Eating Disorder

- Symptoms characteristic of a feeding or eating disorder that cause clinical distress or impairment in social, occupational, or other important areas of functioning predominate.
- However DO NOT meet the full criteria for any of the disorders in the feeding and eating disorders diagnostic class.
- This category can also be used in situations to communicate the specific reason the presentation does not meet the criteria for a specific eating disorder.
- This is done by recording “other specified feeding or eating disorder” followed by the specific reason e.g. “bulimia nervosa- low frequency”.

Examples:

1. **Atypical Anorexia Nervosa:** all of the criteria for anorexia nervosa are met, except that despite significant weight loss, the individual’s weight is within or above the normal range.
2. **Bulimia Nervosa (of low frequency and/or limited duration):** all of the criteria for bulimia nervosa are met, except that the binge eating and inappropriate compensatory behaviors occur, on average, less than once a week and/ or for less than 3 months.
3. **Binge-eating disorder (of low frequency and/or limited duration):** all of the criteria for binge-eating disorder are met, except that the binge occurs, on average, less than once a week and/ or for less than 3 months.
4. **Purging disorder:** recurrent purging behavior to influence weight or shape (e.g. self-induced vomiting; misuse of laxatives, diuretics, or other medications) in the absence of binge eating.
5. **Night eating syndrome:** Recurrent episodes of night eating, as manifested by eating after awakening from sleep or by excessive food consumption after the evening meal. There is awareness of recall of the eating. The night eating is not better explained by external influences such as changes in the individual’s sleep-wake cycle or by local social norms. The night eating causes significant distress and/or impairment in functioning. The disordered pattern of eating is not better explained by binge-eating disorder and or another mental disorder, including substance use, and is not attributable to another medical disorder or to an effect of medication.

Unspecified Feeding or Eating Disorder

- Symptoms characteristic of a feeding and eating disorder & cause clinical significant distress or impairment in social, occupational or other important areas of functioning predominate.

- *However DO NOT meet the full criteria for any of the disorders in the feeding and eating disorders diagnostic class.*
- *Used when the clinician chooses not to specify the reason that criteria are not met for a specific feeding and eating disorder.*
- *This includes times when there is insufficient information to make a more specific diagnosis (e.g. in emergency room setting).*

For further information please refer to: <http://www.dsm5.org/>

Appendix B: Information Brochure⁶⁵

<p>Background</p> <p>Eating disorders are serious illnesses with severe negative consequences on both mental and physical health. Daily life can become very hard for sufferers.</p> <p>The COVID-19 pandemic adds to the daily struggles in various ways. The virus, the accompanying measures, and the uncertainties have taken a toll on the population's mental health in general. Those who already experienced (mental) health issues before this, have been impacted even more severely.</p> <p>Despite everyone suffering from eating disorders deserving help to overcome and deal with their illness and its effects, there is a large underserved population and the vast majority does not receive any treatment at all.</p> <p>Self-help tools can be of great value to those without (enough) treatment, and smartphone applications are one way to provide more accessible support.</p> <p>As a student of Creative Technology at the University of Twente, I am working on designing a self-help app for this target group in times of crisis.</p> <p>This is part of my bachelor graduation thesis, Supporting those with eating disorders in times of crisis, such as the COVID-19 pandemic as part of Supporting Healthy Eating through Technology.</p>	<p>Research types</p> <p>For this part of the project, I am looking for three different types of input:</p> <ul style="list-style-type: none"> A. Healthy adults (18+), who have a healthy relationship with food, to help in the design process leading up to a prototype app. B. Healthy adults (18+), who have a healthy relationship with food, to help for the evaluation of a finished app prototype. C. An expert in the field of eating disorders, to evaluate a finished prototype app and judge whether it is up for testing and evaluation by the target group themselves, as well as provide feedback on the prototype. 	<p>Supporting those with eating disorders in times of crisis, such as the COVID-19 pandemic</p> <p>Supporting Healthy Eating through Technology</p> <p>Paula Clemens Villa p.clemensvilla@student.utwente.nl</p> <p>Supervisors:</p> <p>Roelof de Vries r.a.j.devries@utwente.nl</p> <p>Robby van Delden r.w.vandelden@utwente.nl</p> <p>Graduation Project for Creative Technology, University of Twente</p>
<p>Research procedure</p> <p>This information brochure will provide information on what it means to participate in either of the aforementioned research types, for you to be able to make an informed decision on whether you would like to participate. Research types A and B will take place online through online questionnaires and virtual interviews, and type C can take place either online or in person depending on the expert's preference.</p> <p>If you have any questions, please contact Paula Clemens Villa, through p.clemensvilla@student.utwente.nl.</p> <p>Participation</p> <p>Participation is fully voluntary. If desired, you can stop participating at any point in the research, without any obligation to explain why.</p> <p>Your participation in the research, and the collection of the data from your input, will only happen after you have given explicit consent by signing the corresponding consent form.</p> <p>Risk for accidental discovery in research type A and B</p> <p>By participating in research type A and B, you have indicated to be a healthy adult, with a healthy relationship with food. You will be presented with ideas and concepts for, or a full prototype of an app that deals with disordered eating and thoughts surrounding this.</p> <p>Based on the content you are presented with and how this makes you feel, it could happen that you accidentally discover that your relationship with food turned out to be not as healthy. If any of the content you are presented with makes you feel uneasy or uncomfortable in this way, please withdraw yourself from the research.</p>	<p>What will happen during the research?</p> <p><u>Research type A</u></p> <p>You will be asked for input in the design process of the app. You will receive questions through an online questionnaire where you will be presented with concepts for (part of) the app. You might be asked to rate certain aspects, or choose between different options to find out what you would find more fitting and why.</p> <p><u>Research type B</u></p> <p>You will be asked to evaluate a finished app prototype, whilst keeping in mind that this is designed for people with eating disorders. You will use the app for a few days, and answer questions that will help to properly evaluate it. If you have given permission for this on your consent form, an additional virtual interview will take place.</p> <p><u>Research type C</u></p> <p>You will be asked to evaluate a finished prototype app, and judge its suitability for being tested and evaluated by people with eating disorders. You will be informed about the app, sent the app for you to go through or shown the app, and will be interviewed about this.</p> <p>What data will be collected?</p> <p>Your answers to the questions from the questionnaires or evaluation will be collected. In the case you participate in the interviews, these will be recorded if permission was given for this.</p> <p>How will the data be saved?</p> <p>The collected data will be saved securely and processed anonymously according to AVG guidelines. The research data is stored for at least 10 years according to VSNU guidelines.</p>	<p>Who can access the data?</p> <p>All data collected is only accessible to those directly involved in this research. A list of names of those who have access can be requested by asking Paula Clemens Villa.</p> <p>How will the data be used?</p> <p>The data will be analysed for this graduation thesis. The results will be used for the development of an app aimed to help support those with eating disorders through crisis times. Results discussed in the graduation thesis are fully anonymous.</p> <p>Can I have my data deleted?</p> <p>If you decide to stop participating during this research, all data collected from you so far will be immediately deleted. After an interview, in the case this is recorded, you will be sent the recording and if you indicate you would like the recording deleted, this will be done. If you decide after the research that you would like your data deleted, this is only possible directly after your participation. After this, all data will have been made anonymous, making it impossible to link your data back to you and delete this.</p> <p>More information and independent advice</p> <p>If you would like to receive independent advice, or file a complaint with regard to this research, you can contact the Ethical Committee (ethics-comm-ewi@utwente.nl). This is a committee consisting of independent experts of the university, available for questions and concerns about this research.</p> <p>For any more questions you can contact Paula Clemens Villa, through the contact details on the front of this brochure.</p>

⁶⁵ The information brochure of the project “Smart Sports Exercises in Volleybal” by dr. Dees Postma and dr. ir. Dennis Reidsma, was used as an example for creating this brochure.

Appendix C: Consent forms⁶⁶



INFORMED CONSENT

Research

This consent form is part of the graduation project *Supporting those with eating disorders in times of crisis, such as the COVID-19 pandemic*, for Creative Technology at the University of Twente. This specific consent form is for **research type A**, described in the accompanying information brochure.

Researchers

This is the bachelor thesis of Paula Clemens Villa, supervised by Roelof de Vries and Robby van Delden.

Contact information

For questions about this research, you can contact Paula Clemens Villa (p.clemensvilla@student.utwente.nl) or you can contact the Ethical Committee (ethics-committee@utwente.nl). This is a committee consisting of independent experts of the university, available for questions and concerns.

Research A

I hereby declare the following:

- ☐ I have been fully informed with regard to the research. The goal and methods of the research have been explained to me and I have been able to ask questions as desired.
- ☐ I understand that I can stop my participation at any moment, without needing to explain why, and without any consequences.
- ☐ I give permission for my anonymous data to be used for this research, as described in the information brochure.
- ☐ I have been informed on the risk for accidental discoveries that can come with my participation, as described in the information brochure.

Date:

Location:

..... ✂
..... ✂

Participant name:

Participant signature:

⁶⁶ The consent form for the project “Smart Sports Exercises” with main researchers Dennis Reidsma, Robby van Delden, Dees Postma, Bert-Jan van Beijnum, Fahim Salim, Ivo van Hilvoorde, Jeroen Koekoek, and Wytse Walinga, was used as an example for creating these consent forms.

Ptcpt no.

INFORMED CONSENT

Research

This consent form is part of the graduation project *Supporting those with eating disorders in times of crisis, such as the COVID-19 pandemic*, for Creative Technology at the University of Twente. This specific consent form is for **research type B**, described in the accompanying information brochure.

Researchers

This is the bachelor thesis of Paula Clemens Villa, supervised by Roelof de Vries and Robby van Delden.

Contact information

For questions about this research, you can contact Paula Clemens Villa (p.clemensvilla@student.utwente.nl) or you can contact the Ethical Committee (ethics-committee@utwente.nl). This is a committee consisting of independent experts of the university, available for questions and concerns.

Research B

I hereby declare the following:

- ☐ I have been fully informed with regard to the research. The goal and methods of the research have been explained to me and I have been able to ask questions as desired.
- ☐ I understand that I can stop my participation at any moment, without needing to explain why, and without any consequences.
- ☐ I give permission for my anonymous data to be used for this research, as described in the information brochure.
- ☐ I have been informed on the risk for accidental discoveries that can come with my participation, as described in the information brochure.

In the case of agreement to participation in recorded interviews, recordings will only be available for access to the researchers directly involved in this project, and will never be made public. All data will be saved securely and processed anonymously according to AVG guidelines. The research data is stored for at least 10 years according to VSNU guidelines.

The following is not mandatory for participation:

- ☐ I give permission to participate in recorded interviews, of which the data will be handled in the way I have read about in the information brochure.

Date:

Location:

Participant name:

Participant signature:

INFORMED CONSENT

Research

This consent form is part of the graduation project *Supporting those with eating disorders in times of crisis, such as the COVID-19 pandemic*, for Creative Technology at the University of Twente. This specific consent form is for **research type C**, described in the accompanying information brochure.

Researchers

This is the bachelor thesis of Paula Clemens Villa, supervised by Roelof de Vries and Robby van Delden.

Contact information

For questions about this research, you can contact Paula Clemens Villa (p.clemensvilla@student.utwente.nl) or you can contact the Ethical Committee (ethics-committee@utwente.nl). This is a committee consisting of independent experts of the university, available for questions and concerns.

Research C

I hereby declare the following:

- ☐ I have been fully informed with regard to the research. The goal and methods of the research have been explained to me and I have been able to ask questions as desired.
- ☐ I understand that I can stop my participation at any moment, without needing to explain why, and without any consequences.
- ☐ I give permission for my anonymous data to be used for this research, as described in the information brochure.

Recordings will only be available for access to the researchers directly involved in this project and will never be made public. All data will be saved securely and processed anonymously according to AVG guidelines. The research data is stored for at least 10 years according to VSNU guidelines.

- ☐ I give permission to participate in recorded interviews, of which the data will be handled in the way I have read about in the information brochure.

Date:

Location:

..... ✂
 ✂

Participant name:

Participant signature:

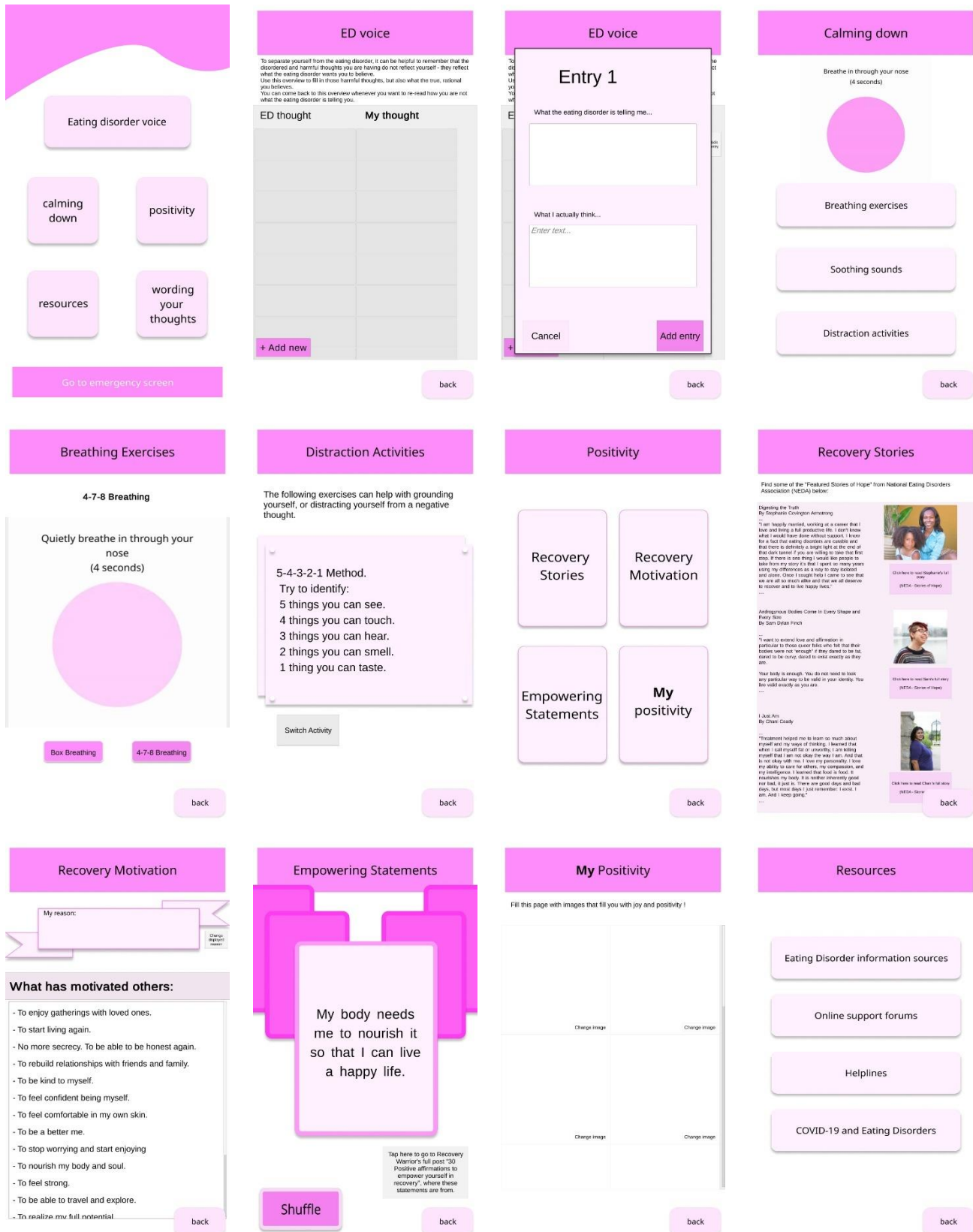
Appendix D: Recovery motivation

List of 17 reasons included in the screen, all coming from other eating disorder sufferers.

What has motivated others:

- To enjoy gatherings with loved ones.
- To start living again.
- No more secrecy. To be able to be honest again.
- To rebuild relationships with friends and family.
- To be kind to myself.
- To be confident being myself.
- To feel comfortable in my own skin.
- To be a better me.
- To stop worrying and start enjoying.
- To nourish my body and soul.
- To feel strong.
- To be able to explore.
- To realize my full potential.
- To be there for those I care about.
- To prove to myself that I am more than my eating disorder.
- To do the things I've always wanted to.
- To work towards my goals, without my eating disorder holding me back.

Appendix E: Screenshots prototype



Eating Disorder information sources

Learn - What are eating disorders?
(National Eating Disorders Association (NEDA))

Eating disorders explained
(Butterfly Foundation, national eating disorder charity Australia)

Learn More About Eating Disorders
(Academy for Eating Disorders (AED))

DSM-V Diagnostic Criteria for Eating Disorders
(BodyKitchen Australia)

Signs and Symptoms of Eating Disorders
(BodyKitchen Australia)

Dutch: Wat is een eetstoornis?
(Human Connect - Centrum voor eetstoornissen)

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Online support forums

The following forums are all free for you to use and make an account for:

Eating Disorder Recovery Forum WMDN
(WhitlatchHers, administrator: Mia-Fridley (Recovery Coach at Beyond Body Coaching))

NEDA - Feeding Hope: Eating Disorder Forums
(National Eating Disorders Association (NEDA))

Dutch: Proud2Be Forum Eetstoornissen
(Proud2Be, Largest online eating disorder help website for The Netherlands and Belgium)

back

Wording your thoughts

Journaling prompts

Messages for reaching out

From feelings to words

back

Journaling prompts

Margherita Tartakovsky, M.S., (writer, and associate editor and contributor at PsychCentral.com, with a master's degree in clinical psychology) put together a list of prompts on a blog post titled "30 Journaling Prompts for Self-Reflection and Self-Discovery".

Go to blog post

Show full list here

Name a compassionate way you've supported a friend recently. Then write down how you can do the same for yourself.

Show new prompt

back

Journaling prompts

Margherita Tartakovsky, M.S., (writer, and associate editor and contributor at PsychCentral.com, with a master's degree in clinical psychology) put together a list of prompts on a blog post titled "30 Journaling Prompts for Self-Reflection and Self-Discovery".

1. My favorite way to spend the day is...
2. If I could talk to my teenage self, the one thing I would say is...
3. The two moments I'll never forget in my life are... Describe them in great detail, and what makes them so unforgettable.
4. Make a list of 30 things that make you smile.
5. "Write about a moment experienced through your body. Making love, making breakfast, going to a party, having a fight, an experience you've had or you imagine for your character. Leave out thought and emotion, and let all information be conveyed through the body and senses." (A prompt from Barbara Alexander's creative book Kicking in The Wall: A Year of Writing Exercises. Prompts and Questions To Help You Break Through Your Blocks And Reach Your Writing Goals.)
6. The words I'd like to live by are...
7. I couldn't imagine living without...
8. When I'm in pain — physical or emotional — the kindest thing I can do for myself is...
9. Make a list of the people in your life who genuinely support you, and who you can genuinely trust. (Then make time to hang out with them.)
10. What does unconditional love look like for you?
11. What would you do if you loved yourself unconditionally? How can you act on these things whether you do or don't?
12. I really wish others knew this about me...
13. Name what is enough for you.
14. If my body could talk, it would say...
15. Name a compassionate way you've supported a friend recently. Then write down how you can do the same for yourself.

back

Messages for reaching out

Here you can store some messages to send in moments you want to reach out to people.

When you feel the need to reach out, you will only have to copy the message to your clipboard with the button and send it, without having to worry about your wording in the heat of the moment.

1. I want to describe...
2. I want to describe...
3. I want to describe...
4. I want to describe...
5. I want to describe...

back

From feelings to words

When it's difficult to find words to describe what is going on, you can use this tool to help you come to some ideas. You can use the buttons to navigate, and when you get to the individual words you can click on a word and it will automatically save to your clipboard.

I want to describe...

go back up

a tone

a feeling

an emotion

The list of Adjectives to Describe Tone, Feelings, and Emotions are from "YouDictionary". Click here to go to the "YouDictionary" webpage.

back

From feelings to words

When it's difficult to find words to describe what is going on, you can use this tool to help you come to some ideas. You can use the buttons to navigate, and when you get to the individual words you can click on a word and it will automatically save to your clipboard.

I want to describe...

go back up

aggravated

awful

chilly

depressed

terrible

tired

ugly

dirty

weak

dreadful

irritated

heavy

tearful

pessimistic

tense

The list of Adjectives to Describe Tone, Feelings, and Emotions are from "YouDictionary". Click here to go to the "YouDictionary" webpage.

back

Help breathing

I need to contact someone I know

I need to call for external help

Put your own quote here

Use this space to fill it with any information that might be good to have on hand when reaching out. For example: Insurance information, your address, your schedule, etc.

(tap to edit)

back

I need to reach someone I know

1. I need to reach someone I know
2. I need to reach someone I know
3. I need to reach someone I know

To Messages for reaching out

back



Appendix F: Evaluation #2 Results

Scenarios based tasks

Scenario 1:

	Did you manage to complete this task?	Overall, how easy or difficult did you find it to perform this task?	Please explain why you gave the score you gave.
1	Yes	7	Self explanatory paths. This feature was also almost highlighted in the home screen, so getting to it was a piece of cake. On top of that the app simply did the logging. quite to the point, nothing complicated about it (which is good I guess).
2	Yes	2	I couldn't find a log option. I tried first "Wording your thoughts".
3	Yes	7	it was very straight forward, the eating disorder voice button was the first button, and the 'add new' button was clearly there
4	Yes	7	It was clearly visible at the top and there are additional instructions under ED voice
5	Yes	6	Few options and rational process

Scenario 2:

	Did you manage to complete this task?	Overall, how easy or difficult did you find it to perform this task?	Please explain why you gave the score you gave.
1	Yes	6	Again, the feature is simple and works. No bells or whistles to get in the way, just edit now, send it when I can. I did, however, get a little bit slowed down the by similar buttons having me read every single one, twice or so. Not that this took much longer, which is why I gave a 6, just wasn't super fast like the previous exercise (which got a 7).
2	Yes	6	I went to wording my thoughts and found the option there. After I wrote the message, I wanted to save but the button to save was written "Edit".
3	Yes	6	it was not super straightforward that it was under wording your thoughts, but still easy to find considering it was not likely to be part of any other section
4	Yes	7	It was easy to find and the descriptions of the labels are clear (messages for reaching out)
5	Yes	6	You are directed to the process

Scenario 3:

	Did you manage to complete this task?	Overall, how easy or difficult did you find it to perform this task?	Please explain why you gave the score you gave.
1	Yes	5	The path to this one task was a little bit more complicated, with similar sounding pages together with the similar looking boxes. For example I got a little bit confused between going from my positivity for my motivation. On top of that, something that didn't bother me was the word limit for my motivation, though it would be nice to mention that this was going to be a thing in the popup screen like twitter (I think).
2	Yes	7	I wanted to motivate myself, so "Positivity" was my first try
3	Yes	7	it makes sense that demotivated means something negative, so to get motivated you go to positivity and then to motivation- adding a reason was straight forward process

4	Yes	7	It is clear how to find different support options and also messages on positivity, which are really nice!
5	Yes	7	Two clicks and you are there

Scenario 4:

	Did you manage to complete this task?	Overall, how easy or difficult did you find it to perform this task?	Please explain why you gave the score you gave.
1	Yes	6	It was really easy to find it in the app, very straight forward. Although, I did get confused about the two different places with breathing activity, though I would guess that if you got to know the app this would be fine, however I would think that if I was in a panic and looking for a breathing exercise, maybe I would not appreciate too much a preliminary semi breathing exercise.
2	Yes	7	Having "Calm" in the menu, I instantly clicked there when I want to calm down
3	Yes	6	i went to calming down and then again to breathing exercises to find the specific exercise, it was not clear whether the one on calming down screen was already 478 breathing though
4	Yes	7	Easy to find under calming down!
5	Yes	5	Some technical wording

Scenario 5:

	Did you manage to complete this task?	Overall, how easy or difficult did you find it to perform this task?	Please explain why you gave the score you gave.
1	Yes	7	The prompts to this page are simple. The page itself is super self explanatory and yet keeps things clean and to the point; this made getting to the feeling very easy, and especially requiring little thinking.
2	Yes	6	I found the correct menu, but I didn't know that clicking a button would copy the word. I kept clicking without any result.
3	Yes	7	it made sense where to find it and copying to clipboard worked
4	Yes	7	Easy to find under "from feelings to words"
5	Yes	5	Screen kept the last choice I made. Easier if get back to start by itself

Questions after free navigation and full exploration of the application prototype

	Overall, how easy or difficult did you find navigating through the app?
1	7
2	7
3	7
4	7
5	6

	Did anything in particular from the app stand out in a positive way?	Did anything in particular from the app stand out in a negative way?
1	Yes, many things. For one, the cleanliness of the pages and the softness of the tones, without giving a feeling of weakness. It is quite powerful and makes the use of it very pleasing. In addition to this, there is still a gleeful aesthetic to it that is much appreciated. The facility of having somewhere on my phone that I can quickly go to and try to organize my head is so useful and comforting, and the fact that this app is there to just use and go is very nice (as in, I don't have to try and hack something here or there to make the most of it).	The only thing that I can think is that there is quite a lot of words and similar shapes and tones (color). This did create a certain need to memorize the places of things or have me reading a bunch and trying to process what it might lead to. I found that this slowed down my getting to places on the app but not significantly.
2	The clear text and flow inside the application.	The size of some texts are not uniform.
3	it was easy to personalize and the layout was very friendly	soothing sounds was odd
4	Everything works very well! I especially like the part "positivity", with the different recovery stories and the empowering statements (that's really cool done!)	No
5	Positivity	Some items require previous work

	Keeping in mind that this app was designed for people suffering from eating disorders, do you believe the app could serve as a support tool?
1	7
2	7
3	7
4	7
5	6

	From the following words, please select the 5 words that you believe are most fitting to this app.
1	Good, Pleasant, Likeable, Motivating, Appealing
2	Attractive, Inviting, Pleasant, Motivating, Appealing
3	Attractive, Inviting, Pleasant, Motivating, Appealing
4	Good, Pleasant, Motivating, Appealing, Supportive
5	Good, Pleasant, Likeable, Motivating, Appealing

	If I were to belong to the target group for this app, I think I would like to use this app frequently.	I found the app unnecessarily complex.	I thought the app was easy to use.	I think that I would need the support of a technical person to be able to use this app.	I found the various features of this app were well integrated.	I thought there was too much inconsistency in this app.	I would imagine that most people would learn to use this app very quickly.	I found the app very cumbersome to use.	I felt very confident using the app.	I needed to learn a lot of things before I could get going with this app.
1	4	1	5	1	5	2	5	1	5	1
2	5	1	5	1	5	1	5	1	5	1
3	5	1	5	1	5	1	4	1	5	1
4	5	1	5	3	5	1	5	1	5	2
5	2	2	5	2	4	1	4	2	3	1