Research Through Design for Myalgic Encephalomyelitis

A phenomenological approach to making and using research products

Oda Sofie Dahl Eide - Master’s Thesis Spring 2018
Research Through Design for Myalgic Encephalomyelitis
A phenomenological approach to making and using research products to mediate human actions related to self-monitoring and self-management of ME

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Abstract

This master thesis explores how to make and use research products to mediate the state of the phenomenal body and generate new knowledge about their meaning for people with health challenges. Specifically, the thesis explores the role technology can have for people with ME in self-monitoring and self-management of their illness, by incorporating new medical research as a design decision in everyday design artifacts. The research process followed a Research through Design approach, making and using a research product called RelaxMe to generate new knowledge about the phenomenon under study. To make RelaxMe, a thorough understanding of the user group and design context was gained. Three exemplars of RelaxMe was then used during a field exploration with four participants, to generate new knowledge about their meaning for people with health challenges. To gain an understanding of the phenomenon of being ill and to design with the phenomenal body in mind, Maurice Merleau-Ponty’s phenomenology was used as an epistemological foundation and theoretical framework throughout the design process. The findings indicate that RelaxMe mediated human actions related to self-monitoring and self-management of ME, and reduced the experience of shrinkage when struck by ME. Hence, this thesis shows how research products can be created and deployed to mediate the state of the phenomenal body through active involvement of the user group and a phenomenological approach to the design process.
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1 Introduction

Imagine waking up one morning and not feeling like yourself, to an aching body, pain in your joints and muscles, dizziness, nausea and a foggy pressure around your mind. For most people, waking up to such a feeling is temporary like a cold, fever or the flu. To some, it might even be temporary like when being struck by a severe but curable illness. To one group of people, this pain and fatigue are not temporary. It is rather their life and their reality. When being struck by Myalgic Encephalomyelitis (ME) in 2018, you are also struck by an enigma. Current medical research published on the cause and treatment strategies are pointing in different directions, from psychological to immune dysfunction to a substantial decline in metabolites and so on. Even when new publications indicate possible treatment options, the road through the process of replication studies, governmental regulations, political and economic issues before the treatment method is applied in clinical practice is long and time-consuming. Hence, finding the best strategies for managing the illness is challenging and often left for the individual struck by the illness to deal with. Many of the sufferers thus have high hopes for future medical research findings.

To take a shortcut through the time-consuming process of replication studies, governmental regulations, political and economic issues and to explore an alternative and imagined future with the user group, this thesis makes it a design decision to incorporate selected, new medical research in design artifacts explored and used by the user group. Through a Research through Design (RtD) approach, three exemplars of a research product called RelaxMe was created based on the user groups’ phenomenal body. Results indicate that RelaxMe mediated human actions related to self-monitoring and self-management of ME, and reduced the experience of shrinkage when struck by ME. Hence, the particular RtD project described in this thesis can be interesting for the Human-Computer Interaction (HCI) community, as it gives a new perspective on how to perform RtD projects with vulnerable users experiencing health challenges.
1.1 Motivation

1.1.1 ME and technology

Even though ME was first described several decades ago (Holmes, 1988), the illness is still stigmatized and poorly understood by doctors, health-care professionals and the general public (Carruthers et al., 2011). In Norway, the illness affects approximately 10,000-20,000 people, both women, men, children, and adults (“Korte fakta om ME – Norges ME-forening,” 2018), and imposes substantial economic costs for the health and social care systems (Jason, Benton, Valentine, Johnson, & Torres-Harding, 2008). At the same time, there have been a lack of research into the illness, both in Norway and abroad, that now has seen a new turn when The Research Council of Norway devoted 30 million Norwegian kroner to research into the cause of ME (“Her er ME-pasientenes forskningsprosjekter - Norges forskningsråd,” 2018).

As science has yet to provide the user group with any answers on the cause of the illness that can be confirmed in replication studies, current treatment strategies are mainly concerned with reducing or controlling symptoms (Bringsli, Gilje, & Getz Wold, 2014). As reducing or controlling symptoms is often done through self-monitoring and self-management of the illness by registering a number of variables (such as nutrition, general well-being, symptoms, sleep, activity, pulse, medication, supplements and so on), technology can potentially have a role when coping with the illness in their everyday life.

1.1.2 Personal motivation

Before starting on this master thesis, I had already developed a passion for working within the gap of technology and healthcare. Through my part-time job as a UX Designer at No Isolation, I have had the opportunity to be part of a team that develops products for vulnerable user groups. The first product, AV1, was created to help children with a long-term illness out of social isolation. While developing AV1, the team and I worked with what showed to be my supervisor, Jorun Børsting, with evaluating the first prototypes with potential users. During this time, I experienced how rewarding it was to create tools to improve the everyday life of vulnerable people with health challenges. When choosing what to devote a year of my
life to, I was determined to work within healthcare and explore what role technology could have in the life of people experiencing health challenges.

Exploring my alternatives of what user group to work with, ME intrigued me in two ways. First of all, it is a stigmatized illness both from the eyes of the general public and from the eyes of healthcare professionals. To have the opportunity to put a focus on such a debilitating illness felt both right and meaningful. Secondly, I have myself been living with a chronic autoimmune illness called Ankylosing spondylitis for almost a decade before receiving a diagnosis. When the diagnose was set I received medication immediately, and my pain, stiffness, and fatigue vanished within a couple of days. Living with the illness for seven years, I suddenly was able to walk normally, sit comfortably and sleep properly. It was fantastic. The years before this was not, mainly due to the mystery of not having a biological explanation. I experienced that people did not believe in my pain, healthcare professionals that applied a wide variety of reasons to why I experienced the issues I had, and doctor’s that insinuated that psychological factors caused the troubles. At some point, I even questioned myself and my own bodily experiences. Even though I can by no means compare my situation with that of a person with ME, I believe this experience made me sympathize with the situation they are in and eventually motivate me to work within design and people with ME.

1.2 Research questions

In this master thesis, I wanted to explore the meaning technology could have in the complex and messy context of a life with health challenges, such as living with an illness like ME. By introducing research products that propose an alternative and imagined future for the user group, I wanted to generate new knowledge about their meaning for the participants. My research question is thus as follows:

How to make and use research products to mediate the state of the phenomenal body and generate new knowledge about their meaning for people with health challenges?

Mediate, in this context, is defined as “to bring about something”, for instance, a physiological effect. (“Definition of mediate in English by Oxford
Dictionaries,” 2018). Hence, RelaxMe was created to mediate bodily processes and let the participants perceive them through their bodily experiences when interacting with RelaxMe.

To answer the overarching research question, three sub-research questions were used to get knowledge about the case of research:

1. How do people with ME experience their illness and how does it relate to the phenomenon of being ill?
2. How to design research products that mediate human actions related to self-monitoring and self-management of ME to reduce the experience of shrinkage when struck by a debilitating illness?
3. How to deploy and generate new knowledge from field explorations of research products with vulnerable users?

1.2.1 Design space

I position my work within what I constitute as my design space, consisting of the phenomenological lens and the methodology of RtD that is used to explore how to make and use research products to mediate the state of the phenomenal body and its specific inquiry into the life of vulnerable users such as people with ME. It is within this design space (see Figure 1) I explore my research questions and situate my research contribution.

Figure 1: Shows the placement of my research in the middle and how it relates to relevant and broader fields of study
1.2.2 KULU research project

This thesis was initially a part of the KULU research project (www.kulu.no), aiming to create cool technology for youth with long-term health challenges. However, I chose to conduct my research with adults instead. Hence, being a part of the KULU research project at the beginning of this process have influenced and inspired my way of working with the user group, as my research still involve vulnerable users. Thus, I have used methods and tools from earlier KULU research projects in my design process and received valuable information about research on children and adolescents with ME and research on designing with vulnerable users.

1.2.3 Illness vs. disease

Aho & Aho (2008) make a distinction between the two words “disease” and “illness.” For them, the word disease is representing the scientific and pathological explanation for when our body is not in a “normal” state, measured by clinical or laboratory procedures. When we, for instance, are struck by type-1 diabetes, a test can show a deviation in our blood sugar levels. When we have a fever, a measurable increase in temperature from our normal state can be detected. Illness, on the other hand, represents the lived experience of not feeling well; the feeling not measured by instruments or laboratory procedures but experienced by the affected person. Aho & Aho (2008) argue that bodily troubles are seen as diseases by physicians but experienced as illnesses by sufferers. I have therefore decided to apply the word illness throughout my dissertation, to emphasize my focus on the phenomenon of being ill as experienced by the user group. I do not want to understand ME as a disease, but rather as the illness experienced by its sufferers.
1.3 Chapter guide

Chapter 2: Presents the Background needed for the reader to understand the user group and design context. First, I present what ME is, common symptoms experienced, and its current prognosis and treatment strategies. Second, I present what the anaerobic threshold is and how it is experienced differently for people with ME. Last, I present existing research on ME and technology and relevant research on technologies for other chronic illnesses.

Chapter 3: Presents my theoretical framework. Based on Merleau-Ponty’s phenomenology and his focus on the phenomenal body, I introduce how phenomenology has guided my way of understanding the user group and design context as well as set the foundation for designing a research product that mediates the phenomenal body.

Chapter 4: Presents my methodological approach used throughout this project. My methodological approach is based on the principles of Research through Design and is also guided by the ethical considerations I need to assess when researching with vulnerable users.

Chapter 5: Presents The design process in a chronically and historically linear way, describing the involvement of the user group in the different stages and the making of the research product, RelaxMe.

Chapter 6: Presents the Field exploration of RelaxMe conducted with four participants suffering from ME. The field exploration consisted of a baseline interview, followed by a one-month long period where three RelaxMe was used in the field by four participants, completed with a final interview exploring the role RelaxMe had in their life. The exploration generated considerable amounts of data that went beyond RelaxMe as technology.

Chapter 7: Presents the Evaluation of the methods and tools used throughout the design process with the user group. The planning, execution, and results of the evaluation of the telephone interviews and the evaluation of the field exploration of RelaxMe is presented.

Chapter 8: Presents a Discussion of my specific RtD project, looking at how my RtD project was carried out, how the knowledge produced during
this specific RtD process was communicated, and what role RelaxMe had in generating the knowledge obtained.

**Chapter 9:** Presents *Critical Reflections* I as a researcher needs to assess when conducting qualitative research. Reflections about my phenomenological approach, the validity of the data, the included participants, my many roles in an RtD process, and the research design is presented briefly.

**Chapter 10:** Presents a *Conclusion* of the findings and discussion in relevance to my research question. I also highlight my contributions and propose possible future work.
2 Background

In this background chapter, I present literature connected to the scope of my research, with the primary goal of providing the reader with a basic understanding and knowledge of the different topics surrounding my research project. I start by presenting what the illness ME is, and what it means for an individual to suffer from such a complex and stigmatized illness. Further, I briefly explain what the anaerobic threshold is, and how the anaerobic threshold is found to be experienced in a different way for people with ME in new medical research, as this is incorporated in the research product of RelaxMe. Finally, I present the already existing research and literature on technologies for ME and similar user groups suffering from other chronic illnesses.

2.1 What is ME?

ME is a complex neurological illness that affects multiple systems of the body (Afari & Buchwald, 2003; Bringsli et al., 2014). The cause of ME is still an enigma, but dysregulations of the nervous, immune and endocrine systems are seen in patients diagnosed with the illness (Carruthers et al., 2011, p. 329). As a result from this, a patient is currently diagnosed based on exclusion of all other possible illnesses (Nacul et al., 2011).

2.1.1 Definition

The last few decades, several clinical labels and case definitions have been used to describe ME, such as “Chronic Fatigue Syndrome” (CFS) (Carruthers et al., 2011). In older literature covering the illness, ME is thus often referred to as CFS. It is important to note that CFS is no longer considered to be the same illness as ME, as CFS is a different diagnosis characterized by long-term chronic fatigue and should not be mixed with the complex pathophysiology of ME (Carruthers et al., 2011).

For this dissertation, the “Myalgic encephalomyelitis: International Consensus Criteria” developed in 2011 is used as the operating definition (Carruthers et al., 2011). The researcher’s developed a set of criteria where
they grouped common symptoms in four different categories. The International Consensus Criteria differ from earlier highly cited definitions, such as the Canadian Consensus Criteria and the Fukuda criteria. In the former, a diagnose demanded that the illness persisted for at least six months (Carruthers et al., 2003, p. 12). The latter definition, a fatigue lasting for more than six months was required before diagnosed with ME (Fukuda et al., 1994, p. 954).

Due to the fact that the illness affects multiple systems in the body, the variety and intensity of symptoms experienced by the individuals diagnosed with ME can be quite different (Carruthers et al., 2011).

The International Consensus Criteria classify the symptom severity into four categories; mild, moderate, severe or very severe (Carruthers et al., 2011, p. 329). The mild cases of ME experience approximately a 50% reduction in pre-illness activity level and is as Bringsli et al. (2014, p. 4) refer to as living on “half capacity”. The moderate cases of ME are mostly housebound and may need careful planning and assistance in order to leave the house (Bringsli et al., 2014, p. 4). The severe cases of ME is mostly bedridden and the very severe cases are totally bedridden and dependent on assistance with basic needs (Bringsli et al., 2014; Carruthers et al., 2011). In this master thesis, I will focus on the mild and moderate cases of ME.

2.1.2 Symptoms

To describe the most common symptoms experienced by people with ME, I will use the categories described in the International Consensus Criteria. The criteria offer a detailed description of the symptoms experienced and gives a holistic view of the complex pathophysiology of the illness. A detailed description of the different symptoms can be viewed in Appendix A, but I will provide the reader with a short summary in the following section.

- The first category of symptoms concerns post-exertional neuro-immune exhaustion, which are symptoms caused by the inability to produce sufficient energy when it is needed. Symptoms may be abnormal fatigue in both muscles (physical) and the central nervous system (cognitive) after minimal effort, flu-like symptoms, pain and
prolonged recovery periods.

- The second category of symptoms concerns neurological impairments, such as reduced ability to reflect, short-term memory loss, impaired concentration, headaches, non-inflammatory pain in muscles, joints, abdomen or chest and sleep disturbance in both sleep patterns and quality of sleep.

- The third category of symptoms concerns immune, gastrointestinal and genitourinary impairments. Flu-like symptoms can be recurrent or chronic, susceptibility to viral infections, sensitivity to food and medications, nausea, abdominal pain, bloating, frequent urination or excessive urination during the night.

- The last category of symptoms concerns energy production and transportation impairments. Symptoms may be an inability to tolerate an upright position, feeling light-headed, air hunger, loss of thermostatic stability or intolerance for extreme temperatures.

### 2.1.3 Current prognosis and treatments of ME

Due to the unknown cause of the illness and the major variety in experienced symptoms a recommended treatment is yet to be established (Afari & Buchwald, 2003, p. 227; M. E. B. Smith et al., 2015, p. 841). When diagnosed with ME, longitudinal studies show that less than 10% of the adult patients (Afari & Buchwald, 2003, p. 230) and around 43-66% of the children and adolescent patients (Garralda & Rangel, 2002; Krilov, Fisher, Friedman, Reitman, & Mandel, 1998, p. 174) experience a full recovery from their illness.

As mentioned above, the illness is highly individualistic in its manifestation of symptoms, and current treatment strategies are therefore broad (M. E. B. Smith et al., 2015, p. 841). Furthermore, the little amount of research in the area are non-conclusive, and results are pointing in different directions. Hence, current treatment strategies vary from medical to behavioral approaches, both distributed by physicians, health care professionals, experimental therapists, nutritionists and the patients themselves (M. E. B. Smith et al., 2015). Research shows that the success rates for the different treatments used are limited, and that the patients often feel the illness is uncontrollable (Ax, Gregg, & Jones, 1997, p. 252). Some patients have experienced benefits from trials with the medication Rintatolimod,
counseling therapies, and graded exercise therapy (M. E. B. Smith et al., 2015). On the other hand, more recent research shows that graded exercise and cognitive behavioral therapy are not effective as recovering therapies (Wilshire, Kindlon, Matthees, & McGrath, 2017), but that lightning process has shown to be beneficial (Crawley et al., 2018). Others report that self-monitoring and balancing of activity inside the Energy Envelope (both avoiding overexertion and under-exertion) have been beneficial for reducing symptoms and improving quality of life (Jason et al., 2013; Jason, Benton, Torres-Harding, & Muldowney, 2009), and that pacing (reducing activity level to 70% of normal capacity) and different meditation and relaxation techniques have improved the situation for two out of three patients (Bringsli et al., 2014, p. 5).

As mentioned above, a primary symptom for people with ME is the inability to produce sufficient energy when needed. Jason et al. (2009) found that staying inside their Energy Envelope could significantly improve physical functioning and fatigue severity for patients with ME/CFS. They further implied that promoting self-monitoring strategies to individuals with ME/CFS could improve functioning over time. Instead of struggling with finding a cure for the still unknown cause of the illness, energy modulation is rather focusing on balancing the symptoms and helping the patient learn to cope with the illness on their own (Jason et al., 2009, p. 238). As Bringsli et al. (2014, p. 6) reported: “Since there is no curative treatment available […] reducing secondary symptoms is the only available option to help patients.”

2.1.4 Stigma

A serious issue reported in the literature is the stigmatization patients often feel when diagnosed with ME, both from friends and family, as well as healthcare professionals (Anderson, Jason, Hlavaty, Porter, & Cudia, 2012, p. 152). A review of 34 qualitative studies on ME concluded that both healthcare professionals and patients struggle to understand ME, which results in the increased stigmatization of the illness (Anderson et al., 2012, p. 154). The same study also concluded that the illness receives too much suspicion of being a psychological disorder from healthcare professionals and physicians (Anderson et al., 2012, p. 153). A user study carried out by the Norwegian ME association found similar results and reported that people
with ME receive both diagnoses and treatment based on a psychiatric clinical picture and that 50% of the study participants did not receive medical supervision, even though 2 out of 3 reported that they would like medical assistance (Bringsli et al., 2014).

This mistrust from others seems to also affect the patients themselves. In a phenomenological study on adolescents living with ME/CFS conducted by Winger, Ekstedt, Wyller, & Helseth (2014, p. 2653) they found that the participants in the study questioned whether their illness truly existed when it is invisible to others. They reported that even family members had a hard time believing the “invisible” symptoms. Another interesting finding from a review of publications on childhood ME/CFS reported the following:

"[...] the fear expressed by children and parents, that exertion will lead to lasting damage, is often encountered. This seems to be central to avoidance behaviour and inactivity and [...] may militate against rehabilitation and recovery.” - (Garralda & Rangel, 2002, p. 173)

It seems as if the development of the illness is hard to comprehend, both for the people around the sufferer and for the sufferer themselves. When wanting to understand the illness as experienced by the sufferer, considering the stigma and feeling of mistrust is thus also a part of the equation.

### 2.2 Anaerobic threshold

One of the primary symptoms people suffering from ME experience is post-exertional symptoms, and energy modulation is a way of avoiding overexertion that can lead to such symptoms. Newly released medical research on ME suggest that a reason for this is that people with ME process lactate acid slower than healthy people (Keller, Pryor, & Giloteaux, 2014). The anaerobic threshold seems to be of importance in this avoidance of overexertion. The finding mentioned related to the anaerobic threshold was important for the design of RelaxMe. Thus, I present the reader to what the anaerobic threshold is and how the anaerobic threshold is experienced differently for people with ME.
2.2.1 Heart rate

All living humans have a heart that beats continually throughout their lifetime. This beating is, simply put, your heart muscles contracting and pumping blood to the rest of the body for you to stay alive. This circulating blood contains, amongst many things, oxygen. The oxygen is what our muscles use to “burn” glucose and produce energy to perform different actions, such as breathing, eating, drinking and walking. The number of times your heart muscles contract and pump oxygen-rich blood to your body in a minute is what is called your heart rate, or pulse.

A person’s heart rate is highly individual and often genetically predisposed. It also changes through a person’s lifetime due to age, health status, and fitness level. To be able to monitor changes in a person’s overall heart rate, the resting heart rate is often used as a variable. The resting heart rate is the pulse a person have when lying down and relaxing. The number is usually between 60-100 beats per minute for the average person, and between 40-60 for an athlete (“All About Heart Rate,” 2018). The resting heart rate is commonly used as an indicator of a person’s health, as people tend to get a lower resting heart rate when being fit and healthy, and a higher resting heart rate when suffering from an illness, being obese or when being unfit. By working out you can increase your fitness level, and “exercise” the heart to pump more blood per beat and thus decrease your resting heart rate. When having the flu, most people experience an overall increased resting heart rate, as the fever causes the heart rate to rise with a few beats.

The heart rate shifts significantly during the course of a day because it is dependent on the person’s state of action. While sleeping or when laying down and relaxing, the person will enter a stage of resting heartbeat. At this point, the body is not working hard and is thus not in need of extra oxygen. As the person stands up and starts to move around, the heartbeat will raise according to how much energy and oxygen the body is in need for to perform a certain activity. If the person starts to jog, the heartbeat will increase even more as the body is in need of more energy, and thus oxygen, to help the legs move faster. But, if you are running from predators this process of pumping more oxygen will only last for a short burst, as escaping predators often means sprinting as hard as you possibly can. For the body
to produce enough energy needed in such an exertion, the “little” amounts of oxygen pumped from the heart are not sufficient, and a process of burning glucose and producing energy without oxygen kicks in, called the anaerobic system (“Anaerobic Threshold,” 2017).

2.2.2 The anaerobic and aerobic systems

In other words, one can say the body reacts differently to changing heartbeats, or actions. This is due to our muscles being able to “burn” energy both with and without oxygen, called our aerobic and anaerobic systems (“Adenosine Triphosphate,” 2017; “Anaerobic Threshold,” 2017). I am not going to go into the nitty-gritty of these bodily processes, as this is not relevant for my thesis and project. Instead, I will try to give a simple explanation of the two systems to give the reader a basic understanding of the mechanisms involved in the new medical research findings that RelaxMe is inspired by. Both systems produce a molecule called “Adenosine triphosphate” (ATP), which is often called the energy currency of life because it is used by our body to do just about everything we do (“Adenosine Triphosphate,” 2017). The aerobic process produces ATP from glucose and oxygen, and as waste we are left with CO2 to breathe out. The anaerobic process, on the other hand, produce lactic acid as its waste, which the body has to remove in other ways than just breathing (“Adenosine Triphosphate,” 2017).

For most people, the energy needed to perform daily activities such as walking, showering, cooking and jogging to the bus is low enough to use the slower aerobic system, burning the energy with oxygen. It is not before entering highly demanding activities such as interval running, a CrossFit session or escaping predators that our bodies utilize the more efficient anaerobic system and burn energy without oxygen. These forms of activities demand a very fast and high-power output, something the aerobic system does not manage to fulfill (“Anaerobic Threshold,” 2017). The anaerobic system, on the other hand, can. The downside of the anaerobic system is that the power supplies are quickly depleted, and when that happens lactic acid starts to build up. If the lactic acid builds up faster than your body can remove it, your muscles begin to feel heavy and sore, and you soon have to stop your activity (“Anaerobic Threshold,” 2017). For most healthy and active people, the body is recovered after a short rest.
2.2.3 The threshold

The limit where your body starts to produce more lactic acid than it can remove is called the anaerobic threshold. The threshold is individual, as it depends highly on your health and age, as well as your current fitness level (“Anaerobic Threshold,” 2017). Individuals with a normal health and fitness level are often said to have an anaerobic threshold somewhere around 85-90% of their maximum heart rate (“What is Anaerobic Threshold,” 2017).

To get a more precise measure, you need to take blood samples during a workout and measure the levels of lactate in your blood (“Lactate Threshold,” 2017; “What is Anaerobic Threshold,” 2017). It is common to use different formulas to define the anaerobic threshold without the need of blood samples or laboratory tests. Two common and easy calculations used are 210 minus age or 85-90% of maximum heart rate (“What is Anaerobic Threshold,” 2017). If you are healthy, it is possible to move the threshold to a higher heart rate by working out correctly, pushing the boundaries of the anaerobic threshold through, for instance, interval training. In this way your body gets better at processing and removing lactate, and as a result, the anaerobic system gets more efficient (“Anaerobic Threshold,” 2017).

2.2.4 ME and anaerobic threshold

The aerobic and anaerobic processes of a person with ME has shown to work differently from healthy individuals. As mentioned in Section 2.1.2, the International Consensus Criteria lists post-exertional neuro-immune exhaustion as a key category of symptoms an individual must experience for she or he to be diagnosed with ME. The inability to produce sufficient energy when it is needed can both apply to cognitive and physical functioning, and the latter has been demonstrated as a fact in several studies using objective measurement tools such as VO2max, HRmax, and lactate levels in the bloodstream of the participants.

Vermeulen, Kurk, Visser, Sluiter & Scholte (2010), Snell, Stevens, Davenport, & Van Ness (2013), Vanness, Snell, & Stevens (2007) and Keller, Pryor & Giloteaux (2014) all performed similar studies that demonstrated, through cardiopulmonary exercise tests (CPET) that ME patients experience an abnormal response to exercise. A CPET is a stress-
test assessing objectively how the heart, lungs, and muscles are working individually and together to perform a gradually more demanding activity. The key to the findings from all the before-mentioned studies was that they used a combination of two CPET sessions separated by 24 hours to assess the performance of their participants on day two. The reason is that both the control group and the participants reached the same levels of VO2max on day one, which means that without a day two of the test no difference could have been demonstrated. With the introduction of a second day, the studies showed how the individuals diagnosed with ME performed more poorly on almost all physiological measures compared to the control groups on day two. More specifically the studies demonstrated how people with ME performed on par with a healthy person on day one but reached their anaerobic threshold earlier than the control groups on day two, and at a much lower workload than on day one. Although the researchers do not agree upon the physiological reasons for the abnormal response in the test subjects, they all agree that a second day of the CPET test is needed to sufficiently demonstrate the atypical and prolonged recovery response seen in ME patients. Snell et al. (2013) also note the fact that the results are both interesting for further research and to explain the severely limited productivity in the home and workplace people with ME experience. Keller et al. (2014) emphasize that the results can be provided as guidelines for individuals with ME and be used to avoid symptom flares and improve daily physical functioning. These results correlate with the positive results saying that staying inside the Energy Envelope (see Section 2.1.3) could significantly improve physical functioning and fatigue severity for patients with ME.

The aforementioned studies are one of many directions within the medical research on ME has taken. As mentioned earlier, research in the area are non-conclusive and pointing in different directions. I have chosen to take a stance on what research I am leaning on when designing RelaxMe, and this includes the aforementioned CPET-studies. The results are, in terms of medical research, quite new, and thus not yet part of clinical practice.

### 2.3 ME and technology

When beginning this master thesis project, one of the first things I did was to search the internet for already existing technologies or research on
technologies for people diagnosed with ME. What I soon found out was that technologies specially made for people with ME and research on technologies for the user group in general was almost non-existent. This was also confirmed by the literature survey on assistive technologies for people with ME conducted by Børsting & Culén (2016b). They found very little research in the field, and the solutions they mention from the literature was all screen based. As they point out, screen-based technology might have limitations for people with ME, as they both have cognitive and physical challenges, as well as being sensitive to light and sound:

“While the screen-based technology can play a supportive role in providing care for many users, the ME/CFS sufferers may have a very limited ability to concentrate, read or even just look at a screen.”(Børsting & Culén, 2016b, p. 3)

In the same paper, Børsting & Culén (2016b) propose that when designing for a complex domain, such as people with ME, researchers need to take a more holistic approach to get expert knowledge about the domain. Through a combination of a literature review, a sense-making session with experts, Actor Network Theory and Giga-mapping, they gained expert knowledge about ME/CFS. The insight they gained was used for further research when doing a qualitative study on adolescents with ME/CFS (Børsting & Culén, 2016a). In their study they tested how the robot AV1 could work as the adolescent’s avatar at school, helping the adolescent’s attending more classes, as well as increase social contact. Their findings showed great potential for the technology, and one of the participants in the study reported that he was able to attend as much school remotely in one week as he had been able to attend the prior three months (Børsting & Culén, 2016a, p. 7).

Some other interesting findings regarding ME/CFS and technologies, is Best and Butler’s studies on the use of the Virtual 3D world, Second Life, by people with ME (Best & Butler, 2012, 2013b, 2013a, 2015). In their first article about the study, they explain that the highly individual symptoms experienced by people with ME caused very different technology needs for the individuals participating in their research (Best & Butler, 2012, p. 4). Some of the participants preferred to communicate in written form because of sensitivity to sounds, while others could not bear the visual stimulation
from the 3D graphics from the virtual world and communicated auditory. They also found that some of the users preferred to use Skype for some of their social interactions within the virtual world, as they found Second Life too technically difficult. The aforementioned switching between Skype and Second Life was a user strategy conducted to reduce the amount of energy used to find the right way of interacting with the software (Best & Butler, 2012, p. 5). They emphasized in a later paper concerning the same study when designing technologies for people with ME one needs to have a knowledge and take into account all the typical symptoms experienced by the user group (Best & Butler, 2015). Second Life was designed by people not aware of the illness’ effect on the sufferer’s abilities, and the software eventually needed to be re-designed to adapt to their needs (Best & Butler, 2015).

When reviewing existing literature, the need for more research on how to design technologies for people with ME becomes evident. The little research that has been performed until now shows that technology as an aid for people with ME has potential. At the same time, it also raises some critical concerns about the need for a thorough understanding of the typical symptoms and disabilities that comes with such a debilitating illness. As a researcher, I need holistic and in-depth knowledge about the experience of suffering from ME to design research products that generates valuable data and is adjusted to their needs.

2.4 Technology and similar user groups

Since research on technologies for ME is in such short supply, I needed to expand my search beyond people with ME to find relevant studies for my project. I thus started searching for technologies for those suffering from other chronic illnesses, as all chronic illnesses are life-long or at least long-lasting with no curable treatment. Since I am working with a user group that has no curable treatment, and where reducing secondary symptoms through energy modulation performed by the individuals suffering themselves is one of the few available options, technologies helping individuals with patient-driven health care through self-monitoring or self-management was of interest. The literature revealed that technology has great potential to assist in self-monitoring and self-management of chronic illnesses.
Chiauzzi, Rodarte, & DasMahapatra (2015) reported that activity monitoring of patients could give patients more control of their health, as well as provide healthcare professionals with valuable data about their patients. They point out that technology potentially can become part of treatment prescription, because the technology promotes self-management. Ayobi, Marshall, Cox, & Chen (2017) illustrate through their interview study on self-tracking practices of patients with Multiple Sclerosis (MS), an unpredictable and degenerative illness, how the patients regained a sense of control over their illness. This sense of control was, according to their findings, a combination of illness monitoring, self-tracking their physical activities and diet, life-journaling about their mental health, and taking time to reflect on the correlations across their tracked data and behaviour through the use of technology. A study by Collinge, Yarnold, & Stoltysik (2013) showed that self-monitoring with the help of technology can enable people with Fibromyalgia to significantly reduce symptom levels over time. Morrison, Mair, Yardley, Kirby, & Thomas (2017) state that self-management of chronic illnesses through the help of technological solution can be effective, especially because it may help reduce the burden of self-management in itself. These findings are especially relevant in the case of ME, where the symptoms experienced by the sufferers are of a nature that can potentially make self-monitoring and self-management hard to carry out in the harsh reality of symptom aggravation.

2.5 Summary of chapter

This chapter presented a brief overview of what ME is, typical symptoms experienced by the sufferer’s, prognosis for the illness and typical treatment strategies. What I realized during the preliminary phase of writing this chapter was that the illness was more debilitating than my initial thoughts, and that working with the user group would be ethically challenging for several reasons as discussed later in Chapter 4. Other than becoming aware of the severe symptoms and reflecting over how my design process should be conducted carefully and ethically, I learned that the prognosis for the illness is not good. When struck by ME as an adult, you have a scarce 10% chance of full recovery. As mentioned in Section 2.1.3, the focus is therefore on reducing secondary symptoms through different treatment strategies. Even though many treatment methods showed limited success rates, the use
of energy modulation through Pacing and staying inside your Energy Envelope have been shown to be beneficial for the user group. Also, literature on self-management and self-monitoring through technologies for similar chronic illnesses showed great potential. Therefore, my interest scoped in on the treatment methods dealing with the concept of energy modulation. Also, as seen in Chapter 5, I later in the research process discovered the importance of the anaerobic threshold in relevance to ME. A review of relevant research into people with ME and their anaerobic threshold revealed a very interesting and intriguing potential of using design to bring forth the results for the user group to utilize in their everyday life coping with the illness.
3 Theoretical framework

In this chapter, I present how the phenomenological school of thought can help me understand and comprehend the subjective experiences of being a sufferer of ME, and how research products can affect their everyday world. Phenomenology as a movement was influenced by several philosophers, such as Edmund Husserl, Martin Heidegger, Jean-Paul Sartre, and Maurice Merleau-Ponty, to name a few. The correct definition of phenomenology can thus be debatable, as the different phenomenologists all differed somewhat in how they defined the term. My focus will be on Merleau-Ponty's ideas of phenomenology, specifically I draw attention to his concept of the phenomenal body, and how the phenomenal body is affected both when struck by a chronic illness, and when using technologies as an aid for coping with the illness.

I begin this chapter by introducing the reader to my understanding of what phenomenology is. Then, I present two of Merleau-Ponty’s main influencers from the phenomenological school of thought, Husserl and Heidegger. I only give a brief introduction to the two philosophers’ works, focusing on the topics and ideas relevant to Merleau-Ponty’s phenomenology. Furthermore, I present my interpretation of the thoughts of Merleau-Ponty, and specifically the theory of the phenomenal body, and how the theory can provide me with tools to understand and design in a better way with and for my user group. Finally, five concepts that I bring with me into the design process will be presented: the phenomenal body, the phenomenon of being ill, shrinkage, body schema and incorporated objects.

3.1 What is Phenomenology?

Phenomenology is the philosophical study of phenomenon, and our subjective experience and perception of these phenomenon. In other words, phenomenology emphasizes the human subjectivity, and states that “knowledge and awareness of the world are always someone’s knowledge and awareness” (Matthews, 2006, p. 5).

But what is a phenomenon, with regards to studying people’s experiences?
A phenomenon, in phenomenology, refers to objects or things that we, as an individual, are experiencing. These things can basically be anything that we are conscious of and experience, like objects and events around us, other people or ourselves. A phenomenon is not limited to experiences of perception. Imagination, memory, thought, emotion, desire, and volition of these things is also seen as a phenomenon, as well as bodily awareness, embodied action, social activity, and linguistic activity (D. W. Smith, 2016).

Phenomenology is, in other words, the study of our experiences of things as experienced by the first-person point of view, the meaning things have in our subjective experiences as we experience them. “Phainomenon” from Greek means appearance (D. W. Smith, 2016), and one can say that in phenomenology we study exactly this; how things appear to us, contrary to how things are in objective reality.

3.1.1 Husserl and the introduction of phenomenology

Phenomenology as a movement originated in the early 20th century, when the scientist and mathematician Edmund Husserl introduced phenomenology in his work Logical Investigations (1900-01). According to D. W. Smith (2016), Husserl combined the world of logic (the scientific way, focused on pure objectivity) with the world of psychological theories (mental activities, focused on pure subjectivity) in order to find a tool to study, describe and analyze the structures of phenomenon, our subjective mental experiences, in a logical way. He did this to “get back to the things themselves” rejecting any objective assumptions that we naturally take for granted about the objects around us (Matthews, 2006, p. 6).

This emphasis on subjectivity was not a way of describing our “inner selves” opposed to an outer objective world, but rather a description of the world that we are conscious of (Matthews, 2006, p. 6). Husserl believed that we are always conscious of something (Matthews, 2006, p. 6). To use Matthews (2006, p. 6) examples: we are always thinking about, afraid of, or hoping for someone or something. This feature of experience, that we always are conscious of an object (object in the sense of being something, e.g., a feeling, a person, ourselves, and not necessarily an object as a material thing that can be seen or touched) when we experience a phenomenon, Husserl termed
intentionality (D. W. Smith, 2016). We experience an experience of or about some object, meaning that our experiences, or consciousness, are always aimed outside ourselves and at an object, called an intentional object (D. W. Smith, 2016). It does not matter if we are experiencing the object (e.g. the feeling of embarrassment when forgetting an appointment) through direct perception (when confronted by the person in question) or by memorizing it (remembering the confrontation when meeting the same person the day after), the consciousness (our experience of that object when perceiving or memorizing) will in both cases be directed at the same object (the feeling of embarrassment). It is not important if the intentional object exists or not, like ghosts or the bogeyman, because phenomenology is interested in how things appear to us, to our consciousness, and not how things are objectively (Matthews, 2006, p. 7).

The theory of intentionality, as described above, states that an object (e.g., the feeling of embarrassment) is shared across different experiences. Whether you perceive it directly or memorize it, the object you perceive or memorize is a shared object in your consciousness. This characteristic of intentionality was of importance in Husserl’s phenomenology, because it made it possible for him to describe certain contents of our consciousness as objective, and thus describe our subjective experiences of everyday life in a logical way (D. W. Smith, 2016). A method Husserl introduced for practicing phenomenology for these logical descriptions of subjective experiences to be possible, was epoché. This method went on by “bracketing” our experiences, trying to unfold the basic structures of our consciousness, returning to the things themselves (D. W. Smith, 2016). With this in mind, one might understand why Husserl defined phenomenology as “the descriptive science of the essences and actions of consciousness” (D. W. Smith, 2016).

### 3.1.2 Heidegger and “being in the world”

Husserl was not alone in the school of phenomenology. Many philosophers have been influenced by and critical to his work, debating on the proper definitions and methods for phenomenology. One of them was Husserl’s student, Martin Heidegger, who eventually challenged his teacher’s thoughts with his own ideas about phenomenology in his work “Being and Time” (1927).
As described by Matthews (2006, p. 12), Heidegger proposed another definition for phenomenology where one was to return, quoting Husserl, “to the things themselves.” In contrast to Husserl’s reductionist philosophy of essences where one should bracket away nonessential elements to study phenomenon, Heidegger was more concerned with our “being-in-the-world” and how we always are “in the world” (D. W. Smith, 2016). As I understand his philosophy, based on reading the interpretations of D. W. Smith (2016) and Matthews (2006, pp. 11–13), Heidegger was thus more concerned with studying phenomenon in their true context, not separating our consciousness from its objects, nor trying to describe a phenomenon in its essence outside its true context. We cannot escape the fact that we are a part of the world we are experiencing, and that we are interacting with the surroundings from a particular place and time, a context. We are conscious of ourselves being in this world as well, a mode Heidegger termed “Dasein”, meaning “being there” in German (D. W. Smith, 2016). With all this in mind, one can see that Heidegger had a different view on the definition of phenomenology, for him phenomenology was “the analysis of how things appear to us in the course of our ordinary human interactions with the world” (Matthews, 2006, p. 12).

### 3.2 Merleau-Ponty and the phenomenal body

Maurice Merleau-Ponty was influenced, amongst many, by both Husserl and Heidegger, but contrary to his colleagues he emphasized the role of the body in human experiences (D. W. Smith, 2016). Merleau-Ponty extended Heidegger’s focus on how our “being-in-the-world” is the basis for our experiences of phenomenon and explained how our body is an important feature in this “being-in-the-world”. For Merleau-Ponty, our body is what meets the world, and it is our body that gives us the possibility to experience the world in the subjective way we do.

“Insofar as, when I reflect on the essence of subjectivity, I find it bound up with that of the body and that of the world, this is because my existence as subjectivity is merely one with my existence as a body and with the existence of the world, and because the subject that I am, when
Merleau-Ponty’s work is not easy readings, and I have found myself lost several times when reading his “Phenomenology of Perception” (Merleau-Ponty, 2002). Thus, I have complemented my understanding of Merleau-Ponty’s philosophy and thoughts with a reflective verification through Eric Matthews interpretations of Merleau-Ponty’s philosophy in his book “Merleau-Ponty: A guide for the Perplexed” (Matthews, 2006). In my interpretation of Merleau-Ponty’s philosophy, I will focus on the topics that are interesting to my own context and thesis, and will leave out equally important topics he discussed that is not interesting for my work and user group, such as his thoughts about sexuality, society or art. Therefore, I want to make it clear that this is not an interpretation of Merleau-Ponty’s philosophy as a whole, but rather a presentation of and a reflection about those concepts and ideas I find most relevant in my research.

3.2.1 Challenging objectivism

When reading Merleau-Ponty’s own writings, he begins “Phenomenology of Perception” by challenging the thoughts about an objectivist, scientific truth:

“I cannot conceive myself as nothing but a bit of the world, a mere object of biological, psychological or sociological investigation. I cannot shut myself up within the realm of science. All my knowledge of the world, even my scientific knowledge, is gained from my own particular point of view, or from some experience of the world without which the symbols of science would be meaningless.” - (Merleau-Ponty, 2002, p. ix)

As Matthews (2006) explains, the scientific view, where 2+2 equals 4, and where our body is seen as a composition of organs, bones and skins, and can be explained anatomically, is in our modern world seen as some sort of ultimate truth. This scientific explanation has been preferred over the non-scientific for a long time, originating as early as in ancient Greece, when Plato explained how mathematical propositions are the clearest example of truth (Matthews, 2006, p. 14). Merleau-Ponty questioned if this objectivistic way of understanding the human being and the world was the only way to
get knowledge about our existence and our world. For Merleau-Ponty, science is an explanation of the world, and will thus always be a construct of our human experience which we already gave our meaning to. He believed that the best way to understanding ourselves could not be found in something that already was a product of human experience, or more concrete, someone's experience. Merleau-Ponty believed that we needed to “get back to the things themselves”, to the direct experiences we have of the world, in order to understand ourselves and the world (Matthews, 2006).

As Matthews (2006, pp. 16–17) explains, this concept of stepping back to the things themselves is a way of epoché, as Husserl introduced. Merleau-Ponty is stressing that this is not a stepping back to find the absolute subjectivity. He is emphasizing that in order for me to be an “I”, there has to be a “you”, and if there is a “you” and an “I”, there is also a world that we together experience. Therefore, I am always tied to the world, “embodied” in a specific time and place, experiencing this world as this world is what gives meaning to my experiences. According to Matthews (2006, p. 20), phenomenology for Merleau-Ponty was a philosophy that “describe our existence in the world, our various modes of being-in-the-world”. We perceive the world as it is because we are in the world, acting upon it as much as we are acted upon by it. We do not passively receive experiences from objects or create a world in our mind; we are experiencing the world as embodied subjects (Matthews, 2006, pp. 36–37).

3.2.2 The lived body

Most importantly to my focus, by emphasizing that we are embodied subjects, Merleau-Ponty rejected the Cartesian separation of the mind, our thinking subject, from the body. From this Cartesian point of view, our body is left as a mere object in the world as all other objects; detached from our mind, who in return are looking at the world from an outside perspective. From Merleau-Ponty’s view, such a perspective meant that the detached thinking subject was not embodied in the world, and thus was not able to give things meaning or value. Our body then becomes an object as any other object, an object to be observed, which Merleau-Ponty emphasize is not how we experience our bodies. We live in our body, and it is through our body we experience the world.
This is not to say that our body is not an object. Indeed, Merleau-Ponty recognizes that for us to be in the world as a subject, we have to inhabit a physical, anatomical, objective body. What Merleau-Ponty is saying, is that, for us to exist as human beings, we are bound to inhabit a body. We need to live our body, and through living in our body, we can experience the world. As Merleau-Ponty put it, “I am my body” (Merleau-Ponty, 2002, p. 231).

This concept of the lived body was originally something Merleau-Ponty inherited from Husserl’s phenomenology. Husserl had made a distinction between two different instances of our body and ourselves, *körper* and *leib* (Aho & Aho, 2008). *Körper* is the corporeal, skeletal and anatomical body as other people and objects experience it. The objective body, as described by the scientific tradition. *Leib*, on the other hand, is the living body that we ourselves experience living through, our way of sensing, perceiving, thinking, remembering and seeing people and objects around us, and how that makes us feel (Aho & Aho, 2008). It is through the lived body we experience all phenomenon in the world, and thus we cannot experience the world without a body. As mentioned above, Merleau-Ponty believed that we are in need of the objective body, the *körper*, for us to inhabit and live through. Our lived body, *leib*, cannot exist without our objective body, the *körper*. Thus, our experience of the world is also an experience of one's own inhabited corporeal body.

This distinction, between the scientific, objective approach of investigation, and the subjective, is of importance in my work for several reasons. ME remains an enigma to the doctors (see Chapter 2), and there is no blood test or physical examination that can establish the diagnosis for certain. The diagnose is rather set after a thorough investigation of the clinical picture, excluding all other physiological or psychological explanations. You can imagine how frustrating and time consuming this can be for a patient that is indeed feeling very ill. Therefore, the diagnosis is, at the end of the day, set on the basis of the person's subjective experience of the illness, and how it affects their lived body, their *leib*. They can report of excruciating pain in their muscles, bones and joints, that is nowhere to be found on medical examinations, in their *körper*. Getting medication or painkillers is therefore not easy, the patient is bound to have a doctor that understands and believes that the illness actually exists, even though it has not been
explained in the *körper* kind of way yet. When doing research with such a vulnerable user group, having emphasis on their *leib*, their subjective experience of the illness, and how it affects their life and their body, is the only way to start understanding their experience of the illness. With a phenomenological approach, I provide my user group with the power to control the design space. I believe that such an approach, focusing on their personal experiences and feelings, will set the right basis for my design space and give me the correct insight into how technology can assist in making their everyday life better.

### 3.2.3 The phenomenal body

Another concept Merleau-Ponty introduced in his thinking was the concept of our body schema (body image). According to Merleau-Ponty, we do not experience our body as an “assemblage of organs” (Merleau-Ponty, 2002, p. 112), but as a single whole:

> “I am in undivided possession of it and I know where each of my limbs is through a body image in which all are included” - (Merleau-Ponty, 2002, pp. 112–113)

He exemplifies how our living body is a phenomenal body, in which we can immediately point to where we got stung by a mosquito (Merleau-Ponty, 2002, p. 121). We do not need to look for our hands or fingers when we are reaching for a glass or using a scissor; they are a part of the bodily space that we inhabit and is not perceived as single objects to be discovered, like the scissor or the glass. We are in complete knowledge of the specifics of our body and know immediately where our left foot, right ear or navel are. The lived, phenomenal body holds the essence of who we are, and therefore we cannot ever objectify a body and understand the totality of the person and their experiences. With this in mind, it becomes obvious that a purely scientific approach can understand a person's objective body, the *körper*, but that such an approach will struggle to understand the person's subjective experience of the illness.

The phenomenal body is of importance for me from an epistemological point of view, as I want to better understand the experience of being struck by ME. I believe that understanding ME through the lived experience of the
person suffering and how it affects their phenomenal body will give me knowledge into the phenomenon of being ill.

### 3.2.4 The phenomenon of being ill

As Aho and Aho argue in their book, “Body Matters” (Aho & Aho, 2008), illnesses is experienced subjectively by each individual, as they are influenced by their own history and the socio-cultural environment around them. In their book, they examine, with a phenomenological lens, how being sick is much more complex than one might think.

ME patients are not only part of a history that has chosen not to perform medical and scientific research on their illness, but also part of a socio-cultural environment that distrust their personal experiences and often stigmatize their illness as a mental disorder they have caused themselves to suffer from. Aho & Aho (2008) state that these facts must be considered as part of the person's experiences of an illness, and that purely objectifying an illness means that you peel off important factors that have a say on the phenomenon of being ill.

Another interesting aspect that the authors raise, is the phenomenon of being struck by illness. As long as you live your life as a healthy human being, you do not experience or think of your body parts as something on their own. You experience “I” as your whole body, as a unison, and it is not until your head aches or your foot is hurting that you actually become aware of their existence. As long as we are healthy, we do not explicitly think about the fact that we are living and are not explicitly aware of the existence of our “I”. We are, as Merleau-Ponty would say, living as “common flesh” (Aho & Aho, 2008, p. 142), and it is not until we are, for instance, struck by illness or feels the anxiety of death, that we actually are conscious of our own existence.

**Shrinkage**

In their book, Aho & Aho (2008) have tried to explain what is happening to a person when struck by illness. They introduce the concept of *shrinkage*, to explain how the world around you collapse when your bodily capabilities change in a negative manner. According to the authors, when struck by an illness you do not only become conscious of your own existence, or your
body parts as single objects. You also experience a change in the bodily 
space you inhabit, and the lived space you are a part of. This lived space is 
not only the three-dimensional geometrical space we know through length, 
height and depth, it is rather the space we are a part of and take for granted 
when living through our body. The lived space is, together with our body, 
what constitutes the understanding of ourselves and who we are.

To illustrate what Aho & Aho (2008) means with a personal example; I am 
a student because I am inside the University’s building, I have climbed the 
stairs to my department’s floor, I have opened the door to my classroom, 
and I have sat myself at a desk to read an article. When being healthy, we 
interact with the lived space as part of it, and it as a part of us, as an 
inauspicious entity. I am in a state where the lived space around me represent 
a “can-ness”, an arrangement of possibilities. I can climb the stairs, I can 
read the article, I can be a full-time student. When struck by illness, this 
feeling of “can-ness” disappears, and instead a feeling of “can’t-ness” emerge. 
The possibilities the lived space once offered vanishes, and the boundaries 
of my world begin to collapse. The stairs are too many, and the article too 
long to read. I can’t be a full-time student.

Another example of this shrinkage in space is seen in Toombs’ (2001) 
reflections of her own bodily changes when living with multiple sclerosis 
(MS). Toombs explain how the cause of her illness can be described through 
anatomical and medical explanations, but that this explanation does not 
capture any of the true experiences she has in her everyday life with the 
illness and its disruptions on her body. When living with MS, you do not 
only have to get used to a set of symptoms that will be with you for the 
rest of your life; you also have to acknowledge the fact that the illness is 
 somewhat “uncontrollable” and will progress with more and more severe 
symptoms and bodily disabilities. Toombs argues that our personal 
experiences of the lived space around us is affected both by our bodily 
capabilities, as well as how the surrounding space is designed. It is no longer 
a question of how far it is to walk somewhere, but rather a question of what 
is between here and there: “Is the terrain suitable for a wheelchair?” 
(Toombs, 2001, p. 249).

Aside from bodily disabilities, pain can constitute the feeling of shrinkage 
(Aho & Aho, 2008). To exemplify what the authors mean, a personal
experience of struggling with Ankylosing spondylitis can illustrate their point: When having pain in your back, pelvis, chest, neck, and knees your bodily capabilities change according to the “control” the pain has over your body. Suddenly, the mere act of walking to the supermarket is now an exhausting journey. Once you are there, the pain is so severe that picking up groceries from a shelf too high or too low can be unmanageable, not to mention carrying the bags all the way home, and up the three floors to your apartment. Once at home, laying down in the sofa to catch a breath is not a pleasant endeavor, you have to cautiously arrange your legs and back for the pain to be bearable, and trying to sleep in such a position is hard, almost impossible. The once taken for granted capabilities of your body is more evident than ever, because they are indeed gone, and you suddenly have to approach the lived space around you in a completely new manner.

When working with people with ME, I argue that understanding their world and how it has shrunk with the onset of the illness will be of importance. As mentioned in Chapter 2, their symptoms are numerous and individual. Their abilities and their lived space can thus be afflicted in many possible ways. For me to understand their authentic experience of the illness, I need to understand how the world has collapsed around them. I need to know how the fatigue is changing how they perceive the lived space around them; I need to understand how the muscle pain, the fever and the flu like symptoms are changing their “world.” As previously mentioned, if I want to design with and for my user group, I need to get knowledge about their lived experience of the illness, the phenomenon of being struck by ME, which I argue also includes their experience of shrinkage.

**Body schema**

As mentioned above, according to Merleau-Ponty, we inhabit a body schema that gives us immediate knowledge about the whereabouts of our body parts and their capabilities. Thus, our body schema gives us knowledge about our phenomenal body and which actions we are able to perform (Svanæs, 2013, p. 12). When struck by illness, our body schema is also affected, as our capabilities change and the knowledge we once had about our body vanish. Changes in their body schema is a concept I would like to investigate with my user group, as I believe that the typical ME symptoms, such as fatigue, pain and cognitive difficulties, will affect their phenomenal body in many ways. By acquiring knowledge about how their body schema
changes with the onset of the illness, I can better understand how technology can contribute to reduced shrinkage.

**Incorporated objects**

When existing as humans, we also exist in a world of other people and objects. Some of these objects have a special meaning to us, in the sense that we can use them in certain ways to accomplish a specific task. When using these tools to accomplish a task we are increasing our capabilities outside human ability. We are incorporating objects into our bodily space, adding to our body schema. A good example of this is seen in Joshi (2017), where he describe how we can expand our body schema by incorporating objects into our bodily space, such as when using a scissor:

“The scissors, as a tool, has become a part of us and through it, we can perceive the paper. By touching the paper through the scissors, we supplement what the eyes see, the nose smells, and the fingers feel. We sense the paper’s material composition through the resistance of the paper as the scissors cut through. Our perception begins not when we grab the scissors, but rather at the point of contact between the scissors and the paper.” (Joshi, 2017, p. 85)

Another example of how we can incorporate objects into our body schema is the example presented by Toombs (2001, p. 256). In the example she describes the experience of how her wheelchair became incorporated into her bodily space, as part of her body, and that she felt the width of the chair as she was automatically turning the wheels round and round to move forward. The objects become an expansion of our body schema and increase our contact with the world. The blind man can orient the world with his stick, the old lady can walk to the supermarket with her walker, the ME sufferer can take a noisy car ride when wearing earplugs.

For me, the concept of adding objects to our body schema is interesting in the way that I am doing research into how to make and use research products to mediate the state of the phenomenal body. In my approach, I combine theory about incorporated objects with research products to generate new knowledge about their meaning for the participants. By doing this, I want to explore how the artifact can be incorporated into the participants body schema and in time reduce their feeling of shrinkage.
3.3 Summarizing the framework

I have now introduced five concepts from phenomenology: the phenomenal body, the phenomenon of being ill, shrinkage, body schema and incorporated objects. The concepts will be used throughout this thesis as guiding concepts to get knowledge about the subjective experience of living with an illness like ME, and how to design research products that can be incorporated by the participants.

The phenomenal body will guide my way of acquiring knowledge, as I am striving for knowledge about the subjective experiences of my user group. In this way, I want to get an understanding of the phenomenon of being ill. This understanding will guide me through the design process as I get knowledge about how the phenomenon of being ill will shrink the participant’s lived space, by reducing their body schema, and how research products can be incorporated to possibly reduce the feeling of shrinkage.
4 Methodology & Ethics

Given the phenomenological “lens” I had taken, as described in Chapter 3, assumptions about the world and how to gain knowledge about that world was already present. I wanted to understand the subjective experiences of living with an illness like ME through the participants’ context and point of view. Hence, a qualitative approach was already given, as qualitative data is used when wanting to understand the deeper meaning of the participants’ lived experiences and the phenomenon through their context and point of view (Marshall & Rossman, 2014). The methodology I chose was based on these underlying philosophical assumptions I had about the world (Myers, 1997). Following the research question and the theoretical lens, my methodological approach already rested heavily on strong user involvement and qualitative data about subjective experiences, as well as making and using research products to generate new knowledge about the phenomenon under study. At the same time, I was also faced with the fact that my research involved a user group that did not have the capabilities to participate in the design process fully, and that had limited capacity to offer me much of their time during our encounters. The ethical considerations of working with a vulnerable user group thus also affected my research approach.

In this chapter, I first present the methodological approach of RtD and explain how this methodology guided my approach (Section 4.1). Second, I present the ethical considerations I needed to take into account in my research approach when working with a vulnerable user (Section 4.2).

4.1 Research through Design

RtD is an emerging approach to the HCI community and is focused on the making and using of artifacts to generate new knowledge about a phenomenon under study. Reflecting on my research question, my approach thus is strongly based on the principles from RtD. In the following section, I present a brief overview of RtD as a methodology, as well as show my specific RtD approach followed during this study.
“Research Through Design is taking design as a particular way of thinking, and a particular approach to knowledge, which helps you to understand certain things that exist outside design.” - Frayling quoted in (Durrant & Price, 2015)

RtD as an approach has had a growing interest in the HCI community the last decade but was initially introduced in the art and design community. Sir Christopher John Frayling first coined the term in 1993, where he addressed the issue of how design and research have been regarded as separate entities for too long (Frayling, 1993). In his article, Frayling emphasized the importance research have had, will have and can have on the practice and teaching of design and art. He then suggested three ways in which research, design, and art can meet; research into art and design, research through art and design and research for art and design. Research into design concerns the research into the human activity of design, and research for design concerns research intended to advance the practice of design (Zimmerman & Forlizzi, 2014, p. 169). Research through design is more of a research practice where the focus is on improving the world by using design as a means to “disrupt, complicate or transform the current state of the world” (Zimmerman & Forlizzi, 2014, p. 169). It is an approach to doing research, and is as Frayling said “about taking a problem outside of design and using design to address the problem and generate new knowledge” (Durrant & Price, 2015). The researcher speculates about the future and ground their design work on a thorough understanding of the user group and the application of available technology (Zimmerman & Forlizzi, 2014). Zimmerman & Forlizzi (2014, p. 167) argue that RtD is “an approach to conducting scholarly research that employs the methods, practices, and processes of design practice with the intention of generating new knowledge.” In this way, designers can take advantage of their skills to investigate a problem through design and create prototypes or research products that will play a central role in generating knowledge about a phenomenon and explore alternative futures.

Gaver (2014) shows the essence of RtD by pointing out the difference between research through science, and research through design. In his paper, he makes his point by polarizing science and design as something that needs “to defend one’s knowledge, on the one hand, and that one’s productions work, on the other” (Gaver, 2014, p. 148). He explains how science is not
concerned with how interesting the results of research are, the novelty of an artifact or which problems the research solve. Instead, science is concerned with proving that the knowledge gathered and expressed is true, by explaining and defending the process and the conceptual, theoretical and practical decisions. What is most important is if the research is replicable, objective, generalizable and is based on causal explanations, and that it can explain phenomena and predict new ones. Design on the other hand, he says, is fundamentally concerned with creating something new that works, and not with explaining the world as it is. He further introduces the concept of epistemological ambiguity, a concept describing the “fluid flow between uncertainty and speculation that design allows” (Gaver, 2014, p. 153). When creating something new, he explains, the designer is exploring a context, developing a design space, making proposals, choosing, refining and creating a working design, and is learning about the design by placing it in the hands of the users. During this process of merging “ideas, materials, technologies, timings, situations, people and cultures” (Gaver, 2014, p. 162), the designer is constantly generating new knowledge. According to Gaver (2014), this generation of knowledge through the practice of design is what constitutes RtD: “[Research Through Design] should not be seen as an attempt to bring the principles of science to design, but as an autonomous approach that uses projection and making as tools for learning about people, technologies and the world” (Gaver, 2014, p. 163). Reflecting back to my research question, such an alternative way of approaching research has been a valuable tool and a necessity in my research approach. With such an approach, I have been able to make and use RelaxMe to generate new knowledge about its meaning for the participants in my research taken into account their vulnerable situation and specific needs.

RtD as a design research approach is as mentioned above relatively new to the HCI community, and questions about the particular qualities of the contributions to knowledge are still being discussed (Gaver, 2012; Höök et al., 2015). Researchers in the field are raising questions about what type of knowledge RtD is generating, the role of the prototype or artifact, if there is a particular way in which RtD projects should be carried out, and how the knowledge generated should be communicated (Stappers & Giacciardi, 2018). There are no finite answers to these questions, and different authors have different opinions on the knowledge contributions RtD as a methodological approach can offer (Gaver, 2012; Koskinen, Zimmerman,
In Chapter 8, I discuss some of these issues in hindsight of my approach, looking at how this particular RtD project was carried out and communicated, and what role RelaxMe had during my project.

4.1.1 Lab, Field, and Showroom

Koskinen et al. (2011) look at how RtD, or constructive design as they prefer to call it, has been successfully conducted the last decade or more. They suggest a framework of three types of design research they call “Lab”, “Field”, and “Showroom”. I will now present a brief overview of the three types, and at last, argue why the Field approach guided my research project.

Lab

The Lab approach has its roots in the natural sciences but is also widely used in design. Koskinen et al. (2011) argue that the controlled environment offered by the Lab approach can be beneficial when testing competing hypothesis’ or alternative explanations. The Lab approach gives the researcher the ability to control specific variables more easily than in a natural setting, and thus look at one thing at the time (Koskinen et al., 2011, p. 55). It can also offer equipment for detailed measuring and observations of the participant’s behavior and responses (Koskinen et al., 2011, p. 56). The pros listed above do come with a price, and Koskinen et al. (2011, p. 63) question if such controlled studies can tell us anything about the real world.

Field

The goal of a Field approach is to look at how people interact with a design in the context of the real world. According to Koskinen et al. (2011), the field approach “contextualizes” the design research performed (Koskinen et al., 2011, p. 69). They call the process of contextualizing and understanding the real world as design ethnography, as the methods used to gain an understanding is based out in the field. The Field approach thus have many similarities to how social scientists work, but adds the extra component of a product, thing, mock-up or prototype to generate new knowledge (Koskinen et al., 2011, p. 75). The authors further explain that prototypes usually are developed to create a dialog between the users and the
researchers, and to focus on what the users do rather than what they say. The process when a design idea emerges from fieldwork can sometimes seem mystical to non-designers, an aspect of the fieldwork approach they raise as a potential issue. Another issue they raise is how the knowledge created from field research is local and temporary and cannot be applied uncritically to other contexts (Koskinen et al., 2011, p. 81).

**Showroom**

In the Showroom approach, design researchers create and exhibit “provocative artifacts that force people to think, to notice, and to reconsider some aspect of the world” (Zimmerman & Forlizzi, 2014, p. 173). The approach is primarily influenced by critical design, an approach that challenge common assumptions and the status quo through the design of artifacts (Zimmerman & Forlizzi, 2014, p. 173). The approach relies on a debate to elicit change in everyday life of people, and a common way to exhibit the objects created in the design process is through prototypes, photographs, and video, as well as books and articles (Koskinen et al., 2011, p. 95).

**4.1.2 My approach**

In my case, I was guided by the Field approach. Following my phenomenological lens, I strove for understanding the context through the eyes of the user group and their subjective experiences. Thus, I wanted to contextualize my approach as the user group is continuously affected by the struggles of a real-life context living with an illness like ME. Through engaging directly with the user group both during a workshop and in-depth telephone interviews, I gained an understanding about the design context that enabled me to create RelaxMe as a research product fitted for the user group. I wanted to let the participants use RelaxMe in a real-life setting, and generate new knowledge based on their interactions with it in their natural context. The reason for this was based on what I wanted to accomplish with this study and reflects back to my research question and my theoretical approach. To be able to explore the real meaning RelaxMe had for my participants, I argue that placing the research products in the field to generate new knowledge about them in a real-life context would generate the kind of knowledge needed to answer my research question. To take a more decontextualized approach and conduct controlled experiments,
such as in the Lab approach, I argue would not have generated the kind of knowledge I was after. I did not wish to look at the relationship between RelaxMe and its usability compared to other similar artifacts, nor did I want to “decontextualize” the participants from the struggles of a real-life context living with an illness like ME. Also, I was not interested in showcasing the research products and provoke critical thinking through an exhibition of RelaxMe.

4.2 Ethical considerations when working with vulnerable users

When looking at the typical symptoms a person with ME can experience, they are at risk because of their diagnosis and can be seen as vulnerable users (Culén & Karpova, 2014). The stigma related to the diagnosis further emphasize this assumption. When working with a vulnerable and stigmatized user group, I argue that the ethical considerations surrounding my study will affect my methodological approach along with the phenomenological lens and guiding principles of RtD. As Guillemin & Gillam (2004, p. 262) emphasize: “The ethical dilemmas and concerns are part of the everyday practice of doing research.” Both the political and personal aspects of my research conducted is something that was taken into consideration, and that I reflected upon during the entire research process through practicing continuous reflexivity (Guillemin & Gillam, 2004).

In the following section, I present the ethical considerations I undertook during my research process with vulnerable users. First, I present the formal approvals or the procedural ethics (Guillemin & Gillam, 2004) I was bound to adhere to. Lastly, I present the microethics (Guillemin & Gillam, 2004) of my research process when designing with and for a vulnerable user group.

4.2.1 Procedural ethics

Guillemin & Gillam (2004) argue that there are (at least) two dimensions of ethics in qualitative research. The first is the “procedural ethics,” which concerns seeking approval from official ethics committees. Because my research gathered and processed personal information, I needed to follow the guidelines for appropriate data processing set by the Norwegian Personal Data Act. As I collected and processed personal information in my
research, I was bound to seek approval for my project from the Data Protection Official for Research in Norway, called the Norwegian Centre for Research Data (NSD). When seeking this approval, I had to make sure to show that I was processing and correctly handling the personal information, storing it in a safe place, and not sharing the information with anyone else. I also had to attach information about what data I was gathering (interview guides, explanation of methods used, etc.), that I was providing my participants with correct and comprehensive information (participation, anonymity, data storage) and that I was getting a free consent from the participants (consent form). I also needed to show how the personal data is minimized, anonymized or deleted once the grounds for processing no longer is valid. My research project was approved by NSD the 1st of February 2017 and later accepted once more on the 2nd of November 2017, when extending the methods to include an exploration of RelaxMe in the field. These approvals contain both the necessary and complete procedural ethics foundations for my research.

**Interviews**

During the whole research process, I was careful to make sure the participants were informed of what participating in a study meant. Thus, before conducting the interviews with the user group I sent information about the interview and a consent form to the users, encouraging them to ask any questions they had before the interview. Also, when beginning every interview, I briefly explained the purpose of the interview, handed out the consent form if it was not already signed (see Appendix E-G) and asked for approval to record the interview. I also emphasized that they should let me know if they if they had any question, got fatigued or wanted to end the interview.

**4.2.2 Microethics**

What is apparent is that the approval from NSD did not state how I as a researcher should behave around my participants beyond what data I was allowed to gather. Neither did the approval direct how I should communicate with my participants, what considerations I should take into account when working with my user group, nor what kind of every day “messy” dilemmas or concerns I might meet during my research process (Crang & Cook, 2007). Guillemin & Gillam (2004) refer to these ethical
considerations as the “ethics in practice” or microethics, which concerns the everyday ethical dilemmas and concerns that arise during the whole research process, and that is typically not addressed in procedural ethics. Culén & Karpova (2014, p. 613) describe how an “awareness of vulnerabilities in a design situation may be helpful in designing better products for vulnerable people” and that such a design approach might even eliminate some of the risks of including them in a research study entirely. Following their statement, I addressed the ethical considerations that affected my research approach and that I needed to consider during the day-to-day course of my research process with a vulnerable user group. The considerations are presented below.

**Designing with vulnerable users**

When considering the many symptoms people with ME might experience, it is easy to imagine how participating in my research study or using RelaxMe could be challenging for them. All sorts of mental and physical tasks which requires either mental or physical effort could potentially aggravate symptoms. In other words, as seen in Best & Butler’s (2012, 2013b, 2013a, 2015) studies on the virtual 3D world, Second Life, just the act of learning a new game or struggle with a technological artifact, or more generally, use some sort of technology, could make a person with ME sicker. Hence, including individuals suffering from ME in my study was not something that should be done without considering the potential physical and mental exertions my research approach might cause. I needed to make sure that the benefits of participating in my study outweighed the drawbacks, and that the technology did not put my participants at health risk (Børsting & Culén, 2016b). Awareness of potential risks was gathered by getting a comprehensive understanding of the user group, before involving them directly in my study. This understanding was gained by reading literature about the illness (see Chapter 2) and by talking to domain experts (see Section 5.1).

**Choosing and customizing methods**

Designing technologies for and with vulnerable users can be a demanding and challenging process. Traditional methods for data gathering might not apply to research situations including vulnerable users, and it can be difficult to modify these methods or to find new ones that would work better (Culén & van der Velden, 2013). In my context, I have found very little
research on how to include people with ME in design research. Hence, I was dependent on continuous reflexivity to make sure the methods I used were modified and improved to fit the needs of the participants. In the context of my research, I definitely agree with Markham (2005) when she argues that every method decision is an ethics decision. In my research, an important aspect when selecting which methods to use was the ethical concerns of working with a user group that experiences debilitating health challenges. When including people with ME in my research, such as through a workshop or an interview, mere participation might aggravate illness symptoms as they need to use both physical and mental effort. As mentioned in the description of the typical ME symptoms, and as described in the research regarding people suffering from ME’s response to the CPET-test (see Chapter 2), it can take hours or days before abnormal fatigue and prolonged recovery period flare up. It was therefore not enough to make sure the participants did not get too tired during participation, as aggravated symptoms might emerge later on. Thus, during the planning of the data gathering, I carefully considered what kind of tools I used and customized them to fit the needs of my users through expert reviews with my supervisor, Jorun, and pilot studies with fellow students. My goal was to create tools that prevented cognitive symptoms from dominating, and that did not stress the participants’ fatigue. By doing this, I hoped to create a safe environment where true participation could happen. At the same time, I made sure that I, as a researcher, got the knowledge I needed, without stressing the participants unnecessary through, for instance, constantly asking if we should end an interview and show deep understanding and sympathy towards their symptoms. What was important for me was to make sure the participants had a voice and a say in the process, and that they felt heard and understood during the interviews.

**Evaluating methods and tools**

Since I was new to working with people suffering from ME, I felt obliged to practice critical reflexivity with regards to the use of methods. As well as doing extensive research about the illness and their potential vulnerabilities before meeting the participants, I decided to evaluate methods and tools used with the participants during the research process. By doing this, I wanted to improve the way I gathered my data continuously throughout the process, reflecting on my use of methods and tools and ways of communicating with the participants. The results of the evaluation with the
Design for all

Users of assistive technologies often feel stigmatized if the technology stands out as assistive (Culén & Karpova, 2014). During the design process, it was thus essential that I made sure the technology was “made for all” and that I avoided design choices that could be stigmatizing for my participants (Culén & Karpova, 2014). During the design process, this was accomplished by talking to the user group about what tools and designs they feel are stigmatizing, as well as looking for design inspiration outside the sphere of assistive tools.

Communication

I have chosen to perform a phenomenological study in a social context, and as Crang & Cook (2007) argue, social research is bound to include conversation-making. During my study, I was constantly talking with the participants, both when recruiting, when scheduling meetings, during interviews, or when doing a survey. I was always communicating with the participants in some way, and how I chose to go about that communication I argue was, in my research, a question of ethical consideration. When working with a vulnerable user group that experiences cognitive symptoms and fatigue, and where every mental and cognitive exertion might aggravate symptoms, communicating in the best possible manner was vital for several reasons.

First, I needed to make the information I handed out as precise and concise as possible. A too long email can scare away potential participants, as well as cause them to feel less about themselves when not being able to read the email. A consent form of several pages can likely cause the participant to miss necessary information about the study, what it means to participate, their right to free consent and their right to anonymity. Second, my way of communicating when engaging in the data gathering would be of importance. It was critical that I asked the most important questions first, talked in a slow, non-complicated and calm way, avoiding jargon or difficult sentences that potentially caused the participants to feel disregarded. Third, I needed to keep a balance between talking about their illness and how severe it is, without reminding them of how “bad” their lives are. I needed to consider that they do experience stigma and mistrust from friends, family
and healthcare professionals, and thus show them that I believed in the illness and the symptoms they have, without stressing a feeling of hopelessness with regards to the illness.
5 The design process

This chapter describes and documents the design process conducted throughout this research project. In chronological order, I describe each step I took from start to finish for the reader to understand how the artifact RelaxMe was created. In Section 5.1, I describe how I performed an expert interview with two domain experts to gain more knowledge about the role technology can have for energy modulation and ME in general. The interview gave me insight into the specific details of energy modulation, and sparked a first prototyping phase, as seen in Section 5.2. In this explorative prototyping phase, I broke down the activity of energy modulation into pieces and looked at the specifics and their relevance to technology. From this exploratory phase, several low-fidelity prototypes were created with the intention of understanding what my knowledge about the design context was. The design ideas were further brought into a workshop with the ME association, as described in Section 5.3. In the workshop, I was able to talk to the user group directly, pitch my ideas for potential technological solutions and discuss the ideas’ relevance for the user group. From the workshop, my interest towards the pulse and specifically, the anaerobic threshold was sparked. Thus, I wanted to perform interviews with the user group as described in Section 5.4, with the purpose of gaining more knowledge about the user groups’ subjective experiences of the illness. Specifically, I wanted to learn more about how they coped with their illness in their everyday life through energy modulation. A merging of this knowledge, the initial ideas about the research product (as described in Section 5.2), research on ME and the anaerobic threshold (as described in Chapter 2), and my own skills as a designer was then used to make a research product that would enable the anaerobic threshold to become observable for the user and thus hopefully make energy modulation more efficient. The making of the final research product, RelaxMe, is described in Section 5.5.

Describing the design process and the making of RelaxMe has been a challenge, as the process of creating RelaxMe includes more than the explicit methods and activities did throughout the project. Several decisions have, most likely, been taken based on unconscious processes that I was not aware
of, as the activities when making an artifact includes a mix of my skills as a designer, my initial understanding of the user context, the theoretical approach, the results from my workshop and interviews with the user group, and revisiting of relevant literature. I also believe that working closely with a supervisor that has experience within the domain has given me knowledge that I am not explicitly aware of receiving. As mentioned earlier, the issue of how to document, describe and communicate the knowledge generated through a design research process has been widely discussed in the RtD community (Gaver, 2014; Höök et al., 2015; Zimmerman, Stolterman, & Forlizzi, n.d.). A discussion of the issue in the context of my project will thus be raised in Chapter 8.

5.1 Expert interview

The preliminary research as described in Chapter 2 acted as an initial scoping phase of my research process. When learning about the illness, its prognosis and treatment strategies, interest in energy modulation was sparked. Specifically, I was interested in how people with ME could potentially benefit from the use of technology when energy modulating. As I already had learned about common symptoms, prognosis and possible treatment methods through my preliminary research, I was intent on exploring the role technology could serve in this context. As seen in Section 2.3, very little literature covers the use of technology when suffering from ME. Hence, I scheduled an interview with two domain experts within ME and technology. The two domain experts have researched on the use of technology by people with ME since 2015. Their knowledge about the user group, technology, and future possibilities was thus expected to be significant. I also asked questions regarding the illness and how to balance symptoms to complement and challenge my understanding from the preliminary research.

My motivation for including domain experts was due to ethical considerations towards the user group. This early in the process, I did not feel I had the knowledge needed to include the user group in my study in a “safe” way, and I would rather talk to domain experts than to put my participants at risk. An efficient, but still indirect, way to gather data about the domain was what I wanted. Kittel (2012, p. 2) argue that expert interviews are a great way to obtain such knowledge about a phenomenon
efficiently.

5.1.1 Planning the interview

I wanted to get deep knowledge about the domain experts’ understanding of the domain and explore the field within the boundaries of my questions. Lazar, Feng, & Hochheiser (2010, p. 178) argue that interviews are a great method for gathering deep knowledge about a phenomenon, as it could be hard to capture through other methods. Interviews vary widely in structure, from open-ended, unstructured interviews, to highly structured and rigid interviews (Lazar et al., 2010). I decided to conduct a semi-structured interview, as I had a theme I wanted to explore, as well as a list of questions to ask. At the same time, I wanted to be able to explore topics and questions emerging from the conversation. This would not have been possible with a structured interview, as the conversation would then be based on a rigid list of questions asked in a well-defined order (Lazar et al., 2010). Additionally, an unstructured interview would not have been suitable, as the conversation than would be based on an overall theme and the interviewee would control the conversation themselves (Lazar et al., 2010). To make sure I asked all the necessary questions, I created an interview guide. The guide still allowed for a randomized order of questioning and the possibility to add new questions, as in line with semi-structured interviews. The interview guide can be viewed in Appendix B.

5.1.2 Execution

The interview was conducted at the Department of Informatics the 14th of February 2017 with both domain experts present. The interview lasted 48 minutes. I did not transcribe the interview but listened to the recordings and wrote down important notes from the conversation.

5.1.3 Key findings from the expert interview

An overview of key findings that I brought with me further into the design process from the expert interview is now presented. A comprehensive presentation of all the results from the expert interview can be viewed in Appendix J.
Key findings:

- The reason for the little research on ME and technology is two-fold. Stigma and suspicion of being a psychological disorder have created a barrier for performing research in the field. Furthermore, the specific symptoms apparent when suffering from the illness (light, sound, cognitive symptoms, fatigue) do not consolidate with technology.
- A somewhat uncontrollable illness and highly individual symptoms make designing technology to people with ME even more demanding.
- Cognitive symptoms and fatigue create a barrier for learning new things, including technological devices that potentially can improve their everyday life.
- Energy modulation is a key activity in balancing and reducing symptoms but is often too demanding to perform for people with ME. Technology’s potential to help with the registration is significant, especially if the technology can register variables automatically.
- A stress-free life is a good life for a person with ME. Technology should thus not be stressful to use or require strict monitoring. Technology can potentially help people with ME live a less stressful life.
- Mental health is important to consider, as people with ME often feel left out of society and find the comfort of having positive aspects in their life. Technology has a potential to help them have more good things in their life.
- A need for technology that helps with energy modulation and cognitive symptoms is present. Currently, many people with ME use, ironically, a fitness watch to measure biometrics like sleep and activity automatically to help with their energy modulation.
- Technology has a significant potential in helping with energy modulation because it can measure biometrics automatically, visualize these biometrics, and tell the user to stop behavior that is destructive (for instance remembering to rest). Variables that are interesting to look at are, e.g., temperature, activity, nutrition, light, and sound.
5.2 The beginning of an artifact

After the expert interviews, I started the making process of the research product to explore the potential use of my current knowledge obtained. As mentioned, I knew that energy modulation was something I wanted to investigate further. The expert interviews strengthened this belief and provided me with an insight of interesting variables to explore with regards to energy modulation and technology. To explore the technological potential for each variable, I started, in a systematic fashion, reviewing the different stimuli and factors that were mentioned in the interview. While reviewing the variables, I also revisited the literature about ME and added a few more factors that have a say on symptom aggravation. The variables I explored in detail was stress, temperature, movement from others, movement from oneself (activity), light, sound, diet, sugar intake, pulse, and sleep.

My initial idea was to explore if it was viable to create an artifact that would make it possible to warn against strong stimuli, such as high noises on the bus or strong light outside. I imagined that with such an artifact, the users could potentially avoid overexertion. At the same time, I also wanted to explore how an artifact could create a statistic of their behavior for them to learn from. Following the exploration of variables that has a say on overexertion, I then explored how the user could easily register variables related to overexertion, such as sleep, fatigue, pain, nausea and general well-being. A mind map of the process can be seen in Figure 2.

A goal for me when designing an artifact for people with ME was to potentially reduce some of the shrinkage people with ME experience by enabling easier self-monitoring and self-management of the illness. As mentioned in the findings from the expert interview, people with ME tend to feel left out of the society, as the world goes on without them being able to follow the normal pace. When designing for a user group that experiences many different symptoms, and where there are very individual experiences of the illness, design choices should be considered carefully. The question of where to place the artifact needed to be considered. Should I place the artifact on the users’ body or not? If on the body, where on the body? If in a room, where in a room? For this phase of the making process, I explored
the possibility for both scenarios and created different prototypes intended for different placements. Reflecting back to my phenomenological lens, the phenomenon of being ill includes the body and the body’s capabilities. A potential weak spot for people with ME is the ability to remember and to have the energy to register data about their behavior. Placing the artifact on the body could thus create possibilities for automatic measuring, such as measuring pulse, sleep or activity, that would not be possible if placed in the room. The expert interview also revealed that many people with ME already use fitness watches to register their activity and sleep. Thus, I explored how an artifact placed in the room could receive the data measured from the fitness watch, as well as register other relevant variables from the user directly. The question of how to represent and visualize different stimuli and factors was thus explored. How can reporting of subjective feelings like pain, fatigue, nausea and general well-being be solved in a meaningful way? The result of the exploration was different low-fidelity prototypes, as seen in Figure 3 and 4.

Figure 2: Exploring the potential variables and questions
I was still in a very explorative stage of the design process and often felt lost while prototyping. The process visualized the usefulness of my current knowledge about the design context, and it became evident what type of knowledge I was missing to create a meaningful and novel research product that could help with energy modulation. The phase was thus more beneficial for understanding how to move further with the design process than to create meaningful prototypes that could be explored with the user group. Nevertheless, before tossing the prototypes aside, I wanted to discuss the ideas behind the prototypes generated with the user group. The two ideas I presented to the user group was:

1. An artifact wore on the body that helps the user notice potential “dangers” such as too strong light and too loud noises around them in-the-moment.
2. An artifact that gathers sleep, pulse and activity data from a fitness watch, and that register general well-being and pain levels from the person to create a statistic of the course of their illness.
5.3 Workshop with the Norwegian ME Association

The prototyping phase gave me an understanding of what knowledge I was missing for the process to move ahead. The ideas generated was based on my knowledge about the user group and design context, and I wanted to discuss the two ideas with the user group and listen to their thoughts about the ideas’ fit in their everyday life with ME. Also, I saw an opportunity to learn more about the phenomenon of being ill through the subjective experiences of people with ME. This learning was done through a workshop together with four women from the Norwegian ME Association.

5.3.1 Planning

The workshop was initially a meeting between the Norwegian ME association, Jorun, and another researcher. Hence, the workshop was scheduled to report the results of their research and discuss potential future work. The planning of the workshop was done by Jorun, and I only prepared a presentation of my research project and the ideas I had been working on through my first prototyping phase. I also stayed for a card-sorting session.

5.3.2 Execution

The workshop was conducted Tuesday the 7th of March 2017. The workshop was split into two parts. First, I presented my research interest and current ideas and listened to the ME association’s thoughts about my plans for the project. Second, a card-sorting session was conducted (see Figure 5), where the participants were presented with a variety of cards with either text, an illustration, or both on it. Topics on the cards were: light, sound, smell, touch, sleep, movement, exercise, time, energy modulation, management strategies, technology, smartphones, social media, treatment, doctors, communication, care, politics, government, NAV, finances, guidelines, healthcare, transportation, home, friends, family, school, and stigma. The participants were then asked to choose a card and talk about their experiences regarding the topic at hand, discussing and sharing their thoughts with each other. They also shared problems they meet in their everyday life and expressed their wishes for future technological possibilities.
Some of the participants from the ME association are sufferers of ME themselves with mild to moderate severity and got fatigued after a while. Hence, we finished the workshop after talking about a few of the topics.

5.3.3 Key findings from the workshop

When presented with my research, the participants seemed positive to my initial thoughts and focus on energy modulation. However, they soon started talking about their ideas and showed little enthusiasm to the variables I had focused on (as presented in Section 5.2). One of the participants made me aware of the problems surrounding build-up of lactic acid and how the anaerobic threshold behaves differently in people with ME than from healthy people. As a result from this knowledge, she decided to try a “homemade” pulse alarm, where she wore a standard pulse strap and set her fitness watch to beep on a certain pulse level by activating the watch’s work-out mode. She said that she learned a lot from this and that it helped her and the people around her to be more aware of her boundaries. This interested me a lot and led me to explore research and literature dealing with the issue. It was at this point in the process I discovered the research presented in Section 2.2.4. After reading about the CPET-studies presented in the aforementioned section, my interest soon scoped in on the pulse and the anaerobic threshold as a variable when energy modulating.

The results from the card-sorting session were not relevant for my specific design context and have thus not guided me further in the design process. However, it was useful to listen to their experiences and learn more about
the issues they meet in their everyday life with the illness. A more comprehensive presentation of all the results from the workshop with the ME Association can be viewed in Appendix K.

5.4 Telephone interviews

As the initial making phase made evident, my understanding of the user group and design context was not sufficient enough to create a new and meaningful design. The workshop with the ME Association was an eye-opening to the potential importance of pulse as a variable when energy modulating. However, I felt that the workshop only gave me a superficial understanding of the user group’s subjective experiences of being ill. Hence, I felt the need to explore this part of my design context further through in-depth interviews with the user group. To keep the threshold for participating as low as possible, I decided to perform the interviews by telephone.

5.4.1 Planning

Recruiting participants

With help from the ME Association, 17 women aged 26 to 57 was recruited through a closed Facebook page for people with ME. I selected 10 of the women that differed in age and location. Six of the 10 women I contacted reached back to me, and we scheduled the interviews the coming week. Their age and location were widely spread (Ages: 26 - 26 - 31 - 33 - 53 - 57, Location: South, East, and North of Norway).

The interview guide

I decided to conduct a semi-structured interview with the user group, as argued in Section 5.1.1. The interviews had a warm-up and a wrap-up, as well as two main parts. The first part was concerned with what types of aids and assistive solutions the participants had been using or was using at the moment. The second part was concerned with typical factors, both positive and negative, that have an impact on the illness. For both parts, a brainstorming around future technological possibilities was also added. The purpose of the interviews was to get to know the user group and learn more about their subjective experience of the illness. As well, I wanted to look into technological possibilities and brainstorm on emerging ideas on how to
design an assistive research product tailored to fit into the lives of the participants.

**Expert review**

I asked my supervisor, Jorun, to review the interview guide, as I wanted to get feedback from a person experienced with researching on ME before talking to the user group. The reason was that it did not feel ethically right to do a pilot interview and test my in-experience on a person with ME. During our session, Jorun pointed out that her experience has shown that answering questions about a topic can make the participants forget preliminary thoughts they had before the interview. Hence, I edited the guide to include an open-ended question at the beginning of each part. The final interview guide can be viewed in Appendix C.

### 5.4.2 Execution

I performed six semi-structured telephone interviews lasting between 30-40 minutes each between the 4th and 10th of November 2017. One of the interviewees (P1) was so eager to talk, that when we reached the pre-defined 30 minutes, we had a lot of the interview left. She uttered that she was starting to feel fatigued, and we decided to schedule a new interview when she was feeling better. However, as time passed, she was not getting better, and we decided to take the rest of the interview via email sending one question at the time.

All of the interviews were transcribed either the same day or maximum the day after they were conducted. As a result, I was left with 84 pages of data to both analyze and use in future work. During the interviews, I noticed that one of the participants (P2) was not diagnosed based on the definition of ME I am working out from (see Section 2.1.1), and I decided not to include the data further in the project and did not transcribe the interview.

### 5.5 Analysis of interviews

I wanted to conduct a thematic analysis, as described by Braun & Clarke (2006), of my interviews with the user group to gain the best possible insight into the material collected. In the following section, I present what a thematic analysis is and describe the thematic analysis I performed. I do
this by presenting each phase, explaining what I did and what I learned throughout the analysis. After explaining the different phases, I present the findings from the analysis in Section 5.6.

5.5.1 Thematic analysis as a method

According to Braun & Clarke (2006, p. 79) thematic analysis is “a method for identifying, analyzing and reporting patterns (themes) within [your] data” through a six-phase process as seen in Table 1. They argue that thematic analysis fits well when wanting to extract the participants’ experiences, meanings, and realities, which is exactly what I wanted to accomplish.

When using thematic analysis as a method, Braun & Clarke (2006) mention a number of decisions that need to be considered and discussed. First of all, I needed to choose if the results should be a rich description of the dataset as a whole or if I wanted a more detailed analysis of a particular aspect of the dataset. The former causes the results to be shallower but will, on the other hand, give the reader an overview of the entirety of the dataset. The latter is more appropriate if one is looking for information on a specific area of interest or with regards to a particular question. I wanted to give a rich description of the entire dataset collected, as all my topics during the interviews were of equal importance.

Another choice that I needed to make was whether I wanted to perform an inductive or theoretical thematic analysis. With a theoretical approach, the researcher is more concerned with finding data that fits into the theoretical or analytical interest in the area (Braun & Clarke, 2006, p. 84). An inductive approach is in a way the opposite of theoretical. The process of coding the data is performed without trying to fit the results into a preexisting theory and is thus more data-driven (Braun & Clarke, 2006, p. 83). My analysis was mainly data-driven, and I thus performed an inductive thematic analysis.

Finally, I needed to decide on the level of analysis. Should I investigate the surface and only look at what has been said, or should I look beyond what has been said or done and look for underlying ideas or assumptions? The former is called a semantic analysis, while the latter is called a latent level
of analysis (Braun & Clarke, 2006, p. 84). I performed a latent level of analysis, as I wanted to understand the complex experience of suffering from ME.

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description of phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Familiarizing yourself with your data, transcribing, reading and re-reading the data</td>
</tr>
<tr>
<td>2</td>
<td>Generating initial codes by coding interesting features in a systematic fashion</td>
</tr>
<tr>
<td>3</td>
<td>Searching for themes by collating codes into potential themes</td>
</tr>
<tr>
<td>4</td>
<td>Reviewing themes and checking if the themes work in relation to the codes and the data set</td>
</tr>
<tr>
<td>5</td>
<td>Defining and naming themes by analyzing and refining the themes over and over</td>
</tr>
<tr>
<td>6</td>
<td>Producing the report by adding useful quotes and relating the data to the RQ and literature</td>
</tr>
</tbody>
</table>

Table 1: Phases of thematic analysis as proposed by Braun & Clarke (2006, p. 87)

5.5.2 Conducting the thematic analysis

Phase 1: Familiarizing yourself with your data

Since I had transcribed all the interviews immediately after they were conducted, I was already somehow in phase one of my thematic analysis. Nevertheless, I decided to re-read all the transcribed data once more and make sure to familiarize myself with what I was about to investigate. While reading through the data, I jotted down initial thoughts and ideas from the different interviews. Before I left phase one for more detailed coding, I skimmed all of the data once more and noted down in a list all my initial ideas about the data and what was interesting about them.

Phase 2: Generating initial codes

For phase two, it was time for coding interesting features of the data in a systematic fashion across the entire data set (see Figure 6), collating data relevant to each code (Braun & Clarke, 2006). At this point, my supervisor, Jorun, also joined the analysis, and we both coded the data individually. To be able to code the data together with another person I saw as a real advantage, as we potentially could discover different codes.
Phase 3: Searching for themes

The codes were then ready for phase three of the analysis, which included collating codes into potential themes (Braun & Clarke, 2006). Jorun and I scheduled a workshop together and booked a room with a whiteboard to use for this phase. We started the workshop by going through the transcripts and comparing our codes for the different segments of text. When we had a code that was the same or meant the same, we decided on a common code and wrote it on a post-it. All the individual codes were also written down on post-its, one by one. When this process was done, we started to use the whiteboard for sorting the post-its in potential themes as shown in Figure 7. After some discussion, we agreed upon the themes that we had made from the codes.

Phase 4: Reviewing themes

When these initial themes had been made with the data and code as the basis, the next step was to check if the themes worked in relation to the coded extracts and the entire data set (Braun & Clarke, 2006). The goal of this phase is to generate a thematic ‘map’ of the entire analysis. At this point, we decided that one of us, me, could do the reviewing of the themes and that Jorun could look at my work and suggest changes if she had some. I started with some fresh, un-coded transcripts, and began to re-read the interviews and used the new themes and codes we had made. During this re-reading and re-coding, I started to note down some changes to the codes.
and themes, relocating some of the post-its on the whiteboard as I went through the pages one by one. The changes can be seen in Figure 8.

Figure 7: Initial themes

Figure 8: Reviewing the themes from phase 3
Phase 5: Defining and naming themes

After reviewing the themes, the next step was to define and refine the themes further, finding the essence of what the different themes were about (Braun & Clarke, 2006, p. 92). While doing this, I created a final digital thematic map of the themes, which can be viewed in Figure 9.

![Thematic Map](image)

Figure 9: Themes from the analysis

Phase 6: Producing the report

The final step in the analysis was to write-up the report, telling the complicated story of the data by selecting vivid and compelling extract examples (Braun & Clarke, 2006, p. 93). This phase of the analysis can be viewed in Section 5.6.

5.6 Results from the thematic analysis

The main results from thematic analysis of the data gathered in the interviews will be presented according to the digital thematic map as presented in Figure 9, Section 5.5.2:

- Illness symptoms
- Coping with the illness
  - Sub-theme: Methods
  - Sub-theme: Problems
- Technology / Design needs
  - Sub-theme: Tech adoption and use
  - Sub-theme: Design needs
- Awareness
5.6.1 Illness symptoms

Many illness symptoms were expressed during the interviews. Some of them were cognitive symptoms, such as struggling with remembering things and getting headaches. Others were physical ones like higher pulse, lactic acid in their muscles, fatigue, contact dermatitis, allergies, sensitivity to temperatures, sensitivity to food, sensitivity to sounds and bright light, anxiety and sleep deprivation. The symptoms expressed was highly individual, and it seemed that the symptoms shifted a lot between bad days and good days.

5.6.2 Coping with the illness

The participants shared experiences of how they were “Coping with the illness”. Specifically, we discussed what kind of methods for energy modulation they have been using to reduce and help with their symptoms, and how they have been using those methods. I also got data on the problems they had been meeting while using their methods, and what major changes they needed in their life for it to work.

Sub-theme: Methods

One thing that was apparent was that rest is medicine for people suffering from ME. When asked about what is the one thing that will reduce symptoms and make them feel better, rest was the key for all the participants. Instead of saying that rest, and rest solely, was the best way to reduce symptoms, one of the participants (P6) had a very clever way of describing how a balanced and sustainable life was the key to getting better:

P6: “No, it is not rest as such, it is to find a sustainable level.”
O: “Yes”
P6: “Right, so there is no one telling you just to rest when you have ME.”
O: “No”
P6: “It is okay, you should, it is good to be as active as you can within your own limits.”
O: “Mhm”
P6: “And sometimes, that means to actually rest, right.”
O: “Yes”
P6: “And it also means that if you have been doing a lot one day, you should probably have a couple of very slow days after that.”
O: “Yes”  
P6: “It is not like you should just go home and lay down and rest for months, you will not get better from doing that either.”  
O: “No, you must have some sort of activity, like some sort of balance right?  
P6: “Yes... safe activities. Balance between activity and rest is the most important.”  
O: “Yes”  
P6: “That is what is important, to find that balance in order for you to have the best possible life.”

Several of the participants talked about how they needed to change their way of life and adapt their lifestyle to their illness and symptoms. Several methods were used to do this, like getting help from family and partners and living apart from spouses (gaining personal space, but still being married). Nevertheless, they expressed how changing their way of living was difficult, as they have been growing up in an active lifestyle before the onset of the illness. Living life in slow motion, be more flexible in their plans and activities, think ahead and be prepared was some of the life changes that was expressed during the interviews: “As soon as I am in a hurry to do something I get bad [...] So my whole life should be slow motion” (P4).

Sub-theme: Problems

During the interviews, the participants expressed several problems that made living with and handling the illness in their day to day life hard. One of the issues was the unpredictability of the illness, as there was almost impossible to predict when bad days would occur. This unpredictability might be explained by how symptom aggravation can appear hours or days after the activity or exertion happened:

P6: “Because... The symptoms often appear long after the activity...”  
O: “Yes”  
P6: “And my experience is, anyhow, or what I’m trying to say to others is that everyone understands how it’s to live with a salary account and a credit card... And if you use less than what you earn, it’s okay. But the moment you start using the credit card, right, mobilizing extra energy”  
O: “Yep”  
P6: “Then you have to pay back before you can have a normal consumption again, otherwise you will end up in the Luxury trap right”
O: “Yes, mhm”
P6: “So what happens is that you do one thing one day, and you tolerate that.”
O: “Mhm”
P6: “But then, then you have a normal activity level the next day as well, but then you actually don’t have enough money to have a normal activity level, so you are actually putting yourself in deeper depths.”
O: “Mhm”
P6: “So, sometimes it can be hard to see the direct correlation between when you are doing too much and the reaction you get in the form of aggravated symptoms.”

Even though their illness shifts through bad and good days, the common state is one of very low energy and ability to perform activities as a healthy person. Basic needs like eating, for instance, could be exhausting, and even remembering to do it can be hard.

Another problem expressed was the suppression of symptoms occurring after experiencing symptoms all day, every day, for several years: “But that is... my daily problem is being too active, and my health therefore evenly gets worse. [...] I am so used to having symptoms, so I have been using my life to suppress symptoms by doing activities” (P1). “I feel that it is hard to remember what is... or what one feels when having ME. When you have been sick for so many years, you sort of forget what is what... I sort of ignore the symptoms I have, because I am so used to having them” (P3).

Social activities, according to the participants, is hard to balance as it demands both physical and cognitive effort. At the same time, some of the participants expressed how being social also made them feel good and not so isolated. One of the participants was studying part-time and thought that the few days she was at school during a month was very nice. Even though she had to pay for the exertion afterward, she said it was worth it: “I notice that... I am spending a lot of time at home when I am... Because I am studying part-time, so I am in Tromsø approximately a week a month so I notice that it is very nice to get out and sort of have that week where I am social, that is something I don’t get to do at home, so it’s like being with other people and not just be by myself... I think that helps me keep my psyche good” (P3).
5.6.3 Technology/Design needs

A theme we defined was one consisting of the design needs expressed by the participants, and discussions we had around their technology adoption and use.

Sub-theme: Tech adoption and use

All of the participants have from time to time used a fitness watch to help cope with their illness (to monitor and become aware of their daily activities, sleep duration, and pulse). Several of the participants had already thoughts about the fitness watch they were using. One of the participants had a watch that needed to be charged every day, and her own words about that were: “I think it (the watch) absolutely should hold up to a week... because it is very dull, to charge every single day” (P1). The participants that have watches that only needed to be charged 1-2 times a week expressed that the charging process was fine.

When asked about wearing a watch all day, all the participants agreed to it being okay. “I think it is... Ehh... it is okay to have it cuz’ you get used to it fast” (P4). “I think it was a bit unfamiliar to use a watch in the beginning, but you get used to it eventually” (P3). “No, I’ve become used to that... I have always been used to wearing a watch, if it’s a normal watch or a (fitness watch)” (P5)

One of the participants said she often feels that the pulse number her watch is showing is a bit off from what she is feeling herself. She also believed that the pulse data presented by the fitness watch was hard to understand, as she had to drag her finger on a graph to see her highest and lowest pulse throughout the day.

Another feature about the fitness watches that has low compliance with ME, and that several of the participants commented on, is the constant reminders that you should move more. As one of the participants said: “It is a little... annoying. You constantly get reminded that you should move more, but you are not able to” (P4). Several of the participants felt the same way and said that it was hard to get such reminders on bad days. One of the participants put the watch away for some time, due to the same issue: “I did not manage that it was whining about me getting active when I was
sitting too long and stuff… So… I just thought that there was no point in using it, I won’t be able to be active enough, I only get a bad conscience. But, later I found out that I could use it as an assistive tool” (P5). She had found out a workaround and turned all the alarms and notifications off: “I can just turn off all the notifications and stuff, to avoid it whining at me for that other stuff when I am sitting too much still” (P5).

The same lady had also found a workaround for measuring her pulse, as her watch demanded her to wear a belt (which she did not like) and to activate a training program to measure her pulse: “Then I just use a pulse-app on my phone instead” (P5).

One of the participants had already tried, several years ago, having an alarm that beeps every time her pulse reached her anaerobic threshold. She said she felt it gave her valuable insight and was a great success: “For me it seemed like it actually had an effect, and that I learned to sort of control my use of energy in a way that I actually… What is it called… Sustainable I can maybe call it [...] so that I actually had more energy the day after [...] and not just pushed myself through a day and crashed the day after” (P6). Eventually, she stopped using it, as she got better and found it annoying that the beeping alarm went off all the time. Nevertheless, she felt that having used the alarm for some time made her more aware of when to stop and not: “It gave me a good deal of AHA experiences about when I actually get a high pulse, and when I push myself” (P6).

Sub-theme: Design needs

During the interviews, there was a lot uncovered that could translate into design needs. Both specific features, technology solutions, and more general characteristics of a design. Some of the findings are ideas generated by me while we were talking as I tried to constantly brainstorm on different issues, problems, and ideas they had regarding their illness. Others were simply ideas they came up with while we were talking, or ideas they had thought of in advance.

Two of the participants mentioned, without me asking for it, the need for some sort of pulse alarm or notification to help them with energy modulation and to prevent the aggravation of symptoms: “I am a bit curious if I simply can use [...] so that I could help myself because I am struggling
really hard with energy modulation. If one could have a watch that tells you that you are getting close to that... Yes, where you go past the (anaerobic threshold)” - (P1).

One of the other participants expressed at the beginning of our conversation that she felt that having the pulse available at any moment could make her stressed. When asked about the idea of a pulse alarm later in our conversation, she seemed positive to the idea: “Yes, it is like you talked about of getting a notification or a beep when you have a high pulse, then you will not have to think so much about having the watch on your arm all the time” (P3). Another participant was skeptical of the idea of having a pulse alarm for the bad days. She talked about how she, on bad days, couldn’t even stand up and go to the fridge without the pulse raising to the sky. She believed it would be stressful to be notified about being too active in those circumstances: “Like, I know I am not well, I know my pulse is high today, I know that it... like I have noticed it” (P5). She suggested that it should be a possibility to turn the device off, or at least change the vibration or beeping to a little light or a reminder on the screen. When asked about what kind of alarm she would like, one of the other participants expressed that it could be a beep or vibration, but that a beep might be a bad idea because sounds can be unpleasant for many people with ME.

There were also some comments about choice of material on physical solutions. Several of the participants have had issues with allergic reactions to some of their watches’ materials and expressed that as a certain factor for abandoning the technology. The participants expressed that the choice of what kind of materials that will be close to their skin is an important one. There were also comments about chest straps, how chest straps were not ideal, and how the participant did not want something that tight.

The esthetics seemed important for several of the participants. When talking about the watches, they expressed that it should look pretty and neat, like something they would wear regardless of being an assistive device. It seemed like it was important not to stand out, that the watch in itself should look normal and not draw any attention, especially not send out some stereotypical message of being this very active and fit person.
Another participant came up with an idea I liked while we were talking, and we discussed the specifics about it in more detail:

P1: *What I need for (the fitness watch) to be able to do, help me to say for example... I got a little idea now that says something like “Jehu... Take care of yourself. Sit down”*
O: Yes
P1: *Like... it has to be in a friendly way, sort of.*
O: *Yes, that you sort of doesn’t do any wrong because you are active*
P1: *Right! Because it sort of should be some sort of friend. That is... Because we need to change our whole way of thinking.*

The idea was about changing the role of the fitness watch, from being this constant reminder of not being able to stay as active and healthy as you should, to be on their side of the table. Instead of being reminded of taking 10,000 steps, they could be reminded of slowing down when they are going outside their limits. She also suggested that instead of only saying that you should stop, the watch could give alternatives on how to calm yourself: “*And... think about if it came to some sort of... Yes, some sort of meditation of 10 minutes...*” (P1).

When it came to interface and choice of data representation, several relevant comments were mentioned. One participant talked about the usability of the current fitness watch she is using, as she believed the watch has low compliance for a person with ME. She expressed how she found it hard to get the information she needed when she was looking at her pulse data, and that important information like maximum pulse throughout the day should have been easier to find: “It is hard to maneuver on the graphs, it had been easier if it was some text below the graph then or instead of me using my finger to find out what I wanted to find out” (P3).

### 5.6.4 Awareness

A common theme that was expressed throughout all the interviews was “awareness” about their own illness. They talked about how they used fitness watches to learn more about their illness and thus be able to control it better as they get to know their limits, symptoms and bodily functions. They looked at their activity levels, their sleep quality and length, and their
pulse. Gathering this information had the purpose of making them more aware of their illness and learn what to do and not to do. For instance, they believed that data about their pulse could potentially help them be more aware of which activities required more energy than others, and thus help them cope with their illness more systematically. However, in reality, it was hard to comprehend the information presented by the fitness watch, and they struggled with analyzing the data in a meaningful way. They also expressed issues with changing their habit of overexerting.

5.6.5 Key findings from the telephone interviews

In Table 2, key findings from the thematic analysis of the telephone interviews are presented. These findings were also brought forward to the next step of the design process: the making of RelaxMe.

<table>
<thead>
<tr>
<th>Illness symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>- There are highly individual symptoms</td>
</tr>
<tr>
<td>- Symptoms are varied and shifting</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Coping with illness</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Subtheme: Methods</strong></td>
</tr>
<tr>
<td>- Rest is medicine</td>
</tr>
<tr>
<td>- Find a sustainable balance between rest and activity</td>
</tr>
<tr>
<td>- Adapt way of life to minimize unnecessary stress</td>
</tr>
<tr>
<td>- Life should be slow motion</td>
</tr>
</tbody>
</table>

| **Subtheme: Problems**           |
| - Illness feels unpredictable    |
| - The importance of avoiding the “luxury trap” – not overexerting on good days as well as bad days |
| - Suppressing symptoms          |
| - Social activities can be both positive and negative |

<table>
<thead>
<tr>
<th>Technology / Design needs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Subtheme: Tech adoption and use</strong></td>
</tr>
<tr>
<td>- Fitness watches are used to monitor illness</td>
</tr>
<tr>
<td>- Watches are okay to wear 24/7</td>
</tr>
<tr>
<td>- Demotivating to be reminded to move more</td>
</tr>
<tr>
<td>- Pulse alarm gave AHA experiences and knowledge into destructive behavior</td>
</tr>
</tbody>
</table>

| **Subtheme: Design needs**       |

72
- Pulse alarm to help energy modulate
- Continuously seeing the pulse can be stressful
- Pulse alarm on bad days could be stressful
- Materials should be fitted to sensitive skin
- Chest straps are uncomfortable to wear 24/7
- The aesthetics of an artifact should avoid looking like an assistive tool
- Alarms should not be loud and abrupt
- A need for an artifact supporting energy modulation

Table 2: Shows the key finding from the thematic analysis of telephone interviews

## 5.7 The making of RelaxMe

In this section, I describe the making of RelaxMe, and how I used my understanding of the design context to create an artifact that would function as a research product in everyday life of people with ME. In Chapter 6, I describe how I used RelaxMe in a field exploration to generate new knowledge about its meaning for the user group.

### 5.7.1 Research prototype vs. research product

When working with vulnerable users that experience several health challenges, I argue that it is important that the artifact created works properly and that they can use the artifact independently from my presence. As explained in Chapter 4, I wanted to place the artifact in the field and explore its meaning for the user group in a real-life context and over time. When investigating such complex human relationships with technology, Odom et al. (2016) argue that the typical method of prototyping may not be sufficient enough. Instead, the authors propose an extension to and an evolution of the prototype they call a research product. Prototypes are to them placeholders for something else and may be a manifestation or testing of a theoretical concept on a point towards a fully realized commercial product. They further explain how prototypes should thus “not to be judged for its actuality or present state, but rather its potential” (Odom et al., 2016,
A research product, on the other hand, is presented to the users as “what it is as opposed to what it might become”. The term product, they emphasize, should not be confused with the intention of being or becoming a commercial product. The artifact is rather a research product in its purest sense, a product created for research into complex matters of human-technology relations over time. This aspect fits well with the purpose of my study, as the artifact per se is not the result of the study, but rather the knowledge it generates through being a research product. They further propose four interrelated qualities of a research product that must be present at once in the design artifact; inquiry-driven, finish, fit and independent. A short presentation of the criteria and a discussion of whether the artifact created in this project fulfilled these criteria or not will be raised in Chapter 8.

5.7.2 Recap

The initial explorative prototyping phase generated two ideas that I presented for the ME association during our workshop:

1. An artifact wore on the body that helps the user notice potential “dangers” such as too strong light and too loud noises around them in-the-moment.

2. An artifact that gathers sleep, pulse and activity data from a fitness watch, and that register general well-being and pain levels from the person to create a statistic of the course of their illness.

During the workshop, the participants showed little enthusiasm for my focus on sound and light and was more concerned with for example sleep, activity and pulse. One of the participants gave me insight into the importance of the anaerobic threshold and described how people with ME could display signs of being physically constantly overtrained. This insight sparked an interest in how technology can help with energy modulation by utilizing new medical research on how pulse and the anaerobic threshold acts differently in people with ME, then healthy people. Furthermore, the telephone interviews with the user group were beneficial to understand how technology can fit into their lives and left me with key findings within the main themes Illness symptoms, Coping with illness, Technology / Design needs, and Awareness, as seen in Table 2.
5.7.3 Pulse as a single variable

In other words, investigating the pulse as a single variable in the artifact became my key interest when beginning the making of a research product. During the interviews with the user group and the workshop with the ME Association, I also got the impression that pulse was something the participants wanted to be able to control in more detail. Hence, I felt that my interest in how technology could improve energy modulation by only using pulse as the variable also fitted the design context. The findings showed that all of the participants were using a fitness watch to help cope with the illness, but that this was difficult as fitness watches are not created to raise awareness about an illness like ME. Rather, they are created with the purpose of stimulating more physical activity. As the findings indicated, the user group gathered a lot of data about their activity levels, pulse and sleep through a fitness watch, but lacked tailor-made functionality that enabled them to utilize those data in a meaningful way. Hence, they lacked the opportunity to get awareness about how their illness affects their body, making it very difficult to change their mindset to a more sustainable life and correctly perform energy modulation. Their shrinkage in space was thus not reduced by the fitness watch, but rather strengthened when getting notifications about being more active.

When looking at the key findings from the telephone interviews (Section 5.6.5), living a sustainable and balanced life seemed to be of utmost importance for people with ME. Rest is medicine, but at the same time, balanced activity is also important, taking things in slow motion. The findings indicated that it was difficult to change their mindset towards a more sustainable life, and no assistive tool had solved this problem in a good way yet. Hence, I saw an opportunity to create a novel artifact that enabled the user group to be active within their limits. The artifact could guide the user group more directly when energy modulating, by helping them to change their behavior “in-the-moment” it was needed and slow down. Instead of figuring out the statistics and keeping a constant eye on the fitness watch, I would rather make a tool that became more connected to the body and the bodily senses. Reflecting back to my theoretical framework, I wished to create a tool that would be incorporated as a bodily alarm, extending their abilities, and help the user group be active within their limits. By doing this, the user group could potentially reduce their
feeling of shrinkage by being able to do more inside their limits.

5.7.4 Inspiration from a single-variable device

During the process of scoping in on the pulse as a single variable to explore, I started to look for inspiration on how other people have created single-variable wearable technology. A technology called DURR, created in 2014 (“DURR - Skrekkøgle,” 2018), was soon on my radar. DURR is a reinvented watch that features only one functionality, and that is to vibrate every 5 minutes. The concept was to help the users of DURR get more sense of time, as people tend to feel that time sometimes passes by slowly and other times fast. Instead of showing the user several variables such as hour, minute, second, or the time of the day, they only had the 5-minute variable. Their take on creating something that simple, but yet so meaningful inspired me a lot. Instead of showing the time from an outside perspective, they took the technology closer to the body and let the users feel the time pass by through their bodily sensations. With their take on time in my mind, I thus started to explore how something so complicated as pulse could be reduced to only one functionality. Inspired by the wish for pulse alarms mentioned by several of the participants in the study and the research on CPET-studies mentioned in Section 2.2.4, the anaerobic threshold became the key. Staying below the anaerobic threshold (where lactic acid starts to build up) might be beneficial for people with ME. Hence, I decided to pursue this idea of creating a single-variable pulse alarm that was inspired by the simplicity showed in the DURR watch and made it a design choice to incorporate the results from the CPET-studies into the artifact.

5.7.5 Watch-like design

Inspired by the DURR watch, I looked back at the results from the telephone interviews. A key finding was that the participants expressed aversion against chest straps and that they emphasized that they wear watches every day without experiencing problems. Measuring pulse at the wrist is also common. Thus, I decided to design the artifact to be wrist-worn and create a watch-like design that was familiar to the user. Also, I transferred the design concept of the vibration on the wrist from the DURR artifact to be a representation for pulse (or more precisely the anaerobic threshold).
The next step was to create a mood board (see Figure 10) to visualize my ideas and thoughts. As watches have been made for as long as we know, I did not want to challenge that end of the design. Rather, I would find inspiration on how to create a watch-like artifact that was comfortable to wear, and that looked like any other watch. I believed that by creating a familiar watch-like design, I would balance the introduction of a novel functionality and keep the artifact from becoming stigmatizing or familiar with an assistive tool.

![Figure 10: Mood-board](image)

### 5.7.6 Low fidelity prototyping

After creating the mood board, two parallel phases of low fidelity prototyping began. The first was 3D printing a casing for the electronics, as I needed to find a shape and a size that would feel comfortable to wear, and that fitted the electronics I needed to measure the heart rate. To me, 3D printing provided me with a fast way of testing out different ideas about the shape and size. I used SketchUp, Autodesk Fusion 360, and Cura to create the 3D models, and printed the prototypes with an Ultimaker 2+. Figure 11 shows some of the process when creating the low fidelity prototypes.
The second phase was to create a low fidelity prototype to test out the technological possibilities, and to validate that the heart rate monitor was accurate enough for me to use in the prototype and that the vibrator worked as I wanted. For a while, it seemed like finding a heart rate sensor with good enough measuring was impossible. Heart rate sensors available for makers usually only measured the pulse when attached to a fingertip or earlobe. Eventually, I found a sensor that worked perfectly on the wrist. I then created a low fidelity prototype of the technical features and tested it out myself to verify that the functionality worked as I wanted. During this test, I validated the heart rate measures against my own fitness watch from Garmin. Figure 12 shows the different low fidelity prototypes created to test the technical features.
5.7.7 Merging the prototypes to a research product

The last phase was then to merge these two prototypes into one artifact and start to iterate towards a fully working research product I eventually called RelaxMe. A wrist-worn artifact needs to be tiny, and the next step was to find a microcontroller that was small, but powerful enough, to handle the heart rate sensor and the vibrator. After researching the different options available, and testing out some of them, I ended up with using a microcontroller called Adafruit Trinket Mini 5V. It was tiny, powerful, Arduino-compatible and cheap - just what I needed. During this process of placing the technical features inside the watch, I 3D printed constantly for two weeks straight. During these two weeks, I iterated towards a shape that would fit the parts in a smart way inside the watch, have the possibility to attach a watch strap, and at the same time be small enough to be wrist-worn.

Furthermore, I decided on which materials I wanted to use for the casing, watch straps and the alarm. The material choices were important for three reasons. The first was that people with ME have sensitive skin, and the materials thus have to be suitable for skin contact. The second was that I wanted the material to be as natural as possible so that the artifact was
comfortable to wear and potentially could be incorporated into the user’s body schema. The third reason was that I wanted to use materials that either could be recycled or reused, as creating tangible artifacts introduce yet another physical product into the world.

**The casing**

As mentioned earlier, I wanted to use materials that would fit sensitive skin and be recyclable. As I wanted to 3D print the final casing (due to it being fast, cheap and available at my university), I used white PVA plastic that I ensured both could be in contact with skin and was recyclable. I also tested to wear the casing on my arm, to ensure that it was comfortable to wear.

**The wrist straps**

For the wrist straps, I used natural leather. I created two types of straps with different types of leather. The first strap was dark brown calf leather that I laser cut and then sewed by hand with vax thread (see Figure 13). The second was lightly tanned cow leather that I hand cut and then sewed by hand with vax thread. Both types of leather were 100% natural and did not contain any chemicals.

![Figure 13: The wrist straps](image)

**The alarm**

The only interaction the users of the artifact needed to be aware of, was the alarm when their pulse passed the anaerobic threshold. To choose which material to use was done through looking at the findings from talking with
the user group and reflecting on the theoretical concept of incorporated objects. Sensitivity to sounds was a common symptom experienced, and I thus decided not to have a beeping alarm. Vibration, on the other hand, seemed like a good way to notify the user. I liked the idea of having an alarm that was invisible to others, as that would make the artifact less stigmatizing and the assistive functionality would not be “out there” for the public to see. Furthermore, I wanted to create an artifact that could potentially become incorporated into the user’s body schema. To me, a vibration would mediate the pulse limit directly through the body, by playing on bodily haptic senses, such as the feeling of being touched.

When deciding on vibration as the material for the alarm, I tested out various vibration modes and also validated the different modes with fellow students. At last, I ended up with a vibration that vibrated three short times to indicate that the threshold was reached.

**Setting the anaerobic threshold**

The anaerobic threshold was coded into the microcontroller, and the user would thus not have access to changing the threshold themselves. I was not able to find scientific research on assessing the AT for people suffering from ME through a generic formula, such as “210 minus age”. What I did find was some suggestions about where the AT normally is for people suffering from ME. One article suggested that it usually is a number between 90-120 (“Enhet for kronisk utmattelsessyndrom,” 2018), and another article suggested a formula, which correlates with the former suggestion, of “(220 - age) x 0,6” for men and “(206 - (age x 0,88 )) x 0,6” for women (“Pacing by Numbers,” 2018). The reliability and credibility of the suggested formulas, however, are low and I needed to keep this in mind when I introduced the formulas to the participants using RelaxMe.

**Battery issues**

A huge issue I struggled with during the phase of finalizing the research product was the battery. As the heart rate sensor was in need of 5V, the classic button cell batteries used in watches was not efficient enough (they are typically 1,5-3V). I tried to connect two 3V button cell batteries in series, as this would provide me with approximately 6V. This worked fine, but when stress testing the pulse alarm an issue with the electrical capacity appeared. The electronics demanded too much electrical capacity, so the
batteries were emptied just after 20-30 minutes. In a real-life setting, the batteries would thus probably hold for up to a day maximum. I tried to create a solution where the batteries could easily be replaced by the user, with no luck at finding a feasible way. As a final solution, I ended up using a power bank that the user would have to wear together with the pulse alarm. Obviously, this was not the perfect scenario with regards to the design, but it enabled the research product to work independently and for several days at a time. The power bank was also easy to charge for the users and offered high battery capacities.

5.7.8 Final research product: RelaxMe

The final working research product is called RelaxMe. RelaxMe is a watch-like artifact that will measure the real-time pulse of the user every minute and vibrate for three short intervals if the person is above their anaerobic threshold. The pulse digit is black-boxed so that the user only needs to focus on that they will feel, through a haptic vibrating alarm, when they trespass their limit. Also, the user can turn RelaxMe on or off by pulling a cable in or out of the power output. RelaxMe does not save any data and thus offer complete privacy. RelaxMe was created of 3D printed white PVA and had watch straps handmade of natural leather. All the materials are suited for being in contact with human skin and can be recycled. For the extra power bank, I sewed a pocket of organic cotton, to make sure that the users would not get an allergic reaction from the materials. Through this pocket, a strap was placed for wearing the power bank on the arm.

In the process of making RelaxMe ready for a field exploration with the user group, I created three exemplars of the research product to be able to involve several participants at the time. In Figure 14 all parts for a final RelaxMe can be viewed. Figure 15 and 16 shows the process of soldering the electrical components together, and Figure 17 shows the three final exemplars of RelaxMe. Figure 18 shows the artifact and its annotated concepts (Gaver & Bowers, 2012).
Figure 14: Final parts, excluded the extra battery

Figure 15: Soldering the final parts together

Figure 16: Testing the parts before placing them in the casing
Figure 17: Show all three final versions of RelaxMe

Figure 18: Shows the annotated concepts of RelaxMe
6 Field exploration of RelaxMe

Three exemplars of RelaxMe was ready to be placed in the field and a real-life context. The goal was to explore the concepts incorporated in RelaxMe and investigate how people with ME interact with a tool created to add a new capability to their body schema. The exploration consisted of three steps. The first was a baseline interview to get to know the participants and to deliver RelaxMe (Section 6.1). The second step was to leave RelaxMe in the hands of the participants for approximately one month (Section 6.2). During this month, the participants could use RelaxMe as much or little as they wanted, without me being involved. The next step was to listen to their experiences with RelaxMe through a final interview (Section 6.3). In the following section, I present the planning and execution of all the steps conducted, as well as the results from both interviews.

6.1 Baseline interviews

The baseline interviews had the purpose of mapping the baseline of the participants. A baseline in this context was meant as an overview of the person interviewed, to learn who they are and how they experience being ill. The reason to map a baseline was two-fold. First of all, I could get to know the participants and possibly use the information to better understand their reported experiences after using RelaxMe. Second of all, the baseline also defined who the results from the field exploration potentially could be applied to, as I would get detailed knowledge of which symptoms they experience and how they experience these symptoms.

6.1.1 Recruiting participants

As I already had a list of 17 names to contact, the recruitment of participants was easy. I excluded the six people already talked to during the telephone interviews and decided to reach out to the rest of the group. After a couple of weeks, I had a list of six names that was willing to partake. During these weeks, one of the five participants was starting to feel very ill,
and I decided not to include her in the test. I also learned that one of the
participants was categorized with severe ME and I decided not to include
her in the test due to her health. The four remaining participants were all
women, from the age of 28 to the age of 50. All the participants lived in
eastern Norway, making it convenient for me to travel to their homes for
the interviews.

6.1.2 Planning

I wanted to create an interview that would fit the needs of my participants.
Thus, I created tools that would, hopefully, help the participants answer
my questions in the least stressful and mind-demanding way. In the
following section, I describe in more detail how I planned each part of the
baseline interview, specifying what I was interested in finding out in each
part, and what kind of tools I created to help the participants answer the
questions. The interview was planned as a semi-structured interview, as I
wanted to guide the conversation through the different parts planned, but
at the same time be able to explore emerging topics and interesting ideas
throughout the interview.

Part 1: Something on your mind?
The first part of the interview was planned as a warm-up, to set the mood
and let the participants share, without boundaries, any thoughts they had
about ME and technology. As I learned from the telephone interviews, this
gave the participants the possibility to share whatever they might have been
thinking about beforehand with regards to the topic.

Part 2: The subjective experience of being ill

In the second part of the interview, I wanted to explore the participants’
subjective experience of being ill. By looking at their symptoms, how these
symptoms affect their life, and how they deal with these symptoms in
different ways I wanted to understand how their lived space has shrunk
with the onset of the illness, and how their loss of different capabilities has
changed their body schema. Asking questions about which symptoms they
experience could be challenging due to the cognitive symptoms the
participants might experience. Thus, I created an interview tool that would
make it easier to remember the symptoms they experience. I sketched a
poster of a woman (as all my participants were women) standing, with a
thought bubble over her head (see Figure 19). As well as this poster, I 3D printed small red pieces that were easy to grab. The activity I planned was to ask the participants to picture this woman as themselves, and the pieces as their symptoms, and then place the symptoms on the body where they experienced the symptoms. Then I would ask more questions regarding the symptoms.

**Part 3: Tools**

The third part of the interview would use the information gathered in part two to explore the different tools and aids for reducing or controlling the symptoms they had. How do they prevent the illness from shrinking their world? As argued in part two, I saw the need for creating an interview tool that would make it easier for them to remember all the assistive tools they utilize, and to help them sort them in what works and what do not. Inspired by the “Cool Wall” as presented by Fitton, Read, et al. (2012) and Fitton, Horton, Read, Little, & Toth, (2012) and further edited by Børsting & Culén (2017), I created a set of cards where I wrote down all the tools I already knew was common for people suffering from ME to use. As I was not interested in the cool aspect of the technology and were working with adults and not children, such as in (Børsting & Culén, 2017; Fitton, Read, et al., 2012; Fitton, Horton, et al., 2012), I decided to change the poster to a traffic light instead. The activity I planned for this part was to hand one card at the time to the participants, ask them if they are currently using or have tried using the tool, and let them place the card at either the red, yellow or green zone depending on how good it worked for them. Red symbolized tools that did not work at all or made them worse, yellow symbolized tools that worked okay, and green symbolized tools that worked well. I would then ask questions about every tool. The initial sketch can be viewed in Figure 19.

**Part 4: Expectations and future possibilities for RelaxMe**

In the last part of the interview, I wanted to introduce RelaxMe, and at the same time explore their expectations for the research product and what kind of future possibilities they saw in such an object. Hence, I created a poster with a picture of RelaxMe that I would use to write down their expectations and suggestions for future possibilities, inspired by the “Avatar Expectations Map” seen in Børsting & Culén (2017, p. 169). The initial sketch can be viewed in Figure 19.
Expert review

As Jorun had done with my previous interviews, she conducted an expert review of the interview guide. She suggested removing an idea I had to use a timer to make sure we kept inside the time limits, as she thought this would be stressful for the participants. The timer was something I initially added as a result of a tip received from a participant when evaluating the telephone interviews. Jorun thought it would be better to keep track of the time ourselves and prevent it from becoming a pressure obvious for the
participants. I changed the interview guide according to our discussion and also designed the posters in Sketch to look more professional. The final poster of the woman, the traffic light, and the expectations and future possibilities can be seen in Figure 20.

![Final posters for the baseline interview](image)

**Figure 20: Final posters for the baseline interview**

**Pilot interview**

After creating the tools in Sketch, I decided to perform a pilot interview to practice the questions and review the flow of the different activities. I conducted the pilot interview as a role play with a friend. Before we did this, I explained typical symptoms and presented what I knew about ME that could be relevant for the interview. The role play worked as I hoped, and I found several pain points that needed to be changed to create a good flow. After the pilot interview, I improved the interview guide and produced the final version, which can be viewed in Appendix D.

**6.1.3 Execution**

All the four baseline interviews were conducted between 23. January and 2. February 2018. My supervisor, Jorun, was also participating all the interviews. The interviews were initially planned to last approximately 45 minutes, but this was a major miscalculation. The first interview lasted for 1 hour and 17 minutes, the second lasted for 1 hour and 32 minutes, the third for 1 hour and 40 minutes, and the last for 2 hours and 20 minutes. Included in this was the hand-off and a brief explanation of RelaxMe. As for the miscalculation of time, the participants showed to be more talkative and in better shape than initially thought. The conversation was mainly led
by the participants, and it thus felt wrong to cut them off when sharing their experiences in such an open, detailed and vulnerable way. All of the interviews were transcribed the same day or the day after. By doing this, I was able to review every interview before the next, finding interesting topics I wanted to bring with me to the other participants. In Figure 21, 22, and 23 pictures from the baseline interviews can be viewed.

Figure 21: Shows the interview tools in action

Figure 22: RelaxMe worn by one of the participants
6.1.4 Results

In the next section, I present the results of the baseline interviews with each of the participants. To protect their anonymity, I have given them aliases. Participant one is referred to as Caroline, participant two as Andrea, participant three as Ingrid, and participant four as Camilla. A brief overview of the participants can be viewed in Table 3.

<table>
<thead>
<tr>
<th>Alias</th>
<th>Age</th>
<th>Severity</th>
<th>Diagnose</th>
<th>Fitness watch (FW)</th>
<th>Started using FW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caroline</td>
<td>47</td>
<td>Mild/Moderate</td>
<td>2010</td>
<td>FitBit Alta HR</td>
<td>2014</td>
</tr>
<tr>
<td>Andrea</td>
<td>50</td>
<td>Mild/Moderate</td>
<td>2014</td>
<td>FitBit Charge 2</td>
<td>2017 (October)</td>
</tr>
<tr>
<td>Ingrid</td>
<td>28</td>
<td>Moderate</td>
<td>2012</td>
<td>FitBit Charge 2</td>
<td>2017 (August)</td>
</tr>
<tr>
<td>Camilla</td>
<td>35</td>
<td>Moderate</td>
<td>2016</td>
<td>FitBit Charge 2</td>
<td>2016</td>
</tr>
</tbody>
</table>

Table 3: Overview of participants
Caroline
caroline told us that she has probably been suffering from the illness since the late 90s without knowing. The first years after receiving the diagnosis, she was considered having moderate to severe ME. The last three years she has been feeling better and has been shifting between mild during summer and moderate during winter. Caroline told us that she is feeling much better now than what she did a few years ago. She said that she feels that her success for getting better has been caused by gaining more knowledge about her illness, as well as starting on a few medicines. Still, she does experience days “with more ME”, as she put it. On such days, all symptoms aggravate, especially the ones concerning lactic acid in the muscles, cognitive symptoms, headache, sensitivity to light, sore throat, nausea, more irritable bowel syndrome (IBS) symptoms, more bladder issues, and dizziness. The only thing she said will help her recover from such days are rest, and she believed that sleep deprivation and overexertion were the two main factors to why she sometimes “crashes” and experience “more ME”. She said that one of the warnings she gets when reaching a “crash” is a sore throat and cognitive issues, further the hands and knees will start to ache and at last the rest of the body will follow.

Andrea
Andrea has probably been suffering from the illness since 2008/2009 without knowing it was ME. She has been shifting between mild during summer and moderate during winter. Andrea said that she is feeling better now than she did a few years ago. She said that she has learned more about what her body can manage and that she recognizes the symptoms better. Nevertheless, she said that she does feel that she from time to time have a hard time keeping her activity levels below her limit because she gets an adrenaline rush that triumph the warning signs. The typical symptoms she has on bad days is more sensitivity to smells, sound, and touch, as well as more pain throughout the whole body, especially the over arms, as well as the flu-like feeling. Warning signs of a bad day is often a “foggy” head, followed by increased pain in her hands and feet before the pain creeps out to the entire body. She mentioned that she often experiences pain when lightly touched and that this can sometimes be so bad that touching herself is painful. When asked if the fitness watch hurts, she answered that it did not because “it is just there”. Andrea emphasized that she has gotten so
used to the symptoms, and often find it hard to distinguish between what is normal and what is symptoms. She said that she suppresses her symptoms all the time, and sometimes forgets to listen to them and recognize that they are indeed present.

**Ingrid**

Ingrid has been shifting widely in severity through the years since receiving the diagnose but are currently at a moderate level. A few days ahead of the interview, Ingrid broke her arm due to a fall on the icy grounds. The accident caused her symptoms to increase a bit, and also forced her to be less active. However, she was eager to test RelaxMe as she often experiences her pulse increasing throughout the day, even when sitting on the sofa and relaxing. She also mentioned that she has been noticing that her resting heart rate increase with the onset of a period of “bad days”, and that it decreases when she is feeling better. Other than an increased pulse, she said that she experiences extreme nausea. She said that the nausea is also worse on her bad days and that she as a result of this lose a lot of weight during the bad periods. When she is about to pass the invisible limit, the warning signs are a sore throat and a flu-like feeling in her body. When trespassing the limit and “crashing”, she then experiences increased symptoms, such as more tinnitus, increased dizziness, higher pulse, more lactic acid in the muscles, colder hands and feet, more pain, fever, headache or sometimes migraine attacks, more sensitivity to light and sound, sensitivity to touch, and increased anxiety. Ingrid talked a lot about how anxiety, panic attacks, and depression have become a part of her everyday life after receiving the diagnose. She explained that when she feels a bad day coming, a lot of anxiety towards her bodily functions arise. She starts to listen too closely to what is happening inside her body, and an anxious feeling starts to build up. She said that she is scared of what is happening to her body and that this fear is grounded in the fact that the illness is an enigma and that a cure is yet to be found. To exemplify, she said that when being hungover she can relax on a whole other level because then she feels that there is a viable explanation for why she needs to rest more than usual. She also mentioned that when having bad days or bad periods, she has a hard time keeping a positive mindset as she feels like the world keeps moving forward while she is lying in bed and not being able to keep up with the normal pace of society.
Camilla

Camilla has probably been suffering from the illness since early childhood without knowing. She is not sure about the severity but says that she recognizes the common symptoms of a moderate degree. Due to her probably having ME almost her entire life, Camilla was not as determinant as the other participants of what is symptoms of ME and what is normal for her. She explained that since receiving the diagnose, she has become aware of many symptoms she thought was “just her”, such as tinnitus, or the need for extreme portions of rest after small activities. When reaching her limit, tension in her neck and shoulders are the first warning signs. She also feels that she becomes apathetic towards other people. Other symptoms she has been noticing, is sleep deprivation, cognitive issues, sensitivity to sounds, dizziness, and a drop in blood pressure, higher pulse, sore throat, nausea, stomach issues, lactic acid and pain throughout her whole body. She said she is also sensitive to sudden situations, such as when an alarm goes off, her phone rings or when someone is at the door. Hence, she, for instance, has her fitness watch on vibration, and not sound.

Symptoms

When learning about their experiences of living with the illness, many similarities in the symptoms arose. In Appendix H, an overview of all the symptoms reported can be viewed. The overview shows what is common for all participants (green) and not (blue). It is important to note that all participants emphasized that most symptoms are present in some way every day, but that they aggravate when having bad days or bad periods.

Assistive aids

When talking about the different tools they use in their everyday life to either reduce or deal with the symptoms, it became evident that there are major individual needs among the participants. Of course, some of the tools were either very much liked or very much disliked by everyone, but mostly the participants expressed different appreciation towards the different options. The only tools that all participants agreed on worked well was pacing (energy modulation) and rest. All participants felt that pacing was a crucial part of their everyday life and that making sure to rest enough was essential to keeping the bad days away. All participants also expressed that they had a hard time keeping themselves below the invisible limit and that resting could be quite boring and lead to restlessness. On the opposite
side, all the participants agreed upon that working-out do not work as an aid for reducing or dealing with symptoms, and therefore either removed it from their map or placed it on the red zone. To them, working-out only aggravates symptoms and will not do them any good.

The most interesting for my project was their experiences with their fitness watches. Both Caroline and Ingrid thought that their fitness watches added great value as they learned how to balance their illness symptoms more systematically. Caroline had used her fitness watch for several years, and said that one of the values it gave her was insight into how much of the day she stayed in the different pulse zones: "Now I gather everything, or it’s in the FitBit like how many hours I have a certain low pulse through the course of the day, and like comparing that block against the block with higher pulse. And sort of wants it to be a good balance between the two blocks... And like keep track of it throughout the day or, like... Yes. Check at the end of the day if I like not are... Ehm... that I... eh... What I can expect for the next day." Ingrid had a similar approach. She tracked her sleep and pulse and used the information to change her behavior to fit with what she saw. If she only slept for four hours, her day would be slower than on days where she had eight hours of sleep. She also felt that the fitness watch had given her great insight into what activities are raising her heart rate and not. Both Caroline and Ingrid also saw a correlation between their resting heart rate going up when bad days or periods were approaching. Andrea and Camilla thought the fitness watch added some value in the form of illness awareness but did not feel that they had learned any specifics about the illness yet. Andrea mainly used the watch to keep track of her sleep, resting heart rate and activity/steps, but did not express any behavioral changes due to what the information gave her. When looking at her sleep, she used the information to verify or challenge her view about how much she slept that night, without changing her day according to the information at hand. The same was true for Camilla, which seemed to track a lot of data in her notebook, without expressing any specific information she was looking for. She also said that she did not feel that the fitness watch gave her that much value at the moment, other than being fun to use.

The participants used many different assistive tools other than the fitness watch, and the results from this can be viewed in Appendix L.
Expectations for RelaxMe
When discussing the expectations for RelaxMe, the participants expressed different thoughts. Caroline said that RelaxMe is something that she wanted a few years back and that she believed it would have been more beneficial for her four years ago than now. She was still eager to test it out and see if it could have an effect and imagined that she would set the threshold higher now than four years ago. She believed it would be very helpful to be reminded to slow down, as it can be hard to keep inside her limits. Andrea expected that RelaxMe would help her keep the heart rate low and that she might dare to be more active when knowing that something would tell her when to stop and relax. She mentioned that past experiences have made her anxious about trespassing the limit. Ingrid already monitored her pulse throughout the day and liked the idea of getting notified instead of checking it manually. She said that she sometimes can be a bit too conscious about her pulse and check it too often. She believed RelaxMe could make it easier to control the illness. Camilla was not sure about her expectations and wanted to take things as it came.

Future possibilities for RelaxMe
Caroline elaborated on how she could have been notified when the balance between low (rest) and high (activities) pulse is unbalanced, like a battery status. She also mentioned that she would love to be able to compare her sleep with her pulse. Andrea talked about how she would like reminders on when she should eat and take her medication. Ingrid did not have any suggestions at the time, and Camilla expressed that she wanted RelaxMe also to track sleep, pulse, and steps.

6.2 RelaxMe in the field
RelaxMe was then left with the participants to use until we visited for the final interview. It was up to the participants to choose when, how much and for how long they wanted to use RelaxMe. I was careful to explain that no behavior was right or wrong and that I would get valuable findings both from them not using it at all, and from them using it a lot. The initial plan was to let the participants keep RelaxMe for approximately two weeks. As time went by, all the participants experienced issues with their health, and I decided to let the participants keep RelaxMe for about one month.
Caroline experienced contact dermatitis after only a couple of hours of use. She used RelaxMe several times the next few days, but the dermatitis kept coming back. After three days, we decided that it was best to collect RelaxMe and let another participant (Camilla) try the artifact. Upon collection, I performed a short final interview (approximately 30 minutes) to learn about her experiences with RelaxMe. I recorded the interview and transcribed the results. At the time, the final interview guide was not ready.

6.3 Final interviews

After letting the remaining three participants have RelaxMe for approximately one month, it was time to listen to their experiences with RelaxMe to collect data from the field deployment.

6.3.1 Planning

I initially planned six parts, a warm-up where the participants could share their thoughts freely, the second would evaluate RelaxMe, the third would explore the design choices I had taken, the fourth would explore future possibilities, the fifth would explore symptoms once again (to compare all symptoms mentioned by all participants), and the final part would evaluate the field exploration of RelaxMe and the final interview.

Expert review

As with the previous interviews, I conducted an expert review with my supervisor, Jorun. We discussed the different parts and agreed upon changing the guide to fit the actual purpose of the interview more, which was exploring and generating knowledge about the role of RelaxMe. Hence, I changed the interview guide completely, only focusing on the most important things. I first and foremost shortened the guide, removing the part with comparing symptoms and with evaluating the field exploration. I would rather do this after the final interview, by email/telephone and a questionnaire (as presented in Chapter 7). The second version of the interview guide had seven small parts, one about general use, one about learnings, one about the vibration, one about the alarm and the black boxed pulse digit, one about design and material, one about future possibilities and one where I evaluated RelaxMe against the traffic light. I also added a part where I tested two concepts that emerged from the baseline interviews.
(and also mentioned during the telephone interviews by P1 in Section 5.6.3), namely a breathing exercise and a meditation exercise with RelaxMe.

Pilot interview

I then conducted a pilot interview with the same person I tested the baseline interview with to review the flow and practice the questions. I only found some minor issues with a few of the questions during the pilot interview. Thus, I iterated once more and created the final interview guide, which can be viewed in Appendix I.

6.3.2 Execution

The interview with Caroline was conducted and transcribed on 25. January. All the three remaining interviews were conducted between 6. March and 12. March 2018. My supervisor, Jorun, was also participating in the last three interviews. The interviews were planned to take approximately 1 hour. The interview with Andrea lasted 1 hour and 12 minutes, the interview with Ingrid lasted 59 minutes, and the interview with Camilla for 1 hour and 25 minutes. I transcribed the interviews immediately after conducting the interviews, at the latest the day after.

6.3.3 Results

In the next section, I present the results from the final interviews with the participants. Even though I did not perform the same interview with Caroline as with the rest, I did get an answer from her on most of the questions I had in the interview guide. Hence, I present the results from all four participants together.

Overview of data

The field exploration of RelaxMe gathered data about more than just the use of RelaxMe or the role of technology in their everyday life. As Figure 24 and Table 4 shows, data about their economy, their experience of the illness, their memories before the onset of the illness, their social life, their use of the fitness watch, their leisure activities and more were collected. To describe all data gathered would not have been interesting for this specific purpose, and I have chosen to only present the main findings directly relevant to the research question.
Figure 24: Shows the overview of data generated from field exploration

<table>
<thead>
<tr>
<th>Theme</th>
<th>Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coping with illness</td>
<td>Economy</td>
</tr>
<tr>
<td></td>
<td>Lack of social support</td>
</tr>
<tr>
<td></td>
<td>Social life</td>
</tr>
<tr>
<td></td>
<td>Society</td>
</tr>
<tr>
<td></td>
<td>Lack of understanding</td>
</tr>
<tr>
<td></td>
<td>Life with illness</td>
</tr>
<tr>
<td></td>
<td>Illness symptoms</td>
</tr>
<tr>
<td></td>
<td>Experience of illness</td>
</tr>
<tr>
<td></td>
<td>Vulnerability</td>
</tr>
<tr>
<td></td>
<td>Sleep patterns and dreams</td>
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<tr>
<td></td>
<td>Need for flexibility</td>
</tr>
<tr>
<td></td>
<td>Government and law</td>
</tr>
<tr>
<td></td>
<td>Leisure activities</td>
</tr>
<tr>
<td>Coping with illness / RelaxMe</td>
<td>Energy modulation</td>
</tr>
<tr>
<td>RelaxMe</td>
<td>Experiences of RelaxMe</td>
</tr>
<tr>
<td></td>
<td>Learnings</td>
</tr>
<tr>
<td></td>
<td>Future possibilities</td>
</tr>
<tr>
<td></td>
<td>Artificial intelligence</td>
</tr>
<tr>
<td></td>
<td>Opinions on RelaxMe</td>
</tr>
<tr>
<td>RelaxMe / Awareness</td>
<td>Changed awareness</td>
</tr>
<tr>
<td>------------------------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td></td>
<td>Changed behavior</td>
</tr>
<tr>
<td>RelaxMe / Technology and design needs</td>
<td>RelaxMe</td>
</tr>
<tr>
<td></td>
<td>Use of RelaxMe</td>
</tr>
<tr>
<td>Technology and design needs</td>
<td>Meditation and breathing exercises</td>
</tr>
<tr>
<td></td>
<td>Sleep data</td>
</tr>
<tr>
<td></td>
<td>Pulse data</td>
</tr>
<tr>
<td></td>
<td>Design and Materials</td>
</tr>
<tr>
<td></td>
<td>Use of fitness watch</td>
</tr>
<tr>
<td></td>
<td>The vibration</td>
</tr>
<tr>
<td></td>
<td>Tech features</td>
</tr>
<tr>
<td></td>
<td>Privacy</td>
</tr>
<tr>
<td></td>
<td>Usability</td>
</tr>
<tr>
<td></td>
<td>Battery issues</td>
</tr>
</tbody>
</table>

Table 4: Overview of data gathered during field exploration with RelaxMe

**Use of RelaxMe**

Due to contact dermatitis, Caroline only used RelaxMe for three days before we decided to end the test. She said that she used it for a couple of hours each day. The last day she even used it while grocery shopping and got experience with how it was to get an alarm. Andrea used RelaxMe sometimes when picking up her daughter from school, which is a 30-minute walk from their house. During the test period, she had a very stressful period due to issues with NAV that mentally drew her energy levels to the ground. Therefore, she did not manage to test RelaxMe as much as she had hoped. She also thought RelaxMe was laborious to put on and said that she would have tried it more if it was easier to use. Ingrid used RelaxMe the two first days of the test period but did not manage to test it more due to her broken arm and the need for help to put RelaxMe on. The two days she used it she wore RelaxMe for many hours but did not manage to test it outside her apartment. Mostly, she wore it when sitting on the sofa and found an alternative use for the battery by replacing it with a mobile charger. Camilla also had a bad period during the test due to a throat infection that would not let go. She used RelaxMe for three days during the test period and wore it for several hours during those days. She did not manage to go outside for a walk, and thus only tried RelaxMe inside her apartment. She also believed that RelaxMe was too laborious to use and thought she would have used it more if it did not have the extra battery.
Experiences with RelaxMe

Caroline experienced that RelaxMe vibrated during grocery shopping. She said that when the alarm went off, she thought that “it was actually kind of smart, because then I noticed that now I am maybe walking to fast”. She said that she initially thought it would not be that useful for her now that she knows how to balance the illness better but realized that there are moments when she does not know that she is trespassing her own limit. She thought that becoming aware of this could be a good thing for her, even now. She also talked about how she imagined it would be back when she had more severe ME: “I think about when I was sicker, then it would have been interesting to have it on a lower threshold like 90 or 95 or something, just to like stop yourself all the times you do a little bit too much, and learn to do things more slowly.. Because I really did struggle with that”.

Andrea also felt that she knew her illness and her boundaries so well that RelaxMe was not necessary for her at the moment. She would rather have loved to have a functionality like this four years ago when she was more of a newbie to the illness. Nevertheless, she said that it is, now as much as before, a good way of becoming aware of your tempo, and to remind yourself to breathe well and take things slow: “Yes, because it’s easy to, when having little time and stuff like that, like even though I have ME I can run, I just shouldn’t right.” She said that on days when she feels good or when big events are happening, RelaxMe would have been nice to have as she tends to overwork. She exemplified with a scenario when gardening: “Now you have to stop, like today you only should plant four potatoes, not fourteen.” She also emphasized that she feels that she knows her physical boundaries well, but not her mental boundaries. During the test period, she experienced a “crash” due to mental exertion and said that she does not believe RelaxMe can prevent such events from happening. When looking at the tracked data on her fitness watch, we saw the opposite. A few days prior to her “crash”, her resting heart rate increased a lot and stayed high until a few days after the crash. She explained that she was sleeping for 20-22 hours a day for four days after the crash, which corresponded with when the resting heart rate started to decrease. She was surprised to see this: “Now I learned something new. It definitely looks like it has registered that I was about to crash.” She seemed excited to learn that mental exertion also can affect the pulse: “Yes, it was a bit cool to see it for myself as well, because now I kind of become aware of it, now I probably can look at it a bit in the future.”
Ingrid said that when RelaxMe vibrated she immediately took it as a sign to stop what she was doing and try to lower the pulse and calm down. She took the alarm as an indicator of her body letting her know that she was doing something that demanded too much of her energy. She said that she usually keeps track of her pulse with the fitness watch and change her behavior in the same way when noticing that her pulse is high. She also said that now, after trying RelaxMe, she sees more value in getting notified when her pulse has been over the threshold for a long period, such as 20 minutes. Her pulse tends to increase a lot the first minutes of her standing up, and she does not see that as a problem: “For me, the pulse goes like up and down all the time, but it is maybe like when it is very high over time, that is probably more.. Or are most relevant. Because I can just like that get a pulse of 135 when just standing straight.. But then it goes down again pretty fast.. So I am thinking that it is more like over.. Yes.. if I have it for a quarter, 20 minutes, half hour, then it is more like.. Have an influence on the rest of the day and my symptoms.” She said that she tries to keep her pulse low throughout the day to avoid “crashing”, and a tool that helps her with that would be useful. She also said that she sometimes can see that her resting heart rate increase a few days before a “crash” or a bad period starting and that her resting heart rate always are higher when having bad periods.

Camilla said that she believed RelaxMe could help her to calm down and remember to take things in slow motion. She felt that she did not know enough about her illness to say if a low pulse would help her or not, but that she was eager to test it out more properly then she was able to during the test. She felt that such an alarm could help her avoid “crashes” and bad periods: “I do not think that I would heal from the ME, but I would have a better everyday life because I wouldn’t have that many symptoms”. She also said that she does think it’s hard to find out where her boundaries are: “Do you manage to play basket for an hour? Of course, I can... but it will have huge consequences afterward, so does that mean that I can manage it? Where is my limit?” She said that she feels that such a functionality could help her take the illness more seriously, and that it can be easier to tell other people: “That it could contribute to better understanding and more respect for the illness, because it’s not just me who... says that no, I’m tired now, but it’s actually a tool saying I have reached my limit.”
The vibration
Andrea thought the vibration was too powerful and referred to the feeling of getting an electrical shock. She emphasized that it did not hurt, but that she was surprised. She said that she liked the vibration from the FitBit better. Ingrid thought the vibration was ok and said that she did not get surprised or scared. She also felt that the length was good because then you make sure that you notice the alarm. Camilla also thought the vibration was nice and said that she liked it being long and powerful. She said that she did not feel stressed from the alarm, as she sometimes can do from doorbells, when the telephone is ringing or the alarm clock. None of the participants would like the possibility of having a beeping alarm.

Design and materials
Caroline experienced contact dermatitis an hour after putting RelaxMe on her arm. She said that she is struggling with atopic skin and contact dermatitis and that she thought she was especially sensitive in the period of testing due to her being sunburned from a recent trip (she came back from vacation a few days before the baseline interview). The rest of the participants did not experience any issues with dermatitis, itching or rashes. All of the participants naturally thought the extra battery was inconvenient. When it came to the design of the watch, all of the participants preferred their FitBit’s and thought RelaxMe was too big and bumpy.

Future possibilities
The participants came up with several great ideas during the interviews for future possibilities. Caroline felt that it would be useful to be able to change the threshold according to her symptoms: “Like if I have a day... Like earlier this week when I did not feel that well... It would be nice to have [the threshold] on 100 so that I sort of have a slower [day]... But on other days when I feel better, it is okay to have it a bit higher.” Ingrid agreed with this and said that she would like to have the threshold at a higher or lower level according to her daily shape and needs. All of the participants agreed on that they would like to see the pulse they have when the alarm goes off but did not agree if it was necessary to see it right away or if it was enough to see it in an app later. Caroline and Camilla found it interesting to be able to see the pulse there and then, Andrea and Ingrid both thought it could
be a good thing not to be able to see the pulse right away as there can be too much focus on the device and your pulse. All of the participants would like to save the data, as they find it interesting to go back and look at the statistics and find correlations. Caroline also elaborated on the idea she had in the baseline interview and said that she would love a feature that would give an overview of how many percentages of the day she has been in low, medium or high pulse zones. She emphasized that such information is much more relevant for a person with ME than, for instance, the number of steps taken or being encouraged to be more active. When Andrea realized that her resting heart rate was influenced by her good and bad periods, she came up with the idea that she would like an alarm to tell her if her resting heart rate deviates from the norm. When presenting this idea to Ingrid and Camilla in their interviews, they found the idea interesting and believed it would be a helpful feature. Andrea also wanted to be able to easily set alarms for remembering her meals and medication. Camilla suggested a functionality that would make it easier for other people around her to understand her boundaries, namely a twin watch. Her idea was that the twin watch would vibrate whenever her watch would vibrate, and by this letting a partner, parents, a friend or someone else know that you are overexerting yourself. When presented with the possibilities of having an artificial intelligence inside RelaxMe that would learn about you and give personal advice, all the participants were positive. They liked the idea of having a computer helping them with finding correlations between their behavior and their symptoms, as this can be hard and energy-demanding.

Meditation and breathing exercise

During the final interview, I also tested two possible features that could help the users of RelaxMe relax more easily after the alarm goes off. The first was meditating to a vibration that was beating in a very slow heart rate. The second was a breathing exercise that would help the user breathe more calmly and systematically by vibrating for every inhalation and exhalation. Andrea liked meditating to a slow heart rate better than the breathing exercise. She said that she thought it was very easy to focus on the continual vibration and that she felt the breathing exercise demanded more of her regarding having a correct and incorrect way of breathing. When she checked her pulse after the exercise, she also saw that it was lower than usual. Ingrid, on the other hand, liked the breathing exercise more and said that it was due to her previous experiences with her panic
attacks. When she is having a panic attack, one of the things that stress her the most is when she starts to focus on her fast pulse. She felt the meditation exercise triggered some of the same stressful feelings. She liked the breathing exercise, and said it was an easy and low threshold way to calm herself down. Camilla did not prefer one of the exercises over the other but said that she liked both. She said they were easy to focus on, which was a good thing: “Yes, I need something that... Pulls my thoughts away, or else they just start spinning... And then I can’t find my inner peace.” When asked if they could get their preferred exercise immediately and automatically after a threshold alarm goes off, they all liked the idea. Ingrid said that she felt it was a low threshold thing to do, and that you could easily do it in public without anybody noticing. These two exercises were not tested on Caroline.

Final judgment
As a final question, I asked where they would place RelaxMe on the traffic light-poster, and why. Both Andrea and Ingrid said they would place RelaxMe between yellow and green. Ingrid said that “It can maybe help and regulate more than many of the other things, which are more like... Symptom relief.” Andrea said that she thought RelaxMe and the future possibilities for it have great potential, but as it is today, it has too many flaws to be regularly used. Camilla would place RelaxMe on the green zone, with the reservation that keeping under the threshold helps a person with ME.

6.3.4 Findings from field exploration with RelaxMe
In Table 5, a selection of the most important findings from the field exploration can be viewed.

<table>
<thead>
<tr>
<th>Part</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use of RelaxMe</td>
<td>Used the artifact as intended and several times</td>
</tr>
<tr>
<td></td>
<td>Health challenges complicated the field exploration, and acted as a barrier to extensive use of RelaxMe</td>
</tr>
<tr>
<td></td>
<td>The extra battery was seen as cumbersome to use</td>
</tr>
<tr>
<td>Experiences with RelaxMe</td>
<td>RelaxMe made them aware of that they trespass their own limit, even though they thought they had good control over their activity levels</td>
</tr>
<tr>
<td></td>
<td>RelaxMe learned them to do things more slowly</td>
</tr>
</tbody>
</table>
RelaxMe made them aware of their tempo throughout the day. RelaxMe is especially smart for good days or big events when it is easy to trespass the limit. The vibrating alarm is seen as an indicator of the body telling them that the activity is too demanding. One participant learned that it is more interesting to get an alarm after 15-20 minutes trespassing the limit. RelaxMe can potentially help avoid bad periods and “crashes”. RelaxMe could potentially help them take the illness more seriously. When technology notify of reaching the limit, it can be more convincing for people around.

<table>
<thead>
<tr>
<th>The vibration</th>
<th>Vibration as an alarm was appreciated</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>None of the participants would like a beeping alarm</td>
</tr>
<tr>
<td>Design and materials</td>
<td>One participant experienced contact dermatitis, she has atopic skin</td>
</tr>
<tr>
<td></td>
<td>The extra battery is inconvenient</td>
</tr>
<tr>
<td>Future possibilities</td>
<td>The participants want to be able to change threshold limit according to symptoms</td>
</tr>
<tr>
<td></td>
<td>Would like to see the pulse when trespassing limit, but did not agree on whether they needed to see it right away or later in an app or similar</td>
</tr>
<tr>
<td></td>
<td>Would like an overview of how many percentages of the day they have been in different pulse zones</td>
</tr>
<tr>
<td></td>
<td>See the data as a battery, how much of their energy is left?</td>
</tr>
<tr>
<td></td>
<td>Get notified if resting heart rate increase or decrease outside of the regular pulse</td>
</tr>
<tr>
<td></td>
<td>A twin watch to help others around the user understand when energy levels are low</td>
</tr>
<tr>
<td></td>
<td>Artificial intelligence that learns about them and gives personal advice tailor-made for people with ME was wanted</td>
</tr>
<tr>
<td>Meditation/breathing exercise</td>
<td>Disagreeing on meditation or breathing exercise was the best way to relax</td>
</tr>
<tr>
<td></td>
<td>They liked the vibration, and that it was easy to focus on</td>
</tr>
</tbody>
</table>

Table 5: Key findings from field exploration of RelaxMe
7 Evaluation of methods and tools

As research with people suffering from ME is scarce, I wanted to take advantage of the valuable position I had and evaluate the methods and tools used in the data gathering and the field exploration of RelaxMe. My motivation for doing this was two-fold. First, I am myself new to researching with individuals suffering from ME. To evaluate the methods used with the participants themselves, I hoped to continually learn and improve my way of obtaining knowledge throughout the research process. Second, I expected to be able to generate some key learnings from researching with sufferers of ME that potentially could contribute to safer and more adjusted research with the user group in the future. In this chapter, I present the results obtained from the evaluations done after the telephone interviews and after the field exploration of RelaxMe, as well as key learnings.

7.1 Planning the evaluation

For the evaluations, I created questionnaires for the participants to answer whenever they wanted after the interviews. For the telephone interviews I created one small questionnaire, for the field exploration of RelaxMe, I created a questionnaire of four small questionnaires, assessing the baseline interview (1), the final interview (2), the interviews in general (3), and using a research product (4). Before sending the surveys to the participants, I performed a pilot survey with fellow students to validate that the questions were understandable, and that the choice of options felt natural. I got some valuable feedback and changed the surveys according to some of their suggestions. At the end of each interview, I asked the participants if they would mind answering a few questions about the interview and explained that they could do so through a questionnaire I would send them. All of the participants said yes to this, and I was careful with explaining to them that there was no rush and that they could postpone answering until they felt they had the energy to do so. Both when evaluating the telephone interviews and the field exploration, several participants forgot to answer. Thus, I sent a reminder a few of weeks after the initial interview. All participants from
the telephone interviews answered their questionnaire, and all but one answered the questionnaire for the field exploration.

7.2 Key learnings

In the following section, key learnings from the evaluation with the participants are presented. A comprehensive presentation of the results from the questionnaires can be viewed in Appendix M.

- There are very different preferences for time length and number of questions when conducting an interview, as participants have different capacity and different symptoms. Flexibility in how to conduct the methods should thus be a priority.
- Talking freely about a topic can be better than to be asked questions, as it can be embarrassing not to understand the question asked. Thus, the cognitive symptoms should be regarded when planning an interview and the researcher should strive for customizing the methods accordingly. This was not done during the field exploration of RelaxMe and was appreciated by the participants.
- Even though all interviews were customized to fit the needs of the participants, all participants but one got fatigued during and after the interviews. However, they said that there was not much to do about that due to the nature of their symptoms.
- Nevertheless, a suggestion of adding a pause during longer interviews could potentially make the interview less fatiguing.
- The wish for contributing to research makes the participants utilize more energy than they should, as a researcher one should keep this in mind and help the participants to not overexert.
- Avoid perfumes and strong colors on clothes
- The researcher should sit close enough so that the conversation can be conducted silently and avoid bright light or uncomfortable seating arrangements. Preferably the participant should be able to lay down and relax while being interviewed.
- Using a new research product can be demanding for the participants. Thus, as a researcher you should carefully consider what the positive and negative outcomes of using a research product are for the participants.
8 Discussion

In my thesis, I wanted to explore how to make and use research products to mediate the state of the phenomenal body and generate new knowledge about their meaning for people with health challenges. As an answer to the overarching research question, I have documented and described my design research process, attempting to provide the reader with the tacit and drifting knowledge generated when making the artifact and using it in a field exploration to generate new knowledge. As mentioned in Section 4.1, several questions are under discussion in the RtD community, reflecting on what RtD is and how it should be conducted. In the following chapter, I discuss my specific RtD project with regards to some of these questions, looking at how my RtD project was carried out, how the knowledge produced during this specific RtD process was communicated, and what role RelaxMe had in generating the knowledge obtained. The chapter is first and foremost a discussion about this particular RtD project put in the context of relevant literature discussing the implementation and documentation of RtD projects.

8.1 My RtD approach

«What can designers claim to know during and after this process? Given the indiscipline that I argue characterizes design processes, productive or not, what can we claim to have learned? From a scientific point of view, the answer is “not a lot”. The complex, idiosyncratic and interpretative nature of design means that there is little epistemological accountability in the results.» - (Gaver, 2014, p. 160)

8.1.1 How was my RtD project carried out?

In the RtD community, a coherent and agreed-upon way of carrying out an RtD project is currently lacking. Some researchers are calling out the need for appropriate protocols, descriptions, and guidelines on how to conduct RtD projects (Stolterman, 2008; Zimmerman, Stolterman, & Forlizzi, 2010), while others suggest that the design research community should be cautious of creating a convergent and standardized approach (Gaver, 2012). The lack
of any agreed-upon way of carrying out an RtD project makes conducting an RtD project challenging. When designing my research process, this became apparent as I struggled with how to go about the knowledge generation. Even though I was guided by the field approach as proposed by Koskinen et al. (2011), it was challenging to plan what kind of methods and activities that should be used throughout the project to generate the type of knowledge I was pursuing. However, the flexibility offered by such an “open” approach also left me with the possibility to let the knowledge generated throughout the different activities guide me to the next step in the process. Without the opportunity to let the project drift while making the artifact, I believe that the resulting research product would have had a different outcome. At the same time, the phenomenological framework guided me in the planning of the different activities and what type of knowledge I was interested in gathering. The combination of a phenomenological lens and an RtD methodology enabled me to create research products that mediated the state of the phenomenal body and then explore them in the field with vulnerable users. I see this flexibility as an advantage of the RtD approach, as I was able to adapt and adjust the process to both fit the phenomenological approach and the vulnerability of my participants, as well as opening up for a flexible and drifting process when making an artifact.

8.1.2 How was my knowledge communicated?

“[T]here are many who could potentially benefit from IxD knowledge. This knowledge can have relevance to designers, design researchers, researchers in other disciplines, and design and design research educators. The challenge is ensuring that such knowledge (or knowing) has utility to each of these practices or, more particularly, is understandable to them.” - (Höök et al., 2015, p. 35)

Due to the unstructured and drifting nature of design practice, documenting and communicating the knowledge generated can be difficult. Some researchers argue that since RtD projects are about making a product, most of the knowledge generated can be encapsulated in the resulting artifact (Zimmerman et al., 2010). Thus, knowledge is lost in the process of writing as it can be difficult to describe it textually (Hengeveld, Frens, & Deckers, 2016). Other emphasize that “designed artifacts cannot “contain” knowledge
as if it were a magic ingredient" and argue that it is rather their makers that need to express their knowledge in their creation (Höök et al., 2015, p. 35). As described in Section 4.1, Gaver (2014) introduces the concept of epistemological ambiguity that is the “fluid flow between uncertainty and speculation that design allows” (Gaver, 2014, p. 153). He further explains how the designer “fit together ideas, materials, technologies, timings, situations, people and cultures” (Gaver, 2014, p. 162) in a synthesis through the making of the artifact. Höök et al. (2015) emphasize that communicating such knowledge obtained through a design research process can be difficult, as the tacit and intermediate knowledge generated is hard to capture and express.

In the context of my project, I can relate to the discussion presented above. As mentioned at the beginning of Chapter 5 (The design process), documenting, describing and communicating the knowledge generated throughout the process of creating the artifact have been a challenging activity. The amount of knowledge generated has been considerable, and the act of writing it up to be read and understood by others have been a challenging endeavor. To explain the process, have at times seemed impossible, as expressing, communicating, and documenting what I have learned in each step is complicated and intricate. The making of the artifact started as a few low fidelity prototypes made of paper and cardboard and sparked a continual stream-of-consciousness that eventually led to the final research product. The making of the artifact was also guided by my increasingly growing understanding of the user group and design context through the conduction of different methods involving the user group, as well as the exploration of different materials and technologies. This thinking, processing, and merging of ideas, thoughts, relevant research, theory, user context, design knowledge, material, technologies and personal interests have been an ongoing activity since the making started. To divide this intricate stream into different steps to be described as isolated activities have been a real challenge. Hence, I believe it is essential to stay critical to my own understanding of my own process and reflect on what kind of knowledge might have been lost in the process of writing this thesis. One prominent aspect is the unconscious thinking done and decisions taken that I am not consciously aware of. Secondly, it can be challenging to describe my own design skills explicitly. Thirdly, when generating ideas, it can be hard to assess where the idea initially started or how it truly developed.
Lastly, it is hard to remember what you did not know about the user group and design context (at a particular point in time) when you finally have learned it.

Nevertheless, I have tried to provide the reader with a detailed description of the design process and the field exploration with RelaxMe. The detailed description of the project is an attempt to highlight how an RtD process with a field exploration can be conducted with a phenomenological approach and the involvement of vulnerable users. By communicating my RtD project in this way, I wish to make it possible for the reader to reproduce the design process and the field exploration, and thus make and use research products to mediate the state of the phenomenal body when working with vulnerable users.

8.1.3 How to involve vulnerable users in an RtD project?

“While researchers spend time designing and planning their research process to concur with the established and universal standards of science, designers need to design their process to accommodate the specifics and unique conditions of the task at hand. “ (Stolterman, 2008, p. 62)

As mentioned in Section 4.2, people with ME can be described as vulnerable users due to their health challenges. Thus, one of the aspects of my process I needed to design with caution, was the inclusion of vulnerable participants. Throughout the process, I strived for continual ethical reflexivity to make sure that I, during and after each method applied, reflected on my use of methods and tools, their effect on the included participants and what key learnings I could bring with me. In Chapter 7, I described the results of the evaluation of the telephone interviews and the field exploration of RelaxMe. From the results, and from the continual ethical reflexivity throughout the process, I have noted key learnings from working with vulnerable users, such as people with ME, in an RtD process.

Flexibility is key

During the project a number of participants have been involved in either participating in a workshop, telephone interviews or during the field
exploration of RelaxMe. As a researcher and designer, I have a natural instinct to plan and predict methods used to make sure the data I am after will be generated through the application of the method. What I learned during the workshop with the ME association, my first contact with the user group, was that the plans and predictions will have to give way to the needs of the users. The workshop was initially planned to last for quite a bit longer, but since the participants started to feel fatigued, we had to stop the session long before we had talked about all the topics on the agenda. The same happened during the telephone interviews when I needed to end the interview with the first participant before we had finished the planned interview guide. We agreed on trying to schedule a follow-up interview one week later, but the participant was getting sicker, and we decided to conduct the interview through email – sending one question at a time. Without being flexible, I would not have been able to perform a full interview with the participant. Even though the methods used where customized to fit the needs of the users, it became evident that this was not enough. As Culén & van der Velden (2013) emphasized, it can be challenging to modify methods or to find new ones that fit the needs of the user group. I argue that, in the context of ME, flexibility can be a solution to the challenge of customizing the methods to fit their needs. What I have learned throughout this project, is that ME is an illness characterized by an unpredictability of when symptoms might flare up. Furthermore, the individuals experience different manifestation of symptoms and thus have very diverse needs when participating in research. Flexibility towards their current situation and their individual needs was needed to be able to generate the knowledge I wanted. As a researcher, I feel humble and grateful for getting the possibility to talk directly to the user group when learning about their illness and symptoms and the fact that participating in the project can aggravate their health. To not only be flexible but also explicitly show the participants that I am flexible, have been important when including them in the design process and was also appreciated by the participants:

“That you have been so flexible, with regards to having a bad day or… that we could postpone or something like that. That is a considerably better way to do it than if you, for instance, have a doctor’s appointment that you must attend. That flexibility is highly appreciated.” – Ingrid, final interview
Be there for them

As people suffering from ME have a tendency to be isolated from friends, family and social life in general, intruding their life as a researcher also means that you are one of the few people they socially engage with during the research period. Furthermore, they often feel stigmatized by friends, family and healthcare professionals, and I might be one of the few people that are “willing” to listen to their experiences of how it is to suffer from such a debilitating illness. During the project, and especially when exploring RelaxMe in the field, I felt the need for remembering to be humble, appreciating the time and effort they were giving me, and at the same time be there for them as one of the few people that believe in their experiences. When being stigmatized and isolated as they are, it can feel good having someone to share their experiences with, and to be cared for and listened to. As a researcher in this particular context and process, I feel it is important to remember this, and not just be the kind of researcher that invades their lives with questions about their experiences, but also be the researcher that listens, understands and shows that I believe in their experiences.

Adjusting methods and tools

As people with ME experience symptoms that include fatigue, post-exertional overexertion and cognitive issues, the mere act of participating in a research project can aggravate their health. Other than having a flexible attitude towards the data gathering, being cautious when designing the methods for including them in the design process was essential. When having the initial telephone interviews, the short time frame and the fact that the interview was conducted via telephone was a conscious choice to create a low-threshold situation for participation. Furthermore, when exploring RelaxMe in the field, the act of adding tools to the interview situation had the purpose of creating an interview situation that was more fitted to their needs. The potential cognitive symptoms were addressed through adding tools that hopefully would make it easier to remember and talk about their experiences of living with a debilitating illness. As the results in Chapter 7 shows, this was evaluated by the participants as beneficial, and they expressed a positive attitude towards the support provided by the tools. The tools used were inspired by the “Cool Wall” as presented in (Fitton, Read, et al., 2012; Fitton, Horton, et al., 2012) and
further edited in (Børsting & Culén, 2017), and was initially created for research with children and adolescents. In this research context, the tools were adjusted to be more suitable for adults. To see that the participants appreciated the tools indicated that the changes were successful and that the tools were not perceived as childish or useless.

The importance of the artifact
Researching with a vulnerable user group has come with many challenges. One of them has been balancing their motivation to contribute to the research and their actual capacity to do so. Their symptoms, such as fatigue and cognitive issues, create a barrier between their motivation to participate in the study and their actual capacity to do so. All of the participants uttered gratefulness with regards to me researching their illness and was motivated to contribute. Because of this motivation, almost all of the participants overexerted themselves during the interview situations (as seen in Chapter 7). During the field exploration of the artifact, I saw a change. When being able to leave an artifact behind, and let them have it, see it, and think about it for an extended period, it seemed as the knowledge generation was accelerated without aggravating their health. RelaxMe enabled the participants to experience the interactions at their own pace. By doing this, they got new ideas and thoughts about RelaxMe’s role in their lives and the role of the anaerobic threshold. All the participants in the field exploration of RelaxMe reported that they were not able to use the artifact as much as they had hoped, as they did not have the capacity. However, during the final interviews, this did not seem to prevent the field exploration from generating considerable amounts of knowledge. It seemed that the mere presence of RelaxMe in their home or on their body created a continuous wave of thought that would not have been generated by a one-time test of a couple of hours. Some of the participants even explicitly expressed that even though they were not able to use RelaxMe as much as they had hoped, they had thought a lot about it (RelaxMe) since the baseline interview. Furthermore, the fact that they were able to experience the artifact on their body, test it at their own pace, and feel how RelaxMe worked seemed to be significant. To sum up, the importance of the artifact when working with vulnerable user group cannot be overestimated as it enabled me to get access to the user group in a unique way I argue would not have been possible without an artifact.
8.2 What was the role of RelaxMe?

“Design practice is about the creation of a desired reality manifested as an ultimate particular. […] The ultimate particular is the actual final manifested outcome and as such a result of an intentional design process.” - (Stolterman, 2008, p. 59)

8.2.1 Addressing new medical research

One of the aspects of my approach is how I exploited the possibility of addressing new medical research about a chronic illness through design. By creating a research product that was indeed based on, amongst many things, newly released medical research about bodily processes of people with ME, I was able to take a shortcut through the time-consuming process of replication studies, governmental regulations, political, and economic questions that needs to be validated before the results of the research are being applied as a valid treatment method in clinical practice. As quoted in Section 4.1, Frayling said that RtD “is about taking a problem outside of design and using design to address the problem and generate new knowledge” (Frayling, 2015). My approach to this view on RtD has been about addressing the problematic activity of energy modulation with newly released medical research and using design as a means to place the new medical research contribution in the hands of the users immediately through a research product. The fact that the research was made available through the design earlier than what the health care system could also was pointed out by one of the participants. She was wondering why her doctors did not apply the knowledge about pulse and the anaerobic threshold when teaching her about energy modulation if research shows that people with ME process lactic acid differently and more slowly than healthy people do.

To be able to create something novel like RelaxMe, not just in the sense of using technology and design in new ways, but also by looking outside of technology and design to find new medical research, can be a quite interesting approach to RtD. However, a risk when taking such a clear stance on new medical research is obviously present. Results from research on ME are non-conclusive and headed in different directions, and I have taken a position on one of these directions. If the research eventually turns out to be wrong, possible unintended harmful effects can occur. Making a
design choice based on new medical research and putting it in an artifact used by people with ME can potentially be severe, as they can get false expectations of what the artifact might bring to their life with the illness. By doing this, I might send signals to the participants that the results can be trusted as valid in the medical definition of the term. It is thus essential to reflect on these possible unintended harmful effects before making such a design choice and ground it on a thorough understanding of the medical research found, and its reception in the medical research community.

8.2.2 Making the anaerobic threshold observable

When making RelaxMe, I was in a sense creating a new possibility for the participants when enabling the threshold to become observable through a bodily haptic experience. This enabling is a vital aspect of the RtD approach because “it creates the possibility for people and products to engage in interactions that were not possible before, and these can come into existence – indeed, become observable – through the design” (Stappers & Giacciardi, 2018). The artifact played an essential role in this enabling, as I could not have carried out this change without the help of the artifact. Of course, one could talk about the possibility of such a tool through interviews, but to test it out, see it and feel the functionality through their bodily experiences I argue was of utmost importance when generating knowledge about the phenomenon. When conducting the baseline interviews, one of the participants (Caroline) argued that she thought RelaxMe was not going to help her much due to her many years of experience with ME. The final interview showed that she indeed got another perspective after using RelaxMe herself. When walking to the grocery store, she experienced the vibrating alarm when she trespassed her anaerobic threshold. She said that the experience left her with a new view of the tool, as she became aware of the fact that she still does, after all these years, trespass her limit without knowing. Another example of how important the artifact was when studying the interactions with RelaxMe was showed by one of the other participants (Ingrid). She had many thoughts about how RelaxMe could help her in her everyday life during the interview. After using RelaxMe for a while, her initial thoughts changed. By experiencing how she interacted with the artifact, she became aware of the fact that it would be more beneficial for her to get an alarm when the pulse stayed over the anaerobic threshold for a longer period, and not just in the moment it reaches the limit. The artifact
thus enabled trespassing of the anaerobic threshold to become observable for the participants through design, and furthermore observable for me to generate new knowledge from the interaction they had with the artifact. The artifact enabled the participants to reflect on the concept of RelaxMe in new ways, generating knowledge that I argue would not have been able to retrieve by only visualizing the functionality through conversations.

8.2.3 The artifact as an example of an incorporated object

During the design process, I got knowledge about the phenomenon of being ill. As I presented in Chapter 3, a critical aspect of understanding the phenomenon of being ill is to understand the shrinkage in space an illness entails. Shrinkage is, shortly described, that the world around a person shrinks with the onset of illness due to reduced capabilities. An illness such as ME comes with symptoms that can reduce the once taken for granted abilities a person has, for instance, when experiencing cognitive issues, fatigue, pain or sensitivity to lights and sounds. By understanding the phenomenon of being ill, I argued in Chapter 3 that I could more easily explore how technology could have a role when self-monitoring and self-managing the illness or more directly increase the person’s abilities by becoming an incorporated object. In this way, technology could potentially reduce the experience of shrinkage and give birth to a new subjective experience of the world and one’s body.

The findings from this study suggest that all types of tools, both technological and non-technological are used by the participants with the purpose of reducing the feeling of shrinkage. Calendar notifications and reminders are used to prevent oneself from forgetting a date with a friend or an important appointment at the doctors. Earplugs are used to reduce the exposure to high sounds, and thus reduce symptom aggravation. In other words, the tools were either used to reduce symptoms (earplugs) or control the consequences of them (reminders). The tools used to reduce symptoms mainly dealt with self-monitoring and self-management through energy modulation, as they were used to avoid overexertion in some way. The fitness watch was a tool all the participants in the study used and had the purpose of gathering data that could potentially be used to energy modulation. However, the findings suggest that the fitness watch was a tool
used by many primarily due to it being highly praised inside the ME-communities, and not because the individual participants saw a direct effect of the use. Several of the participants even said this explicitly; they had used the fitness watches for a while without knowing precisely what to look for in the data that was gathered, and thus did not believe the fitness watch was very helpful - yet. The participants that did know what to look for, on the other hand, used the data to actively change their behavior according to the correlations between pulse, sleep, and activity. The findings suggest that the fitness watch have great potential for becoming an important tool when energy modulating, but that the tool was relatively complicated to use and was not fitted to the context of energy modulation. To compare lots of data and see correlations across them is a cognitively demanding process, and that is why a fitness watch presents you with a detailed analysis of your workouts. When experiencing cognitive problems as one of the primary symptoms, it is not hard to imagine that several of the participants did not experience any learnings from the fitness watches when the comparing and searching for correlations needs to be done manually. The fitness watch as people with ME uses it demands an active stance towards the data and an understanding of the quantified and dehumanized aspects of oneself for the participants to be able to change their behavior in a meaningful way. The findings suggest that this process is experienced as demanding and that the objective data measured are perceived as dehumanized and elusive. Without any perspective, the data are just numbers on a scale that do not make any sense. This lack of perspective was seen in one of the participants (Andrea) that measured her pulse but did not know what to extract from the numbers she saw. It was not before we showed her that her resting heart rate increased when experiencing a bad period that she saw the correlations in the data. The same goes for sleep registration. Several of the participants registered their sleep, but when asked what the information gave them they mentioned that the data confirmed or disconfirmed their beliefs about the amount of sleep they got the previous night, or that they saw that their sleep was indeed as bad as they felt. Thus, they did not change their behavior and did not use the data as it was intended: for energy modulation. The participants that did take an active stance towards the sleep data and used the data to foresee how the day would be like changed their behavior and used the data to energy modulate.
When it comes to actively changing their behavior with regards to data about the pulse, it becomes even more demanding. Either, the user needs to actively check their pulse now and then to see if it is high or low. Or, they need to analyze the pulse data against what they can remember about their previous behavior. What did I do at that exact moment to make my pulse increase that much? The answer is almost impossible to answer without a detailed description of all your activities throughout the day - or a mastermind. The need for an extra bodily capability with regards to the pulse seemed to be there, and the research product was meant to represent this capability by adding the possibility to know when the pulse reached a certain limit. The artifact played on the natural bodily processes of letting you know at the exact moment, making it possible to change behavior accordingly. Your nerves send pain impulses to your brain when touching a hot stove, and you remove your arm immediately and learn that such action is destructive. The same principle was incorporated into RelaxMe so that the user could reduce the activity level directly and learn what type of behavior that aggravate symptoms.

The findings suggest that the participants enjoyed that the artifact mimicked bodily processes, as they mentioned that they liked the possibility of receiving more direct feedback about their behavior. When talking about how they used and would use the artifact in the future, they mentioned aspects that suggested the tool was experienced as part of their body. An example of this was mentioned by one of the participants (Andrea) when she explained how she often say no to requests or acting out on her hobbies in fear of overexerting herself. She imagined that the artifact could support her with this fear and be a helping hand when trying to find out just how much she can manage. Instead of saying no to a request, she could say yes and test her capacity with the insurance of knowing that she would feel, through the vibration, when it was time to relax. This reassurance can potentially change her life, as RelaxMe gave her a third option and showcased an alternative future for her. Instead of choosing between going all in and become sicker, or do nothing and have a boring time, a third option was to do a bit of what she wanted without risking symptom aggravation. The alternative future was now to live fully, within her limits. One of the other participants (Ingrid) described how she experienced RelaxMe as something subtle and discreet, and that she believed it would not be noticeable for other people when it vibrated. She also emphasized
that she liked that the technology now was a part of her, preventing her from strictly (and stressfully) monitoring her pulse at all times. The concept of a twin alarm introduced by one of the participants (Camilla) worn by a partner or family member was explained as an artifact that could potentially convey the bodily experience in a more persuasive way than when telling the person themselves. For me, this indicates that the experience of receiving a vibrating alarm in the moment of trespassing the anaerobic threshold through bodily haptic sensations is more powerful and convincing than when telling the same thing through language, and that it is seen as a part of the user’s body. When testing the two exercises for meditation and breathing, the participants expressed that they believed it was easier to focus on a haptic sensation than listen to a voice. For me, it seemed that the fact that the research product was designed in a way that took the technology closer to the body and bodily functions, acted as a means to incorporate the object. The participants reported that they felt that they could relax more, when not having to check the pulse themselves. Compared to the fitness watch, which dehumanizes bodily functions into numbers and graphs, the research product seemed to be embodied by the participants, mediating the trespassing of the anaerobic threshold through a vibrating alarm. Hence, RelaxMe acted as a new extended capability they could use without “disturbing” and demotivating features such as workouts or motivational notifications about moving more, or strict and stressful monitoring of the data gathered.

8.2.4 Inquiry-driven, finish, fit, independent

As mentioned in Section 5.7.1, Odom et al. (2016) propose four interrelated qualities of a research product that must be present at once in the design artifact; inquiry-driven, finish, fit and independent. In the following section, I discuss the qualities related to RelaxMe and the importance of these qualities when evaluating a research product with vulnerable users such as people with ME. A detailed description of the four qualities is presented in Table 6.
Inquiry-driven: a research product aims to drive a research inquiry through the making and experience of a design artifact. Research products are designed to ask particular research questions about potential alternative futures. In this way, they embody theoretical stances on a design issue or set of issues.

Finish: a research product is designed such that the nature of the engagement that people have with it is predicated on what it is as opposed to what it might become. It emphasizes the actuality of the design artifact. This quality of finish is bound to the artifact’s resolution and clarity in terms of its design and subsequent perception in use.

Fit: the aim of a research product is to be lived-with and experienced in an everyday fashion over time. Under these conditions, the nuanced dimensions of human experience can emerge. In our cases, we leveraged fit to investigate research questions related to human-technology relations, everyday practices, and temporality. Fit requires the artifact to balance the delicate threshold between being neither too familiar nor too strange.

Independent: a research product operates effectively when it is freely deployable in the field for an extended duration. This means that from technical, material, and design perspectives an artifact can be lived with for a long duration in everyday conditions without the intervention of a researcher.

Table 6: Four qualities of a research product as described by (Odom et al., 2016, p. 2551)

**Inquiry-driven**

The research products created during this RtD process had the intention of investigating my research question and explore what role technology could have in the lives of people with ME. The research products were thus inquiry-driven.

**Finish**

The artifact was created and tested to be able to function on its own and be used by the participants as much as they liked. The casing of RelaxMe was 3D printed in white material, and watch straps was handmade in soft, natural leather to make it comfortable to wear for an extended period. Due to the battery issues experienced, the artifact also consisted of a power bank to supply the electronics with enough voltage and capacity. To be able to
wear the power bank together with the artifact, a sock was made to protect the skin from being in contact with the power bank. In the field exploration with RelaxMe, the findings indicated that the participants looked at RelaxMe as a prototype. The extra battery was a drawback for the participants, and they seemed to prefer the design of the fitness watches they were already using. However, results from the telephone interviews (see Section 5.6.5) indicated that the participants were not motivated to have a device that needs to be charged too often, and the extra battery was thus also in a way a positive aspect. Nevertheless, if having more capacity, I believe that the extra battery would be less of a problem. Of course, it is not ideal for any user group to wear a spare battery, and the solution was a last-minute decision when struggling to find a good enough battery option. With more time, resources and help from battery experts, the problematic situation of finding a small and powerful enough battery would probably have been solved. However, the “emergency” solution raised the importance of the quality of finish when including participants with health challenges, such as people with ME. The low capacity and energy levels acted as a barrier for the motivation to use and test new research products. Even though the research product was based on thorough knowledge about the user group and context and was easy to use and learn from a technological perspective, it seemed like it was not enough. Thus, an important learning from this process was that artifacts that are presented to the user group must not only have technological aspects that are easy to learn and use. The artifact should also not include dimensions that are dependent on the user being extra motivated to contribute to the research. Nevertheless, the artifact generated knowledge about the intended inquiry, and the participants both used and talked about RelaxMe as it was intended for, as a pulse alarm. This indicates that RelaxMe had the quality of finish to be characterized as a research product. The problems experienced with regards to the battery only reduced the usage of RelaxMe but did not stop the generation of knowledge about the intended inquiry. Thus, I do not agree when Odom et al. (2016, p. 2558) argue that “a research product is either experienced as an artifact with a high degree of finish or it is not”. RelaxMe was finished enough to investigate what it was supposed to investigate and generate knowledge about its meaning for the participants. At the same time, it is evident that the extra battery reduced the amount of use (use in the meaning of having the artifact on their wrist and with the power on) and a better battery solution would increase the level of finish and thus
increase the time the participants used RelaxMe.

**Fit**

When looking at RelaxMe, the fact that it is a wrist-worn artifact that is similar to a fitness watch the participants already use extensively emphasize it’s fit for the user context. The participants accepted the artifact into their lives and expressed that RelaxMe gave them value in that it could be used for energy modulation. Also, the findings suggested that RelaxMe created a change in their way of doing energy modulation, an activity they usually struggle to manage. In other words, the knowledge created from the field exploration with RelaxMe emphasized how RelaxMe fitted in their everyday lives, and that they used it and wanted to use it in the future. The problematic situation of the extra battery was, of course, a drawback in this context. However, RelaxMe accomplished to generate the knowledge wanted from this study, and the fit dimension must thus have been present regardless of the extra battery. To be able to create a fitted artifact that generated real value for the participants, I argue would not have been possible without the extensive use of methods to understand the user group and design context. The expert interview with domain experts, a workshop with the Norwegian ME Association, and telephone interviews with participants from the user group all contributed to my understanding of the design context that enabled RelaxMe to have fit. This finding indicated that when working with vulnerable users and exploring research products in their life and context, a comprehensive understanding of the user group and design context can be beneficial when creating an artifact that is neither too familiar nor too strange.

**Independent**

The criteria seemed to be of extraordinary importance when working with people with ME. Even though the artifacts was seen as prototypes, the independent aspect of the artifact seemed to be fulfilled. When visiting the participants, I handed over the research product, explained the functionality briefly and left a user manual. During the period, none of the participants had issues with understanding how to use the artifacts, or how to turn them on or off or charge the extra battery. Also, none of the users experienced any technical issues or that the artifact did not work correctly. To be able to leave the artifact for an indefinite time was important for several reasons. First of all, the participants experienced health issues during the field
exploration period, and we thus decided to let them keep the artifacts for a more extended period than initially thought. As mentioned earlier in the discussion, flexibility was of importance when working with vulnerable users, and the independent aspect of RelaxMe contributed to the flexibility I could offer the participants. This flexibility enabled the participants to use RelaxMe more than if I needed to collect them at a specific time due to battery capacity or limited storage capacity (RelaxMe did not save any data). Second of all, to be able to use RelaxMe whenever they wanted without the need for help was important as the illness symptoms fluctuate and they could never know when they had the capacity to use it.
Critical reflections

As this is the first significant research project I have conducted, a retrospective assessment of the process and the choices taken throughout it is needed. In this chapter, I review my research process, pinpointing strengths, weaknesses, and limitations of my study.

9.1 Phenomenological research

The fact that I have followed a phenomenological research approach in my qualitative study can be viewed as a limitation by some scholars, as the data collected are in bottom line dependent on the participants way of sharing their experiences and my way of interpreting them. How I have interpreted the data gathered during the background research and the different activities with the user group have guided my way through this research project, and eventually lead to the results. With the epistemological foundation based on phenomenology, generalizing the results is not the aim of the research. Furthermore, following my research question, my aim was not to create an artifact that could be generalized to the user group as a whole or intended to become a consumer product. My goal was instead focused on making research products and use them to generate data about their meaning for the participants in their everyday life. However, the results indicate that RelaxMe has a potential for the participants included in the field exploration and was also something that was wanted by several of the participants in the workshop with the Norwegian ME Association and during the telephone interviews. A more extensive study assessing the value of RelaxMe for people with ME through a different research design in the future could thus be interesting, especially if RelaxMe could be improved not to include the extra power bank.

9.2 The participants

Choosing how many participants to include in my research have been difficult, as the number needs to match the time and resources at hand. Recruiting participants was easy, as my supervisor already had a contact network within the ME community. What showed to be more difficult was
to get in touch with the participants that showed interest in joining the study. I reached out to many participants that never responded to my request or that was too sick to partake in the study. Having for instance only four participants in the field exploration of RelaxMe can be viewed as a limitation, as more people included could reveal more interesting findings. However, through the entire research project, a more significant number has been involved: five participants in the workshop with the ME association, five participants in the telephone interviews and four participants in the field exploration of RelaxMe gives a total amount of 14 participants included in the study. Also, the field exploration of RelaxMe included an in-depth baseline interview with the participants. This baseline interview generated thorough knowledge about their subjective experience of the illness and especially the symptoms they experience. By systematically reviewing and documenting all their symptoms (see Appendix H), an indication of who the results potentially are valuable for was defined.

As well as the number of participants, another limitation of my study is the fact that it is a single-gender study only including women. Recruiting was done by an insider in the community by posting information about the project on a closed Facebook page. The list we received from the recruiter contained 17 women. It is difficult to speculate about the reasons for why this happened, as the Facebook group also include male members. Whatever the reasons might be, it is essential to reflect on the impact this has on the results gathered. A need for assessing the subjective experiences and exploring RelaxMe through a field approach with male participants suffering from ME is thus called for in the future.

9.3 Validity of the findings

Validity refers to whether a study measures what it is intended to measure (Rogers, Sharp, & Preece, 2011, p. 470). As I wanted to understand the phenomenon of being ill, one fundamental choice to ensure the validity of the data collected was to listen to the user groups experiences first-hand. Furthermore, I wanted to explore the research products role in the lives of people with ME. Making and placing RelaxMe in a real-life context of a person suffering from ME was an intentional move to make sure I generated valid knowledge about the phenomenon. Nevertheless, it is important to reflect on the potential limitations to the validity of the gathered data.
The interviews
As I was interested in getting subjective experiences and understanding the illness and their use of RelaxMe through the participants’ point of view, talking to the user group directly through in-depth interviews was a way to make sure the data gathered was valid. However, such data is limited to what knowledge the participants can transfer and how I as a researcher interpret this knowledge. To strengthen the validity of the data further, I thus verified my understanding with the participants during the interviews to avoid misunderstandings. This verification was especially important when having the telephone interviews, as you lose the essential factor of reading body language.

The thematic analysis
To strengthen the validity of the thematic analysis, I have strived for having a transparent description of the conduction of the analysis and my way to the final results. Furthermore, it has been important to have a curious and open mindset towards the data and the codes, and always reflect back to the purpose of the analysis. A strength of the thematic analysis was that we were two people coding and merging the themes. However, both Jorun and I have previous knowledge about design and ME that probably biased the results. A coder with no experience of ME or design would most likely find other interesting codes and themes and could contribute with more openness. Another strength was that the data used in the thematic analysis was detailed transcriptions from the interviews. For me this was important to be able to dig deep into the data, and look for the true experience of being struck by ME.

Field exploration of RelaxMe
As I wanted to generate new knowledge about research products’ role in the life of people with ME, RelaxMe was created and then explored in the field in a real-life context. A limitation of my approach is that it involves people with a debilitating illness that might have too low capacity to contribute to research fully. Researching with another patient group experiencing fewer symptoms might bring forth more results. Also, people with ME have little offerings within the health care system. Thus, they can be overly positive to the research products presented to them. However, the findings show that their feedback was nuanced with both positive and negative comments.
9.4 My role

As the sole researcher in this project, I had many roles during the process. As I have been working as a designer full-time before starting this master thesis, and also part-time during my studies, I had already experience with being a designer, facilitator and interviewer, working both with developing prototypes and products, testing prototypes and products, and interviewing vulnerable users. However, to combine these roles with being a researcher was new to me, and I feel it is important to critically reflect on my role as a researcher, designer, facilitator and interviewer during this process.

Even though I have previous experience with involving vulnerable users in a design process, the experience is based on performing in-depth interviews with children who have cancer. To work with people suffering from ME, and this time with adults, have been a very different experience. Of course, I believe my previous experience was helpful throughout this project. In hindsight, I see that the fact that I knew how vital background research and getting a thorough understanding of the illness and its effect on the sufferers before involving them in the study was critical learning I utilized. Furthermore, I believe my previous experience made me more confident during the interviews, creating an interview situation that felt safe for the participants. The participants showed me trust when sharing intimate information and difficult experiences, and I believe my previous experience was helpful when creating room for such sharing.

9.5 Reflections on my design process

When looking back at my design research process, I wish I had more time and resources to be able to take this research project further. My project ends quite suddenly after the field exploration of RelaxMe. This abrupt ending is a limitation that all master thesis’ in some way will experience, as the projects are small and with very firm due dates. Furthermore, working with qualitative data is time-consuming. However, to be able to work with this project and user group have been a rewarding and interesting experience. The participants I have met have been incredibly kind and open to sharing their experiences, even though it at times was emotional. To see that RelaxMe was used in a real-life context, being able to generate knowledge on its own, was motivating. If more time and resources had been
available, I would have conducted a more formal thematic analysis on the results from the field exploration as well to strengthen the findings further. Additionally, I would solve the issues experienced with the battery and explored RelaxMe in the field for a longer period. Finally, I would like to make other research products exploring some of the concepts from RelaxMe in new ways.

9.5.1 Assessing the quality of my RtD project

Zimmerman et al. (2007) propose a model with a set of four criteria to make sure design researchers’ contribution are of high quality when conducting RtD projects. In the following section, I assess how I strived for fulfilling these four criteria.

The first criterion is process; documenting the contribution with enough detail to be reproduced. The second criterion is invention; demonstrating that a significant invention is produced, through a novel integration of the context and situation at hand. The third criterion is relevance; instead of expecting that two designers attacking the same problem will produce similar or identical solutions, the focus is shifted towards relevance. The design researcher should clearly state their motivation for their work, details about the current situation and details about the preferred state they believe are missing to display the relevance. The last criterion is extensibility; the work is described so the community can leverage from the knowledge created by the artifact(s) or the research design process.

I have strived for documenting and describing the process in detail, revealing my way of obtaining the knowledge gathered through describing the methods and tools used, the results from each activity, and the key findings I have brought with me into the next stages of the projects. Furthermore, I have described the making of RelaxMe in detail, revealing the design choices taken and the merging of ideas, thoughts, relevant research, theory, user context, design knowledge, and personal interests to demonstrate that RelaxMe is a significant invention. Also, I have demonstrated the relevance of RelaxMe by assessing the current situation for people suffering from ME and the role technology can have in their life. Finally, a thorough discussion of the knowledge generated and the artifacts role in the design process is raised to show the extensibility of the work.
10 Conclusion

This thesis has presented a study aiming to understand \textit{how to make and use research products to mediate the state of the phenomenal body and generate new knowledge about their meaning for people with health challenges}. The research process followed an RtD approach, making and using an artifact called RelaxMe to generate new knowledge about the phenomenon under study. To be able to make RelaxMe, a deep understanding of the user group and design context was gained through preliminary research of relevant literature; an interview with two domain experts; a workshop with the ME association; and telephone interviews with the user group. The data gathered offered insights into how people with ME experience their illness: uncontrollable, individual, stigmatized, mistrusted, and outside of society. The findings were then merged with my skills as a designer and new medical research showing that the anaerobic threshold is experienced differently for people with ME to make three exemplars of RelaxMe. The three exemplars of RelaxMe was then used during a field exploration with four participants to generate new knowledge about their meaning for people with health challenges. To gain an understanding of the subjective experience of suffering from ME and to design with the phenomenal body in mind, phenomenology was used as an epistemological foundation and theoretical framework throughout the design process. Specifically, the concepts of the phenomenal body, the phenomenon of being ill, shrinkage, body schema and incorporated objects guided my way of looking at the data obtained and when designing the artifacts.

The findings from the field exploration suggested that RelaxMe provided an experience of the pulse by making the anaerobic threshold observable for the user. This experience enabled the participants to become aware of their actions, and both change their behavior and their thoughts about the illness. Hence, the design artifact RelaxMe mediated human actions related to self-monitoring and self-management of the chronic illness ME. Also, the findings indicated that RelaxMe was incorporated into the users’ body schema when extending their abilities to include a bodily alarm when their pulse reached the anaerobic threshold.
By combining a phenomenological approach with making and using research products to generate new knowledge, this project gives a unique contribution to the field of HCI research by explaining how RtD is both applicable and beneficial when working with vulnerable users.

10.1 Contributions

My research contribution lies within the field of HCI, and are the following:

- The design artifact RelaxMe itself, and its annotated concepts, as it is adding a new perspective to how to design research products for vulnerable users with health challenges. The artifact has been key to constructing the knowledge gained throughout this RtD process, and the knowledge gained, and concepts annotated can potentially be utilized by others.

- The results that indicate the usefulness of research products in research with participants with health challenges. More specifically, how research products can lower the strain of participation for vulnerable user groups.

- The research design itself: the combination of RtD, research products, phenomenology and vulnerable users. Showing how to make research products that mediated the state of the phenomenal body. The research design can have implications for other similar research processes involving vulnerable users that wish to explore the subjective experiences of their participants.

- The implementation of the field approach with vulnerable users, as it offers a set of methods and tools used when exploring a research product in the field with people suffering from ME, as well as a thorough description of the planning and execution of the field exploration.

- The way I made it a design decision to incorporate selected, new medical research in everyday design artifacts deployed by the user group through an RtD process. Thus, taking a shortcut through the time-consuming process of replication studies, governmental regulations, political and economic questions that need to be validated before the results of the research are being applied as a valid treatment method in clinical practice. This approach is an interesting method of taking a problem outside of design and using design to address it through an RtD process.
• A contribution to how RtD can explore and support self-management of chronic illnesses, based on how the design artifact, RelaxMe, mediated human actions related to the complex activity of self-monitoring and self-management through energy modulation for people with ME.

10.2 Future work

My research process ends quite suddenly after the field exploration of RelaxMe. Accordingly, I want to assess the grounds for future work:

• Iterate on and explore the different concepts incorporated in RelaxMe, such as the concept of “single-variable device”, “awareness of trespassing own AT limit in-the-moment”, or “black boxed pulse digit” in other artifacts or with other user groups.

• Improve the finish of RelaxMe further, by finding a battery solution more adequate for long-term use and potentially explore the participant’s relation to RelaxMe over time.

• Design new digital artifacts that are made to be inquiry-driven by exploring the same questions as RelaxMe, to further contribute to the development of Odom’s notion of research products (Odom et al., 2016).

• Taking other complex health-related issues people with chronic illnesses have and use design to address the issue by incorporating carefully selected new medical research in research products.

• Perform new design explorations into how research products can mediate human actions related to self-monitoring and self-management of chronic illnesses.

• Perform new design explorations with vulnerable users in the field, to further contribute to the execution of the field approach with vulnerable users.

• Include male participants in the study, as this particular project only included female participants.

• Explore the concept of a twin alarm worn by a partner or family member, introduced by one of the participants (Camilla).
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Appendices
Appendix A:

International Consensus Criteria

Myalgic encephalomyelitis: international consensus criteria

Myalgic encephalomyelitis is an acquired neurological disease with complex global dysfunctions. Pathological dysregulation of the nervous, immune and endocrine systems, with impaired cellular energy metabolism and ion transport are prominent features. Although signs and symptoms are dynamically interactive and causally connected, the criteria are grouped by regions of pathophysiology to provide general focus.

A patient will meet the criteria for post-exertional neuro-immune exhaustion (A), at least one symptom from three neurological impairment categories (B), at least one symptom from three immune ⁄ gastrointestinal ⁄ genitourinary impairment categories (C), and at least one symptom from energy metabolism ⁄ transport impairments (D).

A. Post-exertional neuro-immune exhaustion (compulsory)

This cardinal feature is a pathological inability to produce sufficient energy on demand with prominent symptoms primarily in the neuro-immune regions. Characteristics are as follows:

1. Marked, rapid physical and/or cognitive fatigability in response to exertion, which may be minimal such as activities of daily living or simple mental tasks, can be debilitating and cause a relapse.

2. Post-exertional symptom exacerbation: e.g. acute flu-like symptoms, pain and worsening of other symptoms.
3. Post-exertional exhaustion may occur immediately after activity or be delayed by hours or days. 
4. Recovery period is prolonged, usually taking 24h or longer. A relapse can last days, weeks or longer. 
5. Low threshold of physical and mental fatigability (lack of stamina) results in a substantial reduction in pre-illness activity level. 

Category B: Neurological impairments

At least one symptom from three of the following four symptom categories:

1. Neurocognitive impairments
   a. Difficulty processing information: slowed thought, impaired concentration e.g. confusion, disorientation, cognitive overload, difficulty with making decisions, slowed speech, acquired or exertional dyslexia. 
   b. Short-term memory loss: e.g. difficulty remembering what one wanted to say, what one was saying, retrieving words, recalling information, poor working memory. 
2. Pain
   a. Headaches: e.g. chronic, generalized headaches often involve aching of the eyes, behind the eyes or back of the head that may be associated with cervical muscle tension; migraine; tension headaches. 
   b. Significant pain can be experienced in muscles, muscle-tendon junctions, joints, abdomen or chest. It is non-inflammatory in nature and often migrates. e.g. generalized hyperalgesia, widespread pain (may meet fibromyalgia criteria), myofascial or radiating pain. 
3. Sleep disturbance
   a. Disturbed sleep patterns: e.g. insomnia, prolonged sleep including naps, sleeping most of the day and being awake most of the night, frequent awakenings, awaking much earlier than before illness onset, vivid dreams /
nightmares.  
b. Unrefreshed sleep: e.g. awaken feeling exhausted regardless of duration of sleep, day-time sleepiness.  
4. Neurosensory, perceptual and motor disturbances  
a. Neuro sensory and perceptual: e.g. inability to focus vision, sensitivity to light, noise, vibration, odor, taste and touch; impaired depth perception.  
b. Motor: e.g. muscle weakness, twitching, poor coordination, feeling unsteady on feet, ataxia.  
Notes: Neurocognitive impairments, reported or observed, become more pronounced with fatigue. Overload phenomena may be evident when two tasks are performed simultaneously. Abnormal accommodation responses of the pupils are common. Sleep disturbances are typically expressed by prolonged sleep, sometimes extreme, in the acute phase and often evolve into marked sleep reversal in the chronic stage. Motor disturbances may not be evident in mild or moderate cases, but abnormal tandem gait and positive Romberg test may be observed in severe cases.  

Category C: Immune, gastrointestinal and genitourinary Impairments  
At least one symptom from three of the following five symptom categories:  

1. Flu-like symptoms may be recurrent or chronic and typically activate or worsen with exertion. E.g. sore throat, sinusitis, cervical and / or axillary lymph nodes may enlarge or be tender on palpitation.  
2. Susceptibility to viral infections with prolonged recovery periods  
3. Gastro-intestinal tract: e.g. nausea, abdominal pain, bloating, irritable bowel syndrome  
4. Genitourinary: e.g. urinary urgency or frequency, nocturia  
5. Sensitivities to food, medications, odors or chemicals  

Notes: Sore throat, tender lymph nodes, and flu-like symptoms
obviously are not specific to ME but their activation in reaction to exertion is abnormal. The throat may feel sore, dry and scratchy. Fauclal injection and crimson crescents may be seen in the tonsillar fossae, which are an indication of immune activation.

D. Energy production / transportation impairments:

At least one symptom from the following four symptom categories:

1. Cardiovascular: e.g. inability to tolerate an upright position - orthostatic intolerance, neurally mediated hypotension, postural orthostatic tachycardia syndrome, palpitations with or without cardiac arrhythmias, light-headedness / dizziness
2. Respiratory: e.g. air hunger, labored breathing, fatigue of chest wall muscles
3. Loss of thermostatic stability: e.g. subnormal body temperature, marked diurnal fluctuations; sweating episodes, recurrent feelings of feverishness with or without low grade fever, cold extremities
4. Intolerance of extremes of temperature

Pediatric considerations

Symptoms may progress more slowly in children than in teenagers or adults. In addition to post exertional neuro-immune exhaustion, the most prominent symptoms tend to be neurological: headaches, cognitive impairments, and sleep disturbances.

1. Headaches: Severe or chronic headaches are often debilitating. Migraine may be accompanied by a rapid drop in temperature, shaking, vomiting, diarrhea and severe weakness.
2. Neurocognitive impairments: Difficulty focusing eyes and reading are common. Children may become dyslexic, which may only be evident when fatigued. Slow processing of information makes it difficult to follow auditory instructions or take notes. All cognitive impairments worsen with physical or mental exertion. Young people will not be able to maintain a full school programme.

Table A1: Based on Carruthers et al (2001, pp. 329-331, Table 1 Myalgic encephalomyelitis: international consensus criteria)
Appendix B: 

Interview guide – Domain experts

Introduksjon
Introduksjonen vil ikke tas opp, men kun noteres for hånd. Opptak vil starte når vi går over til hoveddelen av intervjuet.
- Introduserere hensikt med studiet/intervjuet
- Besvare eventuelle spørsmål fra deltager
- Forklare og signere samtykkeskjema

Oppvarming
- Hva vil du si er ditt ekspertområde når det kommer til ME diagnosen?
- Hvordan vil du si at du har blitt ekspert på akkurat dette området innenfor ME?

Hoveddel
- Hva vil du si er det verste med å være syk?
  - Hvorfor er xxx det verste med å være syk?
- Hva vil du si at kan gjøre at en ME syk pasient føler seg bedre?
  - Hvorfor tror du xxx gjør så pasienten føler seg bedre?
- Hvordan vil du beskrive teknologibruken til en ME syk, sammenliknet med før de ble syke?
- Er det noen teknologi som gjør at de føler seg dårligere? For eksempel mer kvalm eller sliten?
  - Hvis ja, hvilke teknologier gjør at de føler seg verre? Hvorfor?
- Er det noen teknologi som de kan bruke uten å føle seg dårligere?
  - Hvis ja, hvilke teknologier kan de bruke uten å føle seg dårligere? Hvorfor?
- Er det noen teknologi som dere har sett hjelper ME syke i hverdagen? Hvorfor?
- Hvordan pleier en ME syk å gå frem for å finne ut hva akkurat deres kropp tåler?
o Hvordan fungerer metode xxx?
  o Hvorfor tror dere metode xxx fungerer / ikke fungerer for de?
  o Er metode xxx noe som kan fungere for flere?
  
- Hvis du skal nevne tre ting som forverrer sykdomssymptomene til en ME syk, hva er det?
  o Hvorfor tror du xxx forverrer sykdomssymptomene?
  o Er det flere ting som forverrer symptomene kraftig?

- Hvis du skulle nevnt tre ting som forbedrer sykdomssymptomene til en ME syk, hva er det?
  o Hvorfor tror du xxx forbedrer sykdomssymptomene?
  o Er det flere ting som forbedrer sykdomssymptomene?

- Hvordan ser dere for dere at en tangible teknologi kan hjelpe en ME syk å balansere sykdomssymptomene?
  o Hvorfor tror du at en xxx form for teknologi kan hjelpe en ME syk å balansere sykdomssymptomene sine?

Avslutning

- Hvis du kunne drømt deg bort og lagd den perfekte teknologien som kunne hjulpet en som er ME syk - hva ville det ha vært?
- Har du noe annet du syns jeg burde vite omkring ME diagnosen og teknologibruk?
- De-brief og takk for deltakelse.
Appendix C:

Interview guide – Telephone interviews

Oppvarming

- Introdusere hensikt med studiet/intervjuet
- Besvare eventuelle spørsmål fra deltager
- Alder, kjønn, e-post
- Når fikk du diagnosen ME?
  - Evnt. hvor lenge har de hatt symptomene/vært syk?
  - Hvordan fikk du diagnosen?
  - Hvilken grad av ME? Mild, moderat eller alvorlig?
- Hva slags aktivitetsklokke og hvor lenge har den blitt brukt?
- Hva slags telefon har du?
- Viktig at de sier ifra om det blir for mye, så kan vi ta resten av intervjuet en annen dag.

Innledende samtale - Hva har du på hjerte?

Begynne med innledende spørsmål hvor de får si alt de har på hjertet. Dette er noe jeg tar med rett og slett fordi ME syke ofte sliter med hjernetåke eller kognitive vansker, og derfor gjerne trenger å få muligheten til å si alt de har tenkt på i forhånd for å glemmer det.

- Har du gjort deg opp noen tanker om dette med aktivitetsklokke som du vil dele med oss?
- Er det noen andre ting du har noen tanker om hva gjelder hjelpemidler for din sykdom?

Hjelpemidler

- Bruker du noen hjelpemidler i dag, både teknologiske eller ikke-teknologiske? Når jeg mener hjelpemidler mener jeg ting som: Loggbok(mat, form, aktivitet), helseapper, kalendere, aktivitetsklokke, pårørende osv.?

Med denne delen ønsker jeg å la den ME-syke fortelle om hvilken type
teknologi og andre hjelpemidler de bruker i hverdagen for å hjelpe seg selv å takle/leve med sykdommen. Siden ME syke ofte kan slite med hjernetåke eller konsentrasjonsvansker, kan det å presentere ett og ett hjelpemiddel av gangen muligens hjelpe dem å huske bedre. Hjelpemidler jeg kan presentere for dem kan være ting som aktivitetsklokke, kalendere, mobilapplikasjoner, hjelp fra pårørende, dagbøker, matdagbok, etc.

For hvert hjelpemiddel de nevner ønsker jeg at de skal svare på følgende spørsmål:

- Hva er det du bruker hjelpemiddel X til?
- Hvordan syns du det er å bruke hjelpemiddel X?
  - Er det noen aktiviteter du må gjøre med den som du syns er vanskelig/tungt/slitsom?
  - Hvordan føles det å ha en klokke på hånda hele tiden? Er det noe som får deg til å slutte å bruke klokka?
- Er det noe hjelpemiddel X er spesielt nyttig for?
- Er det noe hjelpemiddel X ikke fungerer så godt til?
- Er det noe du skulle ønske hjelpemiddel X kunne hjulpet deg med, som den ikke gjør nå?
- Er det noe funksjonalitet du skulle ønske hjelpemiddel X hadde?
- Føler du at energimodulering blir enklere å gjennomføre med hjelpemiddel X som hjelpemiddel?
- Er det andre ting ved sykdommen enn energimodulering du føler hjelpemiddel X kan bidra til?
- Bli du noen gang sliten av å bruke hjelpemiddel X?
- Er det noe som forverrer sykdomssymptomene dine som du tror hjelpemiddel X kunne målt eller hjulpet deg med?
- Er det noe som forbedrer sykdomssymptomene dine som du tror hjelpemiddel X kunne målt eller hjulpet deg med?

Hvis de ikke har brukt et hjelpemiddel:

- Er det en grunn til at du ikke har prøvd det?

Til slutt:

- Ha en liten brainstorming på problemene de snakker om for de forskjellige hjelpemidlene, og diskutere løsninger og muligheter som teknologi kan skape.
Faktorer som påvirker sykdommen

- Hva syns du har størst negativ påvirkning på din sykdom?
- Hva syns du har størst positiv påvirkning på din sykdom? Altså, hvilke tiltak har du gjort i hverdagen som du syns har skapt en bedring?

I denne delen ønsker jeg å se på forskjellige kvantifiserbare faktorer som kan påvirke en ME-syk kropp. På denne delen av intervjuet er jeg interessert i å finne ut om det er spesielle faktorer som de selv føler påvirker sykdommen deres i positiv eller negativ retning. Spesielt er jeg interessert i variable knyttet til self-quantification og hvordan de subjektivt oppleves av den individuelle. Slike variable er ting som: Sovnkvalitet, aktivitet, skritt, puls, bevegelse, temperatur, ernæring, lys, lyd, meditasjon, melkesyre, trening osv. For å hjelpe den ME-syke å huske på alle faktorer som spiller en rolle for sykdommen, vil jeg etterhvert som de ikke husker flere selv presentere en og en faktor. For hver faktor de eller jeg nevner skal de få lov til å først velge om den har en positiv, negativ eller ingen effekt på sykdommen.

For hver faktor de mener påvirker sykdommen positivt eller negativt vil jeg stille følgende spørsomål:

- Hvorfor påvirker faktor X sykdommen din positivt/negativt?
- Hvis du tenker på din personlige opplevelse av sykdommen, hvordan føler du faktor X påvirker sykdomssyptomene dine på en positiv/negativ måte?
- Hvis du har noen, hvilke teknikker eller hjelpemidler bruker du for å “kontrollere” faktor x?

For hver faktor de mener ikke påvirker sykdommen noen retning vil jeg stille følgende spørsomål:

- Hvorfor føler du at faktor X ikke påvirker sykdommen din?

Til slutt:

- Brainstorme på hvordan faktorene de nevner kan “kontrolleres” med teknologiske løsninger.

Avslutning

Avslutningsvis har jeg noen veldig åpne spørsomål dersom det er tid og ork til det.
• Hvis du kunne drømt deg bort og lagd den perfekte teknologien som kunne hjulpet deg som ME-syk - hva hadde det vært?
• Har du noe annet du syns jeg burde vite om eller tenke på når det kommer til ME-diagnosen og teknologibruk?
• Ønsker du å bidra mer til studiet, for eksempel gjennom en brukertest eller liknende? Er det ok at jeg kontakter deg ved en senere anledning - det er selvfølgelig ikke bindende?
• Takke for deltakelse
Appendix D:

Interview guide – Baseline interview

Introduksjonen vil ikke tas opp, men kun noteres for hånd. Opptak vil starte når vi går over til hoveddelen av intervjuet.

- Introduserere hensikt med studiet/intervjuet
- Besvare eventuelle spørsmål fra deltager
- Forklare og signere samtykkeskjema

1. Innledende samtale - Har du noe på hjerte?
Ca. 5 minutter

Begynne med innledende spørsmål hvor de får si alt de har på hjertet - så de husker alt, og får sagt alt de planla å si i forkant:
- Har du gjort deg opp noen tanker om teknologi og ME som du ønsker å dele med meg før vi setter I gang?

2. Subjective experience of illness: Faktorer, symptomer
Ca. 15 minutter

Hva jeg er ute etter og hvorfor: I de to neste øvelsene skal vi gå litt bort i fra selve klokka og pulsalarmen, og heller se på din personlige opplevelse av sykdommen og hvordan du syns det er å leve med ME. Alt som har med ME og gjøre er relevant, så her er det du som er eksperten.

Se på denne kroppen og tenk at den er din. Det jeg vil at du skal gjøre nå er å tenke på et symptomer du opplever i din hverdag med sykdommen.
Ta en brikke og plasser den der symptomet passer inn, enten på personen eller rundt personen.

Hvilke symptomer opplever du i din hverdag med sykdommen?
Dårlig søvn, fatigue, kvalm, influensasymptomer, hetebølger, lydsky, lyssky, angst, hodepine, melkesyre, hjernetåke.

- Hvordan føler du at symptom X påvirker din hverdag med sykdommen?
- Hvis du har noen, hvilke teknikker bruker du for å redusere eller kontrollere symptom x?
- Er det noen faktorer som kan påvirke symptomene i positiv eller negativ retning?
  o Søvn, aktivitet/bevegelse, hvile, ernæring, lys, lyd, sosial omgang, meditasjon, pusteteknikker, trening, medisiner.
  o Hvordan føler du faktor X påvirker deg og dine sykdomssymptomer?

3. Hjelpemidler: Rødt, gult eller grønt lys?
Ca. 15 minutter

Hva jeg er ute etter og hvorfor: Med denne plakaten ønsker jeg å få innsikt i hvilke hjelpemidler, teknologiske og ikke-teknologiske, du bruker eller har prøvd i din hverdag med ME. Jeg har foreslått en god del hjelpemidler allerede, representert på runde brikker. Det jeg ønsker at du skal gjøre er å plassere brikken på enten rødt, gult eller grønt lys.
Rødt = Hjelper deg ingen ting
Gult = Hjelper litt
Grønt = Hjelper deg masse

- Hvorfor plasserer du hjelpemiddel X på grønt/gult/rødt?
  o Grave dypere i svarene deres - hvorfor mener de det de mener?
• Hvis grønt/gult: Opplever du noen ganger noen problemer når du bruker hjelpemiddel X?

4. Future expectations: RelaxMe
Ca. 5 minutter

• Hvilke forventninger har du til bruk av pulsalarmen?
• Hva ønsker du deg at pulsalarmen skal kunne gjøre utenom å varsle om at man har nådd anaerob terskel?

Vise pulsalarmen
• Forklare bruk
• Forklare hensyn - vann, fukt, støt
• Gi informasjonsarket

5. Tilbakemeldinger på samtaleverktøyene
Ca. 5 minutter

Det er veldig viktig for meg at samtaleverktøyene jeg bruker for å samle data til studiet mitt ikke bruker for mye av din energi. Det er første gang vi tester metodene jeg har brukt i dag, og jeg vil derfor gjerne få noen ærlige tilbakemeldinger på hvordan du syns intervjuet og besøket har vært.

• Hvordan syns du dette intervjuet var sammenliknet med et vanlig intervju hvor man bare stiller spørsmål uten hjelpemidler?
• Føler du at det var noen av plakatene eller aktivitetene som krevde mer energi av deg enn et vanlig intervju uten hjelpemidler?
Appendix E:

Consent form – Domain experts

Forespørsel om deltagelse i forskningsprosjekt.
"Innsamling av brukerinnsikt til teknologi for ME syke"

Bakgrunn og formål

Dette studiet vil undersøke hvordan en tangible teknologi kan hjelpe ME syke barn og unge voksne å forstå og balansere forholdet mellom stimuli og økte sykdomssymptomer for å kunne stabilisere sykdommen sin. I studien inngår intervjuer med ME syke unge voksne som har eller har hatt ME store deler av sin barndom, for å samle innsikt omkring teknologien vi ønsker å lage. Formålet med intervjuene er å kartlegge brukers behov og ønsker tilknyttet en slik teknologi. Resultatene vil bli brukt til å produsere en prototype.

Studiens innhold og omfang


For å kunne besvare dette spørsmålet ønsker vi å finne ut av de viktigste faktorene som har en påvirkning på alvorlighetsgraden ved sykdomssymptomene hos barn og unge voksne diagnostisert med ME ved å snakke med eksperter på området. Vi vil kun møte og intervjue ekspertene et begrenset antall ganger for å få innsikt i deres eskpertkunnskap. All data innsamlet vil bli fullstendig anonymisert i vårt videre arbeid med resultatene.

Hva innebærer deltagelse i studien?

Din deltagelse i studien innebærer å besvare spørsmål i forhold til
teknologibehov ME syke barn og unge kan ha. Spørsmålene vil i hovedsak omhandle dine meninger omkring hvordan en tangible teknologi burde utformes for å være nyttig for barn og unge voksne diagnostisert med ME. Mer spesifikt vil spørsmålene utforske hvordan ME syke barn og unge voksne kan ved hjelp av en tangible teknologi enklere utvikle en fin-justert balanse av de viktigste faktorene som kan redusere alvorlighetsgraden av sykdomssymptomene. I tillegg vil vi registrere din e-post.

Så lenge det gis samtykke til det, vil det bli tatt lydopptak av intervjue. Deltakelse i studien innebærer at informasjonen du oppgir kan bli brukt i videre arbeid med en prototype av teknologien, samt rapporter, artikler og også eventuelt masteroppgaven som beskriver teknologien og vårt prosjekt.

**Hva skjer med informasjonen om deg?**


**Frivillig deltakelse**

Det er frivillig å delta i studien, og du kan når som helst trekke deg fra studien eller trekke tilbake informasjon som er gitt uten å måtte oppgi en begrunnelse for dette.

Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte Oda Sofie Dahl Eide. Studien er meldt til NSD, som godkjente prosjektet 01.02.17.

Med vennlig hilsen
Oda Sofie Dahl Eide

**Kontaktinformasjon**

Oda Sofie Dahl Eide  
E-post: oseide@ifi.uio.no  
Telefon: 975 93 646
Gir du ditt samtykke til å delta i studien?
Ja Nei

Gir du samtykke til opptak av intervju?
Ja Nei

Underskrift deltager:

-----------------------------------------------------------
Appendix F:

Consent form – Telephone interviews

Forespørsel om deltakelse i forskningsprosjekt.
"Innsamling av brukerinnsikt til teknologi for ME syke"

Bakgrunn og formål
Dette studiet vil undersøke hvordan teknologi kan hjelpe ME syke å forstå og balansere forholdet mellom stimuli og økte sykdomssymptomer for å kunne stabilisere sykdommen sin. I studien inngår intervjuer med ME syke som har eller har hatt ME, for å samle insikt omkring teknologien vi ønsker å lage. Formålet med intervjene er å kartlegge brukers behov og ønsker tilknyttet en slik teknologi. Resultatene vil bli brukt til å produsere en prototype.

Studiets innhold og omfang

For å kunne besvare dette spørsmålet ønsker vi å finne ut av de viktigste faktorene som har en påvirkning på alvorlighetsgraden ved sykdomssymptomene hos mennesker diagnostisert med ME ved å snakke med målgruppen. Vi vil kun møte og intervjue deltager et begrenset antall ganger for å få innsikt i brukerens teknologibehov. All data innsamlet vil bli fullstendig anonymisert i vårt videre arbeid med resultatene.

Hva innebærer deltakelse i studien?
Din deltagelse i studien innebærer å besvare spørsmål i forhold til teknologibehov. Spørsmålene vil i hovedsak omhandle dine meninger
omkring hvordan en teknologi burde utformes for å være nyttig for mennesker diagnostisert med ME. Mer spesifikt vil spørsmålene utforske hvordan ME syke kan ved hjelp av en teknologi enklere utvikle en fin-justert balanse av de viktigste faktorene som kan redusere alvorlighetsgraden av sykdomssymptomene. I tillegg vil vi registrere alder, kjønn, sykdomsølge og e-post.

Så lenge det gis samtykke til det, vil det bli tatt lydopptak av intervjuene. Deltakelse i studien innebærer at informasjonen du oppgir kan bli brukt i videre arbeid med en prototype av teknologien, samt rapporter, artikler og masteroppgaven som beskriver teknologien og vårt prosjekt.

**Hva skjer med informasjonen om deg?**


**Frivillig deltakelse**

Med tanke på at deltakelse i prosjektet kan innebære at man er diagnostisert med ME er det ekstra viktig for oss at intervjuene ikke tilfører stress eller ekstra arbeid for deltager, og spesielt viktig er det at ingen blir sykere på noen som helst måte under eller i etterkant av intervjuene. Derfor vil intervjuene og datainnsamlingen generelt avsluttes øyeblikkelig dersom det er noe som helst tegn på at intervjuene kan ha negativ effekt på deltager. Det er frivillig å delta i studien, og du kan når som helst trekke deg fra studien eller trekke tilbake informasjon som er gitt uten å måtte oppgi en begrunnelse for dette. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte Oda Sofie Dahl Eide.

Studien er meldt inn til NSD, som godkjente prosjektet 01.02.17.

Med vennlig hilsen
Oda Sofie Dahl Eide
Kontaktinformasjon

Oda Sofie Dahl Eide
E-post: oseide@ifi.uio.no
Telefon: 975 93 646

Gir du ditt samtykke til å delta i studien?
Ja              Nei

Gir du samtykke til opptak av intervju?
Ja              Nei

Underskrift deltagar (foresatte for personer under 18 år):

________________________________________
Appendix G:

Consent form – Field exploration of RelaxMe

Forespørsel om deltakelse i forskningsprosjekt.
"Brukertest av teknologi for ME syke”

Bakgrunn og formål

Dette studiet består av brukertesting av en prototype under utvikling. I studien inngår intervjuer om prototypen. Formålet med brukertesten og intervjueene er å kartlegge brukers behov og ønsker tilknyttet prototypen og utforske om den er nyttig for ME syke under aktivitetsavpasning og symptomsregulering. Resultatene fra brukertesten og intervjueene vil bli brukt til å forbedre prototypen.

Om prototypen

Prototypen fungerer som en pulsalarm for brukeren, og har som hensikt å hjelpe brukeren å ikke være i for mye aktivitet som er over deres anaerobe terskel. Prototypen bæres som en klokke, og måler pulsen ved gjevne mellomrom på håndleddet til brukeren. Dersom pulsen er over den anaerobe terskelen som er satt, vil prototypen vibrere for å gjøre brukeren klar over at de har nådd terskelgrensen. Prototypen kan skrus av om natten, slik at brukeren ikke behøver å sove med den. Prototypen tåler ikke vann eller fukt, og bruker bes derfor om å dekke den til godt om den brukes ute i regn- eller snøvær, eller ta den av ved vasking av hender eller dusjing.

Studiets innhold og omfang

Studiet er en masteroppgave som gjennomføres fra Januar 2017 til Juli 2018. Studiet går ut på å besvare følgende spørsmål: «Hvordan designe en teknologi som hjelper mennesker diagnostisert med ME å utvikle en finjustert balanse av de viktigste faktorene som kan redusere alvorlighetsgraden av sykdomssymptomene?»
For å kunne besvare dette har vi gjennomført innledende intervjuer med syv ME syke og hatt en workshop med ME-foreningen. I intervjuene og workshopen har vi undersøkt målgruppens teknologibehov og hva de viktigste faktorene som har en påvirkning på alvorlighetsgraden ved sykdomssymptomene er. Med dette som grunnlag har en prototype blitt utformet av, og vi ønsker nå å teste denne.

Vi vil kun møte og intervjuer deltaker en begrenset antall ganger for å få innsikt brukerens behov og ønsker, samt for å se om prototypen har en nytteverdi for målgruppen. Deltaker vil, i tillegg til intervjuene, teste prototypen i sin hverdag i 7-14 dager. All data innamlet vil bli fullstendig anonymisert i vårt videre arbeid med resultatene.

**Hva innebærer deltakelse i studien?**

Din deltagelse i studien innebærer å besvare spørsmål i forhold til teknologibehov, samt teste prototypen på egenhånd i noen dager. Spørsmålene vil i hovedsak omhandle dine meninger omkring hvordan prototypen burde utformes for å være nyttig for deg. I tillegg vil vi registrere alder, kjønn og e-post.

Så lenge det gis samtykke til det, vil det bli tatt lydopptak av intervjuene. Deltakelse i studien innebærer at informasjonen du oppgir kan bli brukt i videre arbeid med prototypen, samt rapporter, artikler og masteroppgaven som beskriver teknologien og vårt prosjekt.

**Hva skjer med informasjonen om deg?**

All innsamlet data vil bli behandlet konfidentielt. Dataene vil ved behov deles med Oda Sofie Dahl Eide(masterstudent) og Jorun Børsting (hovedveileder og stipendiat). Alle svar behandles konfidentielt og din deltakelse vil bli anonymiseret i publikasjoner.


**Frivillig deltakelse**

Med tanke på at deltakelse i prosjektet innebærer at man er diagnostisert med ME er det ekstra viktig for oss at brukertesten og intervjuene ikke tilfører stress eller ekstra arbeid for deltager, og spesielt viktig er det at
ingen blir sykere på noen som helst måte under eller i etterkant av intervjuene. Derfor vil brukertesten og intervjuene avsluttes øyeblikkelig dersom det er noe som helst tegn på at deltakelse kan ha negativ effekt på deltager. Det er frivillig å delta i studien, og du kan når som helst trekke deg fra studien eller trekke tilbake informasjon som er gitt uten å måtte oppgi en begrunnelse for dette.

Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte Oda Sofie Dahl Eide.

Studien er meldt inn til NSD, som godkjente prosjektet 01.02.17.

Med vennlig hilsen
Oda Sofie Dahl Eide

Kontaktinformasjon
Oda Sofie Dahl Eide
E-post: oseide@ifi.uio.no
Telefon: 975 93 646

Gir du ditt samtykke til å delta i studien?
Ja Nei

Gir du samtykke til opptak av intervju?
Ja Nei

Underskrift deltager (foresatte for personer under 18 år):

--------------------------------------------------------------------------------------------------
Appendix H:

Overview of symptoms

Grey = Experience or have experienced the symptom  
White = Have never experienced the symptom  
Bold text = All participants experience or have experienced the symptom

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Caroline</th>
<th>Andrea</th>
<th>Ingrid</th>
<th>Camilla</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fatigue</strong></td>
<td></td>
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<tr>
<td><strong>Flu like symptoms</strong></td>
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<tr>
<td><strong>Sleep deprivation</strong></td>
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<tr>
<td><strong>Cognitive issues</strong></td>
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<tr>
<td><strong>Sensitive to sounds</strong></td>
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<tr>
<td><strong>Tinnitus</strong></td>
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<tr>
<td>Sensitive to light</td>
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<tr>
<td>Sensitive to smell</td>
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<tr>
<td>Ear canal eczema</td>
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<tr>
<td>Allergic reactions in mouth</td>
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<tr>
<td>Tension headaches</td>
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<tr>
<td>Migraine</td>
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<tr>
<td><strong>Headaches</strong></td>
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<tr>
<td><strong>Dizziness / BP drop</strong></td>
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<tr>
<td>Heatwaves</td>
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<tr>
<td>Anxiety</td>
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<tr>
<td>Panic attacks</td>
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<tr>
<td>Depression</td>
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<tr>
<td>Elevated heart rate</td>
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<tr>
<td>Sore throat</td>
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<tr>
<td>Condition</td>
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<td>---------------------------------</td>
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<tr>
<td>Nausea</td>
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<tr>
<td>IBS / Stomach ache</td>
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<tr>
<td>Allergies</td>
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<tr>
<td>Contact dermatitis</td>
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<tr>
<td>Atopic skin</td>
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<tr>
<td>Psoriasis</td>
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<tr>
<td>Cold hands and feet</td>
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<tr>
<td>Stiff fingers</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Pain in joints</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Lactic acid</td>
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<td></td>
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<td></td>
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<tr>
<td>Pain when touched lightly</td>
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<tr>
<td>Pain in the whole body</td>
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<tr>
<td>Pain in fingers</td>
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<tr>
<td>Pain in hands</td>
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<tr>
<td>Pain in over arms</td>
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<tr>
<td>Pain in lower back</td>
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<tr>
<td>Pain in hips</td>
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<tr>
<td>Pain in thighs</td>
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<tr>
<td>Pain in calves</td>
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<tr>
<td>Pain in knees</td>
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<tr>
<td>Pain under feet</td>
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<tr>
<td>Cramping under feet</td>
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<tr>
<td>Pain around ankles</td>
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<tr>
<td>Interstitial cystitis</td>
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</tbody>
</table>
Appendix I:

Interview guide – Final interview

Introduksjonen vil ikke tas opp, men kun noteres for hånd. Opptak vil starte når vi går over til hoveddelen av intervjuet.

- Introduisere hensikt med intervjuet
- Besvare eventuelle spørsmål fra deltager
- Gi beskjed om at de må si ifra hvis de blir for slitne til å fortsette intervjuet

Evaluering av pulsalarmen


Hjelpemiddel: Symptomkartet og fremtidige forventninger

1. Generelt om bruk

- Hvor mye har du brukt pulsalarmen? Antall ganger/dager og timer per gang?
  - Hva skal til for at du skulle brukt den mer?
- Støtte du på noen problemer ved bruk av pulsalarmen under testperioden? I så fall, hvilke?
- Brukte du fitbiten samtidig som du brukte pulsalarmen, eller brukte
du de hver for seg?

• Brukte du fitbiten mer eller mindre enn du vanligvis pleier under testperioden? Evnt. hvorfor?

2. Lærte pulsalarmen deg noe?

• Hvordan passet pulsalarmen inn i din hverdag med tanke på symptomene?
  o Har noen symptomer blitt verre eller noen blitt bedre?
• Følte du at pulsalarmen lærte deg noe nytt om deg selv og din egen sykdom?
• Følte du at pulsalarmen lærte deg hvor grensa di går?
• Følte du at terskelgrensa var satt på riktig pulstall?
  o Skulle du gjerne hatt muligheten til å endre grensa på et tidspunkt? For eksempel etter dagsform?
• Følte du at pulsalarmen hjalp deg å holde pulsen lavere enn uten den?
• Følte du at det var mindre skummelt å være aktiv nå, kontra før du hadde pulsalarmen?
• Opplevde du at din oppfattelse av sykdommen endret seg ved bruk av pulsalarmen?
• Følte du pulsalarmen gav deg mer informasjon om aktivitetsnivået ditt enn hvis du ikke hadde brukt den?

3. Vibrasjon som alarm

• Opplevde du at den vibrerte i løpet av testperioden?
• Hvordan synes du det var når den vibrerte?
• Endret du adferd etter at pulsalarmen vibrerte?
• Stolte du på at den sa ifra på riktige tidspunkt?
• Kunne du tenke deg at den sa ifra på andre måter, for eksempel gjennom et pip?
  o Kunne du tenkt deg å velge mellom flere måter å få alarm på? Vibrasjon og pip, for eks.

4. Der-og-da varsling og skjult pulstall

• Hva syns du om at du får et varsel i det du trår over grensen, kontra det å måtte sjekke selv eller se det i etterkant i statistikken?
• Hva syns du om at ingen data ble lagret?
  o Skulle du ønske at noe data ble lagret? Hva slags data? Hva
ville du brukt dataene til?

- Hvordan syns du det var å ikke kunne se pulstallet?
  - Var det positivt eller negativt at pulstallet var skjult?  
    Hvorfor?
- Hva slags annen informasjon tror du kunne være nyttig og få om pulsen din?
  - For eks antall ganger over terskel i løpet av dagen, antall minutter over terskel i løpet av dagen, antall minutter i de forskjellige pulssonene?
  - Hvorfor ville informasjon x vært nyttig for deg? Hva ville du brukt informasjonen til?

5. Uforming og materialer

- Hvordan syns du det var å ha klokken på håndleddet?
- Fikk du noen utslett, kløe eller irritasjon av å ha klokka på? Evnt. hvorfor?
- Var skinnremmen behagelig eller ubehagelig å bruke? Hvorfor?
  - Hva skulle til for at den skulle blitt mer behagelig å bruke for deg? Altså at du ikke merker at du har den på.
- Hva syns du om å ha en batteripakke på utsiden av pulsalarmen?
  - Gikk lading greit?
- Hva syns du om at den var rund?
- Hva syns du om fargen?
- Hva skulle til for at den skal bli finere designmessig for deg?

6. Fremtidige muligheter

- Har du tenkt på noen andre fremtidige muligheter for pulsalarmen siden sist?
- Kunne du tenkt deg å få pusteøvelser gjennom klokka? For eksempel at den vibrerte til inn og utpust?
- Kunne du tenkt deg å meditere til rytmiske vibrasjoner? For eksempel at den vibrerte i en lav hjerterytme og at du skulle fokusere og forsvinne inn i denne vibrasjonen?
- Hvis du kunne tatt det beste fra både pulsalarmen og fitbiten og laget en klokke, hva ville du tatt med deg?

7. Rødt/Gult/Grønt lys?

- Hvis du skulle plassert pulsalarmen på kartet med rødt, gult og grønt
lys, hvor ville du plassert den og hvorfor?

8. **Teste andre former for vibrasjon**

- Teste hvordan de syns det er når den vibrerer i rytme ala en lav puls
- Teste hvordan de syns det er å puste til vibrasjon (altså ut på vibrasjon, og inn igjen når den vibrerer gang nr to)?

**Andre ting:**

- Spørre om lov til å sende epost angående symptomer
- Spørre om de kan svare på et spørreskjema ang brukertesten
Appendix J:

Results from expert interview

To ensure the anonymity of the participants, I have given them aliases. Participant one is referred to as Marie and participant two is referred to as Carl. The first question asked was about how they became experts in the domain technology and ME. Carl told that he has personal experience with ME, and that he naturally has been getting more and more knowledge about the illness because of this. Second, he and Marie have been doing research on technologies for people suffering from ME, which have been educational for both of them. During their research they have been talking to people that has been suffering from ME, and the Norwegian ME association. Their focus has been on looking at the illness and its effect on people’s life with a technology perspective. Carl pointed out that other than getting hands on experience from the everyday life of having personal experience with the illness, or from doing research directly with the users, becoming an expert in the field is not that “difficult”, as there is very little research and generally very little knowledge about the illness. The reason for this, said Carl, is both due to the illness being an enigma, as well as it being a very stigmatized illness that people suspect to be a psychological disorder. This has resulted in very little research on ME overall, also in the field of technology. Another reason for the lack of research on ME and technology, said Carl, is due to the specific symptoms apparent when suffering from the illness. Being light and sound sensitive do not go hand in hand with looking at a screen, having cognitive issues makes learning new things difficult, and being fatigued can make any use of technology a too big of an effort.

Furthermore, Carl mentioned how the symptoms can come and go somewhat uncontrollably, including the cognitive problems. One day the person can struggle with numbers, the other day with remembering things, the third with drawing. He also stressed the fact that the symptoms are highly individual, and that a symptom might be non-existent in one patient
and the main issue for another. They mentioned the Second Life-study by Best & Butler as a god example of how people suffering from ME do not have the capacities or energy to learn new things. Carl pointed out that technology made for ME is dependent on having a low steep learning curve. He further talked about how designing technology that fit the needs of sufferers of ME can be difficult, as there is a lot of symptoms to deal with during the design process. They both stressed the importance of being aware of that technology potentially can aggravate symptoms.

When asked about energy modulation, Carl mentioned that he has seen that energy modulation is one of the main tools people suffering from ME use to balance their symptoms. This is something that they typically learn during courses about mastering the illness. It often requires a lot of effort from the ill, as they are told to keep detailed diaries about food intake, activities, symptoms, etc. Carl pointed out that this is something that seems to be too time consuming and energy demanding for most people suffering from ME, and that family or loved ones often need to help out. He also mentioned how issues with energy modulation easily can be solved by technology, through for instance an application.

When asked what the worst about the illness is, both Marie and Carl mentioned the isolation. Marie emphasized that having to watch the world and society move forward without oneself involved seemed to be hard for the affected, and that several of the people they talked to expressed a feeling of being outsiders of society. Having ME your entire childhood prevents you from getting friends, an education, or part-time job experience like everyone else. Marie talked about a woman they met that have been suffering from ME her whole childhood, and how she felt like she had nothing. No friends, no education, no job, no nothing. She felt like she was standing on bare grounds, and that it felt impossible to keep up with fellow citizens.

When asked about what would possibly make a sufferer of ME feel better, both Marie and Carl hesitated for a while before answering. Carl talked about the importance of stress and living a stress-free life. Not just stress free with regards to chores and due dates at school or work, but also simple stress reactions like watching a stressful movie or become scared of a bumble bee approaching your face. All types of stress responses are bad and living without it is good. Marie talked about the importance of making sure the
technology does not require strict monitoring or stressful behaviors from the user, and that the technology should not require too much effort from the user. Other than a stress-free life, Carl also mentioned the importance of having positive aspects in your life. Having a loved one might exhaust a sufferer from ME more physically, but Carl stressed how a loved one might be good for mental health. He talked about how it is easy to get depressed when suffering from such a debilitating and mysterious illness, and that taking the mental health seriously is important.

When asked about the need for technological solutions, Carl and Marie shared results from their research. One of the main things on the participants wish list, Marie said, was the need for technology that could help them in their everyday life with energy modulation and cognitive symptoms. They also talked about how common it is for people with ME to use fitness watches (like FitBit and Polar) to measure sleep and activity levels. The user group seem to like how technology can measure biometrics automatically. Marie mentioned the importance of making things visible in the act of energy modulation. Getting notifications or information about what to avoid or behavior that should be stopped can be beneficial. She stressed that creating such a technology could be complex, as there is a lot of factors that potentially can be monitored from a device, such as temperature, activity, light, sound, nutrition, etc. Carl agreed with Jorun's emphasis on making things visible and pulls forward an idea about giving the user a notification to remember to rest.

They close off the interview with talking about how the symptoms of ME is similar to a lot of other illnesses, such as cancer, depression, and chronic fatigue. They therefore stress how technology made for ME, might be beneficial for other user groups as well.
Appendix K:

Results from workshop

Results from workshop with the Norwegian ME Association

When presented with my research, the participants seemed positive to my initial thoughts and focus on energy modulation. However, they soon started talking about their own ideas and showed little enthusiasm to the variables I had focused on (as presented in Section 5.2). One of the participants expressed how research show that people with ME display signs of being physically and constantly over-trained. She also talked about how the resting heart rate increases with the onset of lactic acid in the muscles. As a result, from this knowledge she decided to try a “homemade” pulse alarm, where she wore a standard pulse strap and set her fitness watch to beep on a certain pulse level by activating the watch’s work-out mode. She said that she learned a lot from this, and that it helped her and the people around her to be more aware of her boundaries. The participants further brainstormed on technological possibilities, extending on the ideas that I presented. One of the suggestions was an app that would gather all the data from a fitness watch together with data about pain and general feeling of sickness, another was a pulse alarm like the one mentioned above. The former was an idea they wanted because they often felt that healthcare professionals, or governmental instances, do not believe in the severity of the illness. By having statistics over how little they move, how high their pulse are and how bad they feel, they could more easily present their case to doctors, nurses, or people working in the Norwegian Labour and Welfare Administration (NAV). They also expressed the need for as much automatic registration as possible, because they have a tendency to forget or lack the energy needed to register all details about their behavior. The suggestion of a pulse alarm was based on the need to be reminded of staying inside their own boundaries. They explained that when a person starts to feel better, the person naturally starts doing more cognitive and physical activities, as the body is inclined to accept more demanding tasks. For a person suffering from ME, this rule might lead to overexertion. A person suffering from ME, they explained, needs to stay inside their boundaries both when having bad and good days.
After presenting the ideas I have been working with and discussing technological solutions in general, we started with the card-sorting session. The card sorting did not last for too long, as the participants got fatigued. The cards they chose to discuss was “NAV”, “Stigma”, “Friends”, “School”, “Movement”, and “Everyday activities”.

The first card the participants started to talk about was the one regarding NAV. The participants explained how the rules and regulations is hard to understand and comprehend. They also often meet people inside the organization that stigmatize their illness, do not believe in its existence, or that simply do not understand the rules and guidelines themselves. A result from this is a lot of uncertainty, stress and concern about their future in terms of economy and work situation, which is negative for the symptom regulation. A technology that could help clarify documents about rules and guidelines would be helpful in fighting their battle to be granted financial support from the government. They emphasized that it is hard to know what is demanded of them, and what needs to be handed in at the different stages in the process. Templates of different application forms, lists over what to remember, and guidance through the process is what they want from this kind of technology.

The next card they discussed was the one regarding stigma. They explained how they often meet people that do not believe in the illness, or that wants to argue whether the causes are physiological or psychological. A result from this is that they often lose contact with these people, or that they avoid telling people about the illness at all.

The next card was “Friends”. They explained how it is difficult to be around their healthy friends, because they often become the “party pooper” in the group. Therefore, being with friends often result in overexertion, because they go beyond their boundaries to avoid being the boring one in the group. Being with other people suffering from ME is thus easier, as they understand the illness, and the needs that comes with it. When talking about friends, they once again returned to technological possibilities and brainstormed around the idea of getting a beep when overexerting. In this way, technology could visualize their boundaries more clearly to people around the ill.
The next card they chose to talk about was about school. One of the participants in the workshop was currently a student at a University in Norway, and she expressed how attending lectures could be very exhausting. She said that she gets a feeling of being hungover as many of the lecturers talks and moves too fast through the class. When being able to record the lectures, she could listen to it in her own pace, but a problem she often meets is not being allowed to record the lectures. She also explained how getting up early is hard for people suffering from ME, and it thus becomes a problem when the lectures are too early in the morning. She talked about how the facilitation for students suffering from different illnesses should be better at school, and that podcasts of the lectures are a very easy way to fulfill this need.

The two last cards they discussed was “movement” and “Everyday activities”. They talked about how moving from A to B can be challenging, as it often requires noise, smells, light and a lot of stimuli. One of the participants expressed that she, for instance, get nauseous of driving the bus. Another participant explained how it is crucial for a person suffering from ME to plan ahead when doing something outside their house, for instance when going on shopping, to the doctor, or traveling for vacation. They also suggested some ideas for technologies that could help them eat healthier, such as recipes for healthy food that is easy to make, or food deliveries that are tailor-made to their nutritional needs.
Appendix L:
Additional results from baseline interview

The rest of the tools, such as headset, earplugs, sleeping masks, sleeping pills, medication, supplements, and calendar to name a few, was placed at different zones and for very different reasons. Earplugs was for instance a necessity for Caroline and Camilla, not used by Andrea, and working ok for Ingrid as she sometimes experiences problems with the earplugs and her tinnitus. Both Caroline, Andrea and Ingrid thought of supplements as something that gives ok value, contrary to Camilla that believes her supplements gives her great value. Sleeping pills, painkillers and medication in general was also received differently among the participants. First of all, Caroline was the only one who received both Gammanorm and Low-dose Naltrexone (LDN), as the other’s had doctors that did not want to prescribe medication that do not have scientifically shown any effect for people with ME. Ingrid also did receive LDN, but was not sure if it had any effect or not, but at the same time she did not dare to stop the regular doses in fear of becoming more sick. All the participants had issues with being able to relax and not becoming bored or restless, and thus had different ways of entertaining themselves while relaxing. Caroline watch TV or listen to a book in order for her to relax, Camilla on the other hand thought linear TV was stressful and preferred TV-series and movies. Ingrid also liked watching TV but played PlayStation as well. Andrea did not watch TV but liked to entertain herself by playing the game “Candy crush”. When asked about the use of breathing techniques and meditation, the participants in general thought of it as boring or difficult. Camilla for instance hated meditating in the “classic way” and had come up with her own way of doing it. Instead of listening to a person telling a story, she laid down on the floor in a specific way that made it possible for her to listen to her own pulse. She then focused on this sound and meditated to it. She thought this was much easier, focusing on a sound rather than on a person talking.
All of the participants use calendars, lists and reminders to keep track of important events, appointments and things they need to remember. They all expressed cognitive issues, and that this is especially evident when in need of remembering, scheduling and keeping track of medication. Andrea expressed the need for an easy way to get reminders to eat and take her medication throughout the day. Caroline, on the other hand, seemed negative to too much reminders. Currently, she has one alarm at 10 in the evening to remind herself to eat if she has not, and to start preparing for bedtime. Ingrid said that she uses the calendar and reminders a lot to be able to remember everything she needs to do. Camilla was the most extreme and had a lot of different lists for both things to remember and lists of the content inside for instance her freezer, fridge or kitchen cabinets. She also had a very impressive notebook where she tracked data from the fitness watch such as pulse, steps and sleep, against her health, supplements, medication, and activity levels. This was all handwritten, and she uttered that she had a hard time finding correlations. When asked about having an app that would help her with exactly the same thing, she was positive. An app such as this was also a wish expressed from Caroline in her interview, as she had used an app called “ME/CFS diary” a few years ago with great success. In the app she could keep track of her activity levels throughout the day, as well as her symptoms.

The most interesting for my project, was their experiences with their fitness watches. Both Caroline and Ingrid thought that their fitness watches added great value as they learned how to balance their illness symptoms more systematically. Caroline had used her fitness watch for several years, and said that one of the values it gave her was insight into how much of the day she stayed in the different pulse zones: “Now I gather everything, or it’s in the FitBit like how many hours I have a certain low pulse through the course of the day, and like compare that block against the block with higher pulse. And sort of want it to be a good balance between the two blocks.. And like keep track of it throughout the day or, like.. Yes. Check at the end of the day if I like not are.. Eh.. that I.. eh.. What I can expect for the next day.” Ingrid had a similar approach. She tracked her sleep and pulse and used the information to change her behavior to fit with what she saw. If she only slept for four hours, her day would be slower than on days where she had eight hours of sleep. She also felt that the fitness watch had given her great insight into what activities are raising her heart rate and not. Both
Caroline and Ingrid also saw a correlation between their resting heart rate going up when bad days or periods were approaching. Andrea and Camilla thought the fitness watch added some value in the form of illness awareness but did not feel that they had learned any specifics about the illness yet. Andrea mainly used the watch to keep track of her sleep, resting heart rate and activity/steps, but did not express any behavioral changes due to what the information gave her. When looking at her sleep, she used the information to verify or challenge her own view about how much she slept that night, without changing her day according to the information at hand. The same was true for Camilla, which seemed to track a lot of data in her notebook, without expressing any specific information she was looking for. She also said that she did not feel that the fitness watch gave her that much value at the moment, other than being fun to use.
Appendix M: – Results from evaluation of tools and methods

Results from telephone interviews
The first group of questions evaluated the time length of the interviews. It is important to stress that all five telephone interviews were conducted within different time lengths, but that none was under 30 minutes and none was above 40 minutes long. Three of the participants answered that the interview length was good, and one participant responded that it would be fine if it lasted longer. One participant answered that it was too long and proposed that 10 minutes was enough. She wrote that talking on the phone is demanding, as she needs to keep focus purely on hearing.

The second group of questions regarded the number of questions asked during the interview. An important note to these results is that the number of questions asked to each participant varied widely, as I conducted a semi-structured interview. Some participants were more talkative than others, and naturally brought up some of the topics in the interview guide without me asking for it specifically. Nevertheless, two of the participants answered that there was a good number of questions, and two participants said it would be okay with more. One person said it was a few too many and emphasized that in general, it is easier to talk freely than to answer questions. She also noted that it could be quite unpleasant and embarrassing to struggle with cognitive actions like this in the presence of others, and she starts to mobilize forces that drain her from too much energy. She expressed that it would be enough with two or three questions.

The third group of questions concerned if they became fatigued, body or mind, during the interview. Four participants answered that they did get a little fatigued, and one answered that she got very fatigued. The reasons for this, the participants believed, was because they had to listen carefully to what I said and focus on getting the sentences together, and that they had
to think about many things at once. One also said that she used a lot of energy on talking as fast and as much as she could as she wanted to say everything that came to her mind.

The fourth group of questions asked if they became fatigued, body or mind, after the interview. One participant said that she did not get fatigued after the interview, two said they got a little fatigued after and two said that they got very fatigued. A loss of energy, need for sleep and a headache was symptoms reported. The reasons for these symptoms was as stated in the third group of questions.

The fifth, sixth and seventh questions concerned if some of the questions asked in the interview were offensive in some way, if the questions should have been formulated in another way, and how they rated my appearance as an interviewer. None of the participants reported that the questions were offensive. One participant said the questions could have been formulated in another way but did not specify how. All of the participants reported that they believed I seemed nice.

For the last two questions, I asked about general tips for a similar interview situation, as well as general tips for a face-to-face interview situation. One of the participants suggested having a timer to help the participants remember to stop at the right time, as she felt that she often get too excited and caught up in the moment that she loses the sense of time. She explained that she wants and likes to contribute to research, and thus use too much of her energy. With regards to the face-to-face interviews, I got several valuable tips: ask the participants beforehand if there is something that should be taken into account for the individuals, send questions beforehand so that the participants can think on their own and take notes, where I physically place myself in the room is important as I want to sit straight ahead of the person and close enough so that we can talk silently, I should wear neutral clothes and avoid perfume, as well as keep my body from moving too much during the interview. One participant emphasized that the precautions needed depends on how “sick” the individual participant is.
Results from the field exploration of RelaxMe

Base-line interview

Two of the participants thought the length and number of questions were good and was open for more questions. The last participant thought the interview lasted for too long, and that it could not have been more questions. A suggestion of splitting the interview in half or adding a pause in the middle was mentioned. All the participants said they became fatigued both during and after the interview, but that they did not see any way to prevent that from happening other than having a break during the session. When asked about the use of tools during the interview, the participants said it made it easier for them to remember, reflect and explain their symptoms and tools.

Final interview

Two of the participants thought the length and number of questions were good but would preferably not have more. The last participant said she thought it could last for longer and that more questions would be okay, especially with a pause. All the participants said they became fatigued both during and after the interview. One of the participants said it is hard to avoid that from happening, another suggested receiving a list of the questions beforehand, the last suggested having a pause.

Interviews in general

One of the participants said she was thankful for our understanding with regards to the symptoms, and that she liked that we had a lot of knowledge about the illness. She also suggested adding a pause in the interviews, because she thinks it can be difficult to suggest that herself. Two of the participants preferred having tools during the interview, as they thought it was easier to remember more. One participant preferred not having tools present, as she thought the activities demanded more of her energy. For future interviews, the participants suggested adding a pause, sit more comfortable when not being dependent on a table and to have short and relaxed interviews.

Using RelaxMe

All of the participants answered that they thought using RelaxMe demanded more of their capacity than they initially thought, but that it did not aggravate any symptoms. A suggestion to make it less demanding was
removing the power bank. One of the participants also said that she would have preferred to receive information about the power bank beforehand and that she would like to receive more information about how to use and when to use RelaxMe. She initially thought it was just for walks or hikes, but later understood that it could be beneficial for grocery shopping and other daily activities as well.