UiO **Department of Informatics**
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Participatory Design for Eating Disorders

A new mobile application – designed with and for young people challenged with eating disorders

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Abstract

Background
During the last decade youth have gained increased access to smartphone devices, partly fueled by the major development in mobile technology. Smartphone applications have an important, but unrealized potential toward enhancing healthcare. This thesis will investigate the intersection between mobile technology and eating disorders, by exploring the potential mobile technology have toward real users challenged with an eating disorder.

Objective
This study investigates how an in-depth knowledge of users lifeworld can shape the design of new mobile technology. The study places the potential user of technology at the center of the design process.

Methodology
The study uses Participatory Design as its primary methodology, including elements from Service Design. The design process focuses on the participation of two users, who have experience from challenges relating to eating disorders. The design process, consisting of three workshops, resulted in a high-fidelity prototype evaluated with the participants.

Theory
The study uses lifeworld as its theoretical framework, focusing on understanding the individual experiences of living with eating disorders.

Results
The design processes show the creation of LifeLine, a new qualitative research method intended to map a user experience connected with a time of day. This resulted in a collection of domain specific needs that shaped the requirements for the design of the mobile application, which reflects the participant's need for social interaction, motivation, privacy, and planning, with a goal of achieving individual well-being.

Conclusion
Lifeworld can be used as a framework to create technology that better aligns with the user groups vision for future technology. The study also shows how participatory design and service design can inform each other in a patient-centered research process, intended to co-create new

technology.

Acknowledgements

First, I would like to thank my amazing supervisors, Margaret and Maja. Thank you for providing regular and consistent feedback, guiding me through hard parts of the thesis and enabling me to make my own choices and mistakes throughout the thesis. You are both honest and extremely proficient, thank you so much for all your help. Margaret, without your guidance I would never have been able to deliver on time, I am very grateful. I have gotten many jealous comments from students on the seventh floor when explaining the dedication and detailed feedback you have provided. Before writing my thesis, I had heard stories of students not getting feedback and supervisors who didn't read through the student's text until the very last minute. You are the polar opposite of this preconception – a perfect example of what a supervisor should be like.

Special thanks to Markus and Eirik for beer-Thursdays and the self-proclaimed mandatory “kjernetid” [1] pushing me to show up, and stay at the University. I would also like to thank Martine (Leo-Leo), Martine and Karoline for random conversations and support, making it easier to get up in the morning, and harder to leave. You are all awesome.

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[1] working hours

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Nomenclature

AN - Anorexia Nervosa

BED - Binge Eating Disorder

BN - Bulimia Nervosa

EDs - Eating Disorders

EMA - Ecological Momentary Assessment

EMI - Ecological Momentary Interventions

GPS - Global Positioning System

OS - Operating System

PD - Participatory Design

SD - Service Design

TEC - Travel Experience Cards

VR - Virtual Reality

Chapter 1

Introduction

This thesis presents the design for a new mobile application – to aid young patients connected with eating disorders. Interaction design is an interdisciplinary approach, exploring the combination of different fields in a design process. The interdisciplinary aspect of design requires investigation the fields that constitute the research project. When you immerse yourself into a subject, you can uncover how complex and interconnected it is, regardless of your initial preconceptions. Eating disorders is a perfect example of this – the media paint a picture of the diagnosis, which in many ways is far from the reality. Eating disorders are highly complex psychosomatic [1] condition, with a high mortality rate. There is no unified treatment method for eating disorders, as the diagnosis can affect each person differently – a patient has a unique relationship to food, triggers, persons of importance, and treatment. Highlighting that everything relating to the diagnosis has a degree of subjectivity based on each person's individual experiences. My research will investigate this connection between mind and body, and how it connects to personal experiences with the diagnosis. Approaching this from a technological perspective, examining how their experiences can inform the design of new mobile technology, connects my research with the field of m-health.

The field of m-health explores mobile computing, sensors, and communication technology for the purpose of enhancing health care [160]. M-health originated from the field of e-health, which investigates the connection between information and communication technologies (ICT) and health [160]. Today, mobile technologies are a large part of our society, and as Lie et al. state, "[. . .] because m-health apps are a recent phenomenon, proven guidelines on what works and what does not in m-health app development have not emerged yet [102, pp.2022]." This thesis places the user at the center of the development process, in a participatory design process guided by a desire to investigate the potential mobile technology can have on the patients affected by eating disorders – uncovering what works and what does not work, in the context of their lived experience.

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[1] Psychosomatic is a term used to cover the connection between mind and body

1.0.1 Motivation

The initial motivation for the thesis is a result of my participation in the KULU research project. The KULU project based at the Department of Informatics at the University of Oslo, exploring the possibilities of creating cool technology for youth with long-term health challenges. The idea that shaped the thesis was sparked after a discussion with a close family member, who works as a nurse at a large Norwegian health institution treating eating disorders (EDs). He illustrated the complexity of the condition, the different diagnosis, and the interplay between cognitive and physical challenges that affect and dominate the everyday life of patients. Highlighting how their department utilizes a limited amount of technology in their treatment programs, and that investigating what potential technology could have on EDs might be of interest to me. Aligning with the objective of my KULU research group, which works toward exploring the possibility of creating cool new technology for youth struggling with long-term health challenges.

The discussion sparked the idea which was further shaped by researching the domain. Eating disorders are gaining significant media attention in Norway, especially after a young girl's death in early 2016 [126, 127]. "No one in Norway should walk around with a deadly disease without the opportunity to get well. It is demanding, but possible to rid us of the disease [126][2]." The quote motivated me to gain more knowledge, investigating the possibility for my thesis. However small and humble my contribution might turn out – I wanted to create something that has the potential to help someone, somewhere, to feel better.

The Norwegian media authority [112] publishes annual reports on youth's media consumption. Findings from 2016 illustrate that 97% of youth (nine - sixteen years) have access to mobile phones [112]. The institute of information and media science [111] presents results covering the remaining part of the Norwegian population (fifteen and older). Showing how 83% have a personal smartphone [111]. These studies indicate, that a large part of the Norwegian population has access to smartphone technology. Surprisingly, there is limited focus on combining the two domains of eating disorders and mobile technology. The field of m-health acknowledges the potential mobile technology can have in the treatment of EDs. However, the field is emerging, and as a result, there is limited academic research covering the intersection between EDs and mobile technology. There is even less literature exploring user involvement in the development of m-health technology for eating disorders, Yet, Shaw et al. [155] argue, that for mobile technology to have a potential for care, it needs to be tailored to meet the specific patient needs [155]. Acknowledging that there is limited research conducted on the field in general, and the degree of user involvement, indicate where my thesis can contribute. Inherent in my participation in the KULU research project is the use of the methodological framework of Participatory Design, which strives toward co-creating technology based on the needs and expertise of

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[2] Authors translation, quote by Tuva Strøm Johannesen

the users in within the research domain.

Bringing it all together – my motivation was sparked by a discussion, challenging me to investigate to what degree technology can contribute to the field of EDs. I am motivated to conducting a participatory design project, to investigate to what extent mobile technology can contribute to the field of EDs – through the eyes of accutal patients.

1.0.2 Research interest

This thesis is part of a research project aiming to create cool technology for youth with long-term health challenges. Established within the research project is the use of PD as the principal methodology. Guided by this approach, I aimed to co-create new mobile technology with young people, affected by EDs. The literature shows that EDs are a highly complex diagnosis, connected with cognitive and physical factors. Combining the complexity of the diagnosis with new mobile technology is essential to my research interest, which is:

> Conducting a Participatory Design project intended to design mobile technology to “better” support youth affected by eating disorders.

Findings from the literature review indicated a limited focus on user involvement in the development of existing mobile technology for EDs. Raising questions about whether technology is created *for* as opposed to *with* users? Moreover, it raises questions to the degree which the developed technology for EDs, actually reflect the needs and desires of the users? To investigate this link, I wanted to inquire into the individual user′s context, to uncover the possibility of creating technology to "better" reflect the needs and desires. *Lifeworld* theory as a framework contributes to investigating this inquiry, with a focus on examining the significance of events and lived body, from the perspective of my participants – their lived experience. I aimed to explore how knowledge obtained through the *lifeworld* lens, have potential to go further than matching needs and desires. Uncovering if users lived experience can contribute to a design that "better" aligns with their pre-existing reality. Indicating that *lifeworld* and PD inform each other, by placing the users lived experience, needs, and desires in the center of the research process. As a result, the research interest inspired the research question:

> RQ: In what way can the concept of *lifeworld* inform a design process intended to design new mobile technology that “better” support youth affected by eating disorders?

1.0.3 Chapter guide

- **Chapter 2: Literature Review** presents an overview of existing academic research on the field of m-health and eating disorders. The literature review covers central elements relating to diagnosis and treatment. Furthermore, the review cover currently existing m-health technology designed toward users with EDs, with emphasis on existing functionality, potential, and the degree of user involvement. The findings contribute to positioning me within the field, and act as a foundation for existing implications in the design of m-health technology for EDs.

- **Chapter 3: Scoping the field** Investigates how the findings from the conducted literature review align with current practices inn Norway. Exploring if the findings are applicable in the geographical scope of my thesis.
- **Chapter 4: Theoretical and methodological framework** presents my theoretical framework, *lifeworld*, and methodological frameworks Participatory Design and Service Design. The chapter highlights how the theoretical and methodological frameworks align, and how they are intended to contribute to my thesis.
- **Chapter 5: Ethics** Highlights ethical considerations relating to my user-group, conducting qualitative research, and my role as the designer.
- **Chapter 6: Workshop one** presents the development LifeLine, a new qualitative research method, designed to investigate the *lifeworld* of my participants. The chapter covers objective, preparations, findings, and analysis from the conducted the workshop.
- **Chapter 7: Workshop two** presents the second workshop, based on the findings from workshop one. Covering objective, preparations, conducting the workshop, results, and analysis. The chapter illustrates the underlying concept for a new mobile application and the prototyping session. Findings act as implications for the design.
- **Chapter 8: Prototype** The chapter shows the argumentation and concepts within the suggested design, with emphasis on the *Role* and *Look and Feel* of the prototype. The chapter also shows the preparation, objective and findings from workshop three. Workshop three focus on evaluation and discussion regarding the suggested design.
- **Chapter 9: Discussion** In this chapter I present discussions of the findings from the conducted workshops, with emphasis on how my theoretical framework affected the design outcome. The chapter also strives to place the prototype within the literature, evaluating the concepts, and highlighting limitations of the research project.
- **Chapter 10: Conclusion** In the concluding chapter, I strive to summarize my findings and how they align with my research question. I highlight my contribution to the respective research fields and make propositions for future work.

Chapter 2

Literature review

2.1 Introduction

This chapter provides a review of the previously conducted, and ongoing research on the topic of mobile technology and eating disorders (EDs). The section cover central concepts and trends within the research field, with the aim of positioning my research and connecting it to my future work. Obtaining knowledge on EDs, barriers for care and current treatments remain relevant to the technological perspective on my thesis. Uncovering characteristics will contribute to my understanding, enabling me to have increased knowledge and ability to relate to situations and terms that might occur in the data collection, prototyping, and analysis. The reviewed literature for this chapter was obtained using various search engines and academic publishing sites, such as Oria, Scopus and Google Scholar. The degree of available literature varied considerably, literature focusing on the history of EDs and current treatments were accessible in large scale, following decades of academic research. The field of e-health and m-health can be categorized as emerging fields. As a result, there is limited academic research published on the field. The articles reviewed in this chapter were all published after 2012. Consequently, there is limited data on the aspect of long-term effects of m-health applications for EDs. This provides my thesis with the opportunity of contributing to an emerging field. The collected literature was reviewed and organized in a mind map(see Appendix: 1) Illustrating the how topics emerged, and the connections between authors.

2.2 Eating disorders (EDs)

EDs is a severe psychiatric disorder, characterized by disturbances in attitudes and behaviors around eating, body weight and body shape [2]. The term contains different classifications of EDs mainly Anorexia Nervosa (AN), Bulimia Nervosa (BN) and Binge Eating Disorder (BED) each with its diagnostic criteria [51]. For the scope of my thesis, it is relevant to gain knowledge and understanding to the core characteristics of each subcategory of EDs.

The main characterization of AN is the pursuit of weight loss, to achieve this, patients follow severe and selective food intake, where food viewed as fattening are excluded. Sometimes supported by excessive exercising or self-induced purging achieved by vomiting or misuse of laxatives. The motivation for restricting food intake can be external psychological processes such as competitiveness and a wish to punish their body. Symptoms of depression, anxiety, irritability, mood swings and impaired concentration are commonly associated with the condition [51, 123].

BN distinguishes from AN by recurrent episodes of overeating. Characterized by consuming a larger than average intake of food during a short time span. The sessions of overeating are followed by compensatory behavior such as vomiting, purging, fasting or exercising (or a combination of these) to prevent weight gain. Abuse of laxatives and other medication may occur. Patients suffering from BN usually maintain a weight within the normal range despite overeating. Patients with BN are often secretive about their bulimic episodes, thus making it harder to uncover without the patient's willingness to seek help [51, 123].

BED also encompasses patients suffering from severe overeating, but is distinguished from BN as series of overeating are not followed by the typical compensatory behaviors of BN, such as vomiting or use of laxatives. BED patients experience the same loss of control over food intake, and patients are not likely to stop before feeling a severe discomfort or sensation of being uncomfortably full [165, 193]

EDs feature prominently in the media attracting coverage and remain of interest to the public, a challenge to clinicians and a mystery for researchers [51]. The cause of EDs are intertwined, elements from social, psychological, and biological processes all contribute to the complexity of the disorder [51]. Despite their severity and complexity, EDs frequently remain undetected, affecting the patients ability to recive care [2]. Becker et al. [12] conducted a study on social barriers relating to the treatment of EDs, findings from the study show that social stigma and shame are associated with the impact of care. The social cost of acknowledging and ED influenced participants to postpone or avoid treatment. Other findings included barriers related to financial constraints and limited specialized care [12]. The findings correspond with results from Cachelin and Striegel-Moore, [32] acknowledging the same factors contributing to limited treatment. The studies from Becker et al. [12] and Cachelin and Striegel-Moore [32] were conducted in the United States. Thus, the findings might not be directly applicable to the geographical scope of my thesis. A recent paper from McNicholas et al. [110] conducted in Ireland show similar results, indicating the need for increased awareness of healthcare services, to minimize the stigma-consensus associated with initiating and maintaining treatment. Highlighting how the social stigma currently acts as a major barrier for initiating treatment [110]. The complexity of EDs, stigma, barriers of initiating care and difficulties of detection are all relevant to researchers working in this field, and necessary to investigate, this is highlighted in Arcelus et al. [7] study. Showing that mortality rates for patients with EDs are generally high, and that people suffering from AN have a much higher mortality rate than any other psychiatric disorders[7, pp.729].

2.3 Treatment of EDs

Treatment of EDs contains elements from physical, psychological and social domains. EDs are chronic condition with long-term physical and social effects making treatment increasingly difficult [123]. Due to their complexity, there is no general treatment method, as it all dependent on the individual needs of the specific patient, the severity of their illness and their specific ED diagnosis. Halmi [68] argue that treatment of EDs should be based on a multi-modal model, recognizing that EDs do not have a single and predictable course. The literature shows a large variety of treatment methods for each diagnosis within EDs.

For AN the key treatment elements are medical management, behavioral therapy, cognitive therapy, family therapy, and pharmacotherapy, used in combination with nutritional rehabilitation contributing to weight restoration [68, 130, 174]. Fairburn [51] argue that in principle, there are four aspects to the treatment of AN. Making the patients see that they need help and motivate to restore weight while managing their overvaluation of shape, weight, eating habits, and general physical function. Achieved through different kinds of therapy. The fourth aspect is the use of compulsory treatment [51]. There are several challenges to the evidence-based treatments for AN. None of the above treatment methods have equal success with established cases of AN, sample sizes are often small, results are hard to replicate, treatment methods are often shaped by original studies and tested on patient groups differing in age, duration and severity [174].

Key treatment methods for BN and BED are *Cognitive behavioral therapy* (CBT), interpersonal psychotherapy, and pharmacotherapy [68, 174]. The literature shows that in contrast to AN several studies have been conducted documenting the effect on the treatment of BN and BED using CBT and psychodynamic therapy both separately or combined [51, 68, 130, 174]. Fairburn argue [51] that the benefits of using CBT make it the clear choice of treatment for BN. Peterson [130] supports this view, stating that the treatment approach most extensively tested in the field is CBT, and that "[...]CBT, has been found to be comparable with or superior to all other psychotherapies [130, pp.687]." Findings indicate that although its potential, CBT has limitations; few patients receive CBT, a possible reason for this can be that "full" CBT requires a trained therapist. Furthermore, no consistent predictors of outcome have been identified [51].

2.4 E-health and EDs

The previous section covered the traditional symptoms and treatments of EDs. For the scope of my thesis, this knowledge is valuable. By moving to the digital domain, we merge what has been categorized as the traditional treatment methods, with new and evolving technology.

Thus, to understand how technology can contribute to the treatment of EDs, a fundamental knowledge of current practice is essential. The use of Internet and technology in the treatment of EDs is a new and emerging field, yet it has received significant attention from academia in recent years. Several studies investigating the potential use of Virtual Reality (VR) in the treatment of body image disturbances have emerged [53, 133, 134]. The studies investigate how VR can be used in combination with CBT to improve body image dissatisfaction. VR have the ability to create virtual environments that trigger real life like emotional responses, and represent a body image in a personal manner, providing patients with sound information about the false mental representation of their body image. It also gives the ability to measure and monitor a vast array of responses from the patients. The studies highlight limitations regarding sample size and limited controlled trials. Furthermore, there are large financial concerns connected with the development and use of VR as a treatment method [53, 133, 134]. Studies by, [136, 137, 191] all explore the potential of using e-mail in the treatment of EDs. Findings illustrate that the use of e-mail increases the frequency of direct contact between patients and clinicians. Giving patients the ability to express themselves freely, to write down their thoughts and feelings whenever they have the desire [191]. Robinson and Serfaty [137] argue that e-mail therapy could be used to provide treatment to patients who live in remote areas, have physical disabilities, or to reduce the social stigma associated with treatment. Ferrer-García and Gutiérrez-Maldonado [53] found that subjects in their study were enthusiastic about the e-mail treatment, showing how the use e-mail therapy was no different from that observed in face-to-face therapy. The research on the use of email to threat EDs shows several ethical issues regarding the use of technology. Privacy being one of the main concerns, where non-encrypted emails might be routed through third-party hosting sites, which poses constraints to the potential of e-mail therapy, as information between patient and therapist is confidential. A possible solution is to use anonymous e-mail services. However, this would limit the communication to general guidance. Regardless of the challenges and limitations, "It seems [. . .] that the potential advantages of this approach greatly outweigh the dangers" [53, pp.191].

2.5 M-health and EDs

In recent years there has been conducted several studies investigating the potential m-health applications have toward the treatment of EDs. Shapiro et al. [154] and Robinson et al. [138] show how the use of SMS can aid in the treatment of EDs. Results from the studies indicate that SMS-based technology can contribute per existing CBT treatment, or as follow-up care after concluded treatment. Challenges and limitations of the studies include small sample size and high drop-out rates. The authors [138, 154] illustrated potential weaknesses to SMS-based therapy, indicating that non-personal communication had potential to de-motivate participants.

Juarasico et al. [87] argue that m-health technologies should be designed to leverage the functionality and convenience of mobile devices to promote behavior change. M-health applications can improve treatment by making it interactive, enhance learning, enriching access to guided treatment, and give potential benefits for people living with EDs. Thus, it has several advantages over the traditional treatment approach, due to its capability to be portable and ability to capture real-time. M-health technology can also utilize the potential of a phone's built-in sensors for collection and presentation of data [87, 179]. The following section will investigate m-health´s potential toward EDs by highlighting topics, themes, trends, and methods from conducted research and application development, and link it to future design work in the thesis.

2.5.1 Self-monitoring

Fairburn [52] argue that self-monitoring has two main purposes in the context of treatment for EDs. Firstly it builds on the premise of monitoring key clinical features such as; eating habits, purging, and binge eating. By tracking the presence, severity, and changing occurrences, this requires that the patients enter and report relevant information. The second purpose is to help patients change. CBT in particular use real-time self-monitoring of eating habits to help patients gain a better understanding of their eating problems and what influences it [6, 52, pp.1039]. CBT is the gold-standard treatment for patients with BED and BN with its focus toward identifying, evaluating, and changing thoughts and feelings regarding food in high-risk periods [86]. Juarasico et al. [86] show that smartphone applications are well suited for CBT as they have the unique feature of enabling treatment outside the therapeutic office. Historically, self-monitoring is associated with logging methods such as pen and paper. However, by utilizing technological advantages of smartphone applications, patients can log and capture real-time data [87]. Shiffman et al. [156] show that logging real time data will minimize involuntary bias, as traditional methods involve a significant degree of retrospective recollection of events, and the act of physical logging can be associated with social stigma [2, 156]. By allowing individuals to log and report feelings, behavior, and food intake in the context they occur can help to minimize the recollective bias and produce a higher degree of accuracy to the logged data. Smartphones cater these possibilities as they are mobile, easy to access and 84% of the youth population in my research domain have access to them [8, 87]. Supported by Ambwani et al. [6] stating: "having a readily available, user-friendly mobile application to prompt self-monitoring could facilitate more accurate data and yield better compliance than more traditional paper-and-pencil self-report methods" [6, pp.318]. Ambwani et al. [6] elaborates further on the aspect of societal unobtrusiveness, that mobile applications potentially reduce the social stigmatization element of logging by receiving unwanted attention. The literature reveals that smartphone applications have a unique potential to enhance the self-monitoring aspect. Regardless, it is not enough to rely solely on mobile applications. The complexity of

EDs shows that therapeutic efforts are needed to help and treat patients. M-health applications may serve as a first step in initiating treatment. [6, 87].

> A particular challenge of in-person treatment is that skills learned in the calm of a treatment office cannot be effectively utilized in the storm of everyday life. Treatment approaches that take place outside the traditional therapy office have been shown to be better at promoting the generalizability of treatment skills. Thus, it is desirable to develop treatments that can deliver interventions when and where they are most needed (i.e., in the moment)[86, pp.809].

Articles from [1, 6, 9, 33, 86] address the notion that self-monitoring and m-health applications is not a substitute for treatment on it's own. M-health applications realize its potential when utilized in combination with therapeutic/clinical treatment. Bauer and Moessner [9] stresses that maintaining the treatment gains after therapy is a proven challenge. Technology enhanced programs can offer the opportunity for clinicians to provide additional support outside of the therapeutic office [9]. M-health can also aid in transferring eating patterns and concepts from treatment into the context of the patient [6].

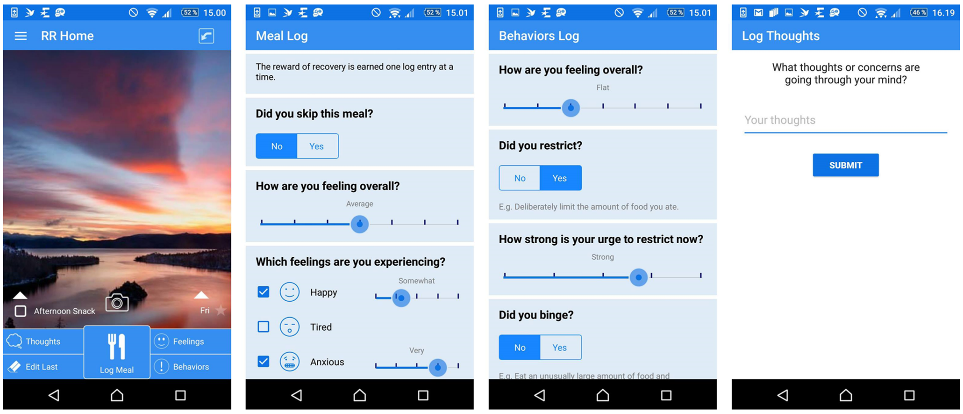
Recovery Record

Recovery Record is an example of how to implement elements of self-monitoring on a mobile platform. In the literature of [52, 87, 179] Recovery Record is referred to as one of the current m-health applications implementing documented treatment methods of self-monitoring and CBT. Recovery Record has the capability for users to log food intake, thoughts, emotions, and feelings. Illustrated in figure 2.1 showing the user's ability to elaborate in free-text boxes and use a Likert-type scale to log overall feelings, happiness, energy level, and emotions such as guilt and anxiety. Juarascio et al. [87] show how Recovery Records logging functionality is consistent with the self-monitoring components in CBT. Furthermore, the application follows the CBT pattern of giving the users the ability to personalize coping strategies for in-the-moment help [87]. Tregarthen et al. [179] state in their article, covering the development and acceptability of the Recovery Record that the application uses features that can have therapeutic value:

> These include reminders, encouraging feedback and rewards, social support, coping strategies, and summative graphs. The addition of these features is also consistent with behavioral theory of practice and reinforcement, which posits that consistent self-monitoring may be more likely when cueing, social support, and positive reinforcement are provided [179, pp.974].

Recovery Record uses reminders and alerts to aid users to log their food intake to create a foundation to try and change eating patterns. The reminders can be personalized with sound, message, and frequency. The use of reminders in m-health for EDs are supported by Juarascio et al. [86], which uses results from clinicians and users, reporting that reminders are helpful in time of need, and can help enhance awareness of triggers associated with EDs [86].

Recovery Records functionality is consistent with the views of [1, 6, 9, 33, 86] that treatment is not a substitute, but realizes its potential when utilized in combination with treatment. Recovery Record has implemented a clinical side to their mobile application. Studies show that inclusion of remote support seems to enhance compliance with other Internet-based treatments [52]. The functionality gives the users the option to invite and connect with clinicians. Once connected the clinicians can access real-time, encrypted patient data collected through the application [52, 87]. Recovery Record also includes embedded links to national eating disorder helplines, providing users in need of assistance with easy access to resources of help [52]. This functionality corresponds with findings from [87]. Who also, indicate that providing users with the opportunity to connect to external sources of help. Can potentially limit a desire to postpone or avoid contacting professional in-person treatment offers.



The reward of recovery is earned one log entry at a time.

Did you skip this meal?

How are you feeling overall?

Which feelings are you experiencing?

☑ Happy

☐ Tired

☑ Anxious

How are you feeling overall?

Did you restrict?

E.g. Deliberately limit the amount of food you ate.

How strong is your urge to restrict now?

Did you binge?

E.g. Eat an unusually large amount of food and

What thoughts or concerns are going through your mind?

Your thoughts

Figure 2.1: Screenshots of functionality in Recovery Record

2.5.2 Context aware functionality

Context-aware applications as a theme emerge in the literature. It revolves around the potential m-health applications hold to utilize technological advantages in mobile sensor technology to enhance the treatment of EDs. By using Global Positioning system (GPS) and geo-location technology in a machine learning algorithm, mobile applications could have the potential of learning a patient's unique behavior patterns such as; eating habits, emotions, cognitive states, activities, environmental, and social contexts. This information can potentially be used to predict times of need and deliver personalized coping strategies [87][86]. Individual triggers are common in patients affected by EDs. These triggers can be internal, e.g. desires and feelings. Alternatively, external, exposure to stimuli associated with behavior factors [87]. By learning a patient's external triggers related to geographical movement, a mobile application could potentially intervene with personal coping mechanisms or offer one touch contact to support hotlines [6, 104]. Luxton et al. [104] argue that context-aware functionality can also be used within the context of therapy. Tracked geographical information can be stored over time and assessed by a treating clinician [104]. Context-aware applications can help enhance the self-monitoring aspect of CBT (see section 2.5.1). Ecological momentary assessment (EMA) "is a method using repeated collection of real-time data on subjects behavior and experiences in their natural environments" [156, pp.3]. EMA is a method used in self-monitoring and often used in combination with more established treatments for EDs such as CBT [86]. Regardless, with the introduction of context-aware functionality, the possibilities go beyond just collection real-time data. The ability to connect a user's geographical location with trigger points provide the opportunity to intervene and provide treatment-based interventions in the time of need, like therapy based techniques or coping mechanisms [18]. This kind of intervention is coined Ecological Momentary Interventions (EMI) [86].

2.6 Functionality in m-health applications

Aside from Recovery Record (section 2.5.1) and the development of SPLENDID application (section 2.8.2) there is limited academic literature investigating different applications and their specific functionality. For the context of my thesis, and future design work it is of importance to map common functionality in pre-existing technology. Not only to gain the overview over the field but to investigate to what extent the applications have been successful, and if its desired target group uses them. This section will briefly cover the functionality in three different mobile applications targeting EDs in a direct or indirect way.

2.6.1 Stopp bulimi

"Stopp bulimi" [1] is a mobile application developed by a Norwegian company "Superego". The core functionality in the application is designed to help recovery from BN or prevent users from being affected (see section 2.3 for more information on the diagnosis) the application allow users to record a personal message, or use pre-installed sound clips. The purpose of the application is to play a recording to counter the desire to purge, which is a key symptom of patients suffering from BN. The sound recordings are intended to help when exposed to triggers, or a pre-defined time a user knows requires help. Apart from the main functionality, "Stopp Bulimi" has a frequently asked questions (FAQ) page, to inform users of different aspects of the diagnosis, and functionality to provide numbers to local

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[1] translated: stop bulimia

emergency response units. Statistics from Google Play Store suggests the application have more than 500 downloads, indicating a limited amount of users. Juarasico et al. [87] refer to audio clips for "in the moment" strategies as a technique broadly based on elements of CBT. Showing how the "Stopp Bulimi" application implement, to some extent, known methods for treatment.

2.6.2 Cognitive Diary: CBT Self-help

A company named Excel At Life develops the mobile application Cognitive Diary. The core functionality revolves around logging and describing significant events in a user's life, and posting quotes of text to help cope with a specific situation. The quotes are not motivational, to help counteract triggers or desires, but rational were the user predefine how and why they want to overcome a challenge. The application builds on core CBT concepts but is not specifically developed to treat EDs. The application implements several supporting functionalities like timed notifications, PIN-code protection, reward pictures when overcoming a challenge, a calendar, and informative articles. According to statistics on Google Play Store, the application has between 100 000 and 500 000 downloads, indicating many users.

2.6.3 The Kissy Project

The Kissy Project is developed by Kirsten Hertog, while she was struggling with AN and BED. The goal of the mobile application is to support teenagers, currently fighting the same challenges Kirsten did. Consequently, The Kissy Project does not implement elements of CBT theory or other scientific measures for treatment. Rather, it is personal developed to create a positive mindset to make the user believe in them self. The functionality of the application centers on daily tasks and quotes of motivation. There is also direct contact to help lines, and a link to Kissy's blog, where she writes about the struggles of EDs. For my thesis, The Kissy Project offers a different approach to creating mobile applications, not centered around known CBT elements, but based on the experiences of a young patient, who have struggled with ED. The application has between 5000-10 000 downloads, indicating a medium amount of users.

2.6.4 What do the applications tell me?

By reviewing three mobile applications, I get an indication of what the market offers, regarding functionality, the inclusion of treatment principles, and the number of downloads. The majority of the applications advertise that the creation of the application was in cooperation with trained professionals from the field of CBT or EDs. The Kissy Project is the only application advertising that a user who has struggled with EDs are central in the development of the application. The review of the above mentioned mobile applications shows that motivational quotes, logging, contacting helplines, PIN protection, rewards, calendars, challenges, triggers, articles, blogs, diaries, and FAQ are common functionalities. Another significant finding is that none of the applications offers direct social interaction, like chat or forums.

2.7 Concerns with m-health applications

Ambwani et al. [6] illustrate that the future of psychology require that we embrace technological advances and incorporate mobile devices. Regardless, it is important to address questions about policy, cost/reimbursement, training, and ethics – or else face the possibility of lagging behind other healthcare disciplines. The following section aim toward uncovering potential limitations to mobile based self-monitoring and applications.

Juarascio et al. [86] present issues regarding reminders and interventions in smartphones. Showing data collected from focus groups where users indicated doubts that applications would not accurately assess when an intervention from the application was necessary or helpful. Highlighting how smartphone interventions could draw unwanted attention to certain behaviors [86]. Juarascio et al. [86] argumentation is supported by Cordeiro et al. [41]. The findings challenge the notion mobile applications have toward reducing the stigma associated with EDs and self-monitoring (Discussed in section 2.5.1. Smartphone applications may also directly interfere with concurrent in-person treatment. Applications not proficiently configured may prompt users to change eating patterns and conflict with ongoing treatment, potentially causing unwanted behavior [87]. Tregarthen et al. [179] agrees that future research must explore the connection between clinicians and patients, to counteract the possibility of substituting face-to-face treatment with m-health applications [179]. Tan et al. [172] conducted a study on e-health and smartphone applications. Showing concerns toward individuals with EDs may use smartphone applications to worsen their illness or increase its severity. Demographic differences in the scope of my thesis are present. However, the concerns transcend geographic barriers and should be taken into consideration in my future design work.

Concerns moving beyond the functionality of m-health applications for EDs are also apparent in the literature. Ambwani et al. [6] raise questions to the fact that patients may become over-reliant on their mobile devices, leading to difficulty coping with situations where they are unable to use a mobile device. Furthermore, Ambwani et al. [6], Luxton et al. [104], and Tregarthen et al. [179] all raise concerns about the aspect of cost in regard to smartphone technology. The high cost of smartphones can exclude low-income families from the potential benefits of m-health technology. Consequently, leading to a less extensive healthcare offer.

Concerns regarding mobile technology and privacy are also apparent in the literature. Tregarthen et al. [179] show that potential disadvantages of using mobile devices for behavioral healthcare are related to user privacy. Ambwani et al. [6] and Shingleton et al. [157] elaborates on this matter and argue that self-monitoring and ED treatment, in general, require the logging of personal and sensitive information. Transferring sensitive information using mobile technology over non-secure Internet connections can lead to loss of sensitive data. Juarascio et al. [86] raise concerns that third parties, such as application developers or outside companies, could potentially access such sensitive data. Ambwani et al. [6] suggest the use of encryption and password protection can counteract this potential risk factor, indicating that future development of m-health applications needs to consider privacy issues in development and design carefully. Future work in the field of m-health also needs to assess the social limitations relating to the use of m-health technology. Investigating the degree of social stigma connected to the use of smartphone applications (see section 2.5.1), and how it can affect the user.

2.8 Pro-ED & Technology

What happens when technology fails or is used to promote unwanted behavior? Findings from the literature on the topic show the emergence of communities and forums on the internet, coined the term pro-ED websites. These pro-ED communities are groups that promote EDs as an alternative lifestyle choice [36]. A common nominator for such sites is the reinforcement of social dynamics that encourage EDs, rather than facilitate recovery [166]. Typical content in these closed communities is information, "tips & tricks", photo galleries, techniques to assist in weight loss, hide symptoms or content glorifying thinness [40, 85, 129]. Pro-ED communities are often hidden from standardized search words, requiring direct referral links [99, 166]. Viewing pro-ED sites can decrease self-esteem and promote a negative body image, and has been found to contribute to disordered eating attitudes [60, 85].

> Online connectivity has changed our experiences of health disorders, both for good and for bad. On one hand, the web provides a candid and emotionally supportive network for communities with socially stigmatized illnesses, e.g., depression. On the other, online platforms have connected people in ways that can enable and amplify the destructive power of eating disorders [37, pp.1201]

Chancellor et al. [37] highlight that closed pro-ED communities to some extent can have a positive effect. Seeking support from a peer group can provide emotional reassurance, not only motivation to worsen the illness [37]. Juarascio et al. [85] and Peebles et al. [129] stresses that "pro-recovery" sites might not resonate well toward all users. Pro-ED sites can have a unique way of offering emotional support and allow socially stigmatized individuals a nonjudgmental, safe, and possibly therapeutic interactive environment to gain support from others. The authors [85, 129] argue that current self-help platforms need to investigate whether their modules for interaction are meaningful to its users [85, 129]. However, this does not imply that these Pro-ED communities beneficial to a large extent. Individuals who actively participate in these sites are more likely to encourage each other to fast, not seek recovery, and have higher levels of body dissatisfaction, compared to individuals that do not view such sites [85].

2.8.1 Social media and EDs

Ease of access and connectivity through social media and pro-ED communities poses a threat to m-health applications, as it can prolong or worsen an ED. Tan et al. [172] raise concerns regarding the use of mobile applications to prolong or worsen the illness. Fairburn and Rothwell [52] argue on the same train of thought; If a smartphone application intended to help in the recovery of EDs has a social element, that allows the users to connect with each other, it can enable well-known characteristic of people with EDs. Including, competitiveness in attempts to diet, exercise, lose weight, share bad advice, and harmful recommendations [52, 87]. "Putting users in touch with each other might intensify such behavior, and it might also result in the acquisition of new forms of psychopathology" [52, pp.1045]. Smartphone applications can provide users struggling with ED with new means of exploring and connect to unwanted behavior. Ruckenstein [140] exemplifies this, illustrating how data from self-monitoring and CBT logging can be shared and misused in pro-ED communities [140].

In recent years several applications designed to help control nutritional and food intake with the goal of counting calories have emerged. Pagoto et al. [128] reviewed 30 of the most popular smartphone monitoring devices intended to control and log food intake. Findings show that many behavior strategies were completely missing for the weight-loss applications reviewed. Including patterns of eating, relapse prevention, social cues, and coping with negative thinking [128]. There is to date no academic research investigating an adverse link between dietitian applications and eating disorders. Regardless, the findings indicate that the line between helpful and harmful is thin and that a user can potentially misuse technology if desired. It might be to count calories, minimize food intake, or to connect with pro-ED communities. Indicating that it is nearly impossible to design an application that has zero possibility to affect the user in a negative way, ultimately a user can choose to use technology for their agenda. Nevertheless, findings suggest, (As stated in section 2.5.1) that an application cannot be a substitute for treatment, but used addition to evidence-based therapeutic guidance. Combining treatment with the use of an application can potentially limit misuse of technology, due to supervision and follow-up provided by a trained professional.

2.8.2 User involvement in design of m-health applications

From the technological and design perspective of my thesis, I reviewed elements of the literature the desire to uncover and map the user's involvement and participation in the design of m-health applications.

Juarascio et al. [86] elaborates on the design process of an un-named m-health application for ED treatment. Showing how the design process occurred. Mockups of the first functionality and design were developed and discussed in interviews and focus groups conducted with both patients and clinicians. The authors conducted a thematic analysis of the qualitative data gathered in the session. It is unclear to what extent the development of the functionality in the application had users involvement [86]. Regardless, a focus on user participation and ability to affect the design is apparent. Moulos et al. [118] illustrate how users were central in the development of the SPLENDID application. The main purpose of the m-health application is to monitor eating and physical activity connected with user behavior. The designed functionality are based on the use of sensors and self-reporting, connected personalized goal setting and feedback [117, 118]. The degree of user involvement appears to be limited to the validation and alteration of pre-designed flowcharts and screenshots. Figure 2.2 show the design process from the development of the SPLENDID mobile application. The numbers in the illustration represent chronological steps in the design process.

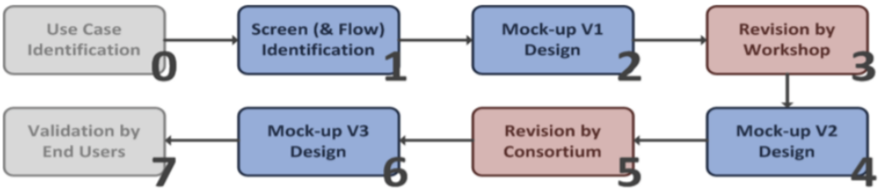

Figure 2.2: Flow diagram showing the UI design method, used in the development the SPLENDID application [118, pp.650].

The mock-ups of functionality were designed based on use-cases with several iterations. A focus group consisting of clinicians, dietitians and researchers revised the final design [118]. The reviewed articles in this section are only available literature that mentions and focuses on end user involvement in the design process and the development of m-health applications. The limited academic focus user participation in the design process can arguably be connected with the emergence of the field. Were the conducted research place emphasis on the potential applications holds for the future of healthcare, rather than the design processes. Regardless, it remains relevant for my thesis, as the limited focus on user involvement in the design processes gives my research the possibility of contributing to the field by using a Participatory Design approach.

2.9 What did I learn?

The literature shows a recognition toward m-health applications potential to enhance the treatment of EDs. The articles reviewed all highlight positive aspects toward the future of ED-based treatment using m-health technology. Regardless, limitations and concerns in regard to randomized controlled trials [6], clinical long-term effects [179], sustainability of products [9], continued usage of applications [86, 179], and dropout rates [1] are apparent. These limitations highlight the future work needed to determine if m-health applications for treatment of EDs is a viable tool to be used in combination with clinical guidance. Clinical trials and randomized control trials are beyond the scope of my thesis. However, within the technical domain of my thesis, findings from the conducted literature review related to context-aware functionality, CBT, current treatment practices, social stigma, self-monitoring, elements relating to the prolonged use, and sustainability of m-health applications are all relevant to my future work. Juarasico et al. [87] state:

> there is a great potential for smartphone apps to increase access to treatment, enhance treatment by provision of extra support outside of the therapy office, and utilize technical capabilities to enhance treatment compliance and skill utilization [87, pp.9]. (...)

The thesis will continue by investigating the potential illustrated by Juarasico et al. [87]. However, I will take a patient-centered approach, striving toward investigating what users who have experienced EDs see as a potential application area for m-health technology, by using the abovementioned findings as a foundation for my future research.

Chapter 3

Scoping the field

3.1 Scoping the field

> Researchers can undertake a scoping study to examine the extent, range, and nature of research activity, determine the value of undertaking a full systematic review, summarize and disseminate research findings, or identify gaps in the existing literature [98, pp.1]

Davis et al. [47] show that the term scoping is ambiguous and poorly defined in academic research. According to Levac et al. [98] there is no universal scoping definition or purpose. However, it is referred to as "mapping", a process of summarizing the evidence with the intention of gaining breadth and depth of a field. [98] In the context of the thesis, this is my objective. To investigate if the findings from my conducted literature review apply to the Norwegian demographic, and gain more depth and understanding around to the central findings from the literature.

I decided not to follow a methodological framework when conducting the scoping activity, even though both Davis et al. [47] and Levac et al. [98] suggested it. Due to my desire to gain understanding and depth relating to my preliminary findings, not to conduct a full scoping study. Using my literature review as a foundation, I aimed at interviewing domain consultants, as Levac et al. [98] argue can contribute to apply meaning, expertise, and perspective. I interviewed one domain expert in my scoping efforts. The interview subject referred to as Aria (29), Is a medical practitioner with a license to practice medicine, she has ten years of experience in Norwegian health care, working within the field of EDs. The interview guide, used as a template for discussion can be viewed in Appendix .5. The interview was conducted in early may, at a location chosen by the domain expert. I gained access to the domain expert through connections in my personal network.

3.1.1 Findings

The following section will present key findings connected with each topic covered in the interview. The findings are based on the professional experience and knowledge of the domain expert. Due to the limited scope and subjective nature of the collected data, I cannot conclude anything based on the findings. Regardless, the findings act as guidance, by shedding light on the findings from the conducted literature review.

Norwegian health care

Aria explained how the Norwegian health care system approaches treatment of ED patients. The system is grouped based on two main categories. The first is the primary healthcare services, acting as an initial step toward treatment, included in the category are general practitioners, nurses, and school nurses. The primary healthcare services are intended to provide treatment options or therapy for patients initiating care. IE, are at an initial stage of illness. The second category, specialize healthcare services are specialized treatment personnel or organizations like polyclinics, hospitals, therapist, and "Regional seksjon for spiseforstyrrelser " (RASP) [1]. The specialized healthcare services are intended as treatment options for patients at an advanced state of the illness and can involve forced admission of patients. Bound by laws of mental health care they provide different treatment options from therapy to force-feeding patients with nutrition probes. Aria emphasizes, that patients under the care of specialized healthcare services can be in an unstable mental and physical state, and can in instances be a danger to themselves and others.

CBT

Aria explained, "CBT is used as a primary way to treat different aspects of EDs, due to its documented effect. Initially, CBT can be provided by both primary and specialized healthcare services. However, based on my knowledge, and experiences from patients, that on a general level, there is a lack of knowledge from general practitioners regarding EDs." Aria emphasized that there can be exceptions, were personal interest and experience can contribute to a particular GP having enhanced knowledge, of EDs and treatment. However, on consensus, there is a lack of knowledge, and as a result, limited ability to provide CBT to patients.

CBT: Logging of food, emotions, and thoughts

Aria explained, "Based on my experience, logging of food can act as a catalyst to drive the sickness, because ED is about control. By logging food intake, you have control over your food intake and can contribute to increasing the "Inner voice" of the sickness. A lot of the treatment we provide is toward helping patients let go of control." Looking past logging of food, Aria illustrated how logging of emotions and thoughts are commonly used in CBT, as steps toward counteracting triggers, and as talking points for in a treatment setting. Such logging can help the therapist understand the emotions and feelings a patient had while eating.

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[1] Regional section for eating disorders

CBT: Motivation

Aria showed how motivation is a central part of CBT and practiced at primary and specialized healthcare services. In her experience working at a specialized healthcare service, patients regularly have motivational cards they use during meals, the cards contain personalized motivation, used to remember why they want to get better, why they should eat, thoughts about the future, and to provide safety toward the specific food intake. Aria stated, "Without inner motivation, it is nearly impossible to get better. If you are forcefully admitted to a specialized healthcare facility, you will eventually be out on leave. If you fail to find your internal or external sources of motivation, it will be hard to counteract the variety specific triggers." Explaining how an intense ambivalence drives patients with EDs, many patients are motivated by a desire to live a normal life, finish an education, or start a family. On the other side, the internal voice of the sickness, much like an addiction, contribute to driving the patient toward disease-related behavior. Aria explains, how motivation is central in keeping in control of your perception of reality, and that motivation can contribute to planning activities or tasks, on the way toward realizing the primary source of motivation, however, small or large that idea might be.

Technology

Aria explains, that based on her knowledge there is currently no m-health application implemented in any treatment program in Norway. In specialized healthcare services, they utilize mobile phones to call or text patients out on leave. She exemplified "last month, I was in ongoing contact with a patient out on leave. During the weekend we send out text messages providing motivation during planned times of the day. The patient also called me, because the patient knew that when passing certain trigger points, the desire to conduct disease-related behavior was high, the phone support acted as a way to counteract the trigger."

Potential and limitations of m-health technology

The last talking point revolved around the potential of smartphone applications. Aria explained that she sees a great potential in the possible use of mobile applications. However, she initiated by emphasizing "Treatment provided in the hospital, should stay in the hospital." Illustrating that regardless of the potential, she struggled to see a potential use of smartphone technology for patients that are emitted to specialized care. Regardless, she believed that smartphone technology could contribute to those out on leave, or patients that were at early stages of the disease, and possibly act as a nudge toward initiating treatment.

Aria explained how CBT treatment currently exists on online platforms, as tools for self-help. However, to her knowledge, specialized healthcare programs do not use such online tools in treatment. "I believe that CBT principles relating to logging of emotions and motivation, and some form of for social contact can be transferred to a mobile platform. I know from experience that patients use smartphones to call friends and family to gain support and motivation. However, this can be a burden for relatives, taking the role as part-time therapists, I see a definite potential for an application that can motivate users to counteract triggers or help during hard times of the day, in other ways than through phone and SMS-based social support. ” She elaborated, explaining how social interaction is prominent on pro-ED sites, where users share tips and ways to worsen the illness. These sites and forums often operate with anonym user accounts, to ensure the privacy of the potential users. However, she stated, “If there is social interaction, like a forum or chat in a mobile application, I do not think this will promote any sharing of pro-ED content, because people who download an application will have a recovery mindset, and a desire to get better.” Aria used another example “From my experience, as previously explained, patients bring motivational cards for self-help during meals, for motivation. An app that allows users to create motivational cards to help them get through the meal has great potential.” Lastly, Aria expressed potential dangers relation to mobile applications, based on her experience. “As stated, a large part of ED behavior relates to staying in control, if an application takes over, and a user is reliant on a technological to keep control of motivation, goals, and tasks it can be a danger. Transferring the power to a phone can potentially harm the patient, what if the phone runs out of battery, is destroyed or lost, it can lead to a lack of control, "fueling" the sensation of failure, which in my experience can result in a desire to engage in a disease-related behavior.”

Lastly, we discussed the concept of context-aware functionality. Since the feature uncovered in the literature is mainly on a conceptual level, the discussions revolved around Arias thoughts of its potential. I presented the concept and terms used in the literature. Aria was unfamiliar with the concepts of context-aware applications and EMA/EMI. However, she stated “I think it holds great potential, if your revisit the example I gave of the patient out on leave, it has potential to "support" the calls or text between the patient and healthcare service. It is not to say that it should replace the contact, but it could potentially be of great help when the patient is out of our care, everyone is eventually phased back into “normal” society. Maybe such context-aware interventions could replace the calls or text we now provide?”

3.1.2 What did I learn?

The scoping interview provided in-depth information regarding current treatment practices and knowledge of the building blocks that shape the Norwegian health care system for EDs. The domain expert showed how key concepts from the literature matches current practices in Norway through several examples: 1) The use of SMS-based interventions (see section 2.5). 2) The use of CBT as a central part of current treatment practice, focused on logging thoughts and emotions as tools to aid therapy (see section 2.5.1). 3) The importance of using motivation, both to realize why you want to get better and as steps along the way to counteract triggers (see section 2.5.2). 4) Indicating how the technology they should not replace, but has the potential to be used in according to ongoing treatment (see section 2.9). 5) The possible negative influence of pro-ED content on forums, and how social interaction is important but needs to carefully consider the potential adverse impact of anonymous contact as a way to contribute to disease-related behavior (see section 2.8.1). The findings from the scoping effort provided insight into "common" thought patterns connected to the “addiction” aspect of EDs. Highlighting potential limitations, going further than the limitations found in the literature (see section 2.7) showing potential risks of being over-reliant on a mobile application to stay in control of the disease.

Due to the inherent limitations of only interviewing one domain expert, the findings will have a limited effect on the argumentation used in the thesis. Regardless, the findings contribute to increasing my knowledge of the complex field of EDs and provided new insight into the potential possibilities and limitations for mobile technology, which will contribute to my future work.

Chapter 4

Theoretical and methodological framework

In this chapter, I will present the theoretical and methodological frameworks applied in my thesis [1]. The conducted literature review indicated a limited focus on user involvement in the development of m-health technology for EDs. My chosen methodological and theoretical frameworks places the user at the center of the process, moving my thesis toward a patient-centered design approach which connects with the theoretical framework of *lifeworld*.

4.1 *Lifeworld*

Lifeworld means a person's subjective construction of reality, which he or she forms under the condition of his or her life circumstances. The concept of *lifeworld* has roots going back to the development of the phenomenological approach. Husserl [80], viewed as one of the founders of the phenomenological movement, strived to make the nature of human-world intimacy more explicit. Not an objective world that can only be perceived. Rather, a world that embraces its qualitative nature, as Husserl [80] calls it, a world-to-consciousness [178]. A representation of the world where we can articulate who we are through the given-ness of experience [178].

Academic endeavors have continued the early work of Husserl [80]. Today, the phenomenological realm offers and existential view of being human. Where we do not consider our lives as separate compartments, with a mind-in-itself or body-in-itself approach. Rather, we view it as the seamlessness of everyday life and its qualitative character [46].

By examining the everyday life and its qualitative nature, phenomenological philosophers have articulated a view.

> human being in which persons are not just other objects that are purely determined by 'natural forces'. Rather, there is an

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[1] Participatory Design (PD) is the principle methodology inherent in my participation in the KULU research project

> existential freedom that makes choice and agency meaningful within certain limits [46, pp.267]. (...)

The quote captures. To a degree, the essence of the phenomenological view, upon which *lifeworld* is founded. *Lifeworld* strive to explore the qualitative world, which acts as a foundation for meaningful knowledge relevant to the humans living in and with it [178]. Emphasis on this qualitative dimension is important and understood in my thesis as lived experience. Todres et al. [178] state, "Any description of the significance of the *lifeworld* is a description of meaningful relationships within a world that is lived, thus indicating the "more" of those relationships [178, pp.56]. The question remains, what relationships should be referred to when attempting to describe a world that is humanly lived? This is were *lifeworld* theory can be helpful [178]. Through five intertwined dimensions, *lifeworld* theory strives to indicate the "what" of these relationships. The following section will briefly cover each of the five dimensions connected with *lifeworld*, and illustrate what it means in the context of my thesis.

4.1.1 The five dimensions of *lifeworld*

- *Temporality* refers to aspects of time as it is humanly experienced, where each moment of experience is part of a story. *Temporality* gives the human experience a storied nature. Todres et al. [178] argue that we live with time in different ways, through feelings of possibility, anxiety or depressing. Describing such temporal meanings that resonate with our everyday life, captures what it means to be human. In the context of healthcare, descriptions of *temporality* strive to capture these feelings, and not "[...] not just the tick-tock measures of, for example, the growth of a tumour [178, pp.56]". I aim to uncover the participants lived experience relating to *temporality*. By understanding a participant's perception of time, and how it is connected to experiences, can help gain valuable insight into their lived experience. Do they have too much, or too little time? Does it affect their health condition? Do they feel isolated when alone? All these questions are relevant in understanding their *lifeworld*.

- *Spatiality* refers to the environing world; a world of places and things that hold meaning to the living. *Spatiality* does not focus on the quantifiable measures of physical things in our life, like centimeters or meters. Rather, it is about capturing things and situations that are close or distant, regarding their significance for our daily lives. "For example, when longing for a missing friend, we may ignore the pot plant that is three inches away, while the presence of the one longed-for is "close" in his or her absence [178, pp.56]". *Spatiality* strives to capture how this personal experience of life changes from moment to moment, in sickness our world might shrink to the immediate environment of our room, the human spatiality, therefore, includes how things appear regarding closeness or distance, and the subjective meaning a thing hold within that space [74, 178]. For my thesis, the dimension of *spatiality* is essential to map and understand events in my participant's life. The significance they hold, and how it affects their well-being and emotional state are all relevant in gaining understanding of their *lifeworld*.

- *Intersubjectivity* refers to how we are in a world with others. Without a reference to how our lives take place in the social world, we cannot be understood as persons. *Intersubjectivity* means that we exist with others in an understanding way, how we are connected. [178].

  > through intersubjectivity and language, we locate ourselves meaningfully in the ongoing interpersonal world. How we are in relation to this interpersonal world is often uppermost in our meaningful living: who I am getting on with, who I am not; worrying about Timothy, looking forward to seeing Jen [178, pp.57]". (...)

  Todres et al. [178] explains that when a person is unwell, the touch of a human can reconnect us with a sense of hope, this hope can contribute to other possibilities of interpersonal contact beyond illness. Describing these the interpersonal relationships is key to describing the *lifeworld* of a person. One cannot fully understand the dimensions of illness as it's lived without understanding what it means to the person [178]. For my thesis *intersubjectivity* can help illustrate the participant's personal connections, whom they love, think about and talk to in their life. It can also contribute to uncovering what relationships are vital to their well-being. Including friends, family or health workers.

- *Embodiment* refers to the concrete "here" of ourselves [178]. Going further than "just" bodies as objects connected in the world. *Embodiment* is associated with the lived body, not described with objective measures, but important relations in the world. "This fluid body shapes itself emotionally to the world – the anorexic body saying "no", not just to physical nourishment but to the dubious offers of emotional nourishment that have come to mean ownership by another [178, pp.57]." A *lifeworld* description goes beyond describing the body. In illness, one needs to look at how the body lives and functions meaningfully in the world. By investigating the *embodiment* one might understand the illness in a more complex way – how it interacts with the world [178]. The dimension of *embodiment* can contribute to increasing my understanding of the complexity of EDs through the lived experience of my participants. It can also show how EDs have influenced their world, what changed when they got sick, what objects connects them to the world, and how does it differentiate from when they were well?

- *Mood*[2] "Lived experience is coloured by mood [178, pp.57]." It can

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[2] Todres et al. [178] also uses the term emotional attunement to describe *mood*

interpenetrate the other dimensions of the *lifeworld*, shaping a person spatial, temporal, intersubjective and embodied horizons.

> " In sadness, other times and spaces may be longed for – the body walking slowly. In loneliness, there is no-one there in a crowded room – little intersubjective fullness. Mood, in some way, saturates our being-in-the-world and is just as primary as spatiality, temporality, intersubjectivity and embodiment [178, p. 57]".

Mood is a complex concept, which can go further than what words can describe. Todres et al [178] exemplify the concept of *mood*, by stating that, just like colors that cannot be separated from objects, *mood* cannot be separated from the *lifeworld* [178, pp.58]. Within the context of my thesis, *mood* can be used to describe the meaning of a situation in their *lifeworld*. It can be used to investigate the degree a specific mood affects their ability to make decisions. Happiness and sorrow are in different parts of the emotional specter. By investigating the dimension of *mood* I aim to uncover how different mood impact their everyday life, and their desire or ability to get better.

4.1.2 *Lifeworld* and healthcare

lifeworld-led care is a way to utilize *lifeworld* theory to understand the concrete, everyday experiences of people, and use that knowledge to underpin care [178]. Gathering such knowledge can be done through interacting with people and aid them in expressing their shared and individual experiences of health and illness, their life journey. The five dimensions of *lifeworld* mentioned above, can guide the collection of such data, to capture the breadth and depth of the descriptions. According to Todres et al. [178] *lifeworld-led* care is based on a core value "A humanizing force for health and social care that moderates technological progress [178, pp.59]." Founded on the core perspective that "[. . .]an understanding of others worlds grounded in experiences of real people living through complex situations – the holistic context for understanding quality of life [178, pp.59]." The core value and core perspectives describe what *lifeworld-led* care tries to achieve. Motivated by humanization, pursued through curiosity about a described reality based on lived experiences, and respecting the holistic interconnections as humanly meaningful stories [178]. The *lifeworld-led* care perspective can be seen as both a deepening of the understanding of patient-centered care and a critique of the dehumanization and depersonalization of care. The aim of *lifeworld-led* care in the context of my thesis is to allow patients lived experiences of everyday life, diagnosis, and technological use, guide the design of new technology [46, 184].

4.1.3 What does *lifeworld* mean for my thesis?

> A *lifeworld-led* design approach, combined with a participatory design methodology, enables patients to be met as co-designers and experts of their own lives and facilitates patient contributions to the design of health IT [184, pp.1]

Van der Velden and Sommervold [184] argue that including young patients in a participatory design setting can provide a significant contribution to the design process. The authors [184] show that a participatory and *lifeworld-led* design process, based on collaborative methods and iterations, give the patients the ability to express needs relating to the five dimensions of *lifeworld* (4.1.1 which can result in specific design requirements, closely connected with the lived everyday experiences relating to technology [184]. Within the context of my thesis, *lifeworld* will be my theoretical framework, acting as a "red thread" throughout my research project. Much like van der Velden and Sommervold [184] study, I aim to combine a participatory design approach with *lifeworld-led* care, to try and map the lived experiences of my participants, and together investigate and design future technology. Dahlberg et al. [46] state,

> Professionals led by lifeworld knowledge do not therefore just offer technical solutions, but are able to offer 'paths' for the patient to step into in their life's journey. Such an interaction, if well informed, can lead to the patient feeling more 'deeply met' in both their vulnerabilities and possibilities [46, pp.269].

The quote from Dahlberg et al. [46] illustrate the importance of making the patient feeling "deeply met" toward their vulnerabilities and possibilities. My chosen methodology strives to achieve such understanding, by placing the participant's needs and desires at the center of the design process.

4.2 Participatory Design

> design and use should not be regarded as two separate and sequential activities, but rather as on-going in parallel, intertwined, overlapping, with shifting foci and agencies [49, pp.125]. (...)

Two important events shaped the development of PD as a design movement. Ongoing changes in the political and economic context in the 1970s raised controversial questions regarding relations of power, democracy and control in the workplace. Combined with the technological development which was rapidly growing with the Scandinavian belief that placing users at the center of technological development could contribute to the successful design of technological innovations. Together these aspects helped create and shape PD into a design methodology [91, 152]. Carroll and Rosson [34] elaborate further on the development of participatory design, arguing that it integrates two radical propositions about design, a moral and a pragmatic view.

The moral view center around people's experience regarding activities and abilities that will ultimately be most affected by the outcome of the design. Therefore, they need to be directly included in the design process. The moral proposition to design has historically had a larger significance to the Scandinavian PD movement, focusing on including users from all aspects of an organization when designing systems.

The pragmatic proportion focuses on people who will need to adapt to the artifact or another outcome of design, and should, therefore, be included in the design process. The authors [34] argue that users can offer expert perspectives and preferences regarding the activity that the design will support, and most likely transform. Focusing on directly including users in the design process will increase the chances of a successful design outcome. Historically the pragmatic view has stronger roots from American participatory design movement. Carroll and Rosson [34] argue further that these two propositions of design are radical because they fundamentally challenge our conceptions of design as a profession, and what it means to be a designer. Stating that

> [...] it might seem purely definitional that the people who shape designed artefacts and systems are the designers. But in participatory design, the designer's role is more nuanced and more complex. Ideally, all the relevant stakeholders participate in even the inner loop of design conception, and all continue to participate meaningfully as the design is specified, implemented, delivered, installed, and used [34, pp.243].

The radical propositions that shaped PD placed the potential users at the center of the process. Understanding that it is both their moral and pragmatic views that lay the foundation of sound design, and by involving the users at the core of the process, they can voice their opinions and expertise regarding their context, as well as shape the design of the intended technology. Kensing and Greenbaum [91] argue that designers who are entering the field, can benefit from understanding the heritage and development of PD. This legacy formed the foundation of what Kensing and Greenbaum [91] calls the six guiding principles of Participatory Design. These principles are not set in stone but created to act as a foundation for practitioners entering the field and to guide the development of a PD process. The principles are connected and intertwined, building on each other to create a foundation.

The first principle covers the topic of *equalizing power relations*, an important aspect of any PD project. It revolves around the ability to give voice to the invisible or less heard in a design process. Björgvinsson et al. [15] further elaborate equalizing power relations, emphasizing that it is a major step to *democratic practices*, which is the next of the guiding principles. *Democratic practices* aim to give knowledge to all participants, providing them with the opportunity to voice their opinions within the context of a project. A democratic process is not abstract but rooted in *Situation-based actions*. Working directly with people in a context they are familiar with, can help to gain understanding in regards to usage and technological development. *Situation-based actions* give rise to the next principle, *Mutual learning* [91]. *Mutual learning* is about encouraging and enhancing the understanding of different actors and challenges, by finding common ground within their context, giving the opportunity to learn from each other [91]. *Mutual learning* connects with what Kensing and Greenbaum [91] referred to as *Tools and Techniques*. Different *Tools and Techniques* can be used to help various actors envision and communicate needs and ideas, by utilizing various *tools and techniques* such as workshops, mockups or prototypes. The last principle is regarding *Alternative visions about technology*. Emphasizing whether it is in the workplace, at home or in the public sphere, ideas can generate expressions for equality and democratic practices [91].

4.2.1 Why Participatory Design in this project?

Hansen and Iversen [70] argue that working with youth and adolescence differs significantly from the blue-collar worker movement for which PD was intended. Acknowledging the fact that PD began as a methodology to analyze and create better solutions to empower users in the workplace. Today, the field of PD have moved away from the workplace, expanding their initial reach to cover youth and adolescents, who have no relations to the classic workplace development. This shift in PD is important for the scope of my thesis, as youth want to contribute to creating better products and services. [59, 70]. Björgvinsson et al. [15] categorize this change in focus as a shift from democracy at work, to democratic innovation. Arguing that new media has entered every aspect of our lives, that design and innovation activities have become distributed across new context and competencies, leading to a blurring of borders between citizens, companies, and the public domain.

"[...] young people's use of digital media and communication technologies defines a generational identity distinct from that of their elders" [82, pp.2]. In a highly disputed nonscientific paper "Digital Natives, Digital Immigrants" Prensky [48] argue that new generations living in the digital age need media-rich ways to retain knowledge and that the ways in which we educate our young is outdated by the digital age. Prensky has no scientific data to support his claims. However, his thoughts in combination with Ito et al. [82] provides a new mindset. Working with youth and adolescent requires different methods and approaches for me as a researcher. The digital youth are accustomed to technological artifacts and communication technologies as they were born into it. By using PD as my principle methodology I place the user at the center of the design process, striving towards what Ito et al. [82] illustrate. "[...] qualitative studies see children and youth as actively constructing their social and cultural worlds, not as innocent victims or passive recipients of media messages" [82, pp.9]. A study by conducted by Iversen and Smith [83] explore the topic of digital natives in the context of participatory design. The authors [83] illustrate that the technological area has shaped youth growing up, and encourages designers to explore how their expertise of technology can help create a valuable design. The result of the project differentiates from the goal of my thesis, as their aim was to create a valuable interactive museum experience. Regardless, the study shows the importance of understanding the guiding principles of participatory design, by allowing the user to shape the creation of future technology.

Another important motivation for using PD as the main methodology for my thesis becomes apparent in a study presented by Currin et al. [45], showing how youth and adolescent within the age of 10-19 are at the highest risk of developing EDs. Shedding light on the fact that not only is my target group experts in regards to technology – they are also experts regarding their disease. Van der Velden et al. [182] the same recognition, that young patients, suffering from chronic disease, have the right to affect and have a say in decisions that influence their own well-being and own health care [182]. Bratteteig et al. [26] use the notion, that having a voice does not mean having a say [26]. Highlighting the importance of honoring the guiding principles of PD, and make sure that the participants have the power to affect the design process, striving to avoid what van der Velden [182] found in their study, that many many design projects involving teenagers showed that they had a voice, but not an actual say [182]. Iversen and Smith [83] uses the same recognition, highlighting the importance of balancing *power relations* is a critical aspect to consider when conducting PD projects. Making sure their voices are heard in the design process, can contribute to youth beeing actively engaged, and gain a sense of ownership to the design decisions.

In my research project I will use PD as a foundation, honoring the six guiding principles to explore the *lifeworld* of my participants. Working with the participants to learn and understand their lived experience, relating to needs, desires, technological use, and their health condition, which can hopefully – lead to my goal of co-design. Bratteteig et al. [26] show that one of the distinctive elements of PD, is understanding that users are the experts within their domain and that designers need to understand this, to create a valuable design. Regardless, I need to be aware of potential pitfalls in the process. Acknowledging the guiding principles of PD might not be enough. Iversen and Smith [83] indicate that a PD process can end up in what they call "cargo cult science" meaning a mirroring of known rituals in design processes to generate a design outcome. To avoid this state, one needs to strive to uncover and design for the underlying values of the participants. I believe that exploring the participants *lifeworld* can contribute to such knowledge. By understanding the potential pitfalls and weaknesses of previously applied methods is important when conducting my research. The need to acknowledge and understand the nature of my participants as digital natives, who within their context have unique values becomes apparent [83]. Fitton et al. [55] express concerns regarding PDs ability to fully represent youth, as they are a highly contextualized part of the population, influenced by a variety of factors. For example, The lack of wealth in their respective families can limit exposure to technological development [55].

The m-health field contains a broad array of mobile applications. The applications contain different health related technology, aimed to improve continuity of care for patients suffering from various health related issues. From my technical perspective, working within the field of informatics, it is important to understand these technologies. Regardless, m-health as a field is not defined solely by its technology, more important is the m-health applications ability to aid the patients. Bringing me to the realization that while m-health consists of health related technology, it is not focusing on health in general, PD as a methodology can aid me as I aim to learn about the specific health related aspects of my user group. Contributing to gaining expert insight into the field of EDs, based on lived experiences.

4.3 Concerns with Participatory Design

Mulder and Stappers [119] state, that while innovation needs continuous investment, their return is not always obvious. Only 1 out of 3000 technological product ideas every makes it to the market, this means that there are numerous unsuccessful ICT products behind every success [119]. van der Velden [181] show that in the collective struggle for life improvement and empowerment, we have all become IT consumers. The author reflects on how this have changed the conditions for PD projects. Participants, ranging from workers, patients to children are now more skilled, and therefore bring needs that are more informed and ideas into a design process. In return, this strengthens the guiding principles of PD such as democratic practices, situation-based actions, and mutual learning [181, p. 2]. Increased technological competence provides the foundation to create sustainable products. The question remains, however, what becomes of the 2999 unsuccessful ideas that never make it to the market? How is PD contributing to this development? Is PD a methodological framework intended to create sustainable and commercialized products? The answer to these questions is relevant within the scope of my thesis, uncovering the potential limitations of PD contributes to my understanding of what constitutes a successful product and can help guide my design process, as I strive to create a design that "better" reflect the needs of my participants.

Kensing and Blomberg [90] argue that issues explored in PD have a double agenda. Researchers are interested in designing useful, experimental technologies based on co-creation with their users. On the other hand, they are interested in developing effective PD methods that can contribute to further research. Sanders and Stappers[146] further elaborate on the matter, stating that PD primarily considered an academic endeavor, with little or no relevance to the competitive marketplace. Investment in user's studies can be a big and expensive step, a step into the unknown. Merkel et al. [113] argue that financial and human resources can limit PD projects and that this can affect the technological outcome of a project. The authors [113] stresses that resources are often short-lived, once the volunteer or consultants are gone; the result is a system that is neither usable nor modifiable to their needs. Kensing and Blomberg[90] uses the same argumentation, which economic conditions predominate the international scene, forcing efficiency over the quality of work, making the power of the worker in organizations to decline. These findings indicate that many PD projects conducted in the past can indeed be seen as an academic endeavor, with the purpose to enhance or create new methods, contributing to the academic field of PD. Furthermore, it indicates that financial funding and time in projects are a possible limitation. The question remains, why the products and concepts developed in the studies do not reach the commercial market? Sanders and Stappers[146] argue that the idea of participation can be the reason. Participation might be antithetical to consumerism, and that several steps in the development of co-creation must be taken to create better and more sustainable products. Bjogvinsson et al. [15] show that an issue with PD relates to the fact projects are tied to support the needs and visions of the users participating in the study. The design should support the user's interest regardless of the number of participations. Stakeholders and immediate users appropriate designs in unexpected ways. Envisioning use is hardly the same as actual use, no matter how much participation the design process contained [15]. Highlighting that a product resulting from a PD process might fail to cater the needs of envisioned users that are not included in the design process, leading to a product that might never reach the commercial market. Merkel et al. [113] argumentation align with Bjögvinsson et al. [15], stating that a real danger to PD projects without direct user involvement might result in a system that does not meet the needs of the group, nor is flexible enough to adapt to changes to address a bigger user group.

Following the hypothesis, that PD is an academic endeavor. The question remains as to what happens to the products designed in the search for academic knowledge? Culén [42] reflects on this aspect, by studying the fate of 120 prototypes developed by students. Findings presented in the paper highlight the need for a more sustainable design practice, linking it to limited awareness of sustainable alternatives in design. Concrete actions such as code sharing, re-use, repair can lead to continuing interest in a project after its official end. By focusing on the concepts of sustainability in, or through a design process can contribute to making a product that lasts, with continued interested after its official end. Culèn [42] state that if one is motivated to reach a goal, behavior modification is needed. Merkel et al. [113] further elaborate on this aspect of PD, stating that designers need to take on a new role, not only providing technological solutions, but motivating behavior change by involving community groups in design to gather requirements, and to focus on issues of long-term sustainability. A step toward achieving this, Merkel et al. [113] argue is by seeding ownership in PD projects. By looking at the participants as owners of the projects, not only as co-designers. Focusing the behavior change and sense of the property when creating sustainable technology in PD projects, one can create better projects. This is where the link to concepts of Service

Design (SD) enter my thesis.

4.4 Service Design

SD as a design methodology is a relatively new and emerging field, compared to PD. SD have roots going back to 1991, It is still developing and therefore has a vague definition. The authors of the book “This is service design thinking” [170] offer various definitions, at the core, is the notion that SD is an interdisciplinary approach that combined different methods and tools to create experiences using a combination of intangible and tangible mediums. It provides numerous benefits focusing on the end users experience, creating better services and products that are useful, usable, desirable and incorporate customer satisfaction, designer satisfaction, problem resolution and economic and environmental sustainability [10, 142, 170]. It is important to note, that the book "This Is Service Design Thinking" by Stickdorn and Schneider [170], is not an academical published work. As a result, the content should only be an indication of the development and concepts of SD. Buchanan [30] show that one of the strengths of design is that it does not have a precise definition, claiming that fields who have rigorous definitions tend to be lethargic, dying or dead fields. By not defining a field – one can challenge what is accepted as truth.

SD strives to create services that are useful, usable, desirable, efficient, and effective [142]. To achieve this, SD uses a series methods, tools, and techniques. Nicola Morelli [115] discusses the tools in the article “Service as value co-production: reframing the service design process”. Illustrating three main categories of tools a designer can utilize, each containing different methods inspired from other design fields, analytical tools, development tools, and representation techniques. Morelli states “Those methods are often borrowed from other disciplines [...] and adequately adapted [...] to the task of service design” [115, p.586]. The methods include design activities such as role playing, enactment of scenarios, personas, prototyping, storytelling, workshops, observations, and cultural probes. There are also unique methodological methods and concepts to service design such as touchpoints, customer journey maps, and blueprints [142, 170]. Touchpoints are according to Zomerdijk and Voss [194] what occurs whenever a customer “touches” elements of an organization, this can happen across multiple channels and at various points in time. Designers can use touchpoints to map the interaction a user has with a brand or service. Combined these touchpoints construct a customer journey. The customer journey involves all activities and events related to the service, from a user’s perspective. These journeys can be used to understand customer behavior, feelings, motivation and attitude when interaction with the service [170, 194]. Blueprints are another technique in SD. The purpose of the exercise is to allow for a quantitative description of critical service elements, such as time, logical sequence of actions and process. Furthermore, it can be used to specify both measures that occur with ongoing interactions in a system or actions that occur beyond the user's line of visibility. Both of these areas can be fundamental for the functionality of the service, and thus they are equally important to uncover [115].

The section above highlight the core characteristics of SD, with some of its unique features. Understanding the core features of SD is important when exploring the relevance of the methodological framework for my thesis. Saco and Goncalves [142] argue how SD can contribute to answering the questions raised by Culén [42] and Merkel et al. [113] concerning co-ownership and sustainability to products originating from PD projects. Arguing that technology has blurred the boundaries between product and service. Thus, leading to increased complexity concerning sustainability, the concepts are getting intertwined covering aspects of economic, social, and ecological degree, but at its core, sustainability is about concerns in regards to product lifecycles [142]. The authors [142] show that to make a significant impact, SD considers the concepts of multidisciplinary teamwork, looking at the entire ecosystems of a design rather than isolated aspects. By applying a holistic view once can consider integrated ways a system can be implemented, connected to strategic, design, and development process [142]. SD can contribute to designing systems that look at the implementation on a larger scale. Striving to design a system that is both scalable and sustainable after a project has ended. Stickdorn and Schneider [170] state that to achieve holistic and sustainable solutions it is crucial to include all key stakeholders. Working with interdisciplinary teams that include customers, employees, and management as well as engineers, designers and other stakeholders involved in both the service design and service provision process. Achieving co-creativity among interdisciplinary teams is a key feature of a good service designer [170, p.123].

The methods used in SD further contribute to the aspect of sustainability. Saco and Goncalves [142] illustrate that keeping an open design architecture, the design solution can be adaptable over time. Focusing on the way a user interacts with a system, understanding that it can change based on a range of factors is key to achieving sustainability. By catering to adaptable touch-points, based on user interaction, one can design a scalable system adaptable to the future needs of the users. As a result, SD systems can address issues presented earlier by Merkel et al. [113] and Bjögvinsson et al. [14]. That by designing flexible systems one can alter the system based on actual user needs, needs that might evolve over time.

The literature on SD shows that the holistic values at the core of SD contribute to scalable and adaptable systems that can evolve over time. Addressing some of the Issues raised from the literature in regards to PD projects sustainability. Stickdorn and Schneider [170] argue that the emotional aspects of a service – the desired customer experience is rooted in motivation and engagement. By addressing this, one can create a sustainable service implementation. Focusing on motivating several different stakeholders and involve them from the beginning of a process is a major step in ensuring that a system implementation is successful. They should contribute to every aspect of a design process from idea generation to prototyping [170].

4.4.1 Participatory Design and Service Design

Several studies are conducted – exploring the link between these two different methodological frameworks and its value toward co-creation [77, 150, 167, 171]. Holmlid [77] indicate that PD and SD share common approaches and values in major areas. They both focus on emancipatory objects, in the case of co- creation, democratic practices, power relations, and sustainability. Furthermore, both methodologies concentrate on cooperative approaches and participatory techniques to achieve this. Concepts and techniques appear ubiquitously but labeled under different terms. Stickdorn and Schneider [170] argue that for designers to develop better products, they need to generate knowledge that can be embedded into artifacts. For the users to understand the value of an artifact in the context of their daily lives, one should strive to learn the user's individual needs, mindset, and motivation. Indicating a clear similarity to PDs guiding principles of understanding practices. Furthermore, SD and PD rely on co-creation through user participation, addressing values of power relations. Relevant to a design process is to acknowledge that a user might experience a fear of saying the wrong or be reluctant to disagree on a topic [170]. The authors [170] further elaborate on the use of contextual interviews, claiming that knowledge gathered from the users in a familiar setting can help generate detail specific knowledge, as people have a tendency to open up in a familiar setting. Intended to gain an understanding of the social and physical environment of the design project. Parallels to the PDs guiding principles of *situation-based actions* and *mutual learning* become apparent.

4.4.2 Service Design for healtcare

The need for a distinction between traditional SD and SD for health becomes relevant for the context of my thesis. As illustrated in section 4.4 SD is primarily used by commercial services to improve customer satisfaction with the motivation to increase revenue or user satisfaction. The same motivation does not apply to health care, where the goal is to aid patients fighting chronic diseases. Jones [66] describe SD within the context of healthcare. The author [66] show that SD aims to enhance consumer's experience while also optimizing the design of service delivery and business transactions. However, healthcare is neither transaction nor consumer-oriented, and the standard of evaluation (or care) is necessarily different than the standard for commercial services [66, pp.141]. Thus, working with SD in a healthcare setting requires me as a designer to think differently. Jones [66] argue that the transition to a patient-centered perspective need a shift in focus. It should be services designed for people with health problems who seek professional care to improve wellness, not presented as patients in a system, but as active agents in charge of recovering their health. Relying on care resources gained for their community and digital services. Jones [66] explain how the aim of design for services was a shift from a user-centered design of things – to ability centered co-construction of meaningful experiences. This change from a service to an experience economy will eventually inspire changes in healthcare. The author [66] exemplifies this by referring to children's hospitals as pioneers, staging experiences for patients using colorful fantasy inspired atriums and play areas. These experiences can distract and offset a patient experience with sickness in a positive way [66].

A different standard of care is necessary when designing a system for professionals or patients rather than for consumers. Jones [66] highlight the need for a foundation based on research methodologies for healthcare applications to understand the principles of practitioners and patients. Working with healthcare services requires following strict rules, but these rules should not inhibit the innovation value from exploratory research. SD then moves away from the concepts of UCD, as the goal is not to design for users, but designing with them [66].

Another aspect of SD within the field of healthcare is to understand that systems are sociotechnical, with a strong focus on value co-creation. That value realized by the customer can come from what the service offer to the user, and from interacting and using the service. Other studies point to the possible rewards of designing for values, see [67, 183]. Jones [66] show how interacting with the interface of a service is the source, where designable values occur. The service-oriented logic has the potential to change the institutional model as a new healthcare organization services are designed [66]. Designing for care requires the designer to think differently than when designing for services. The tools of traditional SD remain the same; it is more about the understanding of with and for whom you are designing.

4.4.3 Concerns with Service Design

SD is a relatively young and emerging design field, established in section 4.4 influenced by a range of other disciplines. Concepts from design thinking have had a large influence on SD, resulting in them being referred to interchangeably [192]. Young [192] try to define the field of designing thinking in practice, stating that it is a combination of three design constitutions: Human-centered, Research-based, and iterative prototyping. Summing the three attributes up leaves us with the concept of design thinking. Sato [169] states: "The good news is that design thinking is systematic; the bad news is that it is not formulaic," [169, p.43] addressing the fact that designers mix and match methods to suit their specific needs in the context of a design challenge. This view is what Nussbaum [5] critiques in his paper "Design Thinking Is A Failed Experiment. So What's Next?" The author focuses his critique on a significant amount of failures in the endeavor to implement design thinking. The reason for this being companies absorbing the process all too well, turning it into a linear by-the-book methodology, that at best delivered incremental change and innovation. The critique is then, mainly situated in the fact that design thinking has transformed, from what it was intended, to a strict methodology, where one is no longer able to pick the desired methods for the context of the design task, but instead tasked with gaining revenue. Sangiorgi [148] further elaborates on this, stating that, SD lacks a research direction and theory [149, p.418]. Nussbaum [5] illustrate that the design thinking has started to do actual harm to the development of technology [5]. Academic circles contest the views off Nussbaum [5], and several authors have responded to his comments. However, for the scope of my thesis, it remains important to be aware of the potential pitfalls that one cannot use SD rigorously as a methodology, but apply methods and techniques, suited for the design task at hand.

4.5 Why combine Service Design and Participatory Design?

By highlighting the potential strengths and limitations inherent in both PD and SD, it becomes clear that an alignment between the two methodological frameworks can contribute to strengthening my future design work. Working with a user group of chronically ill youth patients, PD might be the preferred methodological approach. The hesitation to solely rely on PD connects with PD beeing an academic endeavor. Contributing to the development of the PD tradition, but offering limited effect concerning the outcome of a design process. SD, on the other hand, is an endeavor to increase revenue and improve service satisfaction. What links them together, regardless of their different initial purposes, is the value of co-creation and user involvement in creating better and potentially more sustainable systems. PD and SD both contain a unique collection of methods with tools and techniques. These methods, tools, and techniques are not intended to be applied rigorously but provide flexibility to the design prosses, allowing the designer to choose the set of methods incoherence with the context and problem area – to provide a foundation for co-creation. Knowing how to select between methods is key in developing better services [24, 66, 170]. By using PD as my main methodology, and incorporate elements from SD, concerning sustainability and usability. I hope to explore the link between PD and SD and contribute to an emerging design field. Holmlid [77] states: “At the moment only few actual research studies have been made in the intersection between design as phenomena and service as phenomena” [77, pp.10].

4.6 Youth and Adolescence in qualitative research

Fossheim et al. [57] show that ethical considerations in academic research are defined as moral obligations to the design process and reflecting on the ethical considerations should never be done after you have conducted your research, but rather integrated into the entire process from idea to design. Consequently, this is an important consideration for the scope of my thesis. Reflecting on the ethical considerations in regards to working with youth and adolescence in the early stages of my thesis can contribute to the strengthening my research process. Fossheim et al. [57] state that an important aspect of working with adolescents is to acknowledge the reality, that youth are individual actors with independent rights. The rights connect to the person that they are– not the person they will be once they enter adulthood. The authors [57] illustrate that seeing youth and adolescence as who they are now, not whom they will become calls for several methodological challenges. Youth and adolescence have a fundamental right that research conducted on them should be held to the same standards as research performed on elder groups of the society. Implying an understanding that youth and adolescence are not a homogenous group, but a heterogeneous ensemble with different skills, knowledge, and cognitive ability. One should strive to use their age not as a limitation, but as a resource in the project [57].

Lang et al. [97] state that youth should be able to make complex choices affecting their health and wellness. Thus, they should be included in the design process. The author point to a growing body of research focusing on and ergonomic approach, including the target group in the design process, as this can lead to improved patient safety, better health outcomes, increased user satisfaction, and better implementation into their current lifestyle. Lang et al. [97] show several benefits of including youth in academic research. Nevertheless, a fear associated with navigating official ethical reviews and guidelines are making researchers hesitant to include adolescence in their studies. The authors [97] argue how this is creating a paradox. That the ethical guards and regulations designed to protect youth, is acting as a disincentive to researchers. In reality, rather than protecting adolescents, it may leave them exposed, as advancing research fails to be inclusive of young people. This paradox can, in fact, lead to the exclusion of adolescents in research, resulting in technology devices that are inappropriate, inefficient, or unpleasant to use, which has implications for the overall goal of enhancing long-term health issues [97, pp.8-10]. Lang et al. [97] suggest several approaches to navigating the ethical guards and guidelines in the design process with adolescents. I will elaborate on this in chapter 5

4.6.1 Connecting the concepts, how does it affect my thesis?

This chapter acts as a foundation, shedding light on the strengths and weaknesses of the theoretical and methodological frameworks, which will guide my future research. Throughout my thesis, I will explore how *lifeworld*, PD, and SD can connect in a design process. PD and SD provide the methodological foundation intended to help co-create future technological solutions, based on the needs and desires of the participants. Knowledge of my participants *lifeworld* and the intertwined dimensions inherent in the framework, can contribute to knowledge and ideas not solely shaped by their needs and desires. Rather, future technology connected to how time affects their well-being (*temporality*), what is most meaningful in their life (*spatiality*). How the participants connect with others (*intersubjectivity*). How EDs have influenced their life on different levels(*embodiment*), and how *mood* can color everything. The objective is to create an interconnected holistic picture of the all the dimensions, and how it affects their well-being. If successful, the provided knowledge can aid in the creation of new technology aligning with the lived experience of my participants.

Chapter 5

Ethics

5.1 Ethical considerations

> In a very real sense, every method decision is an ethics decision, in that these decisions have consequences for not just research design but also the identity of the participants, the outcomes of our studies, and the character of knowledge which inevitably grows from our work in the field. [107, pp.251]

Every choice we make in a research process about how to present the self, participants, and the cultural context directly contributes to how the findings are understood, framed, and responded to by our readers. As researchers, we hold a great responsibility toward how we represent the knowledge acquired during a design process. Thus, the task should be guided by through ethical reflexivity [107]. Consequently, every decision I make in my thesis is an ethics decision. This chapter will cover what I deem the most important ethical considerations relating to my methodical framework, my user group, and the Norwegian Center for research data (NSD)

5.1.1 User group

My literature review 2 illustrated how EDs are a complex diagnosis, interconnected with both physical and cognitive challenges, placing my user group within the category of vulnerable users. Culén and van der Velden [44] state that vulnerable users are traditionally viewed as people at risk because of age, frailty, diagnosis, or limited physical or cognitive capacities [44, pp.54]. Working with vulnerable users provides additional challenges for me as a designer. Culén and van der Velden [44] argue that this is due to the lack of appropriated design methods, difficulty in communication, or the researcher's difficulty of empathizing with the vulnerable user's experience of the world [44]. Vines et al. [186] further elaborates on the aspect of working with vulnerable users. As researchers, we might have an interested in creating technologies that use vulnerable users, for the purpose of showcasing a new application. In doing this, we might, in fact, be making people vulnerable. The authors [186] state that “[...]people with certain vulnerabilities may be excluded from experiencing experimental technologies that might bring great personal benefit to them” [186, pp.46]. Consequently, it is the responsibility of the researcher not to focus on what people cannot do, rather on what they can do. Hindering the inclusion of vulnerable users, based on preconceptions or agendas can stop the people who need the technology the most from participating in creating it [186]. In my research project, I need to apply focus on the establishment of a workshop setting where I apply methods that allow the participants to communicate and express their experience of the world. Vines et al. [185] stresses that the agenda of the research needs to be explicitly and focus on reflexive understanding regarding different forms participation can occur. To achieve this, I also need to consider ED-specific ethical concerns. Manly et al. [106] argue that by involving young people with EDs, one needs to be aware of the imaginary audience phenomenon. The phenomenon is connected with the fear of scrutiny, making the patients overwhelmed or fearful of sharing information in the presence of others who may be perceived as evaluating or criticizing them [106]. The authors [106] show that adolescence can experience that their views are not considered important in the decision-making process. Younger patients, usually adolescent girls, may have difficulty expressing their wishes and concerns. Lastly, Manly et al. [106] stress that within children rights, there is an increasing emphasis on empowerment to the to participate in decision making regarding their health care needs [106]. The study presented by Manly et al. [106] is not directly connected with a PD process. Regardless, the illustrated ethical challenges are relevant for my research project, working alongside young people with EDs.

5.1.2 Ethical considerations in PD

Culén and van der Velden [44] show that by including vulnerable users in a PD process, requires the process to hold high ethical standards. Therefore, it is important to illustrate the core ethical principles, within the foundation of PD. In the theoretical and methodological chapter 4.2 I presented the central principles and values of PD. Contained within these values, lies the ethical principles of PD. Robertson and Wagner [135] argue that PDs core ethical motivation is to support and enhance how people engage with others in shaping their world – over time. To achieve this, the authors [135] call for the development of processes and tools that enable designers, users, and stakeholders to learn and understand from each other. To achieve genuine participation, and follow the core ethical principles of PD, the participant’s voices, ideas, and needs to be heard, understood and upheld [135]. For my thesis, this centers around my ability as a researcher to use methods, tools, and techniques that allow my participants to express themselves, to have a say in the choices taken, so that the result of PD process reflect their vision for future technology. To achieve that objective, I need to consider the ethical responsibilities presented above, relating to my vulnerable user group, their diagnosis, and my chosen methodology.

5.1.3 NSD

NSD regulations dictate the process of obtaining valid consent from participants in a study. For the consent to be valid, it has to be voluntarily given, expressly and informed. To achieve this, all participants needs to understand what the consent is about and the consequences it has on their participation in the study. (see Appendix .4 figure (.4) for the consent form) [94]. The consent form introduced in the first workshop (see section 6.5) explained the purpose of the study, means of participation and how I would handle the collected data. Requirements from NSD to the protection of personal data limited my ability to obtain personal information from my participants beyond gender and age. The signed consent from would be in possession of my participants, or a patient organization/treatment option, depending upon recruitment, these are steps to ensure the protection of the participant's anonymity. I created a spreadsheet to cross-reference gender and age toward an alias for each participant, to keep track of the number of participants in the study. All data collected during the workshop were collected, protected, extracted, and stored per NSD regulations. The data were collected using an offline sound recorder, and stored on a USB flash drive, protected in a locked locker within a locked building. After transcription, the recordings were deleted, to ensure the protection of privacy and anonymity of my participants.

5.1.4 Ethics in my research project

Guillemin and Gillam [64] show that there exist two major dimensions of ethics within qualitative research. Procedural ethics involves gaining approval from ethics committees to conduct research with humans. In my research project, contact with NSD and obtaining consent are elements of procedural ethics. The other dimension of ethics is "ethics in practice," referring to everyday ethical issues that arise during qualitative research. Within my research project, ethics in practice are the issues relating to my vulnerable user group, and my methodological framework [64]. Research is an enterprise to construct knowledge together with participants in the study. This is an active process that requires scrutiny, reflection, and interrogation of the data. The authors [64] argue that this is a reflexive process. Reflexivity involves critical reflection on how the researcher constructs knowledge. By being aware of the ethical reflexivity, one needs to investigate what influences the research. Rigorous reflexivity can improve the quality and validity of the research, by recognizing the limitations of knowledge that is produced [64]. Consequently, reflexivity becomes important to my research project, as I start the process of constructing knowledge. "[Reflexivity is] a process whereby researchers place themselves and their practices under scrutiny, acknowledging the ethical dilemmas that permeate the research process and impinge on the creation of knowledge [64, pp.276]."

5.1.5 The role of the facilitator

Gibbs [61] illustrate that being a facilitator demands good interpersonal skills and personal qualities. To gain the participants trust and promote interactive dialog, the facilitator needs to be a good listener, non-judgmental, and adaptable. In the context of my thesis, working with a sensitive patient group, it requires me as a facilitator to take special consideration of the sensitivity of the topics discussed to promote trust, and enable my participants to talk about sensitive subjects. Gibbs [61] illustrate that when conducting research on sensitive data, it poses ethical considerations regarding anonymity and privacy, as there might be more than one participant. Demonstrating the importance making sure the participants are comfortable sharing sensitive information in the presence of others. Tee and Lathlean [173] argue, based on their research, that ethical guidelines are important, but not always enough to counter complexity of an encounter working with vulnerable users. The authors [173] show how a facilitator need to assess vulnerability and sensitivity when conducting inquiry procedures [173]. When doing my research, I will carefully consider the ethical responsibilities of facilitating qualitative research with vulnerable users. Applying sensitivity to the topics discussed, and provide necessary attention to upholding trust, ethics and promote an open dialogue.

Chapter 6

Workshop one

The following three chapters in the thesis will provide a chronological walkthrough of the conducted design process. Highlighting objectives, preparations, methods, findings, and analysis for each workshop. Chapter 9 contain the discussion and reflection regarding findings from the conducted workshops.

6.1 Shaping my field study

At this stage of the process, I had a distinctive aim of what I wanted to achieve through my design process 1) I wanted to conduct my data-collection on the core principles of PD. 2) I wanted to utilize elements of SD to increase the sustainability of the design and enhance the creative process inspired by SD methods. 3) I wanted to investigate the *lifeworld* of the participants living with EDs, and the role of technology based on their lived experience. While keeping the overall objective of the research project in mind – allowing the design process to investigate the potential *lifeworld* have toward creating mobile technology that "better" reflect the needs and desires of youth living with EDs. The following chapter will focus on how I conducted my first workshop and the creation a new qualitative research method to aid me in the process of achieving my defined objectives.

Bowens et al. [21] stresses the importance of motivating young people in participation, by empowering them to consider themselves as innovators. Bowens et al. [21] state that motivation can be achieved through attention to the participatory activities themselves. Using a method that allowed the participants to be motivated to share feelings, experiences, thoughts, and emotions are therefore necessary for my research project. The aim of investigating the participant's *lifeworld* is built on the premises of understanding and gaining access to their lived experiences. Furthermore, EDs as a field is complex, working in a technical domain my knowledge is limited to findings from the conducted literature review and scoping interviews. Therefore, I had to do my fieldwork in a way that allowed the participants to share their personal experiences with EDs.

Young patients with EDs is a sensitive target group, posing ethical and practical challenges to access of potential participants (see chapter 5). Therefore, on June 7, I made initial contact with the patient organization for eating disorders located in Oslo, Norway. The patient organization acts as the first line of support for people struggling with EDs. They are not medical practitioners, but peers who can relate to the challenges of living with EDs. The patient organization offers manned phones, email support, meetings, trips, and other social activities, making it a low-threshold first step of contact and support for EDs [81]. The initial email correspondence led to a meeting on June 10. Where the desired objectives of my research project were presented, along with the core values of my theoretical and methodological framework, such as *mutual learning*, *democratic practices*, *having a say*, and *lifeworld*. These values aligned with the preconceptions and thoughts of the patient organization, as a result, they granted me permission to carry out the study with their assistance. During the meeting the patient organization promoted their agenda, stating that the project could be mutually beneficial to both parties, as the patient organization had plans to file an application seeking financial support to develop their own mobile application. Since our visions for the project aligned, I suggested that my research and design work could act as a foundation for their mobile application and future work.

The patient organization emphasized that the potential participants of the study should be recovering or partly recovering, and at a non-critical state of the illness. According to the patient organization, this would strengthen the study, because EDs involve both complex physical and psychological elements, making the critically ill less likely to offer a consistent contribution to the project, aligning with findings from the scoping interview. The data gathered from the workshops would represent the participants at their current mental state, which can be rapidly changing during critical periods. A change in the emotional or cognitive state of a participant could lead to challenges of scalability in the design solution. We decided on three fixed dates to conduct the workshops. Stretching from June to August. The patient organization in this context acted as *gatekeepers*, a term used by Holloway and Wheeler [76]. The authors refer to *gatekeepers* as stakeholders who hold access to the desired target group, and only by gaining permission from the gatekeepers can one access the user group. The authors [76] also refer to potential dangers surrounding gatekeepers where attempts to manipulate results and outcome of a study to suit their individual needs might occur [76]. However, since both parties had been open about their role and agenda for the project that resulted in a *shared vision* [26] such pitfalls were less likely to occur.

6.2 Choosing a method

This section will cover decisions taken, leading to the creation of a new qualitative research method, utilizing the methodological toolboxes of both PD and SD to gain knowledge of the participants *lifeworld*. Kensing and Blomberg [90] state that traditional approaches to system design make it difficult for users to envision connections from their own work to the more abstract and technically descriptions of a new system [90]. Inspiring my data collection to use a method consisting of tools and techniques that aid the participants in seeing the connection between their experiences and possibility for new mobile technology. Kensing and Blomberg [90] show that innovative tools and techniques are a major factor for PD projects. To achieve innovative tools and techniques, they need to be developed for the specific context of the project. Brandt et al. [24] support this argumentation. Tools and techniques should not be applied rigorously, but fitted to the proper participatory action, with the aim to create a common ground for designers and non-designers. Bratteteig et al. [26] agrees, and state that PD methods cannot be applied like a cookbook recipe, but provides guidelines that must be carefully selected, adapted and appropriated to the specific project and situation at hand [26, pp.118]. It is important to note, that as a researcher I cannot appropriate tools for my project. I can design and create tools for the participants to appropriate to show their visions for future technology.

I reviewed existing literature covering methods, tools, and techniques within SD and PD methodology, to decide which methods to use in my design process. Applying focus toward methods that facilitated the sharing of experiences and expertise. Essential components in exploring my participants *lifeworld* I decided to use a customer journey map, a method that is considered a central part of SD methodology.

6.2.1 From customer journey map to timeline

I choose a *customer journey map* as my initial method for data collection, as it is referred to as one of the most efficient visual tools in SD. The strength of a *customer journey map* lies in its the ability to visualize service elements. Services can be seen as a process that happens over time, and once all the elements are connected the *customer journey map* takes it shape [43]. It is important to note, that the traditional approach to a *customer journey map* would not suit my research project without alteration. Traditionally, the *customer journey map* consists of several *touchpoints*. *Touchpoints* occur when a user "touches" elements of the service. In the context of my thesis I was not aiming toward designing a traditional service – I was aiming to explore the transition from designing of services to designing for experiences [66]. For this purpose, I decided to adapt the traditional *customer journey map* to consist of a new set of *touchpoints*. Not rooted in interactions with service, but *touchpoints* based on participants own interactions in everyday life and experience with EDs. Altering the *customer journey map* include altering the traditional perception of the service concept. Within the context of my thesis, the idea of a service will be the collection of experiences from the participant's lived experience, instead of interactions with an organization or system.

The first step in preparing for the workshop would be to decide how to alter the *customer journey map* to a tool that provided the participants the ability to express important events relating to their lived experience with

EDs. Central to exploring the participants *lifeworld* is the capacity to capture the holistic nature of beeing human, giving the participants the ability to express every aspect of their lived experiences including everyday life, diagnosis, technological use, or significant relations. Investigating what contributes to their well-being, not only what affects their illness or diagnosis [178]. Obtaining knowledge of the participants *lifeworld* can inform the design process and "guide the design of new technology that supports them in living their everyday life with their health challenges [184, pp.2]. " Dahlberg et al. [46] state,

> Entering the phenomenological realm we do not fundamentally find our lives as unrelated compartments such as 'health', 'illness', 'emotional life' 'spiritual life'. Neither do we find mind-in-itself or body-in-itself. We rather find the seamlessness of everyday life and its qualitative character. [46, pp.266].

To capture the "seamlessness of everyday life" the alteration of the *customer journey map* needed to provide the participants the opportunity express every important aspect of beeing human, living with EDs. Due to my research interest in exploring the development of new mobile technology, I was interested in collecting specific information relating to the participant's experience of using mobile technology. Striving to create a tool to express such spesific knowledge, the *customer journey map* were transformed it to a timeline. The intended timeline would be a physical representation of a participants day. The timeline was designed to help support the seamlessness and qualitative nature of the daily life, by only having two predefined *touchpoints*. These *touchpoints* were defined with a home icon and intended to symbolize waking up and going to bed. The remaining timeline would be open, allowing the users to fill in *touchpoints* relevant to their *lifeworld*, their experience with EDs, and also their existing relationship to mobile technology. Inspired by Culèn and van der Velden [43] research, I intend the timeline provide knowledge going further than just the moment a *touchpoint* occurs in the life of a participant. It can potential act as a platform to investigate and capture connections between experiences from a participant's life and the time it occurs (the *touchpoint*). Contributing to obtaining a holistic picture of everyday life, and hopefully, enable understanding of the complexity of living with EDs. By taking this approach, I was able to offer complete freedom to the participants, giving them the opportunity to illustrate what was important to their lived experience with EDs. The timeline was designed on A2 paper, to allow easy interaction. Figure 6.1 shows the predefined timeline. The area marked "bruker kontinuerlig" [1] is intended to illustrate the reoccurring use of technology.

The argumentation for creating a new research tool, like the timeline, align with van der Velden and Sommervold [184] findings from their study. The authors [184] show that a *lifeworld* approach, in combination with PD methodology, enables patients to be met as co-designers and affect the

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[1] Translation: "Continued use"

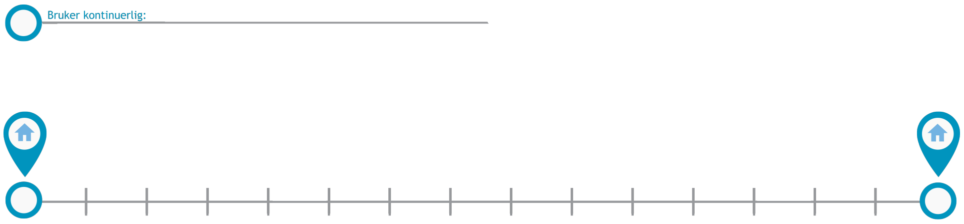


Figure 6.1: The predefined timeline

design of mobile technology [184]. Aligning with the core values of PD, and allowing the participants to show that they are experts of their own lives, and therefore can contribute to the design of IT applications intended to reflect their needs. A process of combining PD and *lifeworld*can contribute to understanding what the participants value in their lives. Furthermore, a *lifeworld-led* design approach can help understanding the role of technology in the lives of young people in general [184]. Transforming the traditional Customer Journey Map to a Timeline focusing on a Lifeworld approach would allow me to investigate the objectives for the first workshop, defined at the beginning of this chapter. However, an important question remained. How would I allow the participants to visualize what was essential to their lived experiences? How would they fill their Timelines? To try and answer this I looked to Culèn and van der Velden [43] research. The authors [43] show the creation of Travel Experience Cards (TEC), the cards were designed with an SD mindset, created to aid the creative process and help the participants in their study visualize their experiences from public transportation services. The goal was to use the TEC cards to create a *customer journey map* consisting of participants *touchpoints* from interacting with the service. Culèn and van der Velden [43] argue that the use of tangible objects, such as inspirational cards that contain images, and can facilitate visual reasoning, creating a common language for communication [43, pp.4]. Culèn and van der Velden [43] goals for the process differ from my research project. Regardless, the premise that using both SD and PD methods to help facilitate creativity and create a common language to exchange knowledge, align with my objectives for the thesis. I decided to build on the ideas of Culèn and van der Velden [43], by using *inspiratioanl cards* for my participants to interact with the timeline. *Inspirational cards* as a research tool aligns with the underlying values of PD and have been used in PD projects (see [22, 163]), as the use of inspirational act as a means to investigate current practices and needs of the participants [163], which can result in *mutual learning*. In chapter 4.4.1 I illustrate the potential benefits of combining elements from PD and SD, as both methodologies share a common value in co-creation. By using elements from both methodological frameworks, I hoped to generate design ideas that would align with the participants *lifeworld*. The following section will illustrate the creation of different kinds of *inspirational cards* that would act as tangible tools aid the participants in interacting with the timeline. Combined the timeline and the *inspirational cards* resulted in a new qualitative research method, which will henceforth be referred to as, Lifeline.

6.2.2 Inspirational cards

Inspirational cards are according to Halskov and Dalsgård [69] physical cards with an image, a title, a description, and a reference. The authors define two broad categories for inspirational cards, namely *technology cards*, and *domain cards*. The former contain technology specific *inspirational cards*, where information regarding concrete technologies is placed. The latter consists of *inspirational cards* with information on the domains we design in, this can include information such as situations, people, settings, themes, and topics from the domain [69]. Halskov and Dalsgård state,

> Inspiration Cards can be used in a number of ways: as a standard for collecting and consistently representing sources of inspiration, as a way to gain an overview of various concepts, as means of communication between designers and domain experts [69, pp.4].

Wölfel and Merritt [189] published a study investigating the use of card sorting methods. The authors identified five design dimensions including 1) Intended Purpose and Scope, 2) Duration of use and placement in the design process. 3) System or Methodology of use. 4) Customization. 5) Formal Qualities. The authors [189] analysis show that for PD, inspirational cards can develop sensitivity and empathy for the context they are applied, and help engage designers and participants in the process. For the context of my thesis I had already a clear understanding of the first three dimensions from Wölfel and Merritt [189] analysis. 1) The intended purpose and scope were defined. 2) I had Identifying the duration of use and placement in the design process, as the cards were designed to fill the timeline. 3) The methodology of use was defined to be within my created method. The last two dimensions of 4, Customization and 5, Formal Qualities will be addressed in the following sections.

Wölfel and Merritt [189] further argue that it is important to acknowledge the time investment required to generating inspirational cards. Consequently, having a clear idea of when to implement them is important. Wölfel and Merritt [189] show that some form of cards are best suited at the beginning of the process, as they can provide input for concept development. The argumentation of Wölfel and Merritt [189] was beneficial to my research project, as I was currently in what Sanders and Stappers [147] refer to as the *fuzzy front end*.

> the front end describes the many activities that take place in order to inform and inspire the exploration of open-ended questions such as 'how can we improve the quality of life for people living with a chronic illness?'[. . .]' The front end is often referred to as 'fuzzy' because of the ambiguity and chaotic nature that characterise it [147, pp.7]. (. . .)

In *fuzzy front end*, the focus is toward understanding the users, their context, exploration and selection of technological opportunities [147, pp.7]. I wanted to answer the questions raised by Sanders and Stappers [147] by using the *inspirational cards* at an early stage, with the aim of exploring and understanding the users, identifying the needs, and explore technological opportunities.

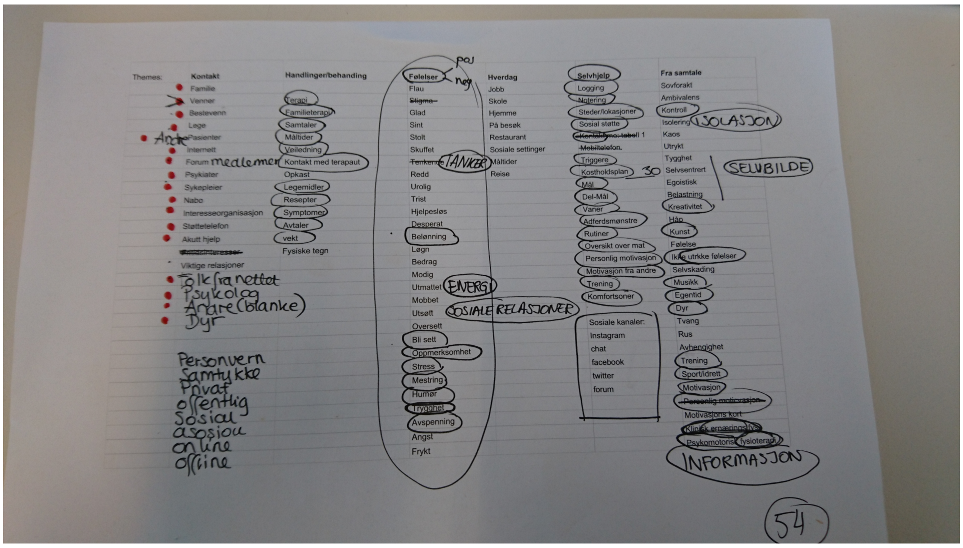
6.2.3 Combining the elements

To summarize, at this stage, I had decided to create a new qualitative research method, LifeLine. The method was designed based on the concept of a *customer journey map*, adapted to a timeline. The timeline would be filled with *inspirational cards* to aid the participants in illustrating lived experiences in the context of their *lifeworld*. The following section will explore the development of the Inspirational cards.

6.3 Creating the tools

6.3.1 Content for the inspirational cards

Wölfel and Merritt [189] state that "[...] designers can choose to use method cards in their design process either by using existing systems or by creating a new set of cards—essentially, should the designer use an existing toothbrush or create a new one? [189, pp.484]" There is limited academic research on co-creating technology for youth connected with EDs, and no known research on the use of *inspirational cards* within this context. Therefore, I could not use someone else's method, I had to design a new one. To do this, I conducted a brief thematic analysis [28] of my previously conducted literature review, scoping interview, and literature provided by the patient organization. The objective at this stage were to generate as many keywords as possible – that hopefully could be the foundation for my *inspirational cards*. I had no predefined limitations to the amount of topics that could emerge. The next step consisted of reviewing the list of subjects that had emerged. Alterations were made, removing my first groupings based on topics, and adding a series of new topics. The topic list were then revised in two separate sessions. Session one consisted of a meeting with Aria, the same domain expert that participated in my scoping iterviews (see section 3.1). The second session were conducted with my master thesis supervisor. Figure 6.2 illustrates the full topic list, highlighting alterations made during the revision process.



Themes:

Kontakt
- Familie
- Venner
- Bestevenn
- Lege
- Andre Pasienter
- Internett
- Forum medlemmer
- Psykiater
- Sykepleier
- Nabo
- Interesseorganisasjon
- Støttetelefon
- Akutt hjelp
- ~~Fritidsinteresser~~
- Viktige relasjoner
- Folk fra nettet
- Psykolog
- Andre (blanke)
- Dyr

Personvern
Samtykke
Privat
offentlig
Sosial
asosial
online
offline

Handlinger/behanding
- Terapi
- Familieterapi
- Samtaler
- Måltider
- Veiledning
- Kontakt med terapaut
- Opkast
- Legemidler
- Resepter
- Symptomer
- Avtaler
- vekt
- Fysiske tegn

Følelser pos neg
- Flau
- ~~Stigma~~
- Glad
- Sint
- Stolt
- Skuffet
- ~~Tenkende~~ TANKER
- Redd
- Urolig
- Trist
- Hjelpesløs
- Desperat
- Belønning
- Løgn
- Bedrag
- Modig
- Utmattet ENERGI
- Mobbet
- Utsøtt SOSIALE RELASJONER
- Oversett
- Bli sett
- Oppmerksomhet
- Stress
- Mestring
- Humør
- Trygghet
- Avspenning
- Angst
- Frykt

Hverdag
- Jobb
- Skole
- Hjemme
- På besøk
- Restaurant
- Sosiale settinger
- Måltider
- Reise

Selvhjelp
- Logging
- Notering
- Steder/lokasjoner
- Sosial støtte
- ~~Kontaktinfo: tabell~~ 1
- ~~Mobiltelefon.~~
- Triggere
- Kostholdsplan 30
- Mål
- Del-Mål
- Vaner
- Adferdsmønstre
- Rutiner
- Oversikt over mat
- Personlig motivasjon
- Motivasjon fra andre
- Trening
- Komfortsoner

Sosiale kanaler:
- Instagram
- chat
- facebook
- twitter
- forum

Fra samtale
- Sovforakt
- Ambivalens
- Kontroll
- Isolering ISOLASJON
- Kaos
- Utrykt
- Tygghet
- Selvsentrert SELVBILDE
- Egoistisk
- Belastning
- Kreativitet
- Håp
- Kunst
- Følelse
- Ikke utrkke følelser
- Selvskading
- Musikk
- Egentid
- Dyr
- Tvang
- Rus
- Avhengighet
- Trening
- Sport/idrett
- Motivasjon
- ~~Personlig motivasjon~~
- Motivasjons kort
- Klinisk ernærings fys
- Psykomotorisk fysioterapi

INFORMASJON

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Figure 6.2: Initial topic list for the *inspirational cards*

Reflecting on the findings from my thematic analysis and reviewing sessions, led me to the conclusion that one category of Inspirational Cards would not be sufficient to express the inherent complexity of everyday life living with EDs. To cater to this complexity, I decided to create three different types of cards, all under the umbrella term of *inspirational cards*. 1: *domain cards*. 2: *technology cards*. 3: *social relation cards*. The following section will address the intended purpose of each category of cards, and cover the last two elements from Wölfel and Merritt [189] analysis, referring to the customization and formal qualities. Figure 6.3 shows a graphical representation of each category of *inspirational cards*.

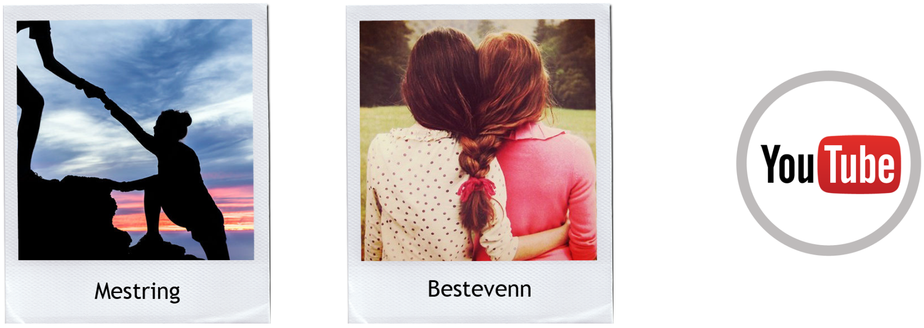

Figure 6.3: Left: *Domain card*. Center: *Social relation card*. Right: *Technology Card*

6.3.2 1: *Domain cards*

The *domain cards* had a clear purpose, they were created with the intent to reflect elements relevant to the domain of EDs. The cards were designed to capture the complexity of life with EDs. Thus, the *domain cards* had a content spanning both abstract and concrete elements. Se figure 6.4 for a full list of all the *inspirational cards*. The *domain cards* were intended to be the main category of cards. The Formal Qualities of *inspirational cards* refer to the physical attributes of the card. Drawing upon the work of Sommervold and Van der Velden [163] were the authors conducted a PD project and created a new design method using inspirational cards to aid adolescence in a transition process from pediatric to adult medical care. I gained inspiration from their way of structuring the formal attributes of their transition cards. Sommervold and van der Velden [163] cards have similarities to how Halskov and Dalsgård [69] defined *inspirational cards*, as they both contain an image, a title, and a reference. I choose to adapt this style but remove the reference attribute.

The *inspirational cards* I designed were small in size, spanning 5x6 cm. Done to make the cards flexible, and easy to work with as discussed in Beck et al. [11]. Each card contained a title and an image. The decision to use images relate to the work of [11, 69, 163] all referring to the utilization of a graphical image to create some degree of inspiration, based on the visual representation on the cards. However, working with the topic of EDs, images can be emotionally loaded and associated with both negative and positive personal experiences. Images with a limited emotionally content were chosen to reduce the amount of negative bias in the pictures. Bias, in this case, would be emotionally loaded images designed to provoke predefined feelings. I applied an Instagram filter to each picture to make it more appealing to the young population, as shown in Machniak [105]. I addressed the design attributes of customization [69] by including blank cards. These cards would act as additional cards and served a clear purpose. It would allow the participants to add cards they felt were missing from the stack, that were relevant to their own experience with EDs. Furthermore, the addition of blank cards was necessary for alignment with the core PD values *mutual learning* and *power relations*. Allowing the users to express their knowledge on the domain freely, and not locked to my predefined cards. Lastly, I made the choice of laminating each card. This choice was made for cosmetic reasons, a laminated card can appear more appealing and shows the significance of detail applied in advance.

6.3.3 2: *Social relation cards*

The category of *social relation cards* contain the same physical attributes as the *domain cards*, but served a different purpose. The *domain cards* were intended to represent the complexity of everyday life living with EDs. The *social relation cards* would act as a supplement to the *domain cards*, but focusing entirely on the concept of social contact. It was intended as a device to further express the need for social support in a particular situation. If a participant, for instance, chooses a *domain card* of importance to everyday life, the *social relation cards* could be used to illustrate the need for a different kind of social interaction at that moment during the day. The pictures included in the social relational cards were intended to create an association with the corresponding text. I laid emphasis on choosing pictures that did not show a clear emotional response. For instances, I avoided showing overly excited and smiling faces illustrating friends, as I had no preconception of the number of close friends my participants would have. Illustrating how the cards tried to limit the amount of bias.

6.3.4 3: *Technology cards*

The *technology cards* flexibility and formal qualities differ from both the 1: *domain cards*, and 2: *social relation cards*. The *technology cards* were designed for a specific purpose, to give the participants the ability to represent their current technological use. However, the *technology cards* were also intended to act as a foundation to discuss desirable attributes of current mobile technology, and uncover elements relating to the privacy of applications. The cards had a different shape than the previous categories. They were smaller in size and had a circular shape. Done to make them easier to interact with on the timeline, the small size would allow the participants to place the *technology cards* freely on the timeline, corresponding to the relevant time of usage. The "bruker kontinuerlig" [2] field at the top of the timeline (see 6.1) was intended to be a collection of *technology cards* representing the different kinds of mobile technologies the participants used throughout the day. The *technology cards* were designed to reflect both abstract and concrete mobile functionality. The *technology cards* had a visual element, in the form of icons representing the application or company associated with the technology on the card. The *technology cards* relied on the affordance of the icons, and did not have a textual representation of the technologies represented on the cards. Figure 6.4 shows the complete list of all the *inspirational cards* to be included in the LifeLine method.

6.3.5 Summing up: A new method: LifeLine

The previous sections have described the creation and modification of existing tools and techniques to create a new qualitative research method tailored for the purpose of my research project. This section will briefly sum up the elements of the LifeLine method. First, the participants would interact with the timeline, using color pencils and *technology cards*, with the aim of exploring and illustrating their current technological use, and map important events in their everyday life. The next step would be to interact with the *domain cards*. The participants would be presented with the full stack of cards and engage in what Fincher and Tenenberg [54] refer to as a "closed sort". A closed card sort is a task where the participants are constrained by predefined categories, and are only allowed to place the provided cards within these categories. I created three predefined categories, consisting of "Technology can help" "Technology can not help" and "both" The purpose of the closed sort was to help the participants illustrate to what degree they envisioned mobile technology could assist with the topics on the *domain cards*. The idea was that the defined categories

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[2] Translation: "Continued use"

Domain cards

- Therapy
- Family therapy
- Conversations
- Meals
- Guidance
- Information
- Medication
- Prescriptions
- Symptoms
- Appointments
- Weight
- Positive emotions
- Negative emotions
- Thoughts
- Energy
- Social relations
- To be seen
- Attention
- Stress
- Mastery
- Mood
- Safety
- Relaxing
- Self-help
- Logging
- Notes
- Places/locations
- Support Phone
- Art
- Express feelings
- Music
- Alone time
- Animals
- Physical activity
- Clinical Nutrition Physiologist
- Psychomotor physiotherapy
- Therapist communication
- Social support
- Trigger points
- Meal plan
- Rewards
- Creativity
- Goals
- Partial-goals
- Habits
- Behavioral patterns
- Routines
- Control over food
- Personal motivation
- Motivation from others
- Motivation
- Workout
- Comfort zone
- Control
- Isolation
- Self-image

Social Relation Cards

- Family
- Friends
- Best friends
- Doctor
- Other patients
- Internet
- Forum members
- Nurse
- Interest organization
- Neighbor
- People from the web
- Psychologist
- Parents
- Psychiatrist

Technology Cards

- Instagram
- Snapchat
- Facebook
- Linkedin
- Reddit
- Imgur
- Flickr
- Forum
- Twitter
- Pinterest
- Messenger
- Safari
- WhatsApp
- Calendar
- Health app

Figure 6.4: The complete set of *inspirational cards* included in the LifeLine method

would allow the participants to freely choose the *domain cards* they felt that technology could support. The next task encouraged the participants to pick ten favorite cards from closed sort category "Technology can help". The ten chosen cards would be used as a foundation for the next step in the method. In the next step the participants were invited to place their ten chosen *domain cards* on sections of their timeline where they felt that the topic of the *domain card* reflected their lived experience. The last task was to include the *social relation cards*. The participants could place the *social relation cards* and connect them to their previously placed *domain cards*, to illustrate how their needs (represented by *domain cards*) could be related to different kinds of social interaction. Figure 6.5 illustrates the formal structure of the LifeLine method [3].

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[3] Thanks to Freepik, providing the template for the figure

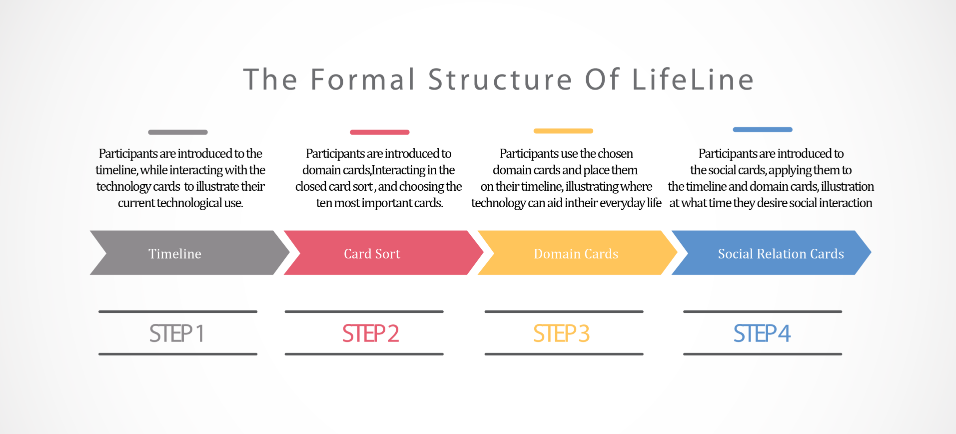

Figure 6.5: The formal structure of the LifeLine method

6.4 Preparing the workshop

Before conducting workshop one with the patient organization, I wanted to test the LifeLine method, focusing on the organization and structure of the method. I also recruited fellow students to aid me in the process of preparing the cards. See Appendix .3 figure 3 for pictures illustrating the cutting and laminating process. The next step was to conduct a pilot workshop.

6.4.1 Pilot workshop

The first pilot workshop was conducted at the University of Oslo on June the 20th. The main purpose of the pilot workshop was to investigate how different tools and techniques worked in combination with guidelines and to practice the role of a facilitator. The pilot workshop provided me with experience in guiding the test participant through the individual tasks and giving directions without biasing the participant. The test participant emphasized that some *technology cards* reflecting her personal use of mobile technology were missing. Leading me to include three new *technology cards* to the existing stack. A second pilot workshop was conducted at the University of Oslo on June the 21st. This test workshop had the same purpose, to make me as a facilitator confident and clear in my instructions, and uncover potential limitations to the method. The workshop revealed grammatical errors in some of the *domain cards* that confused the test participant. The pilot participant also suggested to an additional social card to the stack. Both the pilot workshops provided me with the opportunity to test my technical equipment. I got experience in operating the sound recording deceive, and digital photo camera. Experiencing several of the advantages purposed by van Teijlingen [180]. The author illustrates that a pilot study can be used for in two different ways; a feasibility study, which are small scale versions and trial runs, and a pilot study, referred to as a pre-testing of a particular research tool [180]. I conducted a combined feasibility and pilot study, investigating my method both as a trial run and pre-testing of my research tools. Van Teijlingen [180] present further advantages I experienced by conducting pilot studies. Providing empiric knowledge of the research protocol, investigating if is realistic, identifying logistical problems with the method, training as a researcher in as many elements of the research process as possible, and testing adequacy of research instruments. Pictures from the pilot workshop can be found in Appendix .2 Figure 2.

6.5 Workshop with the patient organization

The workshop was conducted at the regional headquarters for the patient organization, on June 23rd. As stated in section 6.1 the patient organization would be in charge of recruitment for the project. However, I had proposed that we recruit a limited amount of participants. The reason for this was that the LifeLine method required sharing of detailed personal experiences. As the sole facilitator of the workshop, a low number of participants would allow me to give the necessary amount of focus to guide and ask follow-up questions, as discussed in section 5.1.5. Furthermore, I feared participants would feel neglected if I were unable to give them attention when sharing intimate and personal information, as seen in [43]. The following section will highlight findings from each stage of the workshop. Two participants attended the workshop. To protect their anonymity, I have given them aliases. Participant 1 will be referred to as Amanda (23), and participant number 2, Rebecca (25). Both female and both had extensive experience living with EDs. Amanda acts as a proxy participant in the research project (see section 9.5.2 for more information). As discussed in the first meeting with the patient organization, both participants were at a stable physical and mental state, making them suitable candidates to participate in the workshop, according to the patient organization. Before introducing the method, I covered formal elements. The participants were introduced to the consent form and allowed time to read and sign the form, following a presentation of me as a researcher, my project, and the purpose of the study.

6.5.1 Step 1: Timeline

I provided the participants with guidelines on how to conduct this task and was careful to tell the participants that there were no right or wrong way to interact with the timeline. When introduced to the technological cards; Rebecca stated: “I need time to analyze the cards before I can start drawing my timeline”. Illustrating the importance of finding the cards relevant to her experiences and use. This step in the method required individual work, allowing me to focus on taking notes and asking follow-up questions. To explore their current technological use, I asked what features that deemed essential when choosing to use a mobile application, and how interested they were in anonymity and protection of personal data. Amanda stated, “privacy is important, but depending upon the content of the application, sensitive content requires strict privacy and vice versa." Amanda included *technology cards* representing: Facebook Messenger, Instagram, Whatsapp, Calendar, Safari, and Health Applications as technology she used continually, she also included YouTube, Twitter, and Pinterest as technology she used occasionally. However, she felt that the *technology cards* failed to reflect the entire image of her current technological use, as some cards were absent representing technology she used daily. To solve this, I gave her empty *technology cards* allowing her to fill in and apply the technology she felt were missing from her timeline. She decided to add "podcast" and "Spotify" to her existing list of technology. The same issue applied to Rebecca, as she added Spotify to her list of *technology cards* that included: Instagram, Facebook, Facebook Messenger, Snapchat, Health applications, and Whatsapp. Furthermore, she occasionally used Safari and YouTube. Questions emerged regarding several of the *technology cards*. Illustrating that my perception of technological use, differ from their actual use.

The *technology cards* representing popular image sharing sites such as "Flickr, Imgur, and Tumbler" were unknown to both participants, and the affordance of the icons gave no recollection of any application, leading me to explain the technologies and their function. Amanda decided to separate between personal and professional usage of technology "I use a lot of social media in my work, both to publish and edit content, I, therefore, feel it's important to show both private and professional use, to illustrate my needs in both situations." Rebecca took a different approach. She did not separate between professional and private usage of technology, and she did not feel the need to elaborate in detail regarding the use of each technology. Illustrating how the LifeLine method contained tools and techniques that allowed the participants to appropriate them in a personal way, to express their current technological usage, relevant to their *lifeworld*. Figure 6.6 show Amanda and Rebeccas timelines after finishing step one of the LifeLine method.

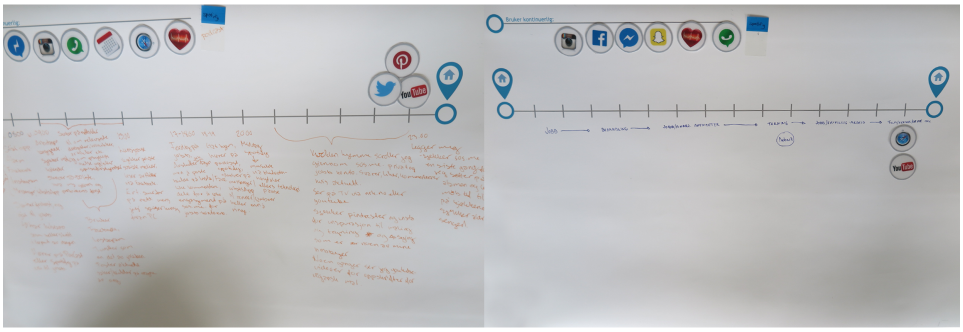

Figure 6.6: Left: Amanda. Right: Rebecca. Both participants timelines after finishing step 1 of the LifeLine method.

6.5.2 Step 2: Card sort

Before the participants interacted with the stack of *domain cards*, I explained my theoretical basis for creating the cards. I encouraged them both to use their own expertise and fill in the blank cards if and when they felt something was missing. The *domain card* labeled "feelings" was a source of confusion, Amanda stated, "I don't really understand this card, a feeling, what do you mean by that? When answering the question, I emphasized that they should think of it in the context of a mobile application, "Can an application in some way help you when you encounter a specific feeling?" Amanda replied, "Oh, ok. Now I understand" Both participants interacted with cards, moving them back and forth. After the initial sort, I presented the next task. However, in the workshop setting, working with real experts it appeared ten cards limiting their creativity. This had not been an issue during the pilot workshops, but the participants felt the need to take along more cards to illustrate the complexity of their everyday life. I altered the task, allowing a maximum of fifteen cards. I emphasized that they could freely change cards from their selected stack with the cards they had left out. Immediately Rebecca decided to change two of her cards. When asked why, she responded, "I acted too quickly, I think an application is more suited to aid with these topics". Amanda posed another question to one of the cards marked "therapy" "I am thinking that this card might be better as a combination card, not like getting therapy, but finding therapy through something like art or music." Both participants were happy with their selected cards, and we could move to the next step.

Figure 6.7: Card sorting: Left: Rebecca's selected cards. Right: Amanda's selected cards.

6.5.3 Step 3: Domain cards

Halskov and Dalsgård [69] argue that the goal of interacting with *inspirational cards* is to inspire the creative process. Any card may be used both directly – Mobile technology can help me with this topic, or indirectly – this technology embodies elements we wish to include in our domain. Halskov and Dalsgård [69] show that any number of cards may be combined, together they can form a design concept. Combining the different *inspirational cards* constitutes the desired outcome of step 3 in the LifeLine method. The participants would combine task 1 (interacting with the timeline) and task 2 (conducting the closed sort) to create ideas. The following section split into two subsections, one for each participant, to illustrate both their contribution to generating design ideas. The next section is a combination of step 3 and 4 in the method, including both the *domain cards* and *social relation cards*.

Amanda

Amanda defined five *touchpoints* in her timeline. The following list summarizes her combination of different *inspirational cards* connected to each *touchpoint* in her life. Figure 6.8 illustrate Amanda's filled timeline.

- Morning: Amanda combined the *domain cards* routines, habits, personal motivation, and partial goals. She included two *social relation cards*, close friends and neighbors. Amanda explained that when she wakes up, it is a struggle to find motivation to complete the day. Why should I take good choices? What is my motivation? Why do I want to get better? What type of plan do I need to make this happen? To do this, she needs good habits, routines, and motivation to reach her partial goals for each day. Amanda explained that in the morning, social interaction is important. Not to reach her specific goals for the day, but to get the sensation of being seen as a person, receiving a smile or a nod when she leaves her apartment. Amanda explains that this sensation can come from interacting with her neighbor or talking with a close friend through a smartphone application. Amanda states that this is a major step to "fuel" her personal motivation and help her achieve the goals for the day.

- Mid-day: Amanda combined the *domain cards*, internet, information, places/locations, and contact with a therapist. *Social relation cards* included, doctor and interest organization. Amanda elaborated: "Ok, so now I have started the day, I envision an application that can help me at this stage, when I realize that ok, now I need help. Something that can help me find or get in touch with help."

- Afternoon: Amanda combined the *domain cards* nurse, psychologist, psychiatry, guidance, and therapy. She emphasized that this was in combination with the mid-day section, that when she needed help and found out where she could get it. She could use a tool to guide her: "Something to help me get in touch with some kind of therapy, to get help and input on how to create new plans when things get rough."

- Evening: *domain cards* included at this stage were, social support, self-help, and interest organization. *Social relation cards* included friends, other patients, family, and parents. Amanda elaborated " Ok, so now I am home, and alone. The need for social support is important. Support so that I don't feel alone, and help to gain self-help. Afternoon and night are maybe the hardest times of the day." Amanda emphasized how the evenings were closely linked with nights.

- Night: She continued to elaborate, "I believe that being alone can be creative (thinking). In creativity, one can find motivation and purpose to continue to fight. If you combine this with social support, one can finish the day with motivation, before it all starts the next morning again." At this stage, Amanda included the *domain cards* motivation, creativity and motivation from others. *Social relation cards*included best friend, people from the Internet and forum members.

Figure 6.8: Amanda's completed timeline

Rebecca

Figure 6.9 represents Rebecca's completed timeline. She presents 4 main *touchpoints* with a her combination of *inspirational cards* combinations of cards.

- Morning: Rebeccas *domain cards* included routines, appointments, and habits. She included one *social relation card*, neighbors. Rebecca elaborated, "Mornings are crucial, it can be used in a way to structure the day. Make plans, and get an overview of the day, including my personal routines. I agree with Amanda, interacting with a neighbor can brighten the day, all it takes is a smile."

- Treatment: The *domain cards* she connected with the treatment *touchpoint* where, mastery, personal motivation, partial goals and clinical nutrition guidance. The *social relation cards* included, other patients, doctors, psychiatrist, and therapist. Rebecca state “Treatment is a key aspect of the day, having the feeling of mastery is important, the feeling that I master going to treatment. Elements of personal motivation and partial goals are also very important. This can help me continue to work toward getting better, and focus on the things that matter to me.”
- Evening/night: Evenings and nights are hard, Rebecca state that the cards for evening and night overlap, she included the *domain cards* music, stress, reducing tension, Internet, self-help, and interest organization. *Social relation cards* included friends, best friends, parents, people from the web, and forum members. “The need for help to address stress arises at evenings and nights. It can be though to get the release of tension or self-help, music or talking to people can be helpful. At night I like to spend time on the Internet, gain information and help myself achieve positive feelings, handle physical and physiological symptoms that might arise, and to cope with triggers. For me, all of these elements are reinforced at night, making it the hardest time of the day.”

Figure 6.9: Rebecca’s completed timeline

Filling the timelines with *domain cards* and *social relation cards* concluded the first workshop. Both Rebecca and Amanda were pleased with the amount of effort put into the tools and expressed joy toward being part of application development, especially toward a domain they had extensive experience. Rebecca stated "It’s so cool to be able to be a part of app development. I love that we got proper tools and not just a post-it notes, and instructions, like "be creative."

6.6 Analyzing the dataset

6.6.1 Thematic analysis

Thorne [176] state that qualitative data analysis is the task of generating new knowledge from raw data. That will be the focus of analytical section – to apply meaning and gain knowledge from my collected workshop data. To achieve this, I will use a deductive thematic analysis [28]. Analyzing themes on a latent level by reviewing them through my theoretical framework of *lifeworld* 4.1 [28]. This analysis section will examine all collected data from workshop 1, referred to as the dataset.

Conducting a thematic analysis requires taking a series of choices. Braun and Clarke [28] illustrate that it is essential to determine what level you want to describe the dataset on. Providing a rich description of the data set, or a detailed account of a particular aspect of it. In the context of my thesis, I will conduct the thematic analysis toward making a detailed account for a particular group of themes in the data. This choice is taken based on the fact that I do not strive to provide a rich description of the dataset. Instead, I focus on investigating the meaning of the set of themes, and how they connect with the *lifeworld* of my participants [28].

Another important choice is whether to conduct an inductive or deductive thematic analysis, also referred to by Braun and Clark as a bottom-up or top-down approach [28]. I believe that an inductive thematic analysis would not contribute to generating new knowledge from raw data in the context of my thesis. Because through my LifeLine method, I planned my research to revolve around four main themes of investigation. The timeline, *Domain Cards*, *Social relation cards* and *Technology cards*. However, by taking a deductive approach to my thematic analysis, I strive toward analyze underlying meaning within each of the predefined themes mentioned above. A deductive approach to the thematic analysis is according to Braun and Clark [28] often driven by the researcher's theoretical interest in the area, aiming to generate a detailed analysis based on the predefined themes. Lastly, it is important to establish at what level I will analyze the themes. Braun and Clark [28] make a distinction between a semantic or latent approach. A semantic approach looks at the themes, applying meaning to the surface of the data, while a latent approach goes beyond the semantic meaning of a theme. Looking to examining the underlying ideas, assumptions, and conceptualizations that shape the theme [28].

Summing up: Thematic analysis of the dataset

To summarize, the following section will show the findings from my deductive thematic analysis, where I analyze the themes on a latent level. The reason for this choice is rooted in the context of workshop one. Where the LifeLine method provided four predefined categorize of themes. The analysis strives to investigate these predefined themes from a top-down perspective, looking to uncover what meaning they hold on a latent level, by viewing the themes through my theoretical framework.

6.6.2 Conducting the thematic analysis

The step-by-step analytical framework provided by Braun and Clark [28] inspired the conducted analysis. The authors [28] stresses that a thematic analysis is a flexible approach to analyzing a dataset. Regardless, the analysis should strive to follow guidelines set by the researcher or project [28]. After getting familiarized with the dataset, I started to code the data, grouping latent codes together, and placing them within the predefined themes. Figure 6.10 show my thematic map, illustrating the most prominent coded blocks of data, and how they connect with the four main themes. The next step in the analysis is to investigate the emerged themes and sub-themes on a latent level. Looking for the underlying topics and apply meaning to conceptualizations that shape the theme, trying to see connects to the chosen theoretical framework. For the analysis of workshop one, it was not necessary to recode and merge themes, due to my interest in doing a deductive analysis, focusing on applying meaning collected data relating to the four main predefined themes.

Figure 6.10: Final thematic map.

I view the data from the collected timelines in section 6.5.3 as a physical representation of each participant everyday life, including central elements of their environing world – showing their needs, desires, technological use, and social relations. The timelines paint a picture of what hold significance in the participant's daily life. As a result, the filled timelines applies meaning to their *spatiality* dimension of their *lifeworld*. The timeline captures their environing world. Where each *touchpoint* in the timeline, hold meaning to my participants within their lived experience. Each *touchpoint* connects to a time of day representing events in their of everyday life, and illustrate how their experiences link to the desire for well-being and positive emotional state. The data collected from section 6.5.3 and section 6.5.3 all contribute in shaping the holistic picture of each participant's individual *spatiality*.

6.6.3 Technology

The following section will focus on analyzing the technology theme on a latent level. Investigating the participant's technological use, and examine how it connects to the different *lifeworld* dimensions. Striving toward applying meaning to the dataset, beyond the what is written and collected [28]. I will exemplify this part of the analysis using data from Amanda's timeline. Amanda showed, that through her *spatiality* different technology holds different meanings in her life. Amanda demonstrated how she uses: Facebook, Messenger, Instagram, Whatsapp, Calendar, Safari, Spotify, Podcast and Health Apps [4] daily. She occasionally uses YouTube, Twitter, and Pinterest.

The different technologies are grouped together in the sub-themes connected with the main theme technology, visible in figure 6.10. Done to highlight how the different technology in Amanda's life, contribute to various dimensions of her *lifeworld*. Messenger and Whatsapp are through my coding phase placed in the subcategory "can connect." Both technologies serve a purpose striving to connect people, allowing them to exchange messages or pictures. Amanda illustrated that through her experience, an emoticon from a friend, through a smartphone application, could potentially hold power to motivate or support her in times of need. Indicating that a mobile application can connect her in life with others, through a social element. Placing this finding within the dimension of *intersubjectivity*, contributing to understanding the importance of social interaction in Amanda's life. Furthermore, the technology can change her *mood*, when receiving supporting words or pictures, it can contribute to increased personal motivation.

Amanda uses Spotify, Podcast, Youtube and Instagram, smartphone applications placed within the category "to support" and "to connect." The applications provide music, video or pictures to entertain and support. In Amanda's *lifeworld*, this holds significance to her *spatiality*, as it is a part of her environing world. By capturing the importance the technologies hold to her *lifeworld*, shows that technology can affect her well-being, by providing motivation or social connections. Amanda uses these applications daily on her commute to and from work. She states that she uses these applications to pass the time or to find motivation when entering hard periods of the day, especially evenings. The dataset reveals that the smartphone applications connect to her perception of time – her *temporality*. Illustrated by her use of Spotify, Youtube or Instagram to find motivation during hard times. Furthermore, the applications mentioned above also have the ability to affect her *mood* as they provide comfort or release stress when used to gain motivation.

Lastly, Amanda uses Facebook and Safari as tools connected with work life. Thus, the technologies are not directly related to her lived experience with EDs, but it shows a degree of *Intersubjectivity* describing how she exists in a world with others. Furthermore, the findings contribute to gaining a holistic picture of her *spatiality*, this is significant, as stated in

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[4] An unnamed step-counter

section 6.2.1 the lifeline method intended to explore connections between the *touchpoints*. Not only how they relate to EDs and a time of day. This information contributes to understanding the technological use, and the significance it can hold in everyday life.

6.6.4 Domain cards, Social relations, and Timeline

This section will investigate how the three themes, domain cards, social relation, and timeline contribute to understanding the *embodiment* dimension of my participants. *Embodiment* help to understand what it means to be human within our bodies, and how one experiences the world through it, in sickness or health [74]. By investigating the themes connection to the *embodiment* dimension, I can gain knowledge and understanding toward the importance of events relating to EDs. For this section, I will use examples from Rebecca's timeline. Rebecca stated, "In my life, it's important to be in places that are safe and quiet after treatment. I need time to relax. Threathment can be exhausting" The statement show two important aspects of Rebeccas *lifeworld*. It illustrates how Rebecca is need of time to recover that after treatment, to relax and reflect. Connecting her to the *temporality* dimension, showing how her perception of time is important when affected by EDs, and that she needs time to relax after treatment. The statement also contributes to understanding the *embodiment* of Rebeccas *lifeworld*. It illustrates a part of the complexity of EDs. The act of receiving therapy, striving toward increased well-being is exhausting. Giving insight into events that is central to her experience of living with EDs.

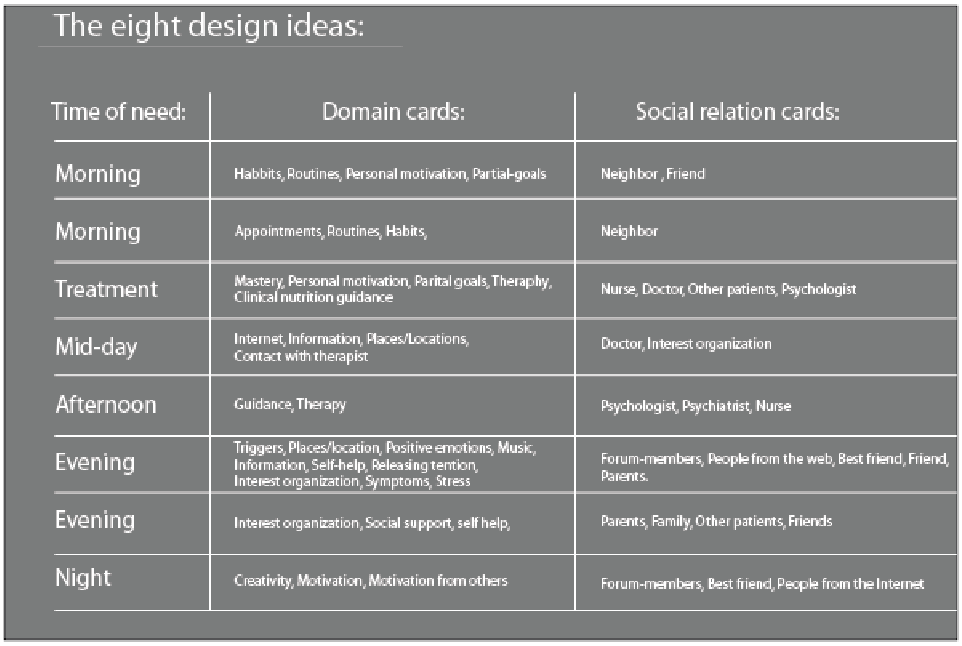
Rebecca stated, "The closer I get to evenings and night, the importance of having people around me grows. My network of family and friends are important, the later it gets, the harder it is to connect. This is when I get on the Internet, forums, and chat. They offer me support regardless of time." The statement shows that in Rebecca's life of living with EDs, social interaction is important. Showing how Rebecca connects in a world with others. Analyzing the data show how friends, family and people on the internet is a part of her *intersubjectivity* and hold power to affect her *mood* by motivating, supporting or providing comfort in hard times of her *embodiement*. The importance of *intersubjectivity* and *mood* is not only apparent at night. Rebecca stated, "I have a neighbor, he is super happy and nice every time I see him. He waves and smiles, and I get the sense that he is genuinely happy to see me. It provides a good start of the day, and can help me gain motivation." The quote contributes to understanding the importance of social interaction in Rebecca's *lifeworld*, and how it holds power to affect her *mood*. The social interaction with her neighbor provides Rebecca with the sensation of being seen as a person. Transcending her struggles with ED and other problems in her life. The smiles, simple in its nature, have the power to change her perception of that moment. If Rebecca had a bad day or struggled to she the point of getting better, social interaction can change her perception of the moment, affect her *mood* and provide motivation to continue getting better.

Findings from the conducted analysis show that the dimensions of the participant's *lifeworld* are intertwined. The analysis tries to demonstrate how the experiences from their everyday life, together, contribute to a qualitative, holistic picture of experiences, technologies, feelings, and social relation that represents their *lifeworld*. My analysis shows how technology plays a significant role in the life of my participants, to connect, work or gain inspiration. The findings of the analytical report will directly contribute to my future design work.

6.6.5 What have I learned from the first workshop?

The first workshop gave me insight into the everyday life of a person with EDs, colored by their needs at different times of the day. The collected data show the participants currently use mobile technology centered on applications that provide social, entertainment, and work functionality. Established in the analysis 6.6. I collected information regarding what functionality they see as important in mobile technology, how their day is structured, and that mobile technology can aid them during different times of the day – by providing social interaction, motivation, affect their *mood*, provide leisure, and help in structuring events during the day. All of the above mentioned elements are essential to my future design work. However, the most important takeaway from the first workshop is the combination of cards created by the participants.

As a researcher I see each unique combination of the *inspirational cards*, occurring at a single time of day, as a potential design idea. Consequently, the first workshop gave me eight raw design ideas that acted as a foundation for my future research. Each idea is generated from the stack of *inspirational cards* and linked with a time of day. See figure 6.11 for an overview and recap of the eight design ideas. I argue that each of the eight design ideas is a combination of two key elements, requirements and time of need. I base this argumentation on the fact that the participants choose the cards from a large deck, with the premise that technology could aid them with the topic on a particular card. The combination of cards is consequently a collection of requirements, based on their lived experience. The question remained in what way technology could match these requirements? Investigating that will be the focus of my next workshop.



The eight design ideas:

Time of need:	Domain cards:	Social relation cards:
Morning	Habbits, Routines, Personal motivation, Partial-goals	Neighbor , Friend
Morning	Appointments, Routines, Habits,	Neighbor
Treatment	Mastery, Personal motivation, Parital goals, Theraphy, Clinical nutrition guidance	Nurse, Doctor, Other patients, Psychologist
Mid-day	Internet, Information, Places/Locations, Contact with therapist	Doctor, Interest organization
Afternoon	Guidance, Therapy	Psychologist, Psychiatrist, Nurse
Evening	Triggers, Places/location, Positive emotions, Music, Information, Self-help, Releasing tention, Interest organization, Symptoms, Stress	Forum-members, People from the web, Best friend, Friend, Parents.
Evening	Interest organization, Social support, self help,	Parents, Family, Other patients, Friends
Night	Creativity, Motivation, Motivation from others	Forum-members, Best friend, People from the Internet

Figure 6.11: A overview of the eight ideas, highlighting the *domain cards* and *social relation cards*.

Chapter 7

Workshop two

7.1 Defining objectives for the workshop

At this stage of the research project, I had a clear vision of what I wanted to achieve. The main purpose of the workshop was to use the findings from workshop one to converge on one design idea and interact in a series of prototyping exercises – with the aim of generating a design proposal. I also had several sub-objectives, important in achieving my primary objective. I wanted to investigate if the requirements collected from workshop one, could be connected to concrete mobile functionality. I also wanted to uncover how a design proposal would fit into the defined *touchpoints*, from the participant's everyday life. The following sections will provide a chronological walkthrough from preparing and conducting the workshop, to findings and analysis.

7.1.1 Preparations

The workshop was scheduled to take place at the regional headquarters of the interest organization, in downtown Oslo. The participant sample would be that same as in workshop one. It is inherent in the foundation of PD that using the same participants throughout a design process can contribute to strengthening the design outcome, making the intended design solution match the actual needs of the participants [161].

7.1.2 Step 1: Choosing an idea

To reach my objective of creating a design proposal, we had to be able to converge on a design idea. Steen [168] argue that project iterations can be organized to combine both a divergent, defined as an open, generative phase. With a convergent phase, focused toward closure. Howard et al. [79] stresses, that separating the divergent and convergent process is useful from a creative perspective, and considered good practice for lateral thinking and brainstorming [79]. Therefore, I decided to initiate the workshop with a recap and brainstorming session, focusing on being divergent toward the ideas generated in the first workshop. I designed a tool to help the participants remember the process we went through in the last session, and the ideas we generated. The tool was simple in nature, created on a4-sized paper and consisting of two main elements. 1: A header of text showing the topic from each of the participant's *'touchpoints'* [1]. 2: Filled with the *inspirational cards* representing the requirements for each *touchpoint*. The inspirational card was attached to the paper using tack-it, this was done to make it easier for the participants to move the cards around. In the spirit of a divergent brainstorming process – encouraging the development of new ideas that might have evolved since the last workshop. Figure 7.1 shows the finished tool.

Figure 7.1: The finished tool for step 1.

Converging on one idea

My research project has inherent limitation connected with time and access to participants. Therefore, we had to move from the divergent brainstorming process to a convergent process in the same workshop, trying to choose one idea on which to base our future work. To do this, the participants would take a blank card, with no predefined headline, and attach the inspirational cards they felt were most important to them. The participants could freely choose from all the cards present on the table. Once the participants had converged on one set of cards, which would collectively represent the requirements for a new mobile technology, we could on to the next phase.

7.1.3 Step 2: From requirement to functionality

The objective of this step was to match the chosen requirements from the previous step, with spesific mobile functionality. The idea behind this

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[1] For an explanation of how touchpoints are understood in the context of my thesis (see section 6.2.1)

was that by having a clear picture of the requirements and connecting it with functionality would create a foundation for the primary goal of the workshop, to conduct participatory prototyping exercises to generate a design outcome. I created a simple tool, consisting of 4x4 cm laminated cards. Each card had one textual reference to a particular mobile functionality. The topic for each card was chosen based on two parameters. 1: I analyzed the mobile technology the participants had placed under the "bruker kontinuerlig" [2] tab from the first workshop, illustrated in picture 6.1 and included known functionality from several of the applications. 2: I added more basic, well-known functionality based on my technological background. That way the functionality cards were co-created based on both my participants current use, and my technological knowledge. The stack of functionality cards is illustrated in picture 7.2

Figure 7.2: The complete stack of functionality cards.

The idea was that the participants would use the functionality cards to match with the chosen requirements from the previous task, and together create a foundation for the prototyping process. Bratteteig and Wagner [25] state that "The more complex a design task, the more difficult it may be to represent a design idea and this often results in a plethora of sketches, scale models, material samples (to illustrate properties), or prototypes. [25, pp.5]." The functionality cards were intended to decrease the complexity of the design task, by having a clear vision of what functionalities to create in the design.

7.1.4 Step 3: From idea to design

The participants would now interact in a participatory design activity, with the aim of generating a low fidelity design outcome. Bødker and Grønbæk [17] stresses that PD calls for cooperative prototyping approaches, which enable designer and users to participate actively and creatively, based on their qualifications. The prototypes help make the participant's visions concrete [17, 50]. Al-Kodmany [93] argue for the use of visualization tools in a PD process. Stating that visual tools can

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[2] Translation: "Continued use"

help create a common language to which all participants — technical and non-technical can relate. Furthermore, it can contribute to raising their design awareness and facilitate a platform for better communication [93]. I used this argumentation as a premise for creating a new tool to use in the prototyping session, based on the concept of visualization. The idea was to create a toolkit, consisting of different core functionalities from mobile applications, spanning different icons, buttons, arrows, and search bars. The kit contained three identical set of icons, individually cut and laminated to make the icons easier to use and more robust. Each participant would get a kit at the beginning of the prototyping session. The toolkit was intended to help the participants have a common language for illustrating functionality; it would also supplement the traditional pen and paper approach to prototyping illustrated by Snyder [162]. Snyder [162] argue that using paper prototyping at early usability stages are essential, and a valuable technique for design and usability testing. The participants would carry out the prototyping exercise using a paper-based template of a smartphone to place the participants in the mindset of mobile technology, working under the premise that this would aid the creative process. Concurring with De Sá and Carriço [141], who argue that when prototyping mobile functionality on paper, sketches should be the same size as the screen of the device and should use similar components as those available for a real device, this includes actual interactions [141]. The provided templates would not be in the same size as the real mobile device. I, however, argue it will provide a more realistic environment to design in, compared to providing the participants a blank piece of paper. Figure 7.3 illustrates the paper template and the toolkit.

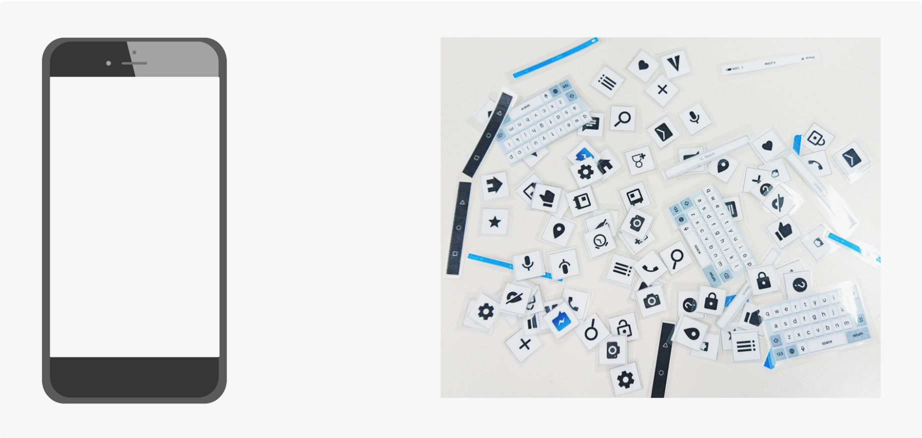

Figure 7.3: Left: Blank template for prototyping. Right: The complete toolkit.

7.1.5 Step 4: Placing the prototype into their everyday life

This last task in workshop two focused on revisiting the timeline introduced in the first workshop (see section 6.2.1) I wanted to uncover if the results of the prototyping session and the suggested functionality would fit into the participant's everyday life. As explained in the theoretical chapter, I wanted to combine elements from both SD and PD. Therefore, it was important to investigate to what extent; the prototype would fit into their everyday life illustrated by their *touchpoints*. To do this, the participants would interact with the requirements and functionality of the prototype, linking a requirement to a corresponding time of day. To illustrate how the suggested prototype would connect with the findings from the first workshop. Moreover, this task was envisioned to build on the premise explained in section 4.3. That by designing technology that would fit into the lives of the participants, one can strive toward sustainability in design and prolonged used after the completion of the study.

7.1.6 Summing up the steps of the workshop

To summarize, the second workshop would consist of four stages.

- Stage 1: Choose an idea, by brainstorming around the purposed ideas from the first workshop session.
- Stage 2: Taking the selected idea and matching it with particular mobile functionality
- Stage 3: Participatory prototyping exercise using the toolkit, to prototype a design of the suggested application
- Stage 4: Link the prototype to *touchpoints* from the participant's everyday life.

7.2 Conducting the workshop

Despite excellent communication and preparations leading up to the workshop, it is hard to plan for unforeseen events. It turned out Rebecca would not be able to attend the workshop. Regardless, the projected tasks could be carried out with only Amanda present. Culén and Van der Velden [44] show how working with vulnerable users in a one-to-one setting can be beneficial, as a way of allowing them to express their particular challenges.

7.2.1 Generating ideas

As planned, I presented my analysis of the findings from the first workshop, in the context of the eight idea cards, with each *inspirational card* attached. I emphasized that my analysis, resulting in the presented requirements, were open for expert input, encouraging Amanda to share her expertise. By discussing the cards at the table, we managed to see three emerging trends. Amanda stated, " What points out, as the most obvious is the feeling of community, an online community not bound by geography. To find a solution that doesn't encourage the sickness, but has a positive, recovery focus."

The other *inspirational cards*, which shaped a course centered around the following theme. Amanda stated, "I see the need for information regarding treatment. There are many places available. To get an overview in the public health domain is hard, with so many offers. To be able to choose, and say that – this is the right therapy for me, or this is the right therapist. Making a decision like this involves taking a series of choices. One cannot say anything about the quality of treatment before actually trying it out."

Lastly, we looked to the morning and evenings, where both Amanda and Rebecca had used many similar cards to illustrate their lived experiences. Both illustrated that evenings are a hard time of day and that the need for social relations is essential. Amanda stated, "I think it would be great to create something to cover these requirements. However, I fear it might be too general? I have personally tried several applications, which seek to support you in self-help by logging or reporting elements, with limited success. However, I feel we should include elements from both morning and night. They are important, but we need to investigate in what way."

After looking at the three emerging trends, we tried to combine elements from all three into one idea. The idea consisted of the following inspirational cards, representing requirements for the future mobile technology: Therapy, Motivation, Self-help, Information, Places/Locations, Social Support and Positive Emotions.

7.2.2 Linking functionality to requirements

At this stage in the workshop, we had collected the requirements to include in the future mobile technology. However, as stated in section 7.1.3 I wanted to reduce the complexity of the following prototyping session by linking requirements with functionality. To initiate discussions regarding the functionality, I did a brief presentation explaining each functionality card, opening up for questions and debates regarding each topic, before matching them to the previously established requirements.

This stage in the workshop shaped the foundation for the main idea of the application, presented in section 7.2.3. By discussing each functionality card, we were able to develop the central concepts of the idea. Illustrated by the following example: Amanda stated, “Oh, we defiantly need notifications in the app” I responded, “Does it connect to a requirement?” Amanda replied, “Yes if you can select at what time a notification should appear, you can match it to a time of the day I need support. If you imagine that it is a normal morning, and I had located a treatment place of interest, the notification can remind me; Did you remember to contact them? That way the notification is not intrusive, but there to help you.” The dataset contains more examples just like this, where discussions around each functionality card resulted in either connecting it to a requirement or discarding the functionality. An example of the latter, happened when discussing the functionality card labeled “newsfeed”. Amanda stated, “A newsfeed would cool, maybe it could contain helpful articles?" After considering the concept for a while, Amanda said, "Hmm, it does require someone to moderate the content, and if we don’t want a user to create a unique profile, it might be hard to keep track of who posts what. Maybe it's best not to include this?"

After discussing all the functionality cards, Amanda stated, "In my experience, an important step toward creating a mobile app is not to add too much functionality, I have experience from using apps designed for EDs, and they have had too much functionality. I think this can lead to them being less user-friendly, discarded, or it can be hard to see the purpose of the application, like ok. What should this app help me with?" Having a step in the workshop designed to match functionality to a requirement, made the transition to participatory prototyping session natural. Because we had already established what the application should do, and what functionality to include. Amanda explained that by taking this approach, she felt more comfortable being creative, comparing it to other creative processes she had previously been a part of, stating: "This is fun, and it is much easier to be creative, then just being handed a piece of paper and some markers." Figure 7.4 illustrate the process of matching functionality to requirement. Resulting in the decision to include the following functionality in the application: Pictures, Contacts, Chat [3], Calendar, Search, Information, and Notifications

Figure 7.4: Linking functionality with requirements.

7.2.3 Design proposal

The idea we had chosen consisted of 5 main functions. The following section will cover the prototyping session, showing requirements, functionality, and concept for each function in the applications.

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[3] Chat was included, as a result of the lack of a card to represent social interaction

7.2.4 1: The map

- Requirements: Places/locations, Therapy, Information and Self-help
- Functionality: Map, search, information.

Figure 7.5: The designed map functionality.

Concept: This would be the core function of the application, built on the idea of supporting people struggling with EDs to gain the right kind of treatment. Amanda and Rebecca had illustrated the struggles of finding the right kind of help. What the map was intended to do was to show, based on GPS location, available options for treatment in an area around you. Each option on the map would be a health institution specialized in the treatment of EDs, vetted by an official health program to ensure the quality of help. Providing the users with accurate information, places and locations they can go to get help, what kind of therapy is available, and aid them in self-help. Information regarding each location would be available, by interacting with the markers illustrated on the map, this would allow the users to call, send information, rate, and save a location. We envisioned that the "send information" functionality would contain a social relational aspect. The idea was that if a parent, friend or health worker browsed the application, and found a place of interest. They could send the information to someone they cared about, whom they knew were struggling, providing social support. We co-created a new rating system, not based on the traditional system implemented on sites such as Google Maps where you rate based on 1-5 stars. The idea was that if you visit a treatment option, and it provided a positive outcome, you could rate it with a star. Users who accessed the application could see how many people who had in fact rated a location. However, there would be no way to elaborate on an experience or number of stars given. Based on what Amanda stated “If a person is not offered a satisfying treatment option from an institution, for instance, a specific kind of medication or that the therapist asked hard questions that triggered negative emotions. People with EDs can be in a mental state, which can lead to emotionally based critique not rooted in actual events." Amanda also stated, "If another user of the application is seeking help, but sees a bad review, written on a false premise, the person might, in fact, choose not to apply for help." Amanda explained, “We need to create healthy choices, to avoid misuse of the provided information. The group is vulnerable and exposed to triggers and sensitive toward negative information. What makes a person focus on the “good” information, as opposed to the “bad”? It’s about creating the good choices” Amanda generated low-fidelity sketches illustrating her vision for the technology. Figure 7.5 shows her suggested design for the map functionality. Amanda envisioned the basic layout of the map to look like Google Maps. Consequently, she did not feel the need to draw sketches illustrating this.

7.2.5 2: Favorites

- Requirements: Self-help and Information.
- Functionality: List

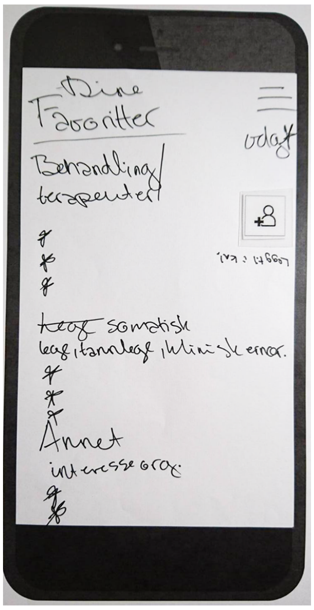


Figure 7.6: The designed favorites functionality.

Concept: This feature was designed to show a list of all places the user of the application had saved as a favorite. Representing locations the user had visited or planned to visit. The basic concept was that each favorite would be sorted based on categories, to make it easy for the users to navigate through the different kind of preferred treatment options. It should also include the possibility of saving your favorite location as a contact. Figure 7.6 shows Amanda's prototype design for the favorite list.

7.2.6 3: Notifications

- Requirements: Positive emotions, Information, and calendar.
- Functionality: Pictures and information.

Figure 7.7: The designed notification functionality.

Concept: The notification feature was created based on Amanda and Rebecca's lived experiences during morning and nighttime. They both emphasized a need for motivation to start the day, to remind themselves of why they wanted to get better and support to feel less alone. To achieve this, they both needed motivation. The notification would show up as an alert on the locked screen of the smartphone, and contain a motivational picture with a quote. By accessing the notification, you would be taken to the applications calendar functionality, explained in section 7.2.7. Amanda stated "I envision a notification to give a boost and provide positive emotions. If you have the time and want to access the application, you will do so in a positive state of mind. You will then be able to see; Ok, this is what I have to do today. Because the group is so vulnerable, this is important, as anything can be viewed as an obstacle. By designing to prevent some of the vulnerabilities of the group, we can strengthen the application. That's why I envision a picture and a quote to be the main content of the notification."

The notification had two primary purposes, to provide “at a glance” motivation in the shape of motivational pictures and text, intended to give a boost through hard times during the day. Alternatively, to act as a gateway to the application, fueled by positive emotions, by pressing the notification you are taken to the calendar. Designed on the premise that if you access the calendar in a positive state of mind, you would be more intended to view the goals of the day in a reinforcing manner. These are all steps in a chain of creating positive emotions, leading to positive life choices, which can result in increased well-being. Figure 7.7 illustrates the prototyped design for a notification.

7.2.7 4: Calendar

- Requirements: Self-help, Partial goals, Positive emotions.
- Functionality: Calendar, Notifications

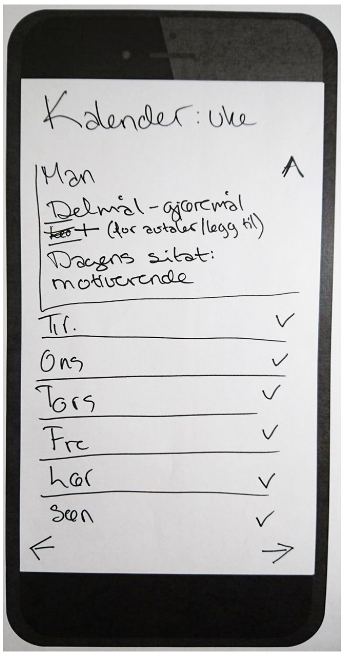


Figure 7.8: The designed calendar functionality.

Concept: The calendar had several new features, compared to a traditional calendar. It was intended as a visual calendar, building on the idea of positive reinforcement. The calendar was designed to represent a full week, compared to a whole month, which a traditional calendar represents. Upon entering the calendar, the user is presented with the current day, hiding the rest of the week. The calendar provide the option of scrolling to either the previous week or the coming week, this might be seen as a limitation to the design, although it serves a clear purpose. Amanda stated, “Long periods of time or schedules can be scary. By getting an overview over your current week, not the entire month, we limit the possibility of being overwhelmed or underwhelmed by the number of planned activities. Having much on the agenda can be seen as high social status, but drain energy and remove the intended recovery focus. On the other hand, having nothing on your schedule can provoke feelings of loneliness or isolation."

The calendar functionality has a unique visual aspect, to promote the idea of positive reinforcement through motivation. Each day of the week is connected to a "quote of the day", designed to give the user a positive push toward completing planned activities. We agreed that the calendar would act as a standalone calendar, not synced with third-party calendar applications, this was done to provide the users with the option of having ED related appointments or tasks separated from other everyday activities. Figure 7.8 shows how Amanda envisioned the calendar functionality.

7.2.8 5:Motivation archive

- Requirements: Self-help, Motivation, Social support and Positive Emotions
- Functionality: Pictures

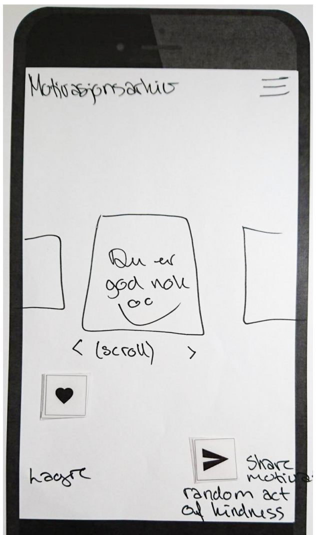


Figure 7.9: The designed motivational archive.

Concept: The motivational archive was designed to provide motivation and social support. Both Rebecca and Amanda defined the need for social support as central elements in their everyday life. The motivational archive is an innovative way of providing social support – through an idea we named "Random acts of kindness." Through the motivational archive, the user can browse a series of motivational pictures. If the image provides a positive emotion, the user can decide to send that picture as a random gesture to another undefined user. This "random act of kindness" feature is a way to provide social support to other users in the same situation, without the use of chat or forum functionality. The reason to design an anonymous motivation feature is rooted in the desire to prevent any form of pro-ana content in the application (see section 2.8.1 for information regarding pro-ana content). Including chat or forum functionality would have allowed a user to promote unwanted content, which might affect a user in a vulnerable state. Figure 7.9 illustrates Amanda's design for the motivational archive.

7.2.9 Placing the prototype in the context of everyday life

The concluded prototyping session resulted in the five core concepts presented above. An important question remained unanswered. How would the application fit into the everyday life of the participants? To answer this, we used the requirements and functionality elements of the application and linked them with a time of day. See figure 7.10. The task revealed that the functionality of the application closely relates to three critical times of day, corresponding with the findings from the first workshop:

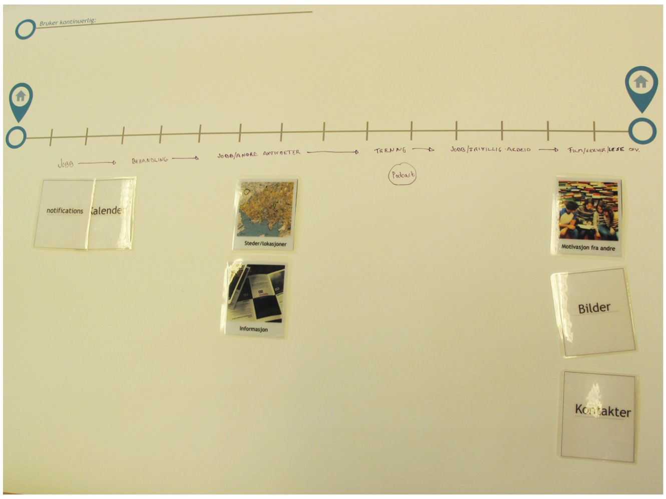


Figure 7.10: Placing functionality on the timeline.

- Morning: The time of day when both participants needed social support and motivation to complete and plan the objectives of the day. The application addresses this requirement with the notification and calendar functionality. Providing the users with positive reinforcement and social support combined with a calendar to plan and define objectives.
- Mid-day: The time off day they when both participants required information and treatment. The application addresses this need with the map functionality. Providing a way for the user to gain information, location, contact details, and recommendations on

available specialized ED treatment options in the proximity of the user.

- Evening/night: The time of day when the participants needed social support and motivation. Identified by both participants as a tough time of day, were feelings of loneliness and isolation were present. The applications motivational archive is a way to try and counteract this, providing social support and motivation through pictures, quotes and the random act of kindness.

Amanda states “It’s incredible to see it all connected, each element in the app linked with what we found out last time, that’s so cool.” This task concluded the second workshop. The next section will analyze the findings.

7.3 Analysis

This section will focus on analyzing the collected data from workshop two, using the same analytical approach as in workshop one (see section 6.6). By viewing the dataset on a deductive and latent level. The methods, tools, and techniques presented to the participants in workshop two, had a limited amount of predefined themes. As a result, the analysis of the dataset can focus on the emerging of new themes and their applied meaning in the *lifeworld* of the participants. Resulting in an analytical approach with stronger similarities to the step-by-step guide provided by Braun and Clark [28]. This analysis section will view all collected data from workshop two, referred to as the dataset.

After coding the dataset, I created an initial thematic map, illustrated in figure 7.11. The figure shows four main themes, connected with several sub-themes. Braun and Clark [28] state that at this stage of the analysis, it is uncertain whether the themes hold as they are, or need to be combined, refined and separated, or discarded completely. Leading me to review the emerged themes from the first thematic map – resulting in a final thematic map [28, pp.91].

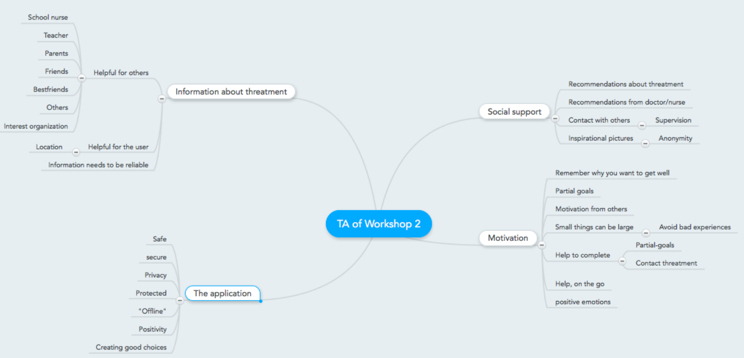


Figure 7.11: Initial thematic map.

Figure 7.12 shows the final thematic map. Braun and Clark [28] stresses, that at this stage, one considers the validity of individual themes concerning the data set, and investigating if the thematic map “accurately” reflect the meanings evident in the dataset as a whole. Providing an accurate representation depends on the taken theoretical and analytic approach. Reviewing the emerged codes and themes through the *lifeworld* lens strongly influenced the final thematic map [28, pp.91].

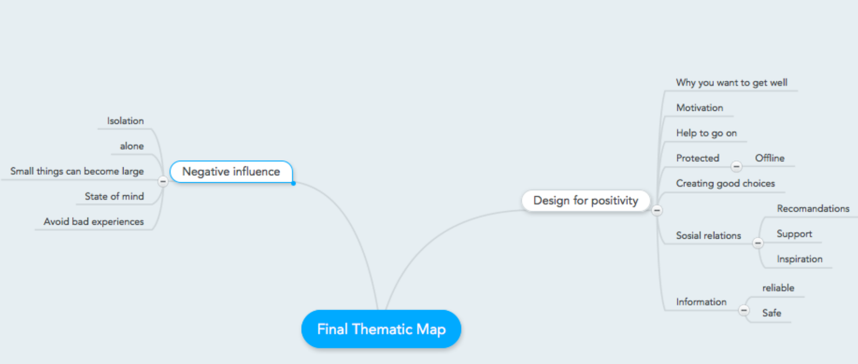


Figure 7.12: Final thematic map.

To explore latent meaning inherent in two main themes of the final thematic map, I will examine the themes through the *lifeworld* lense. Looking at the lived experience of my participants, using the *lifeworld* dimensions of *mood* and *intersubjectivity*. “Lived experience is coloured by mood [178, pp.57].” Todres et al. [178] illustrate that *mood* saturates our being-in-the-world, It can be a powerful tool – In both illness and well-being. Descriptions of *mood* is central to understanding the personal dimensions that shape the holistic picture of the lived body. Todres et al. [178] show how *mood* can act as a great motivator – or a de-motivator of direct action. The dimension of *mood* can be applied to the two main themes from the thematic map – to understand the attached meaning, and how can affect my future design work.

By understanding that in the lived experience of my participants, emotional state, and *mood* is a nominator for action. The two main themes help to highlight this connection. The theme "negative influence" is connected with sub-themes showing a state of mind, that can make small things become large, provoke feelings of isolation or bad experiences. All of which can provoke negative associations – that might direct action. The other theme, design for positivity highlight how positive emotions can be an another director of action. The sub-themes show that design for positivity can provide support to go on, take positive choices, gain motivation and remember why you want to get well. The findings show that the concept of *mood* or emotional attunement as Todres et al. [178] refer to the concepts, are apparent in the dataset and prototype.

The emotional state of a participant upon entering a specific functionality of the application can affect future action. Designing for positivity and motivation, in essence, means to design for *mood* to provoke action. Working toward removing what the participants meant by "negative influence" are components that can affect their *mood* or feelings toward specific tasks or items. Several examples are apparent in the dataset. Amanda states "By creating an application that doesn't have an overwhelming amount of functionality, we can avoid the potential feeling that, ok I failed at understanding the application. Therefore, I fail at getting better. We want to create the impression that you don't have to use the app regularly for it to be useful, and design it in a way that don't demotivate without everyday usage."

By understanding that the potential user group is in a vulnerable physical, emotional, and cognitive state where exposure to triggers can have an enormous influence on the following life choices. The themes show the importance of designing for positivity, by decreasing the amount of exposure to negative influence in the designed application. The dataset shows several examples of how the design for positivity is inherent in the prototype – to increase positive emotions, motivate, and direct future action. The choices to exclude user-generated content in the form of chat, forum, or reviews, is steps to limit potential negative influence. While the motivational archive, calendar, sending pictures through the "random acts of kindness" feature, and using notifications can all be viewed as steps toward designing for positivity, by promoting positivity and decreasing the exposure to negative influence.

The *lifeworld* dimension of *intersubjectivity* is also relevant to the two main themes. *Intersubjectivity* refers to how we are in a world with others, in the context of our lived experience. We cannot be understood without reference to how our lives take place within our social world. We can share the meaning of our life, and relate these meanings to our unique situation as it unfolds [178]. What this means, is that in order to design for positivity one has to understand that social interaction can connect to the participants perception of *mood* and well-being. "When unwell, the touch of a human hand reconnects us with a sense of hope that welcomes other possibilities of interpersonal relating beyond illness, or it can make us feel remote [178, pp.57]." Illustrating how the dimensions of *intersubjectivity* connect to *mood*. The touch of a human is connected with the "random act of kindness" aspect of the application, providing social support. This kind of social support tries to relfect the need the participants have of connecting with others. Amanda stated in her initail thought of workshop two "What points out, as the most obvious, is the feeling of community, an online community not bound by geography." *Intersubjectivity* is essentail to understand that the aspect of social relations is central to their lived experience, and it is connected to their *mood*. The dataset show how social interaction can provide support in difficult times to prevent negative emotions, that can contribute to negative life choices.

7.4 What have I learned from the workshop?

To summarize, workshop two provided detailed information regarding requirements for the design, through the combination of cards: Therapy, motivation, self-help, information, places/locations, social support, and positive emotions. The requirements act as the foundation for the process to investigating how mobile technology can supplement and solve the suggested requirements. Together, through interacting with the provided functionality cards, we established how we could connect functionality to requirements, resulting in the idea for the application. By interacting in a participatory prototyping session, we co-created paper prototypes. Focusing on five main ideas 1) The map, 2) Favorites, 3) Notifications, 4) Calendar, and 5) Motivational-archive. The participatory prototyping session provided detailed knowledge on suggested navigation, based on Amanda's use of the provided toolkit. She used several icons to illustrate different kinds of interactions, based on her experience and use of currently existing mobile applications. Lastly, we revisited the timeline from workshop one. By placing functionality and requirement on the timeline, the link between requirements and a time of day became apparent. The connection between requirement and time of need represents a step toward creating new technology that caters to the needs to my participants, at a unique time of their day. I learned that the suggested functionality of 3) Notification and 4) Calendar are required during the morning, 1) Map functionality is essential mid-day, and 5) Motivational-archive at evenings/night, we co-created a design that fits into the everyday life of my participants. The next section will focus on how I designed a prototype, based on the paper prototypes generated in the workshop.

Chapter 8

Prototype

8.1 The prototype

> "By focusing on the purpose of the prototype—that is, on what it prototypes—we can make better decisions about the kinds of prototypes to build [78, pp.1]."

Houde and Hill [78] argue that prototypes are widely recognized as a core means of exploring and expressing design ideas, and used to represent different states of an evolving design. Regardless, the focus of a prototype should be to provide attention to fundamental questions about the system design, such as "what role will the artifact play in a users life? [78, pp.1]." Houde and Hill [78] show that prototypes are not necessarily self-explanatory – it is not significant what tools or media one uses, or if the prototype is defined as high or low fidelity, rather, how they are employed by the designer to explore or demonstrate the future artifact.

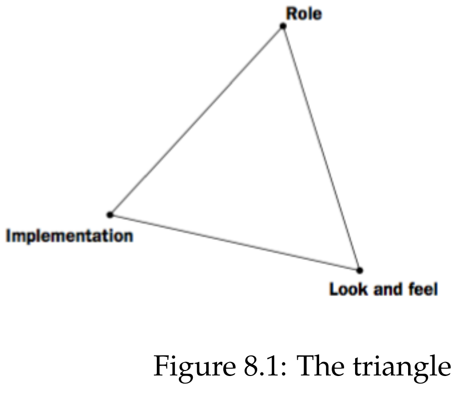


Figure 8.1: The triangle, by Houde and Hill [78].

Houde and Hill [78] present a model of what prototypes prototype 8.1 referring to three dimensions of a prototype, defined as: *role*; *look and feel*; and *implementation*. *Role* refers to questions about the function of an artifact in a user's life, investigating if it is useful to them in their context. *Look and feel* represent the sensory experience of using an artifact, what the user looks at, feels, and hears while interacting with it. Lastly, *implementation* dimension refers to the technical components employed in the artifact. Focusing on how the prototype functions on a technical level, and how it was created [78, pp.3]. Houde and Hill [78] emphasize, that one dimension is inherently not more important than the other. The triangle, seen in figure 8.1 is a subjective representation, what lies in the orientation toward either of the dimensions are the designers own judgment. Consequently, the designer can choose to focus on one dimension or a combination of dimensions. For the context of my thesis, the suggested prototype, that acts as a foundation for this chapter, is as set to explore two dimensions of *role* and *look and feel*. The premise for this choice is rooted in my desire to explore how the prototype fits into the participants lived experience, placing it within the dimension of *role*. I also want to uncover the *look and feel* of the prototype, exploring sensory experiences of using an artifact, the degree of detail, and user interaction. Figure 8.2 places my prototype within the suggested model by Houde and Hill [78].

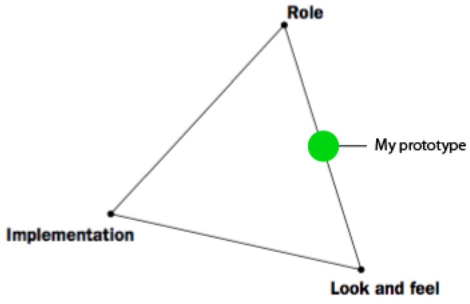


Figure 8.2: My prototypes position in the triangle by Houde and Hill [78]

The following section will be split into two sections. The first section will cover the *role* dimension of my prototype. To do this, I will place the prototype in a scenario, using personas, intended to illustrate the prototypes suggested purpose in the life of the users. The second section will focus on the *look and feel* dimensions of the design, illustrated by flowcharts and screen-shots showing the design choices.

8.2 The *role* of the prototype

8.2.1 Scenarios & Personas

Scenarios are according to Bødker [16] a way to emphasize creativity in design, a way that differentiates itself from standard usability work. Scenarios do not focus on generalizing users action but aim to highlight the richness of actual use situations [16]. “Scenarios are stories; they have a setting, agents or actors who have goals or objectives, and a plot or sequence of actions and events [63, pp.145]." Scenarios can identify a person’s motivation toward a system, or describe the actions taken to reach a goal. Helander et al. [73] emphasize that by developing scenarios, one can help envision future aspects of the user's activity and experience interacting with a system. With the goal of understanding what it means to the user [73]. Bødker [16] state that scenarios are constructions made with a purpose. The purpose aid the constructor of the scenario to be selective, as it may relate to both the type of situation it is dealing with and the kind of design you want to support. Bødker [16] presents three main reasons for making and using scenarios in design:

- To present and situate solutions
- To illustrate alternative solutions
- To identify potential problems

In the context of my thesis, scenarios have the purpose of presenting and situate solutions [16]. Grudin and Pruitt [63] stress that realistic scenarios are a perfect tool for design, as they depict the work practices one hopes to support. However, scenarios on their own not engaging – this can be solved by building scenarios around personas [63].

> Personas are fictional people. They have names, likenesses, clothes, occupations, families, friends, pets, possessions, and so forth. They have age, gender, ethnicity, educational achievement, and socioeconomic status. They have life stories, goals, and tasks. Scenarios can be constructed around personas, but the personas come first. They are not 'agents' or 'actors' in a script, they are people [63, pp.146].

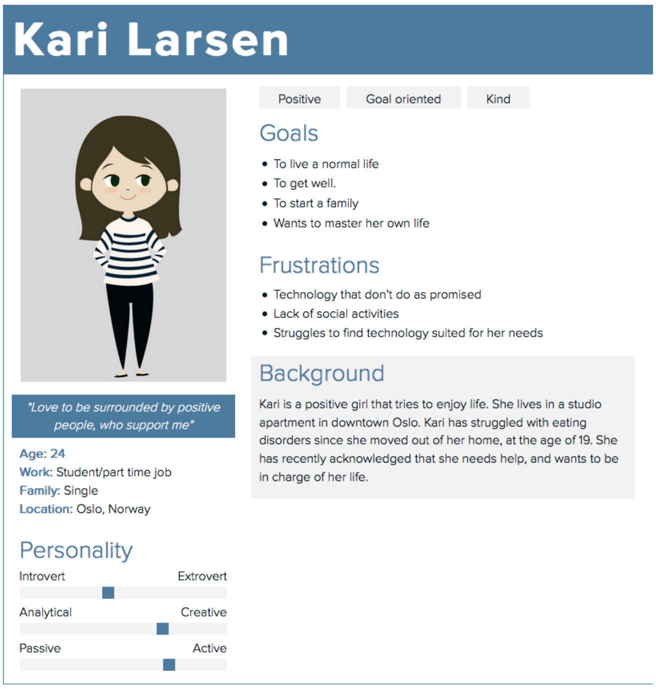
As illustrated above, scenarios are traditionally used to situate or stage test examples during a design process [16], while personas make the scenarios more engaging [63]. In the context of my thesis, they contribute to a slightly different aspect of the process. The scenarios and personas were not included in any of the workshops, or as a tool in the participatory prototyping session. They Rather act as a medium to "present and situate situations" [16, pp.63]. By using the collected data from the workshops as a foundation, the scenarios and personas are intended to illustrate the suggested *role* of the prototype in my co-designers life, and the life of potential secondary users. They also serve another purpose, by using scenarios and personas built upon the information collected from the workshop, they aid the design process, by trying to create a designing to support the primary and secondary user of the application.

Limitations to scenarios & personas

When creating scenarios and personas, it's important to be aware of potential limitations to the tools. Grudin and Pruitt [63] show how creating the right persona is a challenging task, there is a danger that once created, one can overuse the persona to replace other usability methods. To counteract this risk, it's important to understand that a persona should augment and enhance the design process, not hinder it [63]. By designing with personas, Grudin and Pruitt [63] argue that it's better to design for one external person, than vaguely try to design for everyone else. Note that personas, can be overused, and risk filtering out data found that don't match the particular persona you are designing for [63]. The same risks apply to scenarios. Scenarios can be created to justify a feature of a technology. Consequently, it may include unrealistic assumptions about work practice or technology. Grudin and Pruitt [63] argue that scenarios in design struggle to be useful if they are not empirically grounded. "There is often little discussion of the data, if any, on which a scenario is constructed. A scenario created by actual workers might be trusted more [. . .][63, pp.146]."

8.2.2 Creating a persona and placing it in the scenario

The following two personas (figure 8.3; Figure 8.4) are created based on the data collected during the first and second workshop The personas are created using a tool found on: www.xtensio.com. Scenario one aim to illustrate the primary user of the suggested application, while personas two is intended to represent a secondary user of the application.



Kari Larsen

Positive | Goal oriented | Kind

Goals

- To live a normal life
- To get well.
- To start a family
- Wants to master her own life

Frustrations

- Technology that don't do as promised
- Lack of social activities
- Struggles to find technology suited for her needs

Background

Kari is a positive girl that tries to enjoy life. She lives in a studio apartment in downtown Oslo. Kari has struggled with eating disorders since she moved out of her home, at the age of 19. She has recently acknowledged that she needs help, and wants to be in charge of her life.

"Love to be surrounded by positive people, who support me"

Age: 24
Work: Student/part time job
Family: Single
Location: Oslo, Norway

Personality

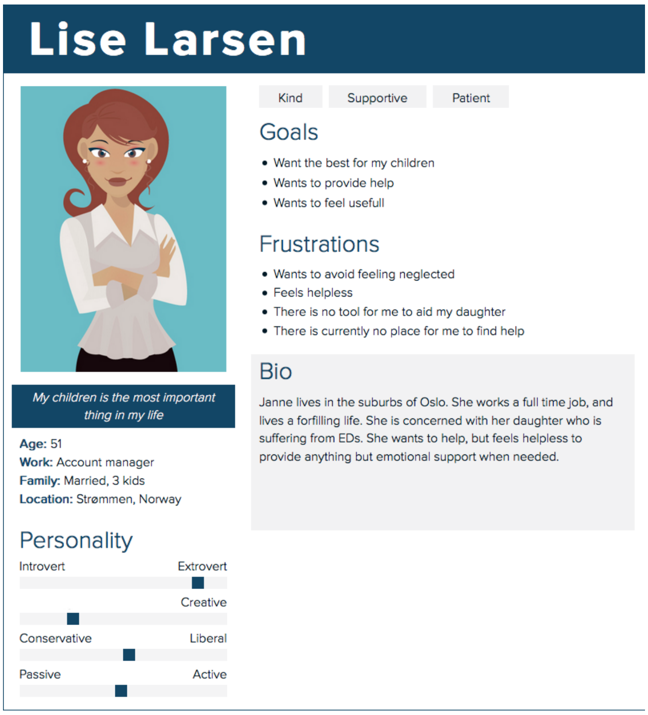
Introvert — Extrovert
Analytical — Creative
Passive — Active

Figure 8.3: Personas: Kari

Scenario one: Kari

This scenario illustrate the effects of using the suggested application.

- The setting is Oslo, Norway, sometime in the future. Kari is at home. She has access to a mobile phone, connected to the internet through a 4G network. Kari is in need of treatment for her EDs, but she is scared of contacting places at random, she wants to find the right kind of help. Action: Kari uses her mobile phone to navigate to the application and interacts with the map functionality. She is able to find a dentist that specializes in treatment for EDs. Kari clicks on the location and is presented with information on the selected location. Kari is pleased that she no longer needs to request information from others regarding good treatment options, but instead she can use the application. The proposed contact information allow Kari to add the selected dentist as a favorite Kari is pleased with finding a dentist that appear to fit her current needs; she is reassured by the amount of people who have recommended the treatment option. Action: Kari sets a personal goal, to call the selected dentist within three days, to do this she navigates to the calendar, where she adds the goal on the selected day. To be reminded of this, she sets a notification, with a motivational picture. Kari feels secure that when the day comes, she will contact the dentist, and is happy that the application provides both information and motivation to reach her goals. At nighttime Kari feels alone, her everyday tasks keep her mind occupied, but at night she needs motivation and social interaction. Action: Kari navigates to the motivation archive; she browses the images and finds one that connects with her state of mind. After saving the picture, she decides to share the picture with a person, hoping to provide social support to someone in the same life situation. The action leaves Kari with the feeling that she might have helped someone in a similar position as herself and offered some support. All in all, Kari feels that the new mobile applications have helped her to be more in control of her own life, and contributed toward taking action to improve her well-being.



Lise Larsen

Kind Supportive Patient

Goals

- Want the best for my children
- Wants to provide help
- Wants to feel usefull

Frustrations

- Wants to avoid feeling neglected
- Feels helpless
- There is no tool for me to aid my daughter
- There is currently no place for me to find help

My children is the most important thing in my life

Age: 51
Work: Account manager
Family: Married, 3 kids
Location: Strømmen, Norway

Bio

Janne lives in the suburbs of Oslo. She works a full time job, and lives a forfilling life. She is concerned with her daughter who is suffering from EDs. She wants to help, but feels helpless to provide anything but emotional support when needed.

Personality

Figure 8.4: Personas: Lise

Scenario two: Lise

This scenario illustrates how someone in a supporting role (see figure 8.4) can use the suggested application.

- The setting is Strømmen, Oslo, sometime in the future. Lise is at home, after a day at the office, she has not heard from her daughter, whom she knows is struggling with EDs. Lise feels helpless, as she is not able to provide any support for her daughter, other than to be there for her if she calls. Action: Lise uses the application, and accesses the map function. She browses the map until she finds a new kind of treatment, which has got many recommendations. Lise thinks that this might be of interest to her daughter, and decides to send it as a contact. Action: Lise accesses the location, and sends the contact information in a text message. In the text, she writes some words of motivation and concern for her well-being. Lise feels that she was able to contribute, thinking that her daughter will see the treatment offer and believe that it is a good idea. All in all, Lise is happy that the application provides a way for her to help her daughter, in a domain where she has limited knowledge. She is left with a feeling that she might contribute to her daughter's well-being.

8.2.3 What do the scenarios tell me?

The scenarios presented above illustrate the intended functionality of the application and the *role* it can have the life of its users. Houde and Hill [78] state that the *role* dimension of a prototype should investigate questions of what an artifact can do for a user, and how they can benefit from using the prototype. To demonstrate the *role* dimension of the prototype design, I Introduced personas combined with scenarios. Intended to show how the suggested application would fit into the everyday life of its users. Moreover, it illustrates that the application has a potential benefit for secondary users, connected to people affected by EDs, as the suggested application can provide an opportunity to give motivation or and support.

8.2.4 The *Look and Feel* of the prototype

By exploring the *look and feel* dimension of the prototype, I aim to describe the design choices taken in the process of creating the prototype, covering decisions I took regarding navigation, symbols, color, and mental models. "By their very nature, prototypes involve compromises [. . .] [139, pp.396]." Compromises in design are something every designer need to address – it means taking design choices. The choices you make, effect what you can investigate with the prototype. The questions a prototype can answer the designer is limited. Therefore, one has to design with the key issues in mind [139]. A typical compromise in design, one, which all designers need to address, is to choose between functionality provided versus depth. Rogers et al. [139] state

> "These two kinds of prototyping are called *horizontal prototyping* (providing a wide range of functions but with little detail) and *vertical prototyping* (providing a lot for detail for only a few functions) [139, pp.398]."

The goal of my design work was to compose the functionality we had co-designed in workshop two. To do this I had to prototype a broad range of functionality, placing my prototype in the *horizontal* category. According to Rogers et al. [139] a designer needs to address the compromise of a low vs. high-fidelity prototype. Although, I rely on the argumentation from Houde and Hill [78] that what you wish to explore with the prototype is more important than the chosen fidelity. The important thing for my design process was to utilize the tools necessary to realize the participant's vision for future technology, and not apply specific focus to the chosen fidelity. The following section will present the design choices taken in creating the prototype, followed by a presentation of the five core functionalities of the designed application.

Color

Findings from my workshop, show that both Rebecca and Amanda had a clear vision regarding what the colors should represent in a design. The consensus was that colors should be, professional, gender natural, and not too bright. Amanda elaborated on this "I believe that the colors should be natural, and not tacky and bright." She also stated, "I think that the map functions should be clean concerning color. However, the calendar and other functionally can be more visual. Not too much, but I believe there is room for colors to spark some emotion.” Picking a color pallet that fits the criteria can be hard. My choice landed on the color pallet, shown in figure 8.5. The pallet includes colors that I believe promote a clean and professional look. The chosen pallet also tries to reach a gender-neutral expression. A desire Amanda expressed in workshop two (see section 8.5.7 for more information regarding the topic of perceived gender neutrality).

Figure 8.5: The chosen color-pallet.

Design patterns

Choosing the preferred navigation structure can be a difficult task – it is a matter of compromise. The first compromise I have to make is which mobile operating system (OS) to design for, Amanda and Rebecca has experience using both Android OS and Apple OS, providing no indication of preferred OS platform. I took the choice of designing for the Android OS platform. Sanders and Stappers [147] explain that in a co-creating process, a designer needs to be able to make necessary decisions in the absence of complete information [147]. It is concerning the notion of power in the process. PD is formed on the heritage (4.2) within this is heritage is the concept of *power-relations*, central to decision-making in design. Bratteig and Wagner [25] determine that the issues of power in a project needs attention, although, it is less critical when working with a homogeneous group, as my research project. Nevertheless, designers need to be respectful of the knowledge of the users [25]. The designer has the power to translate preferences into a design result. Materializing choices by “locking” them in an IT artifact is an act of power. The participant’s power lies in their ability to create the choices, based on their expertise [25]. I have to make design decisions, regardless of the complex interplay between user and designer. Therefore, it becomes necessary to evaluate my choices with the participants, to investigate if my decisions align with their views of future technology.

The following section will examine the decisions I took, leading up to the first prototype. I had to decide on the navigational structure of the application. Amanda had illustrated in Figure 7.5 and 7.9 some elements of navigation, which she was familiar. Besides, she stated that “navigation in the applications needs to be intuitive” working within the Android OS toolbox, I decided to use the principles of *Material Design*. *Material Design* is a UI design language, developed in 2014. It focuses on a grid based structure currently deployed in various influential applications [1]. Since the

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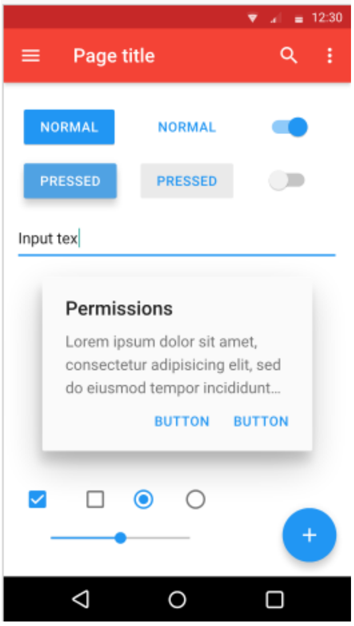
[1] Gmail, Google Drive, YouTube, and Google maps

core functionality of the application would be the map feature. It appeared like a logical choice for my design to adapt a navigational pattern used by Google Map. Figure 8.6 illustrates some of the core *Material Design* components. It is important to note, that as a researcher, I provided the tools for Amanda to visualize navigational structure, the icons I provided were, to a large extent, from Google *Material Design* library. Hence, one can argue that she was biased toward a decision. However, she did stress her familiarity with the icons, and what she believed each icon represented, this is visible in the transcribed data-set.



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Permissions

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Figure 8.6: Core *Material Design* components.

By using *Material Design* I apply a Google-promoted framework, this can be a limitation for users only familiar with Apple OS or Windows Phone OS. Nevertheless, I do not rigid follow the *Material Design* framework guidelines. I manipulate the color pallet, shadow, animation, and navigation to fit the established requirements of the prototype. The time limitations of my research project, restrict the ability to create a prototype for both Android and Apple OS frameworks. I believe that by using the *Material Design* framework as a foundation, and by altering it with unique functionality I can create a semi-platform independent design. By deciding on a navigational structure, I start to materialize my conceptual model of the system [2] to an artifact. In his famous article, Norman [125] show the importance a conceptual model has in designing artifacts. It involves "The major clues to how things work come from their perceived structure—in particular from signifiers, affordances, constraints, and mappings [125, pp.26]." A conceptual model is my conceptualization of the envisioned system — what the system is, how it's organized, what it

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[2] also referred to as a *Mental Model*

does, and how it works [71]. As a designer, it is my responsibility to create a system that matches my conceptual model with the conceptual model of my users.

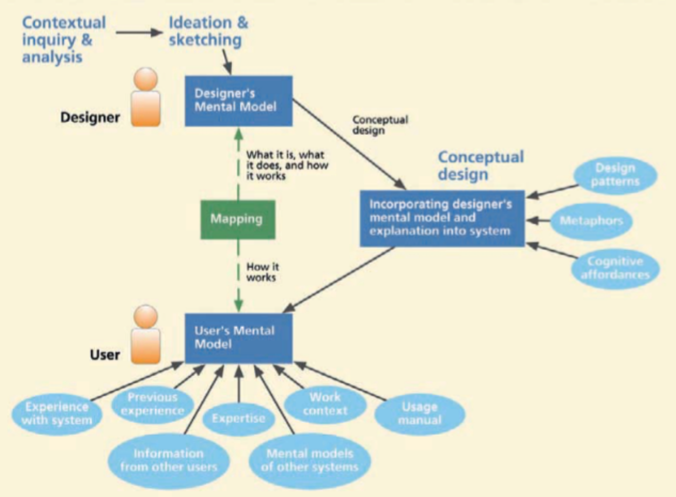


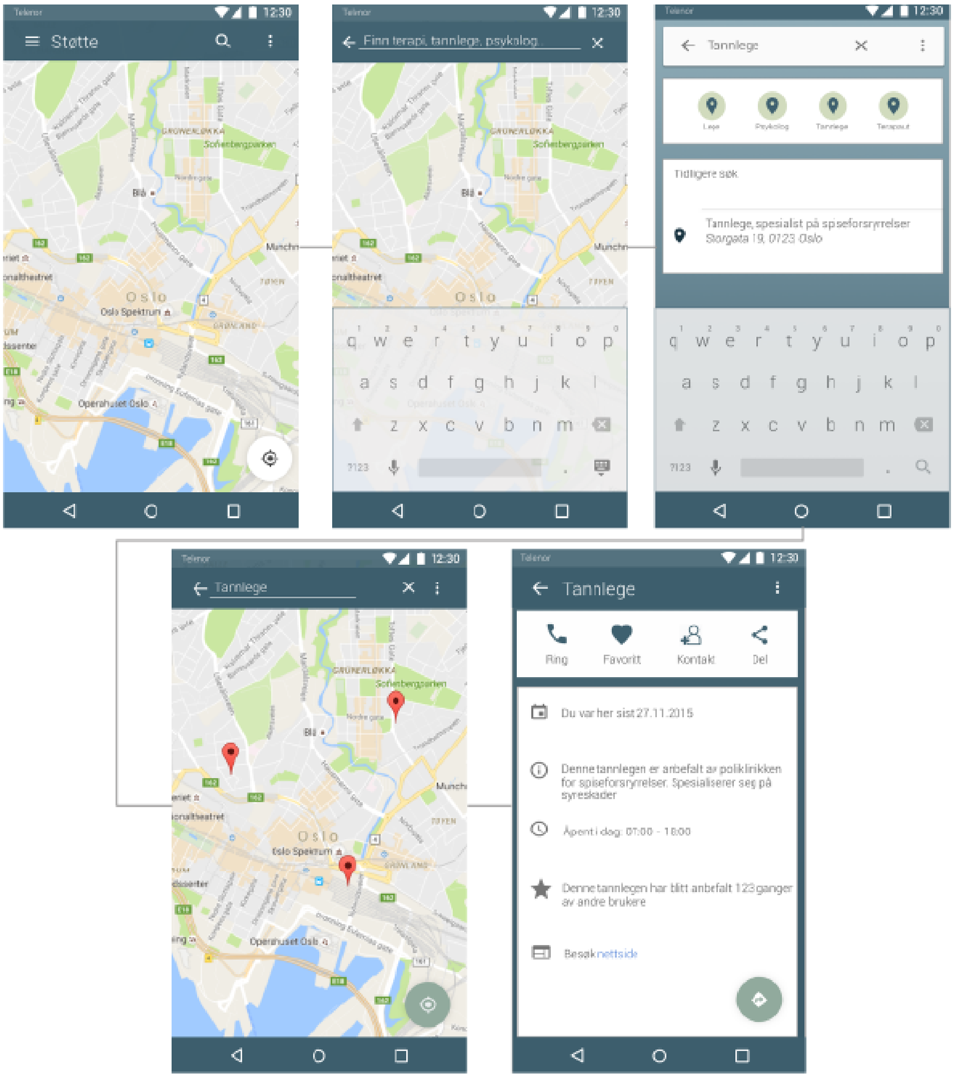
Figure 8.7: Connecting a designers mental model, with the users mental model [71, pp.301].

Figure 8.7 show that when incorporating the designer's mental model and explanations into a system, it should illustrate how the system works, and highlight design patterns, metaphors, and cognitive affordance. Norman [125] show that *affordance* is a intertwined concept that's often misused in the context of interaction design. My perception of affordance is essential to understand the design choices. *Affordance* is connected with what Norman [125] refers to as *signifiers*. *Affordance* are the possible interactions between people and the environment. While *signifiers* signal things, in particular, what actions are possible and how they should be done. *Signifiers* needs to be perceivable, else they fail to function [125, pp.19]. Norman [125] argue that in design, *signifiers* are more important than affordances, because they communicate how to use the design. In my prototype *signifiers* are the icons and words, while the affordance is the ability to understand that the possibility of interaction. I used Google's icon pack, connected with my *material design* navigational pattern. In the second workshop, Amanda emphasized that a "hamburger" menu, is a good way to illustrate choices. Showing that the icon to Amanda represents a *signifier*, with an *affordance*. Furthermore, Amanda consistently used the vertical dotted icon to show "settings". Leading me to design a navigational pattern with this icon, signifying its usage. These design choices, are fundamental steps to creating a prototype that connects the user's conceptual models and mine.

8.2.5 Presenting the prototype

This section shows the different core functionality of my prototype, highlighting the chosen navigational structure and design choices. To interact with the clickable prototype, follow this url: https://projects.invisionapp.com/share/XF85FSAHR

Map functionality



Tannlege, spesialist på spiseforstyrrelser
Storgata 19, 0123 Oslo

Du var her sist 27.11.2015

Denne tannlegen er anbefalt av poliklinikken for spiseforstyrrelser. Spesialiserer seg på syreskader

Åpent i dag: 07:00 - 18:00

Denne tannlegen har blitt anbefalt 123 ganger av andre brukere

Besøk nettside

Figure 8.8: The design: Map functionality, following the navigation of possible interaction from left to right.

Calendar

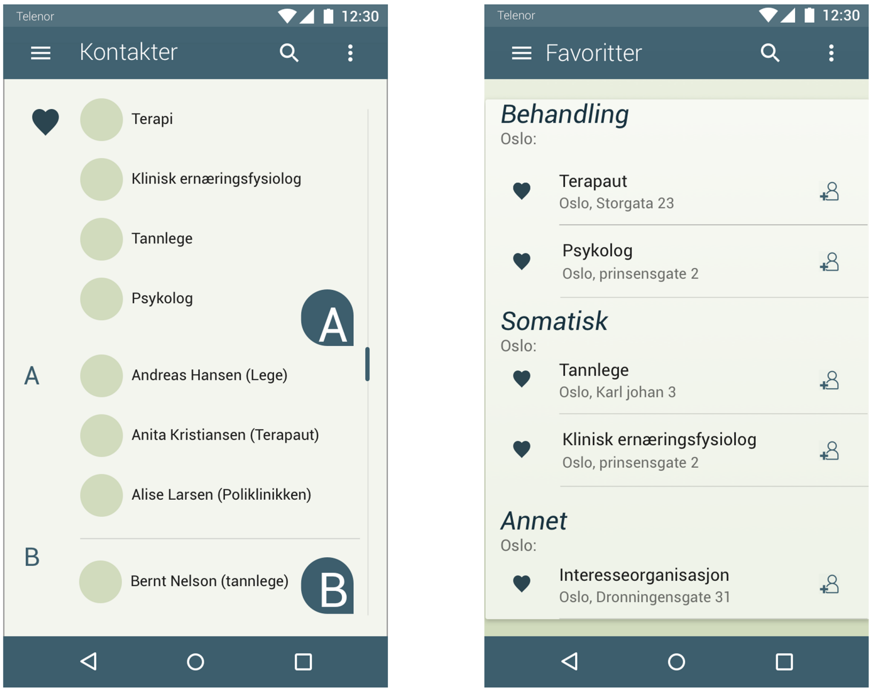
Mandag
«Dagen er din, og du er unik»

09:00 Kontakte terpaut
18:15 Gå på Kafè med Henriette

Mer du vil oppnå i dag? +

Figure 8.9: The design: Calendar functionality

Favorites & Contact list



Terapi
Klinisk ernæringsfysiolog
Tannlege
Psykolog
A
Andreas Hansen (Lege)
Anita Kristiansen (Terapaut)
Alise Larsen (Poliklinikken)
B
Bernt Nelson (tannlege)

Behandling
Oslo:
Terapaut
Oslo, Storgata 23
Psykolog
Oslo, prinsensgate 2
Somatisk
Oslo:
Tannlege
Oslo, Karl johan 3
Klinisk ernæringsfysiolog
Oslo, prinsensgate 2
Annet
Oslo:
Interesseorganisasjon
Oslo, Dronningensgate 31

Figure 8.10: The design: Favorites & Contact list functionality

Motivational-archive

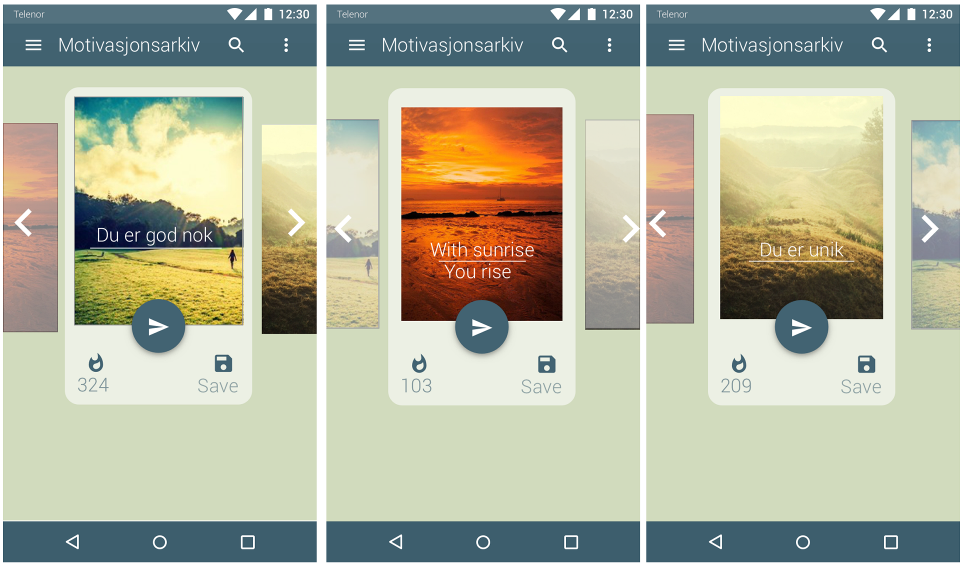
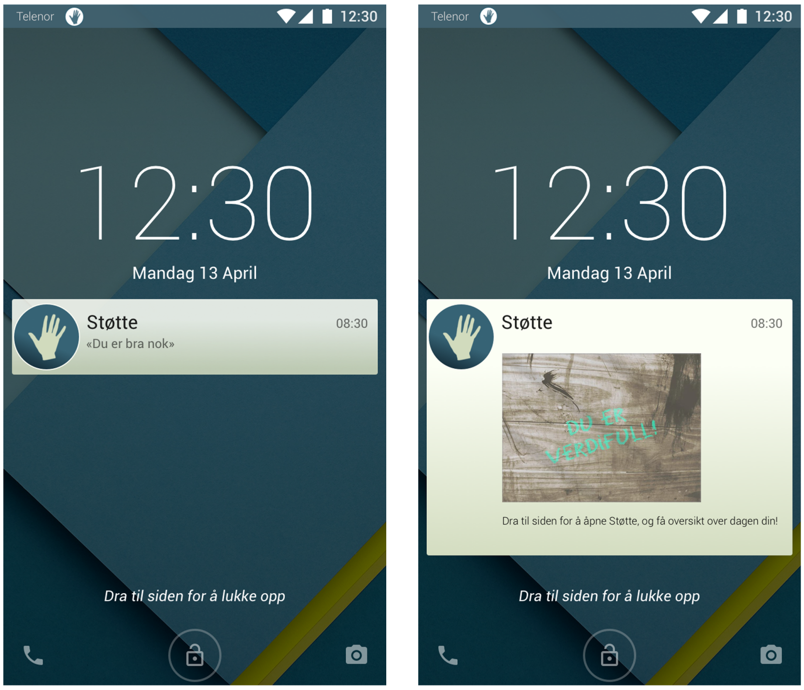


Figure 8.11: The design: Motivational archive functionality

Notifications



Dra til siden for å lukke opp

Dra til siden for å åpne Støtte, og få oversikt over dagen din!

Dra til siden for å lukke opp

Figure 8.12: The design: Notification functionality

Navigation structure in the prototype

Figure 8.13 shows the navigation structure of the prototype, placed in a diagram to illustrate the possible navigation in the application.

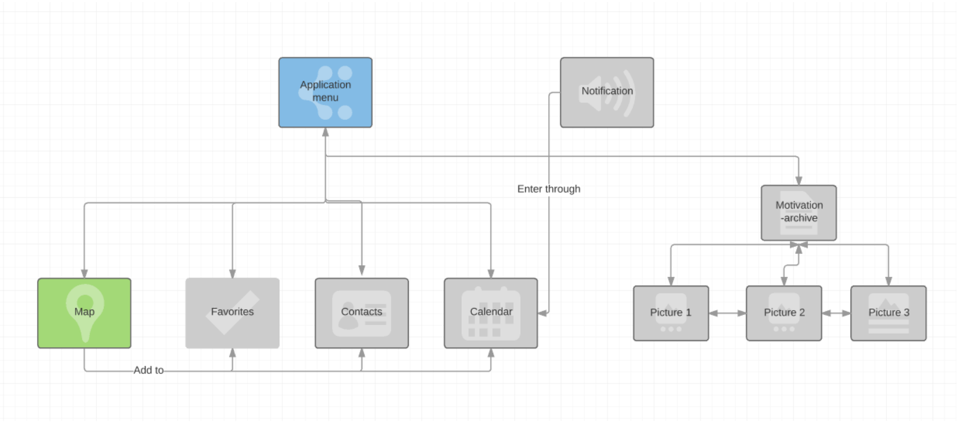


Figure 8.13: Navigational diagram illustrating likely navigation in the prototype

8.2.6 Summing up

By presenting the prototype I intended to illustrate both the *look and feel* and the *role* of the prototype. I give argumentation for my choices regarding navigational structure, icons, menu, and how my conceptual model tries to align with my users conceptual model through the prototype. I constructed personas and placed them in scenarios to illustrate the use of the application, and how it can fit into the user's life. The next section will look into the third, and final workshop in my research project – evaluating the prototype.

8.3 Workshop three

> ”Every design process is unique. The preconditions for design work change from one occasion to the next. This means that design work is impossible to predict. If the outcome can be predicted, it is by definition not a design process [177, pp.9].

A design process is a unique process, where the outcome is hard to predict. Whether I chose to use PD, User Centered Design (UCD) or SD, it involves design iterations. They come in different shapes and definitions, like Schön and Wiggins [151] PD approach of “see-move-see”, or a more traditional UCD approach [3]. What connects these diverse approaches to design is the desire to create a product. When conducting design iterations, one evaluates the effect of a design choice with the user, and this can be seen as a step to create better-designed solutions. However, my research project has defined time limitations. Workshop three would be my final workshop.

As a result, I do not have the time to iterate in cycles until I reach a perfect design outcome. Löwgren and Stolterman [177] state, "The complexity of design situations prohibits completely rational approaches, which means that there can never be a perfect design process with a perfect outcome [177, pp.3]". Acknowledging that there can never be a perfect outcome helps me to realize that the objective of workshop three, will be to evaluate the prototype, as it exists in the current state of my process, without the possibility of endless iteration cycles. I have to carefully decide on what aspects of the designed prototype to evaluate, resulting in my objectives for workshop 3:

- Main objective: Investigate if the prototype aligns with my participants vision of the technology.
- Sub-objectives: Investigate to what extent navigation, symbols, and design is easy to perceive.
- Investigate the role of the prototype in the context of a service.
- Investigate possible changes to the design.

The question remained – how would I achieve my objective for the workshop? There is limited academic research on evaluating prototypes in PD. A potential reason for this can be that the focus in PD projects is not quantifiable measurements of success, as an amount of clicks to reach a goal, or monitoring eye movement to evaluate a navigation structure. It is about uncovering to what extend the prototype matches the needs of the participants. Brandt [23] state that its is important to allow the participants the opportunity to bring up whatever the design model evokes in them, as this can be valuable for the success of the design proposal. For my research project, this involved designing tasks that would allow the participants to express themselves, while at the same time evaluating the design proposal. The following section will briefly cover how I developed the workshop, to reach my objectives.

8.4 Creating the tools for workshop three

The workshop would begin with a quick recap session, presenting the paper-prototypes created in workshop 2 (7.2.3). This step was intended to make it easier for the participants to understand my design decisions and refresh their memory of the previous workshop sessions.

8.4.1 Step 1: Exploring the prototype

After completing the recap session, I wanted the participants to explore the prototype. I presented the participants with the interactive, clickable prototype. Giving them three minutes to interact with the prototype freely, to familiarizes themselves with the design and functionality. After the three minutes, the participants would be presented with a series of tasks. The tasks were designed to test the functionality, navigation, and symbols in the design. The participants were encouraged to *think-aloud* [84]. The combinations providing tasks, and encouraging users to *think-aloud*, is traditionally associated with UCD approaches [3, 190]. Muller and Druin state [120] "One of the weaknesses of the literature on participatory practices is the dearth of formal evaluations [120, pp.41]." Because of the limited academic focus on the evaluation of PD prototypes, I have to choose methods and tools that enable me to reach my primary objective for the workshop. I believe that understanding the user's perception of the system, uncovering the user's thoughts regarding navigation, icon usage, and colors are important steps in designing a sustainable system that "better" reflect their needs and desires. I hold that it should not be reserved for those taking a UCD approach to design. Bossen et al. [19] conducted a review of evaluation in PD projects. The authors [19] show that after reviewing sixty-six PD projects, only two projects focused on evaluation with participants to support decision-making and inform to what extent aims had been met. The limited academic guidelines for evaluation in PD projects provide me freedom to choose the methods I see fit to evaluate the prototype.

8.4.2 Step 2: Evaluating the screenshots

After completing the provided tasks, I gave the participants a set of selected screenshots from the prototype. The screenshots displayed the design of the five core functionalities, presented in section (7.2.3). Combined with the screenshots I provided the users with a toolkit, consisting of color pencils, post-it notes, and paper-arrows. The idea was that the participants would interact with each screen, and discuss elements of the design, using the toolkit to make alterations when needed. Allowing the participants to do a thorough walkthrough of the designed functionality, is a step in the process of investigating to what extent my design aligned with their vision of the technology. Step two in the workshop were intended to empower the participants to make alterations to the design, highlighting aspects of the design they felt were unclear, or failed to reflect their vision of technology.

8.4.3 Step 3: Discussion

After reviewing the screenshots in step two, the participants would engage in a discussion connected to three main topics. The aim was to investigate the following:

1) Does the application have any features missing? I wanted to uncover if the participants felt something was missing, and providing them a final opportunity to express themselves regarding the design.

2) If developed, how would the application be published? This question was intended to explore an SD link to the mobile application. The aim was to uncover if the mobile application would be part of a service, supported by elements such as; web portals, brochures, flyers, or advertisements.

3) How would the application be technically maintained? The question was intended to provoke thoughts regarding maintenance of the application. The idea was to investigate if the application could be designed to require minimal maintenance, as a step in the direction of creating an application, realizable and scalable after the completion of my research project.

Summing up

Workshop three would be an evaluation workshop, where the participants would interact with the prototype, conducting a series of tasks. During the completion of tasks, the participants were encouraged to *think-aloud*. After finishing the appointed task, the participants would evaluate each screenshot representing the designed functionality. Allowing the participants time to assess the screenshots equipped them with the possibility of making alterations, and expressing thoughts regarding the design. Lastly, the participants would discuss the suggested prototype in the context of three main topics.

8.4.4 Pilot workshop

Before conducting the workshop with the patient organization, I conducted a pilot workshop (see section 6.4.1 for information regarding pilot workshops). The pilot workshop was performed with a fellow student at the Department of Informatics, on August 5th. The primary objective of the workshop was to allow the participant to interact with the prototype, and determine if the tasks were easy to understand and solve. The pilot workshop uncovered issues relating to navigation on a mobile device. Access to the interactive prototype is limited through the mobile phones browser. The participant's native browser acted as an overlay over the prototype applications navigation, causing the prototypes navigation to be inconsistent and hard to use. The participant also uncovered an additional issue of navigation between two screens in the interactive prototype, causing a "lock", where she was unable to move to the next step in the presented tasks. The pilot workshop was a feasibility study [180] conducted as a trial run.

Alterations were made to the prototype, based on the collected data from the pilot workshop. By changing the navigation system to allow the participants to move back and forth in the prototype freely. I took the data regarding navigational issues on mobile devices into consideration for my future work. Furthermore, the pilot workshop provided me as a researcher with valuable practice in conducting an evaluation activity.

8.5 Conducting the workshop

The workshop was conducted at the headquarters of the patient organization. Unfortunately, only Amanda could participate in the final workshop.

Nonetheless, Amanda was the sole participant of workshop two, I decided that it would be logical for her to have a central role in evaluating the prototype, and decided not to postpone the workshop, awaiting participation of Rebecca.

8.5.1 Exploring the prototype

After encountering issues of accessing the Wifi network, I introduced Amanda to the interactive prototype and conducted a quick recap from the last workshop. I choose to display the application on a laptop, instead of a mobile device. Deviating from De Sá and Carriço [141] argumentation, implying that prototypes should be displayed on actual devices. I took the decision to use a desktop device, due to the issues encountered with the mobile browser during the pilot workshop 8.4.4. Moreover, the primary objective of the workshop was to learn from the participants, and evaluate if the prototype aligned with their visions for technology. I believed this goal could be achieved regardless of screen size. Immediately upon interacting with the prototype, Amanda stated, “ Wow, this is precise as we designed, that’s so cool.” After freely exploring the application for approximately 3 minutes, I presented the predefined tasks I wanted her to complete. Amanda completed all the tasks without encountering problems; she stated, “ The application have everything we discussed, it’s simple without unnecessary elements.” She also stated, “I like the navigation, and the symbols you included in the menu helps me to understand what each item means, that’s great.” Figure 8.14 show Amanda interacting with the prototype”

Figure 8.14: Amanda interacting with the prototype.

8.5.2 Evaluating the screenshots

Evaluating the screenshots allowed Amanda time to reflect on the functionality and express her thoughts regarding the entire application. Amanda expressed her gratitude and was impressed with the work put into the application. “I think this is so cool, I had not dared to think that the outcome would be so great. We have created an application!” By chronologically walking through the screenshots, Amanda highlighted four minor alterations to the design. Amanda demonstrated how she envisioned the changes on post-it notes, visible in figure 8.15 The following section will briefly explain each alteration, illustrating how I changed the design, to best reflect Amanda’s vision of the technology.

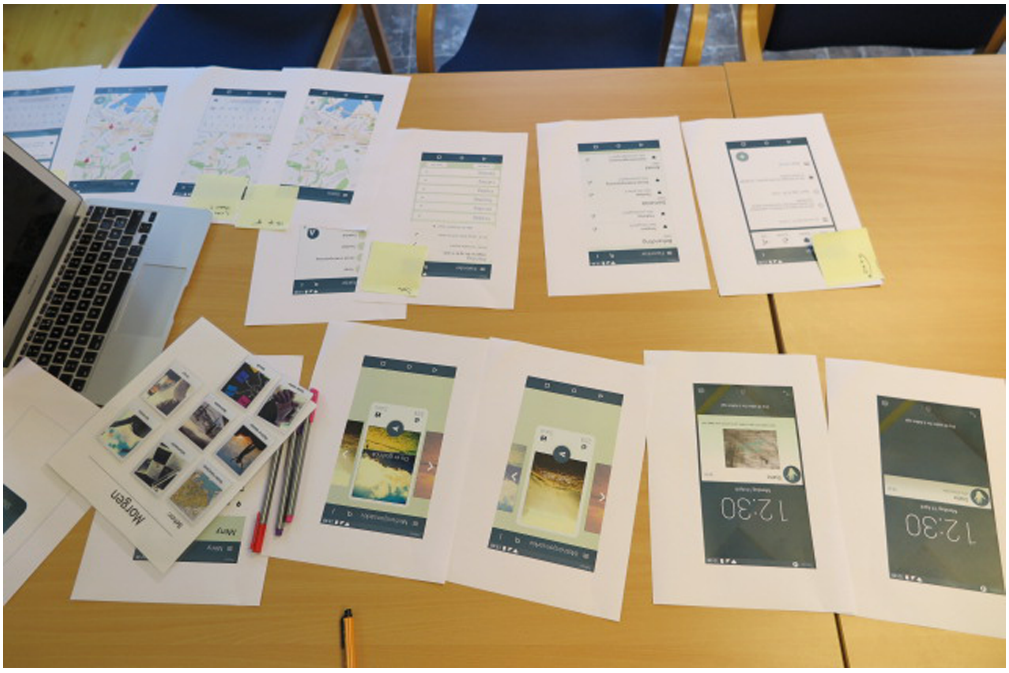


Figure 8.15: Amanda evaluating the screenshots.

8.5.3 Map: Searching for locations

Figure 8.16 shows the design alterations made after the evaluation:

Amanda suggested that we alter the search functionality within the map, stating that “Hmm, I am not sure about the “tidiligere søk” [3] label. What if you clicked one of the icons to help you find a location. Instead of wondering – what was the name of that place again? You could get suggestions. If you take therapy as an example, there exist many variations, from behavior therapy, musical therapy, to metacognitive therapy. Each variety of treatment offers different paths. I believe that this would be better, especially those new to EDs, thinking – Ok, Therapy. Without knowing with direction to take.” The discussion regarding search

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[3] Translated to "previously searched"

functionality, resulted in the design changes seen in figure 8.16. Where the label "Tidligere søk" [4] have been replaced with a list. The circle in figure 8.16 illustrates a potential user is touching the screen. Pressing the icon for “terapaut" [5] presents the user with a list of different kinds of available therapy in the close geographical vicinity of the user.

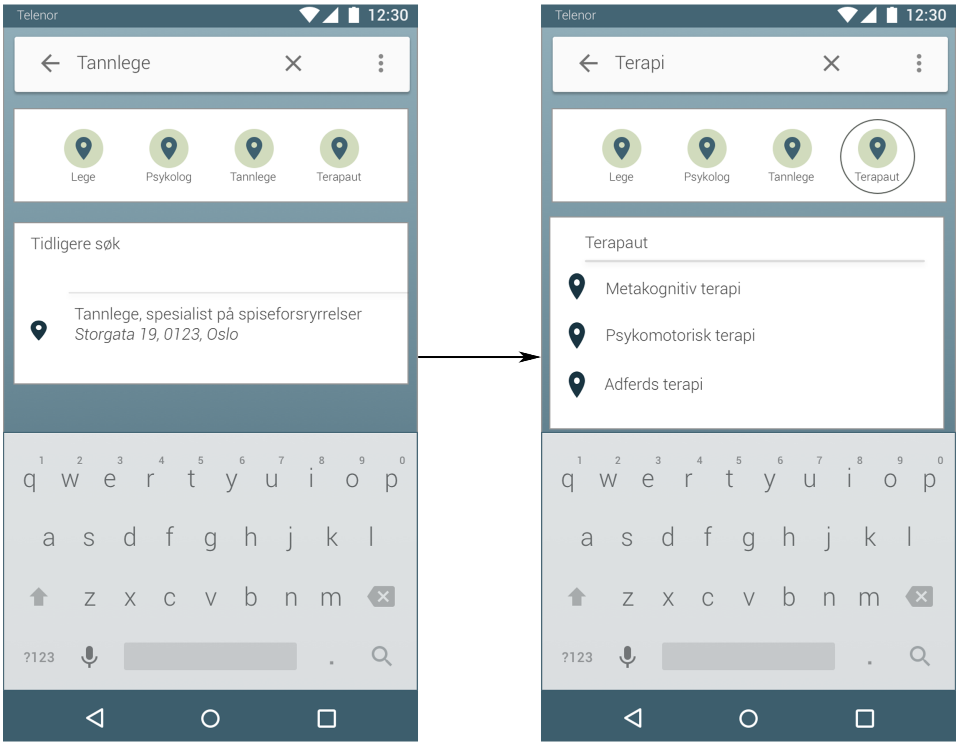

Figure 8.16: Left: The screenshot Amanda reviewed. Right: Alterations made based on feedback from Amanda.

8.5.4 Map: Information on a location

Further evaluation of the screenshots connected with the map functionality, resulted in another alteration. Amanda wanted to rearrange the information related to a particular location. She stated, “I think that the information connected with “sist besøkt” [6] can be moved further down. I am not so sure that’s the first thing you need to see when viewing a particular location” We concluded that we should rearrange the location specific information and the rating system. The results of the alterations can be seen in figure 8.17.

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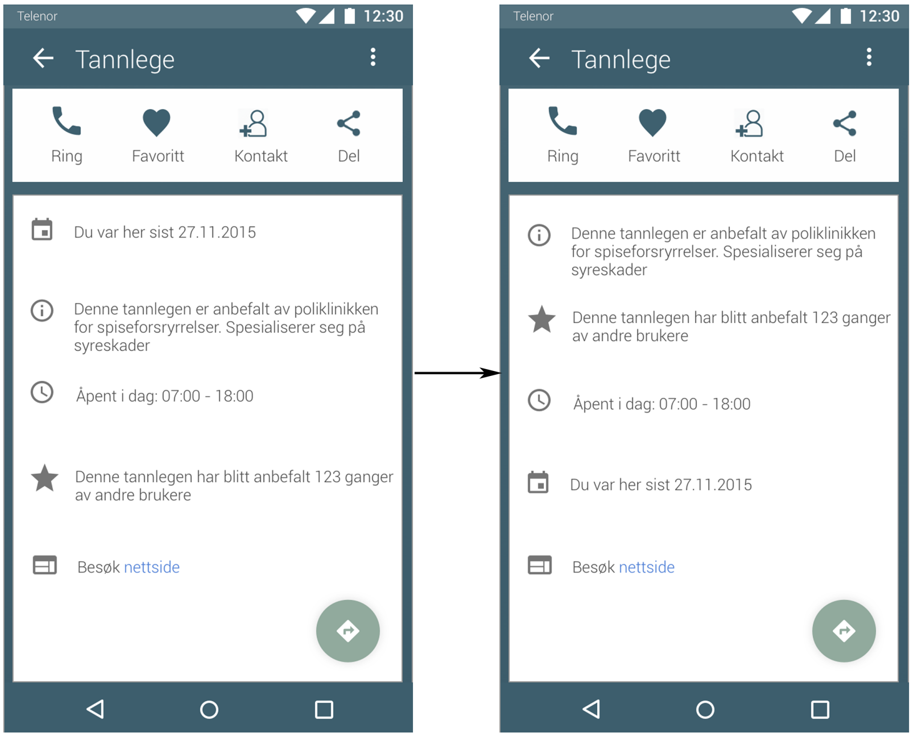
[4] Translated to: "previously searched"
[5] Translated: Theraphist
[6] Translated: Last visited



Du var her sist 27.11.2015

Denne tannlegen er anbefalt av poliklinikken for spiseforsryrrelser. Spesialiserer seg på syreskader

Åpent i dag: 07:00 - 18:00

Denne tannlegen har blitt anbefalt 123 ganger av andre brukere

Besøk nettside

Denne tannlegen er anbefalt av poliklinikken for spiseforsryrrelser. Spesialiserer seg på syreskader

Denne tannlegen har blitt anbefalt 123 ganger av andre brukere

Åpent i dag: 07:00 - 18:00

Du var her sist 27.11.2015

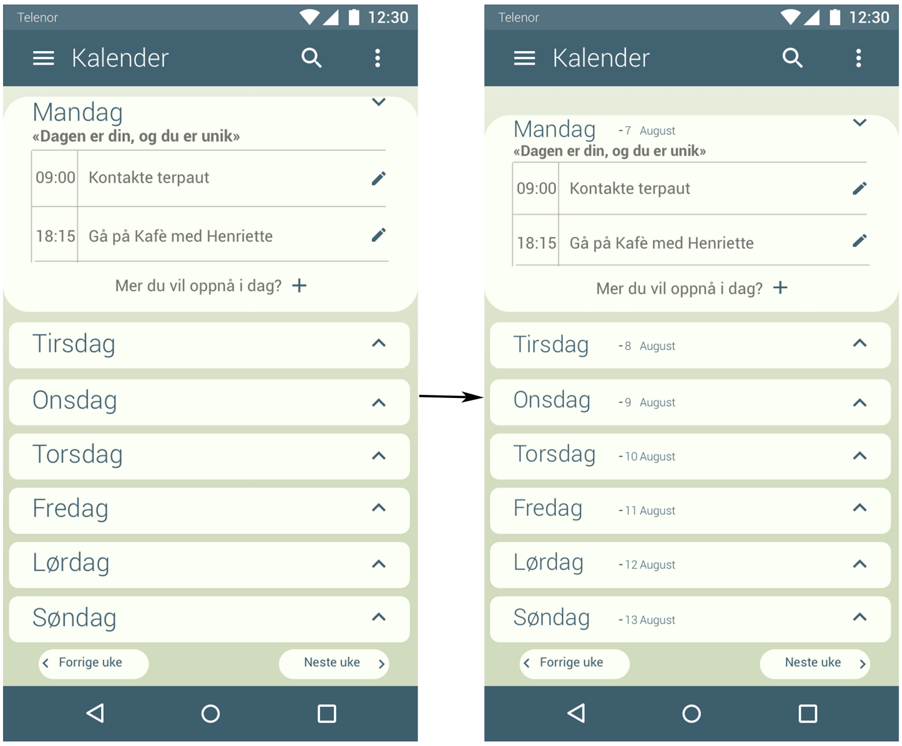
Besøk nettside

Figure 8.17: Left: The screenshot Amanda reviewed. Right: Alterations to information about a location, made based on feedback from Amanda.

Amanda stated, “I think that aside from the changes we made to the search functionality and information of a particular location, there is nothing else i would like to change, i think the map is clean, simple, easy to use, and understand.

8.5.5 Clendar: Date

The last alteration to the design became apparent after evaluating the calendar functionality. Amanda stated that “I enjoy the design, it’s just like I thought it would look. Still, I believe that if you have an appointment on a specific date, you should be able to see what day of the month it is.” The initial design was a result of the desire to create a visual calendar, not focusing on extended periods of time (see section 7.2.7). Nevertheless, we decided that the application would be easier to use if could view the date connected to a specific day. The alterations resulted in the new design, seen in figure 8.18.



«Dagen er din, og du er unik»

09:00 Kontakte terpaut

18:15 Gå på Kafè med Henriette

Mer du vil oppnå i dag? +

«Dagen er din, og du er unik»

09:00 Kontakte terpaut

18:15 Gå på Kafè med Henriette

Mer du vil oppnå i dag? +

Figure 8.18: Left: The screenshot Amanda reviewed. Right: Alterations to the calendar made based on feedback from Amanda.

The contact list

Discussions regarding privacy and anonymity during workshop two (see section 9.3.1) resulted in a decision to keep the application "offline". In the context of my thesis, "Offline" refers to a standalone application not synchronized with third party applications or the phone's native functionality. The desire to keep saved locations private resulted in the need for a contact list. Amanda stated, "You can get unwanted questions, if, for example, a friend is borrowing your phone to call someone, and sees different kinds of therapists in your contact list." During workshop two, we discussed the concept of a contact list. However, we did not conduct a prototyping session on the functionality. Resulting in a designed functionality, created based on my knowledge as a designer. As argued for in section 8.1 I can take these decisions in a PD process. Amanda interacted with the screenshots for the contact list, and stated, "It's clean and straightforward, I like the alphabetical order. The only thing I am thinking is, maybe we should remove the heart symbol?" I agreed with Amanda, the heart symbol in the contact list was intended to be a way to mark a contact as your favorite. However, the functionality was unclear to Amanda, and after discussion, we decided to remove the symbol. See figure 8.19 for the altered contact list. The design alteration highlights the importance of evaluating design choices with the users. Much like Schön and Wiggins [151] show, that by "seeing" in designing, one can detect, judge, or appreciate the quality of a configuration, as a consequence of a design “move”. In my case, the “move" was creating the contact list, "seeing" its effects and conducting a new "move", to alter the functionality.

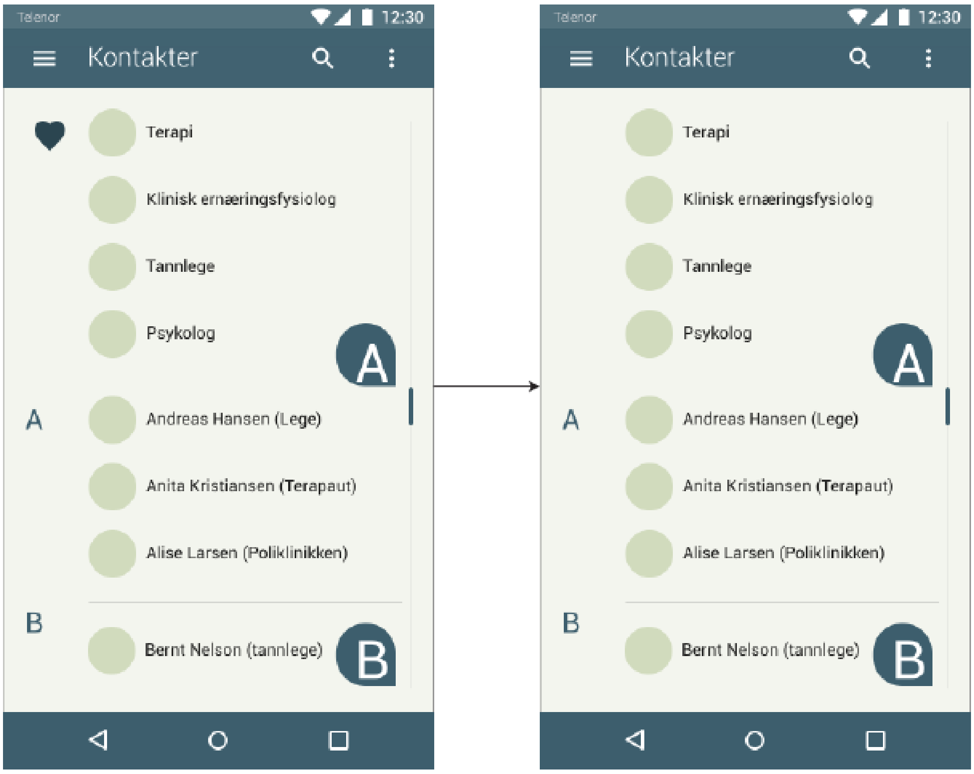


Figure 8.19: Left: The screenshot Amanda reviewed. Right: Alterations to the contact list made based on feedback from Amanda.

The four design alterations illustrated above concluded the evaluation of the prototype.

8.5.6 Discussions of the prototype

The last step of the workshop was a discussion between Amanda and me. The goal was to uncover practical aspects surrounding the designed mobile application, such as maintenance. The objective was also to explore if there should be a link toward traditional service elements to support the mobile application. (See section 8.3) For the main topics of discussion. The following section will briefly cover the most significant findings.

- Missing features: Amanda emphasized that she did not feel the application had any missing features. Instead, she stated, “ It’s amazing to see that we created a mobile application after three meetings, I think cool to see our ideas visualized in such a way and to be part of the entire process, it’s rewarding. I am super, happy with the result, and I don’t think we could have included any more features.”

- Service elements: Amanda said, “Primarily, the app needs to be free. It should be a low-threshold aid tool, and it should, therefore, be released in combination with the patient organization.” Amanda continued, “The patient organization has contacts in the major media outlets, I think if developed, the application can be published using the patient organization network. Maybee it can be supported by flyers, notice in the journal they publish monthly, press releases, social media and maybe in newspaper articles?" Amanda stresses that the patient organization has several important channels that can be utilized if needed. The discussion continued toward supplementing features for the mobile application. Together we decided that, if the mobile application were to be developed, it could be supplemented with a web application. The web application would be a step in the direction of providing a tool for secondary users of the application, such as doctors, nurses, school nurses or parents to provide accurate information about local treatment options for EDs. In the scoping interview (see section 3.1) I uncovered how general practitioners in Norway had limited ED-specific knowledge, a web application could be a step toward aiding the primary health care services in Norway distribute information.

- The next discussion point was connected with service maintenance. We created the prototype toward functionality that required minimum maintenance. By not allowing forum or chat functionality, we limit the amount of user-generated content. Amanda emphasized, “The only real maintenance I can see, is the number of pictures available in the motivation-archive. Also, if a treatment option is closed/opened, that needs to be updated in the application.”

- The workshop session was concluded by a brief discussion regarding the chosen color pallet. I wanted to evaluate to what degree my design aligned with Amanda’s desire to create a gender natural design. Amanda was pleased with the color pallet, and stated, “I think it promotes a professional look, I like that you used more colors in the motivational archive, and calendar, compared to the map. It’s just like we discussed.”

8.5.7 Perceived gender neutrality in the prototype

Amanda stressed that she believes the application promotes a gender-neutral design. Rooted in her vision, that men and women could use the application equally. Braun et al. [27] present findings indicating that apparent similarities in behavior and attitude, in both male and female patients with EDs. The data submitted encourage continued efforts toward using similar strategies to detect and treat EDs among both men and women[27]. It’s important to note, that the prototype does not strive toward treating EDs. However, based on the findings of Braun et al. [27] if the patients of both gender experience the same attitude and behavior, the suggested mobile application could hold the same value for both genders. Consequently, making the concept of gender neutrality in the mobile application important to investigate. To do this, I decided to perform *guerilla testing* [175]. *Guerilla testing* is a quick way to yield useful results regarding design, it requires few participants and doesn't require audio recordings [175]. I conducted the *guerilla testing* with students at the University of Oslo, on September 8th. The purpose of the experiment was to investigate if the designed prototype had appealed to the chosen male population. I conducted the testing by bringing three screenshots, showing core functionality of the mobile application to male students at the Faculty of Informatics. I asked all the participants to express their thoughts regarding colors used in the prototype, and to what extent they felt the design had a clear gender appeal. Results from the *guerilla testing* show that five out of five male test subjects, agreed that the application did not appear to have a distinct gender-specific design. I can not conclude anything based on these preliminary findings. However, they provide an indication that the suggested mobile application has an appeal to both genders.

8.5.8 What did I learn from workshop three

I was able to present the design proposal for the new mobile application and together we evaluated the proposed functionality, color, navigation, symbols, and icons in the mobile application. The results from the workshop allowed me to conduct a final iteration in the design process. I altered the designed functionality to align with Amanda's vision for the mobile application. I decided to present the design alterations in this chapter, to show how my participants directly influenced the changes made to the design. To view the result of the final iteration see figures 8.19, 8.16, 8.18, 8.17.

The discussion conducted in the workshop provided feedback on necessary steps in ensuring that the mobile application – if developed, was designed in a way that promotes continued use after the completion of the study. The discussion with Amanda gave me information regarding system maintenance, web applications, operations, and publishing. We also discussed how potential supporting elements to the mobile application, like flyer's, articles, journals, and press could promote the potential use of the designed mobile application.

Chapter 9

Discussion

> Every design, however small, is part of what can be seen as the largest design project of them all – the joint design of the world as a place for human life. [177, pp.12]

In this chapter, I will present a discussion of my collected data. With an emphasis on findings, that contribute toward answering my research question. To achieve this, I will discuss the concept of design for positivity, my theoretical frameworks impact in the designed prototype, methodological implications in the project, limitations, and summarizing the design process.

9.1 What is "better"?

> Round wheels are better suited than square wheels for rolling; therefore, round wheels are said to better afford rolling. Stairs are better suited than fences for climbing; therefore, stairs are said to better afford climbing [100, pp.22]

Inherent in the concept of "better", is the desire to create something that is better than what was previously available – a higher standard. This can be seen as either a grand gesture or an impossible task. I acknowledge it is nearly impossible to achieve something "better" because the perception of the concept better is entirely subjective. What can be labeled better for one participant might not be better for another user? Hence, in the context of my thesis, I strive to investigate what is “better” – in the *lifeworld* of my participants. To achieve this understanding what might constitute as "better" I used my theoretical and methodological frameworks of *lifeworld*, PD, and SD. “Better” designed solutions is design based on knowledge gained from exploring the participant’s *lifeworld*, transferred to the design of mobile technology. I label it “better” – because it might reflect the needs and desires of my participant’s better than currently available mobile technology for EDs. Kenny et al. [89] argue, that by understanding the end users needs one can shape future m-health applications so that adolescence will be more likely to use them. In my thesis, “better” design is the combination of functionalities and concepts from a *lifeworld-led* design approach. Discussing the functionalities and concepts will be the focus of this chapter. However, at the center of these functionalities is the idea of designing for positivity. A concept that my participants deemed central to their lived experience with EDs, and a concept that we strived to include in the designed application.

9.1.1 Design for positivity

Through lived experience, my co-designers illustrated how the balanced between taking negative and positive choices could be affected by what initially appear as normal events. However, to those living with EDs marks a vital importance in their everyday life. These events can be anything from receiving or not receiving a smile, to reading text online with a positive or negative mindset. Each event contributes to the perception of that moment and can reflect their ability to take positive or negative life choices. My co-designers showed that every day is a struggle toward making positive choices, and reminding themselves as to why they want to get better? Why do I want to make positive life choices? For the thesis, it became necessary to answer the following question. How can I translate this knowledge into a mobile application? Throughout the research project, we have strived toward co-creating functionality to reflect the participant's *lifeworld*. As a result, the term "better" are interchangeably connected with *lifeworld-led* design. Because, every design decision is based on the co-designers lived experience, and the desire to create something that "better" connects with the particular participants needs and desires.

Inherent in my *lifeworld-led* design approach is an idea that is not only tied to a specific functionality but acts as a mindset for the designed application. The concept emerged during the analysis of the dataset for workshop two 7.3, and was labeled "design for positivity". The idea of designing for positivity is to try to design for the creation of positive emotions, which might result in a commitment to taking positive life choices. The concept of design for positivity is at the core of my participant's *lifeworld* because their mental state holds power to affect the actions they take. If technology fails to motivate or provides negative influence, it can act counterproductive, or according to Amanda, potentially worsen their illness, and as a result, affect her general well-being. Design for positivity as a notion is connected with three intertwined elements. 1) Motivate a user through positive reinforcement. 2) Use said motivation to perform positive life choices that, 3) can affect a users well-being. The following section will explain how the three notions connect through design for positivity.

Motivating a user through positive reinforcement has similarities to the theory of positivity as it is referred to in Phycology [58]. It is beyond the scope of this thesis to fully discuss the concept of psychology and its use of positive emotions. Nevertheless, as Kanis et al. [88] illustrate, positive emotions such as joy, interest, liking and loving can be realized through technological artifacts that can improve the quality of life. Fredrickson

[58] who is a leading researcher on positive emotions within the field of psychology, show how the presence of positive emotions can contribute to a state of mind and modes of behavior that indirectly prepare an individual for hard times ahead. It can also have a role in improving long-term quality of life, concerning mental wellbeing [58, 88]. Design for positivity tires to realize the effects described by Fredrickson [58]. By providing positive reinforcement to individuals at difficult times of the day, to affect a user to take positive life choices. Realizing this, can according to Fredrickson [58] build enduring personal resources [58]. Hassenzahl et al. [72] claim that a challenge for interaction designers attempting to design for the emergence of positive emotions is to gain a profound understanding of what a positive experience is, and how it links with events [72]. In my thesis, the knowledge about what constitutes as a positive experience lies in the ability to uncover elements that have a significant positive effect on my participant's everyday life, living with an ED. Consequently, the concept of designing for positivity emerged as a result of my participants lived experience, especially their experience connected with the dimension of *Mood*. Todres et al. [178] claim that *mood* has organising power, and can act as a great motivator or de-motivator of direct action [178, pp.58]. The participants demonstrated through the different workshops, how *mood* can affect their individual ability to take positive or negative choices, toward recovering and committing to their daily goals. Findings from my research indicate that any form of negative influence can change their perception of a moment, to a significant enough degree that my participants might take negative choices. As a result, the designed application aims to focus on positivity and to exclude any form of negative influence that might interfere with their perception of mood.

Van der Velden and Sommervold [184] illustrate how knowledge of participants *lifeworld*, and dimension of *mood* can affect a design in different ways – depending on the lived experience of the unique participants in the study. In the context of the authors [184] study, the co-designers were chronically ill patients transitioning for pediatric to adult care. The study resulted in the design of a mobile transition application, named "KOOLO". The KULU application attempts to capture the co-designers perception of *mood* by allowing the users to tag images with a corresponding feeling. Principal to the participants of van der Velden and Sommervold [184] study was the ability to articulate a full specter of emotions. Ranging from joy, calm or happy, to angry, sadness or isolated. Having the ability to articulate such emotions was necessary for the participants *lifeworld*[184]. Van der Velden and Sommervold [184] demonstrate an implied benefit to *lifeworld-led* design, as it reveals that capturing the holistic picture of the participants lived experience, can result in unique functionality.

In the context of my thesis, the perception of *mood* as my participants experience it, demonstrate a different reality. A reality which requires a focus only toward the positive emotions that can affect *mood*. There might be a connection between the participants in van der Velden and Sommervold [184] study, who struggled with a physical illness – as opposed to the participants in my research, fighting with a complex cognitive and physical illness. Showing how uncovering different perceptions of mood unique to the *lifeworld* the participants, help to shape the holistic picture of the lived body, and their unique experiences with a continual health condition.

Having established that perception of *Mood* holds the power to affect my participant's motivation, reveals the importance of designing for positive emotions in the context of EDs. Nevertheless, the question remains, how can design for positivity contribute to take positive life choices? Lockton et al. [103] seeks to answer this, by introducing the concept of design for intent. At the core of the concept lies the desire to create "design intended to influence or result in certain user behaviour [103, pp.382]." Lockton et al. [103] explain that to design for intent, the researcher has to uncover intentional or unintentional impacts that can cause real user behavior. In the context of my thesis, the knowledge of my participant's *lifeworld* gives such knowledge, by showing how *mood* and positive emotions hold power to influence behavior. Lockton et al. [103] explain that to design for intent one should establish a range of target behaviors and connect them to behavior patterns. One can then create design suggestions that try to address these surfaced patterns, with the purpose of creating technology with the specific intent of changing the uncovered behavior [103].

Lockton et al. [103] introduced ideas of designing for intent, follow with what my participants envisioned a mobile application could provide for them within their struggles with EDs. Where the designed application attempt to influence behavior with positive emotions, that can contribute to producing positive life choices, with the ultimate goal of positively affecting the participant's well-being. Brey [29] demonstrate that it is possible to design for a user's well-being. To achieve this, the designer needs to uncover stories that can connect to a positive effect on a user's well-being. Such knowledge can only be obtained by exploring a particular user's context, and their individual perception of well-being. The research project has applied a significant focus toward exploring the unique context of the participant's life, through *lifeworld*. As a result, I have uncovered what my particular participants define as well-being and the stories of lived events that hold power to shape their well-being.

Technological artifacts can produce outcomes that might influence the well-being of the user´s. Nevertheless, it is important to perceive that by designing for particular user's well-being – it can negatively influence another. "It may be possible to design artifacts in such a way that a certain desired consequence is bolstered or an undesirable consequence is avoided [29, pp.370]." The statement joins with the purpose of designing for positivity. The idea of design for positivity is to limit the possibility of undesirable outcomes, and promote a design with intent to take choices that promote individual well-being.

Brey [29] state, that a perception about a user's well-being can not be determined objectively, but requires in-depth understanding and knowledge of users own preferences, values, desires, and their social embeddedness. Aligning with the *lifeworld-led* design approach I have in the thesis, where a desire to investigate the participants *lifeworld* have provided such in-depth understanding. Where the need for social relations, positive reinforcement and motivation hold the value and desire to take positive life choices, which can lead to increased well-being. Brey's [29] conceptualization of design for the value of well-being summarizes to a extend what I try to archive in our designed prototype.

> to say that an artifact embodies a value such as well-being is not to say that the artifact will deterministically bring about well-being, however and by whomever it is used. Rather, it is to say that given a particular user or range of users, and in a particular context or range of contexts, the use of the artifact will tend to promote well-being. Given one's knowledge of user and context of use, it is therefore possible to design for well-being [29, pp.370]." (...)

Brey [29] note, that well-being sometimes is compared with happiness. Nevertheless, well-being can imply more than just having a happy or positive mental state it can connect to elements beyond positivity. At the core of the concept of well-being is a state of the person, which designates that they are happy, flourishing and that life is going well for them. Showing the importance in capturing the holistic picture of well-being in the eyes of my participants. Striving to co-create a design that places the unique person at the center, and tries to design for a sensation that life is taking the right direction. Brey [29] offers a framework for how to design for well-being, this is beyond the scope of my thesis. Nevertheless, the ideas presented by the author [29] on how to design for well-being is central to our designed prototype.

Design for positivity, what does it mean for the design?

The notion of design for positivity emerged as a result of the findings and analysis of my conducted research, reasoned in the knowledge of my participants *lifeworld*. Design for positivity is a combination of three concepts: 1) Design to promote positive emotions. 2) Through design with intent. 3) That attempts to affect the well-being of the user. Brey [29] explain how well-being is on of the highest values one can achieve in life, and it is possible to reach through design. I am not claiming that our design will ensure individual well-being, what I suggest is that our design, which originated from knowledge my participants *lifeworld*. Tries to design well-being through the co-created functionality, as a step toward creating something that "better" reflects the needs of my individual participants, living with EDs.

In the following sections, I will discuss and illustrate how knowledge of the participants *lifewrold* influenced distinct functionality in the co-designed application. Design for positivity affects many of the designed functionalities, and as a result, it acts as a mindset for the whole concept of the application. Todres et al. [178] refer to *mood* as "[...] colours cannot be separated from their objects, so emotional attunement cannot be separated from the lifeworld [178, pp.58]." Design for positivity is inherent in my co-designers *lifeworld*, and the desire to get better. Hence, it can not be separated from the designed application. Kanis et al. [88] show that encouraging positive emotions through technological artifacts can be achieved by designing specific technological interactions. Arguing that, ”It is important to have the intended emotion in mind from the beginning, so that appropriate mechanisms and features can be designed accordingly, and are then more likely to result in the desired (emotional) outcome [88, pp.571]." Demonstrating the importance understanding the concept of designing for positivity early in the design process. Attempting to match specific functionality in the designed application to reflect the participant's need for positive reinforcement. Kanis et al. [88] show how designing for positive emotions poses a series of new challenges for design and usability, and it requires an understanding of the indented users and their need for emotionally based support [88]. The following section will show how *lifeworld* knowledge obtained through my research, was applied in a *lifeworld-led* design approach. Highlighting how it directly influenced the designed solution. Kanis et al. [88] designing for positive emotions can ”[. . .] facilitate the creation of useful, usable and pleasurable applications that could mentally and socially benefit those who use and experience them [88, pp.571] ."

9.2 *Lifeworld-led* design

9.2.1 Map

The Lifeline method enabled my co-designers to illustrate the significance of events that shape their everyday life – their *spatiality*. It also revealed how these events relate to their experiences with EDs – their *embodiment* The map functionality seeks to address these unique experiences of *spatiality* and *embodiment*. My co-designers revealed a desire to gain relevant information about available treatment options. Amanda stated “If you are in a situation, where you want to start therapy, but you have limited knowledge of available options. For instance, therapy can be seen as an umbrella term, covering anything from CBT and group therapy – to art therapy or musical therapy. Getting support to those who struggle with finding the right kind of help can be a valuable step in the process of getting better and was something I experience as hard.” Though it is not only about therapy, take for instance dental health, as Amanda said “If you have struggled with EDs for say, ten years. You will most likely have severe acid and dental damage.” The proposed application design could aid a user with finding a dentist specialized in acid damage and treatment of ED patients.”

The collected data further reveal that my co-designers experienced issues where school nurses or medical practitioners might struggle to recommend the right kind of help, this aligns with findings from the conducted scoping interview, where the domain expert pointed out the same lack of specialized ED knowledge in the primary healthcare service. The co-designers had also experienced a lack of available information connected with the many different kinds of available treatment. Akter et al. [4] demonstrate that "[. . .] ensuring the right information to the right person and at the right time [4, pp.106]." can be seen as an enabler for a change in healthcare. This is the premise of the map functionality, to be able to provide context specific location data to the user, helping them get the right information, about the right kind of treatment – at the right time. The use of map functionality to represent location-specific health data or treatment options is a new concept within the research field of m-health. Regardless, it holds a potential to enhance future m-health applications.

Kumar et al. [95] show, that by using geolocation and GPS to connect patients with nearby hospitals it can aid the patient in finding the right kind of help and save both hospitals and patients valuable time in case of an emergency [95]. Plourde [131] show how the application "Health4Me" connects users to physicians, pharmacies, or health facility in proximity through map the use of mobile-based map functionality. Nash [122] stresses that "Health4Me" can offer users valuable information by comparing health services based on quality. The statement by Nash [122] correlates with our co-designed application were my co-designers expressed a desire to rate a location with a star button. To represent that they had a positive experience at the specific treatment option. The design choice of not allowing users to leave feedback, beyond rating a location with a star, are according to with ideas of design for positivity notion. By restricting the ability to leave personalized feedback on a location, the design prevents negative feedback, which might negatively affect the users of the application, resulting in decreased well-being or negative life choices.

The use of location services and GPS location through GoogleMap have been used in a variety of applications designed for different purposes within the field of m-health. Gustafson et al. [65] show how applications using GPS signals can help to initiate treatment for people suffering from alcoholism. Shree et al [158] point to how GPS and location services can be used in map applications to track patient suffering from Alzheimer's disease. Song and Maheshwari [164] present the application "ClickHealth" which utilizes Google Maps to help homeless people locate health-related facilities that are open and offer affordable treatment. Sheeta and Priyanka [153] illustrate how applications can use map services to connect users with blood banks in proximity. Lastly, "Porselesguiden" [1] is a Norwegian mobile application designed to help people with inflammatory bowel disease. By using map technology to visualize available, clean toilets, in proximity to the user. [132]. All the applications mentioned above have a common denominator in the case that they all attempt to offer the right kind of help, to the right kind of users, at the right time, with the use of location services and map functionality.

My research indicates that there is currently no studies done on the use of maps and location functionality to help ED-patients find the right

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[1] Translated: Porseleneguide

kind of treatment. Regardless, there is literature indicating potential dangers to the use of location services for general m-health application. Even though the findings are not ED-specific, they highlight potential dangers to location services that are relevant to our application design. Boulos [20] show the importance of using location-based information that is immediately relevant to the user, to limit the possibility of overloading the user with information. To counteract the possibility of overloading the user with information on our design, we discussed the opportunity to develop the database of available treatment options in cooperation with polyclinic department for EDs and the patient organization, who according to Amanda have detailed information regarding different kind of treatment options for EDs. Amanda's statement align with findings from the scoping interview, where the domain expert explained how the polyclinic is a part of the specialized healthcare services in Norway, and have expert knowledge. Developing the database of available treatment options in cooperation with specialized providers of ED information can contribute to trust. A concept Akter et al. [4] argue is of importance to all m-health applications. "[...] if the system fails to achieve trustworthiness, it will remain underutilized, be bypassed, or used as a measure of last resort [4, pp.104]." Trust can be defined as a general willingness to depend on another in situations of risk [4]. For a user to trust the designed application to provide the right information at the right time, it is essential that the application can predict and provide updated and tailored information relevant to the user. This is where the obtained knowledge of *lifeworld* has contributed the most to the map functionality. The lived experience of my participants helped reveal and explore exactly what kind of information that is relevant to my specific participants, and as a result shaping the map based on their needs and experiences. Providing information on trustworthy treatment options in the proximity of the user, and giving the users the ability to contact, save, rate or send a specific location, composes the desire to create something that "better", because it better reflect the specific needs of my unique participants struggles with EDs. As Matthews et al. [109] argue, by moving away from a top-down mental healthcare focus, toward a patient-centered approach, we allow the systems functionality to be controlled by the users. Providing the patients with an active role in their treatment – can contribute to increasing feelings of self-efficacy and factor in positive outcomes [109].

9.2.2 Motivational archive

The motivational archive is a measure toward designing for positivity, based on the participant's desire to gain positive reinforcement and motivation through pictures and text. The participants illustrated how they at different times of the used different technology like Instagram, Facebook, or the Internet to look for pictures or input to provide personal motivation. The motivational archive attempts to provide similar functionality, resembling the above-mentioned applications. Amanda's use of Spotify inspired the design of the motivational archive, much like browsing albums or songs on Spotify the user of our designed application can browse motivational pictures for motivation. Liu et al. [101] conducted a study investigating the interaction between pictures and words, showing how they can provoke emotional stimuli to users. Good et al. [62] reveal how the use of pictures or meaningful prompts can be useful to people who struggle with day to day living as a result of low mood. Pictures or other items that can promote a positive association can increase a sense of well-being. The motivational archive such positive reinforcement with the use of motivational pictures and text. The co-designers stressed that the patient organization regularly posts motivational pictures on their Instagram, and this had the ability to brightening their day or lift their mood. The functionality tries to incorporate what Kenny et al. [89] suggest, that health apps must be engaging and interacting, a way to achieve this is through content such as music or pictures [89].

The motivational archive contains another important feature, building on the need for social interaction in the *lifeworld* of my participants. The notion of design for positivity and discussions of privacy and anonymity (see section 9.3.1), restricts the amount of direct social interaction in the designed application. The participatory prototyping session and discussion with the participants resulted in a new way of offering social interaction, coined the term “random acts of kindness.” Sakata et al. [143] illustrate how the concept of “random acts of kindness” in mobile applications is connected with increased happiness and can have short and long-term benefits to the users. “Our user testing substantiated our outside research finding and link random acts of kindness with improved optimism, increased levels of happiness and reduced stress levels [143, pp.223].” Sakata et al. [143] point out how random acts of kindness can make users consider how activates they naturally engage in, can have positive benefits for others. It can also encourage users to perform an active role in improving the lives of those around them [143].

Random acts of kindness are evident through the send functionality in the motivational archive. By pressing the “send” icon on a motivational picture that provoked a positive emotion for the user of the application. The picture is transferred to another user of the application, totally anonymous and at random. The functionality is design to provide anonymous social interaction between different users of the application. Klasnja and Pratt [92] stressed that for m-health applications to contain a social component, it needs to efficient, and well liked by the users, and should capture the significance, usefulness, and acceptability of social interventions. [92]. The send functionality reflects the participants need for social interaction, uncovered through knowledge of their *lifeworld*. It "better" represents the participants need for social interaction, because it is anonymous, following the notion of design for positivity by limiting the possibility of negative influence associated with other forms of direct mobile communication.

Kanis et al. [88] indicate that technology can be useful for sharing positive emotions, by implementing feelings or emotions into something that can be ”seeded” to other users. [88]. The random act of kindness feature tries to achieve the intent presented by Kanis et al. [88]. Nevertheless, it is important to investigate to what degree it is possible to design pictures that only provoke positive emotions. Liu et al. [101] reports that pictures can have negative bias under different conditions, and Morris et al. [116] clarify that bias has a tendency to recall the most intense and recent emotions. As a result, the designed application ability to avoid negative bias is rooted in how the individual user perceives the pictures they recive. Discussions around the topic show two initial ways we believed could counteract occurrence of such biases. 1) By creating the database containing motivation pictures based on pictures previously posted by the patient organization. 2) Removing an initial proposition by Amanda, that users could upload or set up their own motivational pictures in the database. The two steps above can be as steps toward achieving what Akter et al. [4] referred to as trustworthiness of m-health applications. By using content provided by a trusted source, the user is more likely to trust the application to provide what the user needs when the user needs it [4]. Kenny et al. [89] show how social interaction can provide a sense of belonging and connection, which is important for improved well-being and emotional stability [89, pp.278]." The motivational archive and random acts of kindness attempt to provide a sense of belonging, to other users who might be in the same life situation as the participants in this research project.

9.2.3 Calendar

Exploring my participants *lifeworld* revealed how they experience different intervals of time, their *temporality* and how this connects to lived experiences with EDs. Such knowledge is visible in the participant's use of technology to gain social support during hard times of the day, or the participants desire for time alone after therapy. Knowledge about the participant's individual experiences with time is a foundation for the calendar functionality.

The co-designers explained how a full calendar, packed with tasks can act as a barrier, taking the focus away from important aspects of their recovery, and might lead to stress, social pressure or decreased well-being. On the other hand, an empty calendar can result in feelings of isolation, loneliness, or a sensation of failure, as the participants indicated that their target group drew a connection between having lots to do and social status. A physical calendar can be seen as an artifact representing stretches of time. Understanding how the co-designers perceive a calendar contributes to understanding the *temporality* dimension of their *lifeworld*. The designed functionality attempts to include this temporal knowledge. The concept of integrating a calendar in m-health technology has been done in different variations, to track and overview menstrual cycles [160], tracking periods of fertility [160], aiding in medication management [159], managing calories or food intake [13], or tracking doctors appointments [184].

Calendar functionality has been implemented in m-health applications for EDs. As mentioned in the literature review (see chapter 2). Recovery Record also implements calendar functionality, as I encountered in testing sessions with the application. Juarascio et al. [87] do not point out how Recovery Record (see section 2.5.1) uses a calendar functionality The calendar feature is most likely implemented in the design after the paper was published. Nevertheless, the calendar is used to track a user's personal goals and appointments. The schedule in Recovery Record syncronizes with a user's Google Calendar account, merging ED-specific appointments with appointments relating to a user's personal life. My participants lived experience of *temporality* resulted in the design of a calendar functionality that separates from Recovery Record, and "better" reflect their individual needs relating to their experience with EDs. In our design, the calendar functionality acts as a standalone "offline" application, not synchronized with any third party services. As a result, the calendar functionality in the designed application is only intended to keep track of events associated with ED-related activities. This standalone approach is similar to the one taken in the development of the "KOOLO" application [184]. Lastly, the participant's lived experiences relating to periods of time resulted in a design that only highlights the current day – hiding every other day of the week. The calendar also limits a users potential to navigate further than the next, or previous week. This design choice is a direct result of knowledge obtained from lifeworld and their perception of *temporality*. It is a design choice rooted in the desire to create a design which "better" reflects my participant's unique experiences with EDs, and the notion of designing for positivity, as long reaches of time, empty, or full calendars can negatively affect the participant's ability to take positive life choices.

9.2.4 Notifications

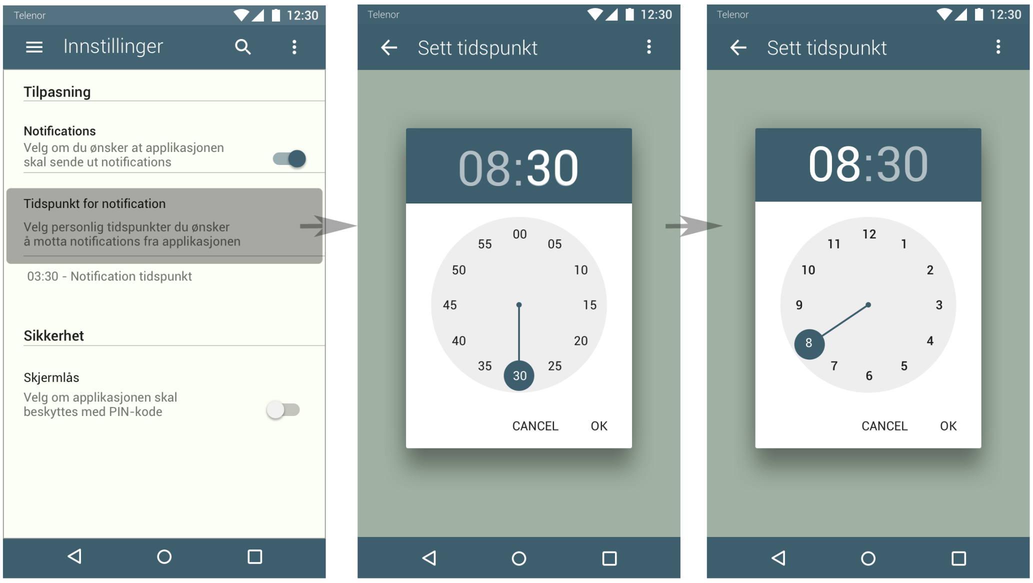
The use of notifications and reminders in mobile technology to promote motivation or action is not a new concept within the research field of m-health, as discussed in the literature review (see chapter 2) Whittaker et al. [188] show a study using SMS-based reminders as part of CBT treatment. The interviewed domain expert illustrated the use of SMS-based reminders within Norwegian specialized health care, to motivate or help patients counteract triggers (see section 3.1) Tregarthen et al. [179] show how reminders can contribute to CBT treatment by providing positive reinforcement and motivation [179]. The Recovery Record application uses notifications to promote CBT components, such as motivation, logging of meals, emotions, and feelings.

Klasnja and Pratt [92] show that the content of reminders matters and should be motivating, reminding the users not only what they need to do, but also why they are doing it [92]. The notifications in our design strive to achieve what Klasnja and Pratt [92] deem as necessary. Through knowledge of the co-designers *lifeworld*, we revealed what they believed notifications could aid them within their challenges with EDs. The designed notifications incorporate this knowledge, attempting to create technology that "better" reflect their unique needs living with EDs. As a result, the notifications serves three main purposes. 1) They are designed to provoke positive emotions through the use of motivational pictures and quotes. 2) The notifications are intended to appear at moments my co-designers identified as decisive toward taking positive life choices. Such moments are identified as morning and evenings, times of the day where both participants planned activities and were in need of motivation. 3) The notifications function as a ″gateway″ to the calendar functionality. A gateway in this context is a connection between the notification and the calendar functionality. By first motivating a user through the notification, the user is transferred to the calendar. Illustrating the intent inherent in design for positivity, as this specific design choice is intended to use positive reinforcement and connect it to tasks on a corresponding day. Striving to motivate users to take positive life choices which might result in improved well-being.

Klasnja and Pratt [92] reveal how users in their paper received reminders through mobile interventions as a positive element, and unobtrusive due to the exclusion of sound effects. Our co-designed notification functionality tries to achieve the same unobtrusive interference. Visible in figure 8.12 the initial notification simply shows a quote and the icon for the application. Providing what Klasnja and Pratt [92] present as ″at a glance″ solutions. The authors note how a glanceable display support persistent awareness of health goals, this can increase the likelihood that user will engage in health-promoting behavior [92]. The designed notification functionality tries to incorporate the same at glance awareness, with the intent of motivating the participants to take positive choices.

Whittaker et al. [188] show how users in their study wanted a limited number of reminders, and the ability to set personalized times for the notifications to appear [188]. Connecting with the findings from my research, where the participants expressed a desire to configure the time of the notification. The designed application allows for the participants to set the personalized notifications, connected to their individual needs. The design has a implemented settings menu, where the user can define the time and number of notifications to occur (See figure 9.1). Klasnja and Pratt [92] maintain that finding ways to minimize disruptiveness, and design effective reminders for health interventions requires attention to both content and frequency of reminders, indicating that this fluctuates from person to person, based on their individual needs [92].

The notification functionality is designed to be adaptable, customizable and unobtrusive to reflect the participant's desire to receive motivation at different times of the day. The notifications try to achieve what Klasnja and Pratt [92] identifies as thoughtfully designed reminders, which can potentially do more than just remind individuals – they can motivate and increase the probability of being effective [92].



Tilpasning

Notifications

Velg om du ønsker at applikasjonen skal sende ut notifications

Tidspunkt for notification

Velg personlig tidspunkter du ønsker å motta notifications fra applikasjonen

03:30 - Notification tidspunkt

Sikkerhet

Skjermlås

Velg om applikasjonen skal beskyttes med PIN-kode

08:30

08:30

Figure 9.1: How to set a timer for notifications in the designed prototype

9.2.5 Summing up the *lifeworld-led* design process

The section above demonstrates how knowledge of the participants *lifeworld*, uncovered through the conducted workshops and analysis, directly influenced and shaped the designed application. Each functionality attempts to reflect a specific need, originated from the lived experience of my participants, living with an ED. The section also reveals how knowledge of participants *lifeworld* and the notion of design for positivity can contribute to functionality, which "better" reflects the specific needs of my participants.

9.2.6 *Lifeworld* as a limitation to design?

Through the use of *lifeworld* theory, I have attempted to investigate my participants lived experiences with EDs, guided by the methodological frameworks of PD and SD. This section will investigate to what degree the chosen theoretical and methodological approaches might have narrowed my understanding.

Jones [66] believe that the human health is a uniquely manifested in a person's history and experience [66]. I would argue, that my developed LifeLine method enabled the participants to express their individual interpretation of their human health, and how that this knowledge directly affected the outcome of the design process. Nevertheless, it is important to consider, that it does not serve us well to declare any preferred design methodology as optimal for a given problem. Our chosen methods might bias the solution toward the outcome that the method enables [66]. Bias is a part of every qualitative research project, it connects to all aspects of the research, concerning methods, tools, techniques, and research focus [39]. However, it is important to acknowledge how the applied focus toward *lifeworld*, might have biased and influenced my research to overlook important events in the *lifeworld* of my participants.

Inherent in all my applied methods is the desire to investigate the lived body of my participant's, shaped by experiences of living with EDs. To explore this perspective, I applied a strong focus on their lived experiences. Moving toward what Sanders [145] refer to as experience design. Hassenzahl et al. [72] reveal how experiences can be seen as a story that connects with feelings, thoughts, motives, and action. The stories contain when, where, and what – detailing a temporal-spatial structure of an experience, in the eyes of the users [72]. "We understand the practice embedded in an experience as the first important arena of design, because it provides the activity in context to fulfill a particular need. This in turn provides positive affect and meaning—two important ingredients of happiness [72, pp.3]." Hassenzahl et al. [72] indicate how a focus on exploring and designing for experiences can lead to an understanding, connecting activities, positive experiences, and happiness. Connecting to a degree, with what I tried to achieve by designing for positivity. Sanders [145] takes the concept of experience further, stating that using experiences for inspiration and ideation of design, can lead to solutions that have more relevance to users, meaning they are simultaneously useful, usable, and desirable [145]. Using the lived experiences of my participants *lifeworld* as a foundation to create "better" design was something I attempted to do in the design process. Comparing the desire to create something "better" with Buchenau and Suri [31] argumentation shows that experiences with products and systems are a complex integration of personal and circumstantial factors. People will have experiences with our design, whether we intend them or not, in ways we cannot hope to predict entirely [31, pp.432]. This argumentation tells me that the focus on uncovering the lived experiences of my participants might not reflect the totality of the needs of the user group. Other potential users might have other experiences at the center of their lived experiences with EDs, and as a result, the designed application might be used in unpredicted ways.

The collected research data show that what my participants deemed important to their lived experiences with EDs, to a degree separates from what the literature sees as important for patients living with EDs. The published academic research, reviewed in section 2.5.1 designate a strong focus toward self-help elements connected to logging, reporting, tracking food intake, dietary guidance, and motivation. Some of these elements are central to CBT and most likely essential for future academic research on m-health applications for EDs. Nevertheless, what can be seen as necessary for future research did not signify what my participants deemed necessary for their well-being. Indicating the strength of taking a patient-led design approach. My participants did not need help reporting food intake, logging, or dietary guidance – it was not at the center of their *lifeworld*, nor did they believe a mobile application could aid them with it. They wanted motivation and help to find the right kind of treatment. I believe this indicate that the *lifeworld-led* approach has not acted as a limitation, rather enhance the process to center around the experiences of my co-designers. Showing how they place other needs at the heart of their lived experience, and that these needs "better" reflect what a mobile application can aid them with, compared to that of the conducted academic research. Meurer [114] illustrate how this can be a strength to design. A design must be seen as a mode of specializing according to the given context, this does not mean that the various disciplines should be discarded. Instead, the nature of the context can change focus toward issues that are relevant to them, rather than to focus on traditional disciplinary areas [114].

Van der Velden and Sommervold [184] argue that a *lifeworld-led* design approach can contribute to understanding the role of technology in the lives of young people. By designing for future users of technology, we increase the chance that it reflects the needs and values of that particular group [184], our design attempts to achieve the same result. The question remains if the needs and desires uncovered by the research focus on *lifeworld*, reflect the needs and desires of my user group? In essence, this is a question about the scalability of the design. Hill [75] argue that scalability have different definitions. One definition that is technical oriented. The other definition concerns the multiprocessor aspect of a system, connected with positive feelings [75]. Technological scalability is beyond the scope of this thesis. However, it is important to investigate if my focus on *lifeworld* limits or enhances the degree of emotional scalability in the design. Forlizzi and Battarbee [56] introduce the concept of scalability in experiences.

”Scalability of experience can help to build an overall picture ranging from details of product interactions to the stories and meanings that people use to articulate their experiences [56, pp.265].” By designing for scalability in experiences, the design attempts to create an application covering details of interactions and experiences that hold meaning to my participants, and that the experiences from their *lifeworld* are scalable to experiences from individuals in the same user group. It is beyond the scope of my thesis to uncover the degree of scalability, as it requires detailed evaluation with other users in the target group. Nevertheless, by designing an application rooted in the lived experiences that constitute the *lifeworld* of my participants, I intend to create a design that is also desirable to the target group. Forlizzi and Battarbee [56] show how emotional responses are hard to understand and quantify. New research methods are needed to investigate the relationship between what we feel, and what we do. I believe a focus on *lifeworld* is a step toward investigating this relationship, as the conducted research indicate that *lifeworld* can be a tool to understanding emotional responses and connecting it to specific experiences or triggers, this is visible in the notion of design for positivity. Regardless of the complexity of quantifying emotional responses.

9.2.7 Placing our design in the literature

This section tries to place the designed prototype within the available literature – to investigate to what the degree it matches previously conducted research. To do this is split the following section into three parts, comparing differences or similarities regarding research focus, concepts, and functionality.

Research focus

Attempting to place the designed prototype within the available literature – to investigate to what the degree it pairs with the previously conducted research, will be the focus of this section. To achieve this, the following section is split into three parts, comparing differences or similarities regarding research focus, concepts, and functionality.

The literature establishes that m-health applications for EDs utilize its highest potential when combined with evidence-based treatment methods (2.8.1). Of the reviewed applications currently published and developed for EDs (see section 2.6), four out of four implements known CBT principles. The matter I would like to reflect on is two-folded. If used in combination with therapy, m-health applications can enhance the treatment by providing self-logging, motivation, and support to counteract triggers all of which are elements that connect with CBT treatment (2.5.1), with the objective of changing behavior. Nevertheless, as I displayed in section 9.2.6 my participants placed other values at the center of their *lifeworld*, that to a degree differentiate from previously conducted research. The participants illustrated that they did not need or want technological help to log food, provide dietary guidance, or direct communication with medical practitioners. Instead, they required help to find the right kind help, motivation, and planning. These findings indicate a difference in research focus. I contend that the chosen focus on a patient-centered approach, supported by the core principles of PD, SD, and *lifeworld* provide my research with a unique perspective on the patient and that this point of view results in a different research focus than the literature.

There is limited research conducted highlighting the degree of user involvement in the design and development of m-health applications for EDs. There can be numerous reasons for this. Amanda highlighted one of these potential reasons, she attended a workshop for the development of "Stopp bulimi" [2](see section 2.6.1). She experienced a limited focus on the requests she suggested for the application, rather, she experiences a focus toward connecting patients with therapists or other medical practitioners. There is no right or wrong approach, but as my research project is patent-centered with no commercial agendas, it might be natural that the focus is different from that of the commercial market. It is necessary to note that I was aware of the intentions of the patient organization, to investigate a possibility of developing their own mobile application. However, they are a non-profit organization that has no commercial agendas.

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[2] Translated: stop bulimia

Jones [66] state, that when designing services for healthcare, one should rethink the concept of a patient – as a patient is seen as a health seeker actively responsible for his or her health and well-being [66]. The author argue, "If design research methods remain proprietary or applied only as commercial engagements, the value of design-led research will not be fulfilled on a wider scale" [66, pp.137]. Following a patient-centered approach, we attempted to create technology that would fit into the participant's pre-existing lives, based on lived experiences. As opposed to the literature, where the focus is toward creating recovery-focused technology, implementing broader elements of CBT. Nielek And Wierzbicki [124] show a possible reason for this difference in research focus. "In the present-day world innovation is driven neither by technology existing in laboratories nor by pure human needs. In applied computer science innovation are motivated by business [124, pp.123]." Financial incentives or market interests do not motivate my thesis and can be an implied reason for the slight differences in research focus.

9.2.8 Concepts

Discussions with the co-designers revealed that social interaction has a central place in their *lifeworld*, exemplified through physical interaction with a neighbor or digital social interaction through WhatsApp, Messenger, or different Internet forums. However, the participants had also experienced several cases where social interaction could contribute toward unwanted behavior. Both participants explained how had they encountered pro-ana content on Instagram and Facebook, through the various comment sections. They had experienced that forums or chat rooms could contain advertising or false information intended to promote unhealthy attitude toward food. These experiences indicate, that including elements of social interaction can lead to unwanted content that influence users, regardless of the initial idea to support communication or provide motivation.

The notion of design for positivity, limit the ability the proposed application hold to promote content which might have a negative influence on users. We decided to exclude any form of direct social interaction in the application. This decision led us to discard several ideas for functionality like a review section for each treatment location within the map functionality, or the ability to type in personal messages when sending a motivational picture. The notion of limiting social interaction in m-health applications is established in the literature (see section 2.8) Fairburn and Rothwell [52] and Ruckenstein [140] both note how the inclusion of a social elements can contribute to unwanted behavior, and promote competitiveness in dieting, weight loss, or exercise. Supported by Klasnja and Pratt [92] who indicate a link between the structure of individuals social networks, and their ability to influence a user's health and behavior [92]. The decision to limit direct social interaction is also rooted in the research question. Attempting to create a design that "better" support youth connected with EDs. Exclusion of direct social interaction is an example of direct step taken to promote the notion of "better" because it better reflects the unique needs of my participants, linking to their lived experience with EDs.

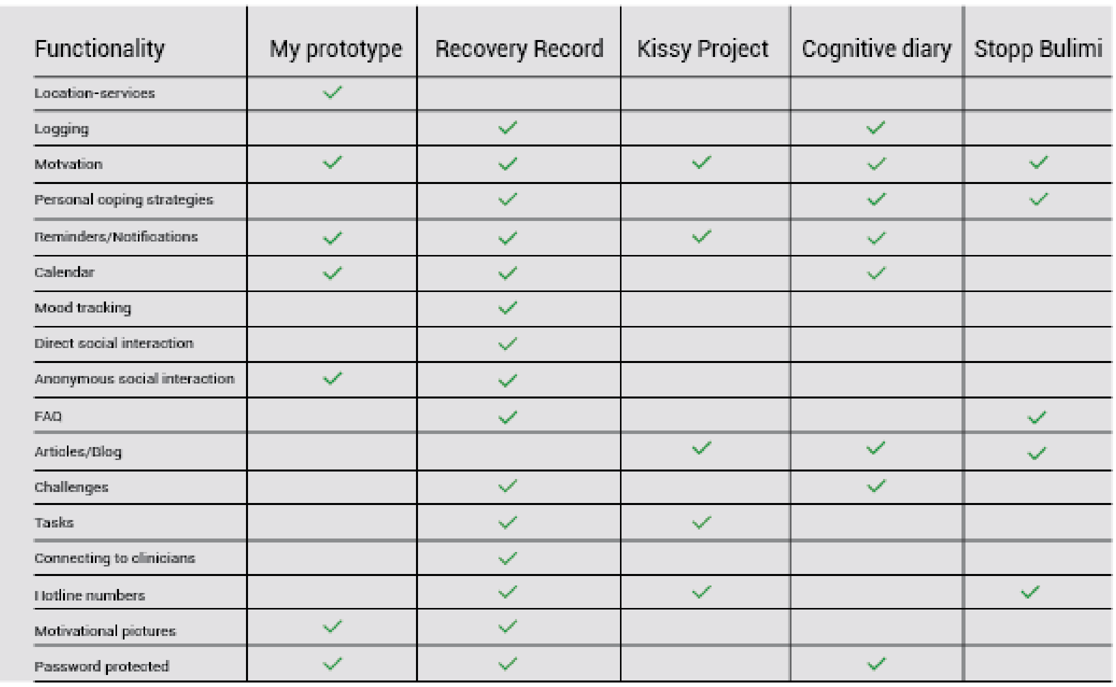
Inspiration from SD methodology led to a wish to design an application that had value to the users after the completion of the study. Limiting direct social interaction makes the application easier to develop from a technological point of view, but also easier to maintain after the conclusion of the study. Discussions with the participants showed that by not including direct social interaction in the shape of user generated content, there was significantly less maintenance required. And as a result, there is no need to moderate content or user profiles. These are steps toward attempting to create a design that is sustainable and has value to the participants after the completion of the study.

In section 9.2.4 I illustrate how the concept of notification functionality has been developed based experiences from the *lifeworld* of my participants. To a degree, my findings differentiate from the literature. Juarascio et al. [86] and Cordeiro et al. [41] show uncertainty regarding the effects of notifications and reminders. The authors [41, 86] indicate doubts to the use reminders and interventions in mobile applications, raising questions due to the ability to accurately assess when and response from the mobile application is needed, or if it is helpful. Notifications can also contribute to the aspect social stigmatization by causing unwanted attention toward an individual. Becker et al. [12] and McNicholas et al. [110] both stresses how social stigma has the potential to act as a barrier to initiating and maintaining treatment. Kenny et al. [89] argue that a potential way of reducing the stigma associated with m-health applications is to ensure that the design is discrete and easy to conceal on the device. In the *lifeworld* of my participants, reminders that could motivate toward taking positive live choices, which might result in increased well-being were deemed essential, and are the premise behind the notification functionality. The participants were conscious that a notification is personal, and the time of need for a reminder relates to each person own perception of a moment. Consequently, the design implements a functionality designed to set predefined times for a notification to occur, or turn notifications off. It is also designed to act unintrusive and discrete, steps taken to limit the amount of potential stigmatization associated with the notifications.

Within the literature, there are references to both positive and potentially negative aspects of interventions and reminders from mobile devices. The uncertainty regarding its effects contributes to the perception of an emerging field, which requires more research. For the scope of my thesis, it is important that the designed application reflect the participant's vision for future technology that "better" reflect their needs and desires. By implementing ways to alter, personalize, or turn off notifications in the designed application, it has the potential to be removed for those who associate reminders with stigmatization, or feels it limits their potential to get better. On the other hand, it can be used for the purpose my co-designers wanted and deemed necessary to their lived experience – to motivate and create a positive entry to the application, reminder or motivating the participants of why they want to get better.

9.2.9 Functionality

Figure 9.2 illustrates core functionality from the four reviewed applications, compared to functionality in our design. The figure illustrates to which degree the designed application implements functionality from published m-health applications for EDs.



Functionality	My prototype	Recovery Record	Kissy Project	Cognitive diary	Stopp Bulimi
Location-services	✓				
Logging		✓		✓	
Motvation	✓	✓	✓	✓	✓
Personal coping strategies		✓		✓	✓
Reminders/Notifications	✓	✓	✓	✓	
Calendar	✓	✓		✓	
Mood tracking		✓			
Direct social interaction		✓			
Anonymous social interaction	✓	✓			
FAQ		✓			✓
Articles/Blog			✓	✓	✓
Challenges		✓		✓	
Tasks		✓	✓		
Connecting to clinicians		✓			
Hotline numbers		✓	✓		✓
Motivational pictures	✓	✓			
Password protected	✓	✓		✓	

Figure 9.2: Core functionality in the reviewed mobile applications

Figure 9.2 illustrate to what extent the designed application incorporates evidence-based treatment techniques from CBT. A distinction is apparent with the absence of logging functionality in the prototype. Integrated into the logging concept is the user's ability to log food intake, emotions, thoughts, and feelings. Capacity to log such events is a key characteristic of CBT therapy 2.5.1. Looking past the logging aspect of CBT, all the reviewed applications incorporate elements relating to motivation. Motivating for behavior change is another important part of CBT. Motivation occurs in different shapes throughout the various applications reviewed. The kissy project focuses on motivational quotes, "Stopp bulimi" incorporates motivation through personalized coping strategies, and cognitive diary uses reminders and personal feedback. Motivating to achieve a change in emotion or behavior is a central concept in CBT. Our designed application therefore incorporates known elements of CBT. Nevertheless, with the exclusion of logging food, emotions, and feelings I do not try to implement the most central concept in CBT. Connecting my research with argumentation from Jones et al. [66] that as designers in the domain of healthcare, we might not have the specialized skills needed to implement elements of treatment [66]. In the context of the thesis, working within the field of informatics, I need to take care, and not claim to implement evidence-based treatment, as I am not qualified. Nevertheless, what I have done is to transfer my co-designers vision for future technology, and inherent in this vision is the need for positive reinforcement. Motivation and focusing on positive emotions with the intent to take positive life choices is also a part of CBT. Showing that the designed application to an extent implements CBT elements, but not with an intention to treat EDs.

The figure 9.2 reveals that Recovery Record implements an extensive collection of functionality. With the only exception being a link to articles or blog entries. Discussions with the participants revealed that from their experience, a high number of different functionalities could potentially lead to confusion, and produce the sensation of defeat if they failed to use the application regularly, or failed to understand all the provided functionalities. The use of an extensive amount of different functionality is an example of what my participants, based on their experience, deemed as poor design. Moreover, is the opposite of what we tried to co-create in the designed application, striving to create a design that "better" reflect the needs of my the participants, rooted in knowledge of their *lifeworld*.

9.3 Ethical considerations in the application

9.3.1 Privacy and anonymity

This section of the discussion tries to highlight how knowledge of my participant's *lifeworld* formed ethical considerations in the design, linking to their expressed values of privacy, anonymity, and security. Van der Hoven et al. [183] claim that PD is a value-centered approach to design since political and ethical considerations are value-centered theories. The authors [183] show how PD projects can frontload a set of values appropriated by the particular context. Illustrating that the way my participants appropriated the methods, tools, and techniques allowed them to demonstrate how values of privacy, anonymity, and security are important in their lived experiences, and that should be implemented in the design. Halloran et al. [67] emphasize the importance of designing for values. Showing how values emerge during co-design – as the design process evolves, it can affect the design solution.

> This bottom-up, data-driven approach to value identification can provide leverage in solving a number of practical co-design problems as the process unfolds; as well as focusing design activity relevant to the users, it can help with the alignment of values between researchers and users, supporting the design relationship, helping users to understand and contribute at functional and technical levels, lead to user insight about their own values and enable the expression of values both during the design process and, ultimately, in the designed artifact [67, pp.271].

By using examples from the conducted workshop, I aim to show the dynamic relationship between transpiring values and the design process.

Highlighting the importance of privacy, anonymity, and security in the *lifeworld* of my participants. Discussions in workshop one demonstrated how both my participants valued privacy on a general level, connected to their current technological usage. The discussion revealed how both Amanda and Rebecca were aware of the privacy settings on their respective Facebook pages, and how easily elements can get shared trough the Internet. As the design process evolved and we converged on one idea, the ethical values became more distinct and visible in the design. To protect user privacy a distinction between the suggested application and the phone's ability to access information were drawn. Building on the *Privacy by Design* principles [35]. The *Privacy by Design* principles offer a "road map" to identifying fundamental principles relating to privacy in mobile communication. The hallmark of the success in implementation textitPrivacy By Design relies on a collaborative effort across various parties [35]. For my thesis, this collaborative effort between my participants and me went toward achieving value-alignment [67]. Together we had to connect my technological knowledge of possible implementations and limitations to privacy, with my participant's needs and desires relating to privacy, Illustrating an occurrence of *mutual learning*. The *mutual learning* resulted in value-alignment, and is visible in the two unique measure taken in the designed application to uphold the values central to my participants *lifeworld*.

Connections

Following the The *Privacy by Design* [35] principles ensures privacy as default in the application, not an additional feature. To accomplish default privacy protection, the designed applications user generated data, such as calendar entries, contacts, favorites, and saved pictures are envisioned to be stored on the phones internal memory. Ensuring that data is not transmitted through third party services. The designed map functionality will require geo-location data, running through a third party API to present users current location, and available treatment options in the close geographical vicinity. Initially, this can be viewed as a limitation to our design, and a failure to uphold the *Privacy by Design* principles. During workshop two, I explained to Amanda that to create map functionality, the phone would need to access geo-location data. The collected data would be transferred to the selected map features API, this is needed to provide location-specific services. Amanda replied that as long as the application informs the users upon installing the service, she believed that it would not be a problem. Following with research conducted by Myles et al. [121], the author illustrate that a step toward protecting the user's privacy is to notify them and request information, this can be done by including a dialog box that informs the user of the request to collect and transfer location data [121]. Central to Amanda's value of privacy was the protection of sensitive details regarding her current health condition, treatment, appointments, and contacts; not necessarily geo-location data. Nevertheless, it is important not to take the significance location-data hold lightly in connection to a user's privacy, as Lane et al. [96] state, "Respecting the privacy of the user is perhaps the most fundamental responsibly of a phone sensing system. People are understandably sensitive about how sensor data is captured and used, especially if the data reveals a user's location [...] [96, pp.149]." We agreed that the only permission the application would require upon installation were "location services," the remaining functionality would be completely free of third party access. Concurring with findings from the literature, Tregarthen et al. [179], Juarascio et al. [86], and Ambwani et al. [6] all raise concerns regarding the transfer of sensitive data using mobile technology, highlighting risks of losing data or allowing third party access. Arguing that the future of m-health need to carefully consider privacy issues in development and design of new applications.

Pin-protection

Discussions with Amanda revealed that *Designing for Privacy* might not be enough to protect the totality of her values of privacy and anonymity. Illustrated by an example she gave during workshop two. If someone wants to borrow your phone to make a call and sees an application for eating disorders, it might raise attention, stigmatization or generate unwanted questions about the app, or her current health condition. Klasnja and Pratt [92] argue for privacy-preserving aspects of applications, in case someone were to see a recipient's phone. The designed application tries to limit the possibility of such privacy invasive occurrences with two specific design decisions. Giving the users the ability to pin protect the mobile application. Relating to the findings from Kenny et al. [89] and Ambwani et al. [6], whom both claim that m-health applications can counteract potential risk factors relating to social stigma and privacy, by using password protection. Van der Velden and Sommervold [184] also suggest the use of password protection in the design of m-health applications, to separate the content of the application from the phone's memory, and to protect privacy [184]. The second design decision we took to prevent privacy intrusion and stigmatization was to create the mobile application logo and reminders that appear neutral because they contain no image or text indicating a relation to health sensitive data or EDs. Connecting with argumentation from Kenny et al. [89], the author shows that discrete design to a mobile application can potentially reduce attention to its users [89].

9.4 Methodological contribution in the thesis

In the following sections, I will discuss to what degree I honored the heritage of PD (see section 4.2) throughout the conducted research project. Discussing the occurrence of *Mutual learning*, *Power relations* and *Having a say*. Moreover, I will discuss to what degree *lifeworld*, PD, and SD mutually inform each other, and how the applied methods influenced the findings –

as a limitation or strength.

9.4.1 Sharing of power

Kensing and Greenbaum [91] explain that the principle of *equalizing power relations* lies at the core of a PDs heritage, due to the importance of allowing users to voice their ideas. *Equalizing power relations* is central toward designing solutions that reflect the participant's vision for future technology, and aligns with the domain, *equalizing power relations* is essential to grant the opportunity for every participant voice to be heard. Kensing and Blomberg [90] show how PD projects are not defined by the work supported, or by the technology developed, it is rather a commitment to worker participation in design, through rebalancing the power relations between a user, and technical experts [90]. Kensing and Blomberg [90] argumentation connect to my conducted research project. In the early stages of my research – the *fuzzy front end* (section 6.2.2) I had limited understanding of what kind of mobile technology we would create, or how to accomplish it. The initial objective was to communicate with the participants and allow them to illustrate their *lifeworld* revealing their lived experience toward technological use, social relations, and EDs. To accomplish this, it is necessary to provide the participants with a platform that promoted power, not only to make decisions but the power to express their thoughts and emotions, connected with their *lifeworld*. Chung and Lounsbury [38] show that failure to *equalize power relations* in PD can result in powerlessness and cynicism, regardless of the level of participation in the process. In the context of my thesis, I applied methods, tools, and techniques focusing on transferring power to the participant, visible through various steps.

The LifeLine method presented the participants with the power to express context-specific details, central to their lived experience with EDs. The inclusion of participatory prototyping activities and *inspirational cards* act as examples of tools that promote the sharing of power, as they can be appropriated by the participants to illustrate their unique needs and desires connected with their *lifeworld*. In section 9.2 I discuss how the knowledge of the participants *lifeworld* is visible through the notion of design for positivity, particular functionality, and the desire to design something that "better" connect with the needs and desires of my participants. I believe that our co-created design represents the sharing of power because obtaining knowledge of the participants *lifeworld* would be difficult without providing the participants with the power to express their unique needs and desires.

Through the design process, I have avoided using unnecessary technical terms when explaining concepts and ideas, which is another important step to *equalizing power relations* Every step taken to ensure the transfer of power toward my co-designers was a way to bridge barriers that might exist between the roles of designers and participant [34]. Steps to equalizing power relations connects with the ability to interact in the process of *mutual learning*.

9.4.2 *Mutual learning*

Mutual learning is a central notion in PD projects, and an essential principle to uphold when trying to achieve what Wagner and Piccoli [187] refer to as genuine participation. The concept of genuine participation connects to elements relating to the pragmatic propositions of PD projects (see section 4.2). Within the pragmatic view, the idea of *mutual learning* is vital. IT designers need knowledge about the work environment that forms the domain for the design project [187]. *Mutual learning* can be achieved through various activities that focus on sharing knowledge and learning about the research domain. Wagner and Piccoli [187] claim, that *mutual learning* can also contribute to a shared understanding of the problems that the design project aim to solve, and it may help to anchor the suggested solution within the organization.

Mutual learning is an essential part of methods that I developed and applied throughout the research project, as shown in section (9.4.3). Kensing and Greenbaum [91] note that *mutual learning* is about enhancing the understanding of different actors and challenges, by finding common ground within their domain, with the overall aim to learn from each other and building a *shared vision* for technology. Learning from my participants is of particular importance when entering a field with limited preexisting knowledge. *Lifeworld* theory contributed to enhancing the aspect of *mutual learning*, as the participants shared information and educated me as experts in their domain and their unique health condition. Highlighting how they had lived experience encountering the Norwegian health system, the patient organization, available treatment options, and therapy techniques. They also shared personal information leading me to learn about their unique needs, desires, thoughts for the future, and important events in their day. Illustrating how it is all connected with their ED and part of their *lifeworld*. Implied in the concept of *mutual learning*, is that both parties transfer knowledge and learn from each other. Consequently, it is important that the participants learn from my technological domain. The participants learned about how technology could help realize their vision for future technology, teaching them about privacy in applications, design possibilities, technical limitations, and opportunities. The result is a sharing of knowledge that connects the two domains and helped create a common platform for design.

9.4.3 The applied methods

Throughout the research project, I have used a combination of well-established methods like participatory prototyping, as well as developing new methods, tools, and techniques, such as the LifeLine methods, and the use of functionality and requirements card. I hold that all my applied methods have a common desire to promote mutual learning and transfer power to the participants, making sure the participants *have a say*. Kensing and Bloomberg [90] cited Grønbæk et al. (2010)., state, "To design cooperatively, to develop visions of technology in use, it is important to give these visions a form that allows users to apply their knowledge and experience as competent professionals in the process [90, pp.177]." The authors [90] claim, that this type of cooperation requires adequate prototyping tools. I hold that my Lifeline method acts as a set of adequate tools and techniques, giving the participants the power to appropriate the tools and techniques in a way that promoted *mutual learning* and the ability to show the significant of individual events from their *lifeworld*.

The use of inspirational cards (see section 6.2.2) helped illustrate elements of significance from lived experiences of my participants *lifeworld*. Each card describes a topic with a perceived significance to the participants, adding to my understanding of the domain, and the *lifeworld* of my participants – a step toward *mutual learning*. The *inspirational cards* in the LifeLine method can be viewed as *triggers* [90] in discussion, that attempt to connect knowledge of the participant's domain with technological opportunities [90]. The LifeLine method also incorporates SD elements, striving toward what Jones [66] intends as ability center co-construction of meaningful experiences. The LifeLine method centers on the participant's ability to express lived experiences and investigating how they connect to the different *touchpoints* in their everyday life.

Another measure of including the core values of PD in the applied methods is visible through my use of paper-based participatory prototyping. Lowgren and Stolterman [177] illustrate how low-fidelity prototypes on paper, can enable participants to engage in design activities without the need to understand technical language. Contributing to *equalizing power relations*, by presenting the participant's tools they can appropriate to fit their vision for future technology. Moreover, the authors argue, that paper-prototypes might be easier to criticize or discuss, as they are less invested in than their higher-fidelity counterparts. Brandt [23] demonstrate how different levels of prototypes and mock-ups, affect the amount of detail in feedback from users. Showing how low-fidelity mockups might offer more general and honest feedback, that can be easier to alter in the design, while higher-fidelity prototypes often provide more in-depth and focused feedback [23]. I initiated the evaluation workshop three by showing the participants the low-fidelity paper prototypes we co-designed in the previous session. Giving the co-designer the ability to voice ideas that might have emerged in the time-period between the workshop sessions, before exploring the designed prototype in a higher fidelity. An example attempting to provide power to participants, and making sure they *have a say* in the design outcome.

It is beyond the scope of this discussion to highlight every example connecting to the core values of PD. Regardless, this section illustrates that the methods applied throughout the research project strived to uphold the heritage of PD. Toward the goal of creating a common platform for co-creation. Connecting with Kensing and Blomberg [90] argumentation, the authors show that tools and techniques in PD all have a common goal of linking current and future work practices through envisioning new technologies.

9.4.4 PD, SD, and *lifeworld* – do they mutual inform each other?

Bratteteig et al. [26] introduces the notion that PD projects sometimes receive criticism for being small, local and isolated initiatives, that has little impact outside the project, where solutions created during the process, tend to die after the project stops. The authors [26] note, that for PD projects to have a lasting effect, it should be part of a long-term strategy grounded in the organization, or in the context of a larger strategy that addressed more than one of many societal levels [26, pp.131]. Applying concepts from SD methodology was an effort toward countering some of the suggested limitations for PD projects. Attempting to create technology that was "better" connected with the specific needs and desires of my participants, living with EDs, but also technology that holds value to my participants after the completion of the study. I believe that SD and PD mutually inform each other attempting to reach the same objective of co-creation (see section 4.4.1). Utilizing elements of SD methodology in my research project led to discussions going beyond the specific functionality and offered insight into digital maintenance, distribution, possible supporting web services, and the potential the application could hold for secondary users and primary healthcare services, such as school nurses, parents, and health institutions. Such information contributes toward an understanding of service elements, and to an extent, answers some of the limitations to PD projects, presented by Bratteteig et al. [26].

The most prominent effect of using concepts of SD methodology is visible through the adaptation of the *customer journey map* to a timeline. The collected data from the LifeLine method help form a picture of my participant's *lifeworld*. Connecting their needs and desires to *touchpoints* throughout their day. I dispute that the collection of such data would be hard with PD as my sole methodology. Applying an SD-mindset provided the collection of data looking further than the participant's vision for future technology, by connecting *touchpoints* to *inspirational cards* I got information connecting time of day with needs from their lived experience. This knowledge acts as the foundation for designing "better" solutions for my participants because it originated from their lived experience with EDs.

The SD mindset further offered reflections on how technology might affect other societal levels and healthcare providers. Envisioning how our designed solution might provide the Norwegian primary healthcare service a platform with ED-specific information and treatment options. Discussions further illustrated how the suggested design could provide relatives with the opportunity to provide motivation and social support, to close relations struggling with EDs. I believe that these are examples illustrate how the applied SD mindset contributed to the design process, looking further than the vision for future technology, connecting the design to other societal levels. Factors Bratteteig et al. [26] implied could contribute to prolonged use after the completion of the study. I believe that the PD and SD mutually inform each other because they both contribute to investigating different aspects of the designed solution, but align with the common desire to co-create new technology.

It is important to establish, that while PD and SD mutual inform each other in the important aspect of co-creation, both methodologies contribute to obtaining information connected with the *lifeworld* of my participants. The applied methods allowed the participants the power to illustrate their lived experience relating to both their health condition and their lived body. The knowledge of the participants *lifeworld* is the essence of the notion of design for positivity, and is what constitutes the foundation of "better" solutions, because it better reflects their needs living with EDs. I maintain that the combination of *lifeworld*, SD, and PD contributed to a new mindset, obtaining knowledge I believe would have been impossible had I chosen another methodological approach or theoretical approach. Illustrating how the methodological and theoretical framework have a mutually informing relationship, providing unique insight into the *lifeworld* of my participants.

9.5 Critical reflections

9.5.1 My chosen methodology

Having highlighted SDs contribution to my research project, I believe it is important to illustrate that, regardless of the input the SD-oriented mindset had to the research project, PD remains the most prominent methodology in my research project. Using PD as my sole methodology in combination with my theoretical framework of *lifeworld*, removing any influence from SD, might have created a different design proposal. By only using PD the suggested design could potentially reflect the needs and desires of the user in a “clean” way, by not considering elements of scalability, prolonged use, or the technology’s effect on other users. This critical reflection is rooted in the pragmatic proposition of PD, presented in section 4.2. Looking beyond the LifeLine method, the contribution of SD is primarily relating to elements transcending the scope of this thesis. It would require a developed application of the prototype to test the designed applications effect on different societal groups, implemented as part of an organization structure, and if it promotes prolonged use after the completion of the study.

9.5.2 My co-designers

The number of participants included in the research project is limited to two. Initially, this can be viewed as a limitation, which might raise questions to what extent my findings reflect the needs of my user group in general. However, as noted in section 5.1.1 there is various reasons for the inclusion of a limited number of participants when conduction research on users affected by a sensitive health condition. Connected with cognitive ability, emotional and physical state. It is also related to me being the sole facilitator (see section 5.1.5) having the responsibility to devote my full attention to the participants, when they share sensitive information. Connecting with the view of Sandelowski [144]. The author [144] show, that the adequacy of a sample size in qualitative research is relative. The sample size needs to reflect the purpose of the study and is ultimately a matter of judgment [144]. Due to the sensitivity of the subject, and the sharing of personal details I believe my sample size is adequate to investigate the research question of the study.

The first workshop had both participants present, while the following two workshops had Amanda as the sole participant. This raises questions to the designed application ability to "better" reflect the needs and desires of youth affected by an EDs. To an extent, this can be the case. However, Amanda has overcome many of the challenges living with EDs and is currently in a position where she communicates and helps young people, trying to overcome the same problems. Amanda's participation in the study both reflect her lived experience living with EDs, and the needs of her peers currently in the same situation. Amanda's involvement can, as a result, be seen as design by proxy [97]. Indicating that the data gathered and the suggested prototype is likely to align with the needs of a larger part of the user group, and not necessarily limited to Amanda's needs.

9.6 Limitations in my research project

An interpretive element is inherent in all qualitative research. It can be viewed as a limitation to the entire research project. The way I interpret the data, and as a result, how I conducted my research, might have implications for the generalizability of the designed prototype. Moreover, the knowledge of my participants *lifeworld* that led to the notion of design for positivity, and shaped my understanding of what constituted a "better" solution. Is collected based on the *lifeworld* of my participants. I cannot conclude that the findings apply to the entire user group, without further evaluation and testing. I believe that this displays some degree of contradiction in my research focus, where future research is needed to determine if *lifeworld-led*-design can combine with the desire to promote a sustainable solution that results in prolonged use after the completion of the study. Nevertheless, Amanda's role as a proxy participant [97] can contribute toward counteracting a degree of this inherent subjectivity of my findings. Her central role in the design process as a whole helped design technology that not is not only "better" for her lived experience with EDs but also including experiences that originate from her interaction with patients in the same life situation. Amanda's role as proxy participants contributes to reducing the apparent limitation of including few participants, and hopefully resulting a solution that "better" reflects the needs of the user group.

Limitations to thematic analysis

Braun and Clark [28] argue, that a limitation to thematic analysis can become apparent if the data is not anchored in a theoretical framework, to view the analytical claims that are made. Furthermore, the flexibility of the method, which allows for the wide range of analytical options, can both strengthen and weaken the result. It makes developing specific guidelines for “higher-phase” analysis complicated, and can potentially overwhelm the researcher, making it hard to deciding on what aspects of data to focus on. Marks and Yardley [108] highlight another potential limitation, to the point that the analytical method abstracts issues from the way that they appear in life. The researcher organizes material according to their own sense of how it connects, rather than the inter-relationship of themes in the participant’s mind [108]. Throughout my thesis, the issues presented by Marks and Yardley [108] are not directly applicable to my conducted research. Due to my LifeLine methods focus on mapping experiences, I was able to analyze the data connected with the way they appear in the life of my participants. Nevertheless, the aspect of reaching a higher-level analysis is a limitation that applies to my conducted analysis. I acknowledge that as a novice academic researcher, it was hard to arrive at a higher-level analysis, based on a series of factors. It might be a result of the difficulty in applying focus to the right section of data, or difficulty in the flexibility of the analytical framework. Regardless, the conducted analysis of workshop one and two helped gather and highlight important themes, which directly shaped both future data collection and the final design. The limitation to my conducted analysis is linked to what extent my findings reached a higher-level.

9.6.1 Limitations and strengths to the LifeLine method

The created LifeLine method has visible limitations. It applies a very particular focus to a user’s ability to represent their lived experiences on the timeline, indicating restrictions to the number of users that can be included in the research process. Creating the tools needed to conduct the method is time-consuming, which is a potential a limitation to PD and qualitative research in general. There is also a restriction that users representation of their day, illustrated through the use of *inspirational cards*, might not tell the full story of their lived experience. Drawing parallels to ethnography, where one is emerged in the domain, contributing to a richer description of the participant’s everyday life. It is important to note that while ethnography has the potential to capture a more detailed picture of experience for a participant life, it is a qualitative method that is time-consuming and costly.

The LifeLine method also contains a series of strengths that I would like to highlight. I believe that the main strength of the method lies in its ability to obtain in-depth knowledge of a participant’s *lifeworld* and lived experience. As a result, it holds potential for other academic endeavors exploring a *lifeworld-led* or experiences based design approach. The domain cards applied can be altered to fit a researcher’s interest in the domain, and the method is flexible enough to be adapted to the desired research field.

9.6.2 Summing up the design process

Reflecting on the design process as a whole, I wish I had more time to continue my research, conduct more design *moves*, and start developing prototyping focusing on the technical aspects relating to the *implementation* [78] dimension of the design. Due to time limitation, my research ends abruptly after workshop three. However, this is not a unique situation and can be seen as a limitation to all master projects . Especially the once that choose to use PD as a principle methodology, as it is a time-consuming process. To demonstrate my design process, I created figure 9.3 illustrating the different steps of the design process, connected to the core principles of PD. The figure is inspired by the figure in van der Velden et al. [182, pp.109], which builds on the work of van der Velden and Mörtberg.

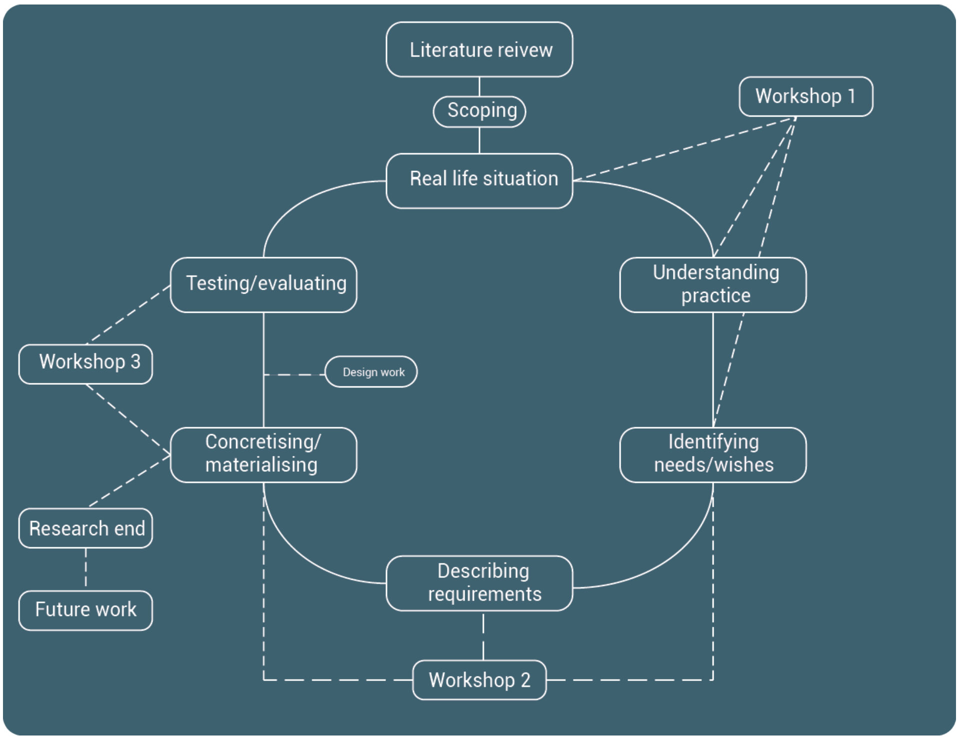


Figure 9.3: Illustrating the design process

Figure 9.3 show how the process started with a literature review and scoping interviews. Followed by workshop one, investigating real life situations, understanding the practice, and identifying needs and wishes of my participants Workshop two continued the work by revisiting the needs and desires, describing the requirements of the idea, and concretizing it on paper-based prototypes. Between workshops two and three I took the paper-based design and created a higher fidelity prototype, which acted as a platform for workshop three, were we evaluated and tested the prototype. After workshop three I did a final set of design moves (see section 8.5.2) that concluded the design process.

The figure 9.3 illustrate the design process, and how it aligns with a traditional PD process. It is not intended to show the contribution of *lifeworld* or SD to my research, that is inherent in each workshop and in the research question. Rather, the figure tries to summarize the process, and show how it aligns with traditional ways of conducting PD research.

Chapter 10

Conclusion

10.1 Conclusion

My research interest in this thesis was:

> Conducting a Participatory Design project intended to design mobile technology to "better" support youth affected by eating disorders.

The overall research interest was shaped by my motivation to conduct a PD project on an understudied topic – investigating how mobile technology can contribute to the life of youth patients affected by an ED. The literature review and scoping efforts confirmed that mobile technology can have a meaningful, but currently unrealized potential to patients affected by EDs. My research shows how the degree of user involvement in the development of existing m-health technology for EDs is limited, and inconclusive regarding the extent of user participation in the creation of specific functionality. I approached this research interest by taking a methodological and theoretical approach which places the user at the center of the process, exploring their *lifeworld* and their lived experience relating to needs, desires, and vision for future technology. Resulting in the following research question.

> RQ: In what way can the concept of *lifeworld* inform a design process intended to design new mobile technology that "better" support youth affected by eating disorders?

The core values of PD guided my approach to answering the research question. Inspired by SD methodology, I strived to explore the *lifeworld* of my co-designers. Focusing on investigating the participants lived experience and lived body connected to different dimensions *lifeworld*. My contribution is summarized in the following section.

Lifeworld & *lifeworld-led* design

The conducted research demonstrate how knowledge of participants *lifeworld* can inform the design of new mobile technology. As a result, my research contributes to academic endeavors investigating *lifeworld* and *lifeworld-led* design, and have theoretical implications for future studies. Findings from my research show how knowledge of participants lived experience can shape the design of mobile technology in two primary ways. The designed application has location services through map functionality as its core functionality. Isolated, the feature is not unique and can be found in commercial map applications. Yet, the map functionality has a unique value in the *lifeworld* my participants and their lived experience with EDs. Where the need to find information about specific treatment options has value, and is currently lacking in current technology. I argue that such context-specific knowledge can only be obtained by investigating the *lifeworld* of my participants.

Knowledge of the participant's *lifeworld* has also contributed to the creation of new innovative functionality, such as the motivational archive. Designed to reflect their need for social interaction, and the desire to gain motivation. The concept of using motivational pictures with quotes is in itself not innovative. However, combining the elements, and creating the "random act of kindness" feature, contributes to understanding the impact *lifeworld* can have in creating technology that "better" reflects the values, needs, and desires at the center of my participant's *lifeworld*.

The notion of design for positivity emerged as a result of analyzing the research data. The concept acts as a mindset for the design, in its desire to create positive associations with the specific functionality and design choices. Design for positivity is design for positive emotions, with intent to improve the general well-being of the user. My contribution here is not the concept in itself, as Brey [29] state, the ultimate goal of well-being is a grand gesture. A gesture I can not claim to have achieved, without extensive testing. Nevertheless, design for positivity has theoretical implications, as it contributes to show how knowledge of *lifeworld* can provide an understanding of the important aspects of the participants lived body, as it is experienced. The need for positive reinforcement and motivation is a central part of life with an EDs, and central to my participants *lifeworld*. This understanding goes beyond needs and desires – it shows elements that have a real value in their lived experience. As a result, design for positivity has a central part in informing the design of mobile technology, and contribute to a solution that "better" support the needs of the target group affected by EDs. My contribution is then twofold, as it has a theoretical implication for future research investigating *lifeworld*, and a contribution toward understanding how *lifeworld* knowledge can be implemented in design of mobile technology.

M-health

The research projects contribute to the research field of m-health technology for EDs. Demonstrating how technology can be designed by placing the user at the center of the design process. Taking a patient-centered approach can result in the design of functionality the patients deem significant to improve their individual well-being. My research demonstrates that patients affected by EDs value application design that implements a limited amount functionality, focus on motivation, and positive reinforcement. These findings do not have theoretical implications. Rather, as m-health technology for EDs is a new and emerging field, these findings contribute to understanding the value of placing the patient at the center of the process. Taking this approach can result in technology the patient deem "better" than what is currently available.

LifeLine

My research project contributes to academic research investigating the combination of PD and SD methodologies. The most prominent contribution is the developed LifeLine method. The LifeLine method is a new qualitative research method that explores the combination of mindset, methods, tools and techniques from the respective fields of PD and SD. My research demonstrates how the LifeLine method contributes to obtaining *lifeworld* specific knowledge covering participants experiences, needs, desires, social relations, and technology usage – linked to a time of day. Obtaining this knowledge can hold value to other researchers exploring the potential of designing new technology. The flexibility of *inspirational cards* can be altered to match context specific needs relating to a domain of interest. Illustrating how the LifeLine method can hold value to other research endeavors and theoretical frameworks that hold future users values, needs, desires, and experiences at the center of their research focus.

Concluding remarks

Merkel et al. [113] calls for *seeding of ownership*, striving to create a sense of ownership to the design. My research showed a focus toward elements not traditionally connected with a PD project, considering issues of digital maintenance, scalability in experiences, how to conceptualize a reliable database of locations, restricting social interaction, and finding central privacy elements. An approach I claim goes further than a designing only based on a vision for future technology. The designed application shows a focus toward investigating the value a design can hold to other societal levels. Shown in the suggested use for secondary users, like parents and friends; or the Norwegian healthcare services who can use the application to provide information to ED-specific treatment locations. What all of these considerations have in common, is the desire to create a design that holds value after the completion of the study.

To what degree my design has value after the completion of the study is hard to validate without future work. Nevertheless, now that my research is completed, I can reveal that the patient organization has decided to seek funding to continue the development of the designed application, indicating the suggested prototype is realizable, and hopefully won't be part of the statistic of unrealized PD projects. The findings relating to the designed prototype does not have academical implications for future research, but the designed prototype is a contribution to the patient organization, participants, and hopefully for youth affected with EDs. A design that tries to "better" match their specific needs, living with EDs.

10.1.1 Future work

As I anticipate my future role in the possible development of the application, I would like to address the grounds for future work. The first step for future work would be to investigate the natural limitation to the qualitative nature of my collected data. Looking past Amanda's role as proxy participants, future work is needed to examine to what extent the needs central to my participant's *lifeworld*, lived experiences, and desires for future technology, align with the corresponding needs of youth patients in my target group. Conducting evaluations to investigate these aspects do not require a developed prototype.

While I have attempted to lead the design process toward a prototype that holds value going further than the participants in the study, this needs to be investigated by conducting further evaluations with a developed prototype. Further evaluations with a developed prototype can also assess if the notion of design for positivity, essential in the design of the specific functionality, in fact, contribute to improving well-being for users in the target group.

Future work needs to investigate the designed applications potential toward secondary users, by including these users in an evaluation process. Lastly, it is apparent that the conducted testing on the notion of the perceived gender neutrality in the application design needs to be assessed with a significantly larger sample of users.

Future work should carefully consider central limitations to m-health technology for EDs, like the cost of an application – to no exclude potential users. As well as the dangers of creating technology that can replace evidence-based treatment. Conducting research on patients with EDs has given me enormous respect for the struggles that shape their life's, as the diagnosis is immensely complex, with the power to stay with you for life. Future research needs to consider these aspects carefully.

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Appendix

.1 Mind-map of literature review

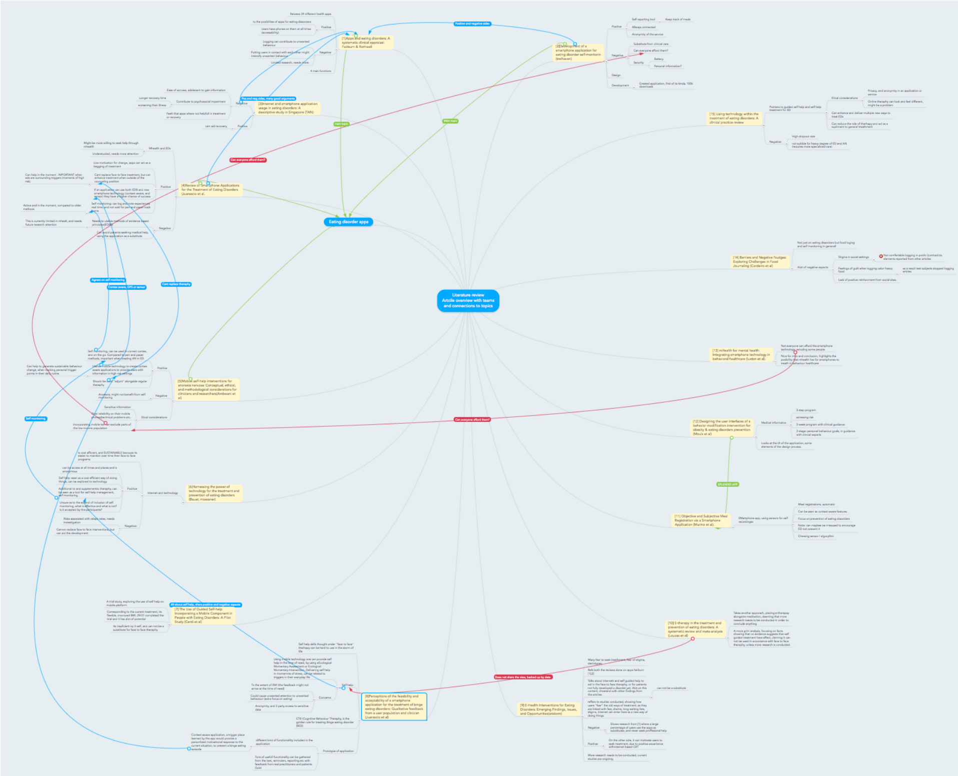

Figure 1: Mindmap of literature review

.2 Pilot workshop

Figure 2: Picture from the pilot workshop

.3 Creating the inspirational cards

Figure 3: Picture illustrating the making process of the inspirational cards

.4 Consent form

Forespørsel om deltagelse i forskningsprosjektet KULU
Design av kul teknologi for unge med langvarige helseutfordringer.

Bakgrunnsinformasjon

Dette er en forespørsel til deg om å delta i en forskningsstudie som omhandler design og bruk av helserelaterte applikasjoner blant unge med langvarige helseutfordringer. Formålet med studien er å kartlegge i hvilken grad mobile helseapplikasjoner kan bidra til å løse utfordringer i hverdagen til personer med spiseforstyrrelser. Studien ønsker å avdekke deltagerens forhold til teknologi, hvilke mobile applikasjoner de bruker, og hvordan mobil teknologi kan hjelpe dem i hverdagen. På bakgrunn av den innsamlede informasjonen ønsker jeg å utvikle en eller flere prototyper av helseapplikasjoner, og dens funksjonalitet.

Hvem kan delta?

Til dette formål ønsker jeg å snakke med unge mennesker mellom 12 og 25 år, som er rammet av spiseforstyrrelser og som har et forhold til mobile applikasjoner.

Hva innebærer studien?

Hvis du sier ja til å delta i studien, vil dette innebære at du blir bedt om å delta i et intervju med en påfølgende workshop. Samtalene vil dreie seg om mobile teknologier med fokus på helseapplikasjoner og deres design. Vi vil også drøfte hvordan teknologi hjelper/kan hjelpe til i din hverdag. Intervjuet vil også dekke elementer knyttet til design av helseapplikasjoner og funksjonalitet. Workshopen baserer seg på design aktiviteter, med formål om å utvikle papirbaserte utkast (prototyper) til design. Formålet er at vi i felleskap kan utforske og forme en løsning basert på dine behov og ønsker. Eventuelle kostnader du måtte ha forbundet med intervjuet dekkes av prosjektet.

Mulige fordeler og ulemper

Det antas ikke å være noen ulemper ved å delta i dette prosjektet utover eventuelt ubehag knyttet til intervju/workshop settingen. Fordelene ved å delta i denne studien er at du kan være med på å forme fremtidig teknologi for unge i liknende livssituasjon situasjon som deg, samtidig vil du få et unikt innblikk i hvordan man kan designe nye teknologiske løsninger.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan trekke ditt samtykke til å delta når som helst, uten å oppgi grunnlag for ditt valg. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side i dette dokumentet. Du kan også fritt trekke deg når som helst, uavhengig om du tidligere har svart ja til å delta i studien.

Hva skjer med informasjonen om deg?

Intervjuene vil bli tatt opp på en lydopptaker som senere transkriberes (skrives ut) til en tekstfil for videre analyse. Når lydopptakene er skrevet ut vil de bli slettet. Tekstmaterialet vil bli anonymisert under transkriberingen og deltageres anonymitet vil bli ivaretatt. Dette vil i praksis si at navn og personidentifiserbare detaljer du måtte nevne under intervjuet ikke blir skrevet ned. Det anonymiserte tekstmaterialet vil kun bli lest og analysert av meg.

Informasjonen som registreres om deg skal kun brukes som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn, fødselsnummer eller andre direkte gjenkjennelige opplysninger. En kode knytter deg og dine opplysninger gjennom en navneliste. Det er kun jeg som har adgang til navnelisten. Ved prosjektets slutt vil koden som knytter deg til opplysningene du har gitt, samt all annen personidentifiserbar informasjon som er registrert om deg bli slettet. Ingen enkeltpersoner vil være gjenkjennelige i den ferdige oppgaven. Forskningsprosjektet er meldt til NSD (Norsk Samfunnsvitenskapelig datatjeneste), personvernombudet for alle norske universiteter, høyskoler og flere sykehus og forskningsinstitusjoner.

Rett til å kunne se og slette opplysninger om deg

Dersom du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som jeg har registrert. Du har også rett til å korrigere feil i disse opplysningene. Dersom du velger å trekker deg fra studien kan du kreve at de innsamlede opplysningene blir slettet.
Alle som deltar i studien har rett til å få informasjon om utfallet/resultatet av studien.

Kontaktinformasjon

Hvis du har noen spørsmål angående studien eller hvis du har senere lyst til å trekke deg, kan du kontakte meg på tlf. 40059628 eller sende en epost til audun.karlsrud.larsen@gmail.com. Du kan også kontakte min veileder på oppgaven, Margaret M. Sommervold ved Institutt for Informatikk på 404 69 782 eller via epost: margarma@ifi.uio.no.

Med vennlig hilsen
Audun Karlsrud Larsen

Ole Johan Dahls hus
Gaustadalléen 23B, 0373 OSLO

Samtykke til deltakelse i studien

Jeg har mottatt informasjon og er villig til å delta i studien.

Jeg vet at:

- **Jeg kan når som helst trekke mitt samtykke uten å oppgi noen grunn**
- **Jeg har rett til innsyn og sletting av opplysninger om meg**

_ _
(signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien:

_ _
(Audun Karlsrud Larsen, Masterstudent, dato)

.5 Interview guide – scoping the field

1. **Introduksjon**
2. Forklare formålet med intervjuet, og presentere meg og oppgaven min.
3. Forklare hvordan funnene skal brukes i oppgaven.
4. samtykkeerklæring
    (a) **Hoveddel**
    (b) **Behandling av spiseforsyrrelser:**
    (c) Basert på din kunnskap/erfaring:
    (d) Hvordan behandles spiseforstyrrelser?
    (e) Hvilke elementer inngår i behandlingen
    (f) Hvilken rolle har Kognitiv adferdsterapi i behandlingen;
        i. I hvilken grad benyttes dette?
        ii. Hvorfor/hvorfor ikke?
        iii. Hvis ikke, hvilke andre behandlingsformer benyttes?
    (g) Hvor stort fokus er det på logging av mat,følelser,tanker?
    (h) Hvor nøyaktig blir resultatene?
    (i) Brukes dette i kombinasjon med terapi?
    (j) I hvilken grad brukes motivasjon i behandlingen?
    (k) Hvilken rolle spiller personlig feedback?
        i. Positivt eller negativt?

    (a) **Pasient:**
    (b) Basert på din erfaring;
    (c) Hvilke elementer preger dagen til en person rammet av spiseforstyrrelser?
5. **Teknologi:**
    (a) I hvilken grad brukes teknologi til behandling av spiseforstyrrelser?
    (b) Ser du potensialet ved bruk av teknologi i en eventuell behandling?
    (c) Har du erfaring/kjennskap til bruk sms/epost/virtuelle virkeligheter i behandling?
    (d) Hvordan tror du mobile applikasjoner kan bidra i behandling?
        i. Har du kjennskap til mobile applikasjoner rettet mot behandling spiseforstyrrelser?
            A. hvis ja, hvilke?

ii. Ser du negative aspekter knyttet til mobil helseteknologi?
    A. hvis ja, hvilke? etiske/finansielle/personvern?
iii. Basert på din kunnskap og erfaring, kan kognitiv adferdsterapi kombineres med mobile applikasjoner?
iv. I hvilken grad tror du mobile applikasjoner kan erstatte eller støtte opp under eksisterende behandling?
v. **(Forklare context aware applikasjons)**
    A. Hvilket potensiale tror du slik teknologi har for behandlingen av spiseforstyrrelser?
    B. Ser du noen etiske problemer med slik teknologi?
vi. Har du kjennskap til pro-ed communities?
vii. Hvis ja: Tror du mobil teknologi kan bidra til å øke eller minke deling av pro-ed content?
    A. Hvorfor/hvorfor ikke?