A Qualitative Study of Self-Tracking in Healthcare

- How self-tacking technology mediates experiences and knowledge with heart patients

Anders Riis Vestergaard

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Aalborg University, Copenhagen

School of Architecture, Design and Planning

Study Board for Techno-Anthropology, Sustainable Design and integrated Food Studies
A.C. Meyers Vænge 15
2450 København SV

Aalborg University Copenhagen

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Anders Riis Vestergaard
Student number: 20162256

Resumé

Teknologier som mHealth og weareable åbner op for nye innovative muligheder. De er med til systematisk at monitorere og tracke forskellige kendetegn af den enkelte patient, og den hverdag patienten befinder sig i. Inden for sundhedssektoren bliver mHealth teknologier aktivt brugt til at fjernmonitorere patienter, og spiller derfor en aktiv rolle i patienternes hverdag.

Denne specialeafhandling har sit udgangspunkt i tre hjertepatienters hverdagsoplevelser af at benytte et Fitbit fitness monitoreringsarmbånd i ca. 2 måneder. Ydermere fokuserer projektet på hvordan selvmonitorering som teknologi medierer oplevelser, erfaringer og viden hos de deltagende patienter. Ligeledes hvordan de datagenererede indsigter påvirker patienternes kropbevidsthed og sygdomsopfattelse. Denne undersøgelse fandt sted fra Februar 2018, til slutningen af Maj 2018 hos Rehfeld Medicial som i samarbejde med Hjertecenteret på Rigshospitalet udgjorde rammerne for undersøgelsen. Projektets empiriske materiale blev indsamlet via kvalitative semistrukturerede interviews, og den metodiske fremgangsmåde er forankret i Action Research. Jeg udførte 9 interviews over tre omgange, hvor jeg både besøgte patienterne i eget hjem, på deres arbejdsplads og hos Rehfeld Medical. Det første interview omhandlede onboarding og introduktion til projektet, hvor patienten fik udleveret deltagerinformation og underskrev samtykkeeklæring. Det andet interview fokuserede på de umiddelbare problemstillinger, som patienten kunne have mødt, og de første indtryk de dannede sig. Det tredje og sidste interview koncentrerede sig primært om de dybere indsigter som patienten havde gjort sig efter ca. 2 måneders brug af Fitbit armbåndet.

På baggrund af det indsamlede empiriske materiale, identificerede jeg adskillige situationer, hvor Fitbit trackeren medierede individuelle oplevelser. Jeg identificerede også situationer, hvor patienterne, uafhængigt af hinanden, dannede ensartede indtryk af teknologien. Jeg konkluderer på baggrund af min analyse, hvordan disse indsigter og oplevelser skaber sammenhænge men også kontrasterende situationer mellem patienterne. I denne opgave forsøger jeg ikke at skabe generaliserende materiale, men kan blot berette om hvordan de tre deltagende patienter oplevede at data kan skabe mening i hverdagen. Jeg konkluderer ligeledes, hvordan patienterne skaber forskellige

relationer til teknologien i forhold til daglig motion, søvn og indsigt i egen krop på baggrund af den adfærdsdata de producerer. Afslutningsvis præsenterer jeg anbefalinger, som jeg mener, man som sundhedsfagligperson bør overveje, hvis man introducerer selvmonitorering til hjertepatienter.

Abstract

Background: Mobile and wearable technologies allow for new ways of systematic tracking of specific characteristics of the self and everyday life. In healthcare, mHealth technologies are being used to remotely track and monitor patients and play active roles in the everyday life of these patients. This thesis revolves around self-tracking technology and how it mediates experiences and understandings with focus on illness perception and behavioural changes in everyday life of ICD patients.

Methods: This investigation was carried out from February to the end of May 2018 at Rehfeld Medical, who through their collaboration with the Heart Centre at Rigshospitalet. The study builds on the qualitative method of semi-structured interviews and the approach of Action Research. I conducted 9 interviews with 3 ICD patients during three sessions; 1. On boarding and introduction, the second interview after 2 weeks and the third after approximately 2 months of wearing the Fitbit. The purpose of the interviews was to gather insights from the patients' experiences with the technology.

Results: Based on the empirical material I identified several insights where the Fitbit mediates experiences individually both also correspondingly among the participating patients. I outline x recommendations which should be considered when introducing self-tracking to ICD patients.

Conclusion: I conclude how these insights create certain dilemmas and connections based on experience and interaction with the Fitbit. The cross roads of the patients' relations towards data, data sharing and data trust intersect in various situations and form a foundation for future use of the technology.

Keywords: mHealth, eHealth, telemedicine, Fitbit, self-tracking, healthcare, mediation of technology, human-technology relations, qualitative methods, ICD, cardiac heart disease, remote monitoring.

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Firstly, I would like to express gratitude to my advisor associate professor at Aalborg University, Copenhagen; Lars Botin, for his continuous support, guidance, patience, motivation and knowledge which has assisted me throughout the time of this process.

I would also like to thank the research and management team at Rehfeld Medical for their help and for making this thesis possible and for facilitating the contact to the participating patients. And for providing me with insights in how mHealth technologies function in practice.

Finally, I want to extend my thanks to the patients for their time and for sharing valuable insights in their everyday lives. Without the participation of these three patients, this thesis would not have been possible.

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1. Motivation

This thesis is an investigation of the crossroads where mHealth, telecare and wearable technology intersect and where new technological opportunities and challenges are produced.

The topic I have chosen to focus on is dear me. Not only because it is interesting in itself because of my professional background working with heart patients and as an amateur self-tracker-

Throughout my years as a therapist I encountered a vast variety of patients with different conditions, among them heart patients. As a physiotherapy student, I did my clinical exam on heart patients as well.

Interviewing patients was an important and everyday activity from day one. When recording a medical journal, it is always important to let the patient tell their own story. The importance of words and phrases cannot be underestimated as these expressions represent the world and experiences of the patient. It becomes a collaboration between you as the health professional and the patient to try to comprehend the complete story and together you ‘make sense’ of these insights.

However, when attending to patients who suffer from chronic conditions the purpose of the interview can change. The chronically ill patient often has deep insights into their own condition.

As mentioned, self-tracking is no new phenomenon for me either. As a more than average athlete, not to seem overconfident, fitness as well as gathering and examining data has been a part of my life since I started doing sports as a teenager. After I stopped competitive sports, self-tracking was more a tool for me to systematize my workouts and keep track of my progress. It never became what others would call a passion, as one might say when considering Thomas Blomseth Christiansen, has tracked every time he sneezed for more than five years[1].

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[1] https://qz.com/507727/a-man-who-recorded-his-every-sneeze-for-five-years-might-have-a-fix-for-your-pollen-allergy/

As the participants in this study are equipped with a Fitbit Alta HR tracker, I have myself worn the tracker and undergone the experiences it may mediate both in terms of gaining insights and digital competition which I will elaborate in section 3.3. I have tried to get my steps up, paid attention to the move reminders and reviewed the sleep data or checked my resting heartrate.

Through my professional experience with patient interaction and embodied relationships with the self-tracking technology, I dare to state that I have a fundamental comprehension of and insights into what the patients participating in this study are undergoing, not as a chronically ill individual but as one who understands how a technology can influence your life.

2. Introduction

As part part of a large-scale R&D project such as SCAUT, I have been given the opportunity to study how these mHealth phenomena unfold in ways that had otherwise been problematic and most reasonably I would not have been able to study them in these ways.

2.1 Telecare & mHealth

mHealth services and self-tracking technologies, such as wearables and innovative smartphone applications are rapidly growing in population. Such technologies create and facilitate new possibilities in communication, how to retrieve information and gather data. Development within mHealth technologies are creating extensive methods to monitor and track behavioural data, such as everyday activities and experiences of patients.

As it is today, people using technologies can self-monitor almost everything (Neff & Nafus, 2016). Additionally, healthcare providers are progressively relying on the development of self-tracking technologies and remote patient monitoring to gather data in the telecare of chronically ill patients. Operationalizing such technologies in the everyday life of patients and clinical treatments has been connected to patient empowerment, thus increasing the independence of their users (Ibid; Storni, 2013). Current studies regarding self-tracking are mainly influenced by activities where the focus is to improve the health and fitness on a more rudimentary level, such as weight loss or general fitness. Only a limited number of studies have focused on the use of self-tracking in healthcare (Chung et al. 2016; Storni, 2013).

In this thesis, I aim to explore the connection of self-tracking and the experiences mediated by the technology in patients with an ICD.

The theoretical aspects of self-tracking and patient empowerment have been investigated by scholars, but within both dimensions there is a lack of practical focus rather than theoretical statements (Salmon & Hall, 2003; Pantzer & Ruckenstein, 2015; Lupton, 2013a). Lupton (2013a) states that in practice patients frequently end up being passive subjects of health technologies instead of being involved more in the improvement of them. With this thesis, I seek to break with this practice by involving the patients, thus contributing with practical knowledge of how patients experience self-tracking and what insights they might gain.

The global progress and structured use of information and communication technologies (ICT) in healthcare has grown in recent years. Health information technology (eHealth) has developed with the expectation of efficiently improving the cost and quality of healthcare, even though there is no existing conclusion that this is correct (Jamal et al., 2009; Bardhan & Thouin, 2013; Wicks et al., 2014; Woodward et al., 2014)
eHealth is defined by the EU as:

> *"the use of ICT in health products, services and processes combined with organizational change in healthcare systems and new skills, in order to improve health of citizens, efficiency and productivity in healthcare delivery, and the economic and social value of health. eHealth covers the interaction between patents and health-service providers, institution-to-institution transmission of data, or peer-to-peer communication between patients and/or health professionals"* (EU, 2015)[2].

eHealth consists of many different socio-technical solutions, in this study the focus will mainly be on *telemedicine, telecare* and *mHealth*, but more exist.
Telemedicine includes a wide-ranging of technology services only related to clinical healthcare services. It involves the use of digital communications and software to deliver clinical services to patients without an outpatient visit. It typically involves follow-up visits, management of chronical diseases or medication, specialist consultation but there many more (WHO, 2009:8)

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[2] http://www.europarl.europa.eu/

Telecare is the utilization of ICTs to provide healthcare and facilitate collaboration between physician and patient over extended distances (Bos et al. 2008:166; Bardram et al., 2005:295; Oudshoorn, 2011:4). However, such technologically remote medical care is not new and has existed since the invention of the telephone and its introduction to healthcare (Bardram et al., 2005:295). With the technological development of medical devices, telecare has branched into the internet and now provides the opportunity to progressively monitor the health data of patients (Bos et al. 2008:166). Bos et al. (2008) furthermore claim that telecare will play a future key role in enabling, cooperation and interaction between patients and clinicians (Ibid: 166). This is a future made gradually possible due to the growing accessibility of mobile technologies and smartphones, as well as other measurement device technologies, such as wearables. This growing accessibility of mobile technologies and its functions within healthcare has led to the term *mHealth*, which is the use of mobile phones, apps and other related tools in healthcare (Lupton, 2013b:393). One of the specific applications of new mHealth technologies is the usage of mobile and wearables devices to gather data about the everyday activities and bodily experiences of the user (Ibid:394).

The use of telecare technologies has been met with doubt, since it is argued that such technologies often neglect the possible aspect of collaboration and rather focuses primarily on efficiency aspects (Andersen et al., 2011:113; Oudshoorn, 2009:390). Bardram et al. (2005) problematize this issue arguing that if the collaboration aspects are neglected, it may lead to the production of systems that do not function due to lack of "*support for communication, coordination, knowledge sharing and mutual awareness"* which greatly affect the potential of such technologies (Bardram et al., 2005:302). Andersen et al. (2011) debate that if innovative healthcare technologies in telecare are to prosper within the areas of patient empowering and involving the patients more in treatment, researchers and designers need to embrace the collaborative elements seriously and re-introduce the patients as agents (Lupton, 2013; Salmon & Hall, 2003; Andersen et al., 2011; Storni, 2013)

3. Problem Area

As described above, the problem area of this thesis revolves around the use of mobile wearable technologies in healthcare, and what this this technology mediates for patients who have an ICD. Remote monitoring is no new field for

3.1 The Treatment of Heart Patients with Advanced Pacemakers

I study patients who have a special kind of pacemaker implanted in their body a so-called ICD or implantable Cardioverter Defibrillator. The ICD helps to keep a steady heart rhythm and in special situations can function as a defibrillator and restart the heart in case of a heart attack. Commonly, the ICD is also referred to as a *pacemaker*, but with more than a monitor function. The ICD can be monitored over a distance and is often used as a classic example of a telecare situation.

Technically, the ICD is a small battery-powered impulse device, which consists of a cardioverter, that helps to stabilize the heart, and a defibrillator that can deliver treatment for irregular heartrates (Skov et al., 2015:828).

Currently, around 1900 ICD implants a year are performed in Denmark. 62% are first-time implants, 30% are battery replacements and 8% are systems upgrades[3]. ICD patients are usually at risk of unexpected cardiac arrest due to ventricular fibrillation or ventricular tachycardia, which in short are uncoordinated contractions of the cardiac muscle or rapid heartrate. If the ICD register irregular heartbeats or cardiac arrhythmia it will regulate the irregularity by providing treatment, which involves an electrical impulse or a shock, thus restoring the heart rhythm to normal. In case of heart failure, the ICD will react in a similar way by providing a shock to the heart and thereby prevent the heart from

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[3] http://www.nbv.cardio.dk/icd

stopping[4]. The ICD, as other types of heart monitors, record data whenever it detects arrhythmic events but it also logs selected conditions of the body such as heartrate, activity and duration.

As Andersen et al (2011) explains these data serve to provide insights in the patient's condition, act as support in clinical decisions and deliver information regarding the ICD (battery status & need for re-programming among others) (Andersen et al., 2011:113). This collection and remote monitoring of the patient, establish ICD data as a key player in the use of patient-generated data in the care and treatment of chronic heart failure patients. A long with an ICD, patients are often provided with a remote home monitor, which is a box the size of an internet router. The remote monitor box is the link between the outpatient clinic and the patient. It allows for the ICD to send data to the healthcare providers while the patient is at home (Skov et al., 2015:828). The box will typically read data from the ICD once every 24 hours, and if any abnormalities are detected it automatically transmits the data to the server located at the patient's assigned clinic. This practice leads to fewer in-clinic patient visits as well as it provides the clinicians with possibilities of knowing more details about the patient's condition (Ibid).

3.2 The SCAUT Platform – A Telecare Spin-Off from University Research

This thesis was made possible by the collaboration with the interdisciplinary research- and development project SCAUT. The following section provides an introduction of the associated partners and what the platform facilitates.

SCAUT is a research project involving collaboration between the University of Copenhagen, the Heart Centre at Rigshospitalet, Medtronic, a pacemaker producer based in the United States, and Rehfeld Medical. The project took form after another research project which ran from 2008-2013 called CITH (Co-Constructing IT and Healthcare).

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[4] https://hjerteforeningen.dk/alt-om-dit-hjerte/behandling/defibrillator-icd-enhed/

CITH consisted of collaboration between the University of Copenhagen, Technical University of Denmark, CBS (Copenhagen Business School), ITU (IT University of Copenhagen) and Rigshospitalet. The project concentrated on using internet communication technologies for improving the relationship between chronic heart failure patients with implantable Cardioverter-Defibrillators (ICDs) and health care professionals at the Heart Centre at Rigshospitalet to improve the overall treatment and care (SCAUT, 2017). As it became evident to the researchers that they were quite passionate about the subject and embraced the possibilities of the collaboration they created a follow-up project and named it SCAUT.

SCAUT – *"a short for Self-, Collaborative- and Auto-Detection of signs and symptoms of deterioration"* [5]has the purpose of facilitating communication between patients with a cardiac device and the health care professionals. The patients communicate through a mobile application, and the clinicians through a web platform. The platforms are meant to function as a tool that eases and optimizes the work practice involving cardiac device patients, who has and knows how to operate a smartphone. More in depth, it aims to reduce some of the time-consuming practices such as phone calls and face-to-face in-clinic consultations or follow-ups, but still maintain a high level of professionality and comfort for the patients and not just create workloads elsewhere in the healthcare system.

Andersen et al. (2011) suggest that *"the integration of new technologies leads to redistribution rather than reduction of work"*, which means that it is vital when doing IT innovations in healthcare, that you do not simple shift the workload from one situation to another and that the actual health care staff experience the reduction of work and constitute meaning based on the systems (Andersen et al., 2011). Previous work done by Skov et al. (2015) states that the work practice regarding pacemaker patients used to be where the clinicians would only contact the patients if they discovered irregularities and, in effect a "no news is good news" practice was extradited (Skov et al., 2015). However, cardiac device patients are known for being particularly worried about their condition and therefore suffer from anxiety (Magyar-Russell et al. 2011).

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[5] http://www.scaut.dk/

3.3 Wearable mHealth – The Fitbit Study & The Alta HR

What is Fitbit?

Fitbit was founded in 2007 in San Francisco by James Park and Eric Friedman who shared the vison of leading people to healthier and more active lifestyles by empowering them through data. Currently, Fitbit offers an innovative selection of tracker devices, audio headphones, smartwatches and smart scales. Fitbit products are listed and sold in more than 78 countries all around the world. The Fitbit platform facilitates personal experiences, insights and advice through wearable devices and software solutions. As of 2017, Fitbit registered more than 25 million users worldwide[6].

The device used in this thesis is the Alta HR model.

(Fig. 1: The Alta HR model)

What can the Fitbit Alta HR do?

It tracks steps, distance travelled (without GPS), number of calories burned and your sleep. It shows you notifications and incoming calls and SMS from the connected smartphone. It has optical heartrate sensors built into the underside, which records heartrate throughout the day and night and provides you with an analysis of your sleep put into four categories. If the user wears the band to bed it also provides her with an addition of resting heartrate.

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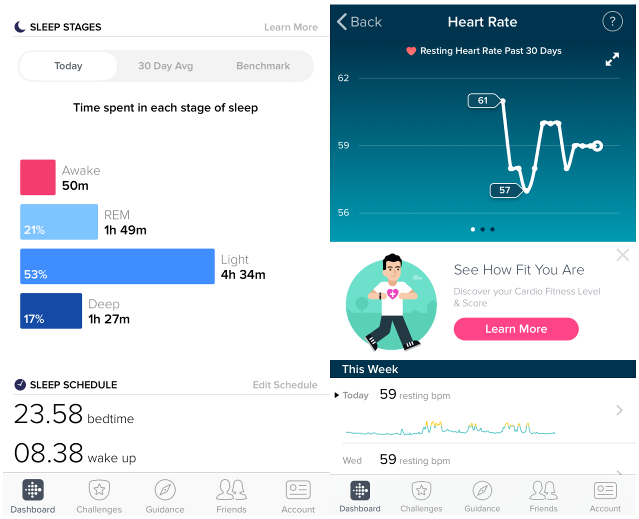
[6] https://todd-benschneider.com/2018/02/19/technology-ventures-fitbit-ipo-superstar-struggling-for-survival/



(Fig. 2. shows the four different sleep stages, and an example of how the resting heart rate can look over time)

The tracker also has several nudging features such as reminders to move, you can set an alarm to wake you up based on the amount of sleep you would like to get, etc.

It has a standard of 10.000 steps programmed which it will tell you to reach and if you do you receive digital fireworks and a complimentary “Good job”. Or if you reach the 250 steps it tells you to move several times a day through a message “It’s time to move”, “It’s Step a’ clock” or “Wanna stroll?” you will receive a similar digital compliment.

Try hitting 10,000 steps a day!
That’s the American Heart Association

Today	10.818 steps
Wed	11.457 steps
Tue	13.259 steps
Mon	12.029 steps

(Fig. 3. shows an example of how the measured number of steps are visualised in the Fitbit App)

4. Problem Formulation

With the problem area introduced, I would now like to formulate the research question that will guide my research and thesis work.

4.1 Problem Formulation

- *How do Fitbit self-tracking devices mediate experiences and understandings from ICD patients and how does these data mediate in a clinical and organizational context?*

4.2 Research Questions

From this problem formulation, I derive two research questions

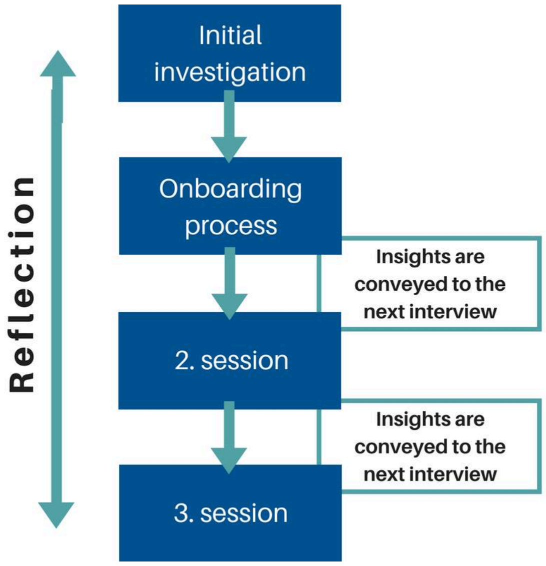
RQ1: *How do ICD patients experience wearing a Fitbit fitness tracker, and how does this affect their perception of their illness?*

RQ2: *What kind of behavioural changes are the patients subject to and do they view self-tracking as a useful tool in the future life of a heart patient?*

5. Methodology & Research Approach

In the following section I will provide an overview of the primary and secondary research methods along with the theoretical framework. This master thesis was carried out from February to the end of May 2018 at Rehfeld Medical, who through their collaboration with the Heart Centre at Rigshospitalet provided the possibilities to make the project take place.

The aim of this thesis is to explore insights and experiences mediated by self-tracking technology, from patients with an ICD, who are a part of the SCAUT research project. The patients are equipped with a Fitbit self-tracking device for approximately 10 to 12 weeks, and three sessions of interviews were conducted. The ethnographic research process can be seen below (fig xxx)



(Fig. 4. shows the empirical process. How the initial investigation feeds into the 3 sessions of interviews, and how the insights are connected through the whole process)

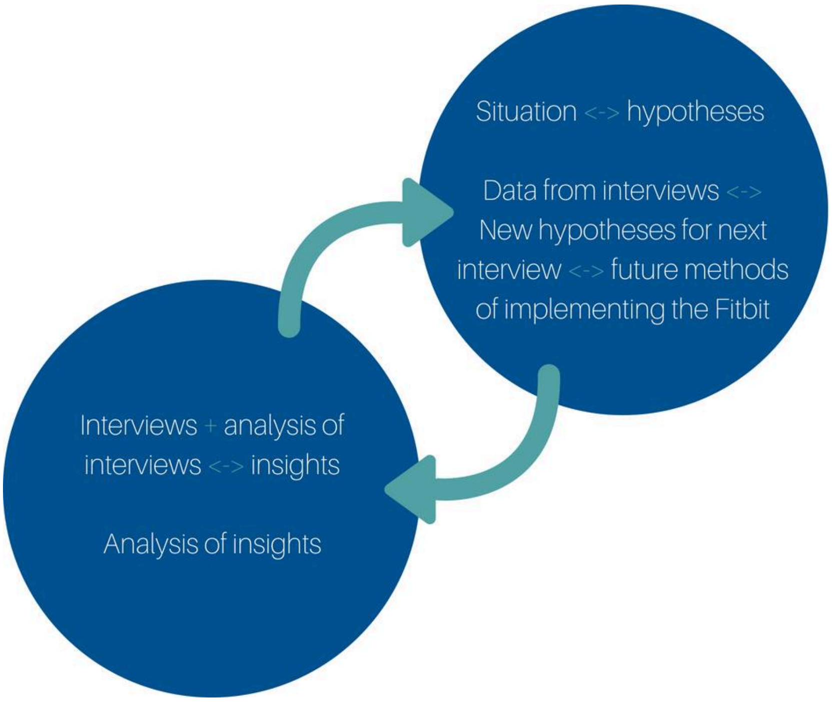
I have decided to use Action Research as a research approach, which will be elaborated in the corresponding section. As the research in the field of self-tracking of patients who have an ICD is scarce, I have conducted a literature review with focus on selected papers and articles which create a better understanding of the phenomenon.

Furthermore, I expect to gain insights that can contribute to the current knowledge and foster further curiosity and reasons to explore this field more, In the following I will provide an overview of Action Research as a research approach. Next follows a section regarding the qualitative method used in this master thesis which consisted of semi-structured interviews inspired by Steinar Kvale & Svend Brinkmann (2015). Finally, I unfold my choice of theoretical approach which consists of Peter Paul Verbeek's Post-Phenomenology and his mediation theory followed by Critical Theory of Technology by Andrew Feenberg.

5.1 Action Research

Having its origins from post-positivism, action research is an 'interventionist approach' for obtaining scientific knowledge (Baskerville & Wood-Harper, 1996). Action research (AR) when used as a method is both interpretative and ethnographic, as it observes but also intervenes (Ibid). In AR researchers collaborate with their subjects of study to contribute to a positive and *'democratic social change'* within the subjects' environment (Ibid.; Brydon-Miller et al., 2013). And as David Coghlan states *"human systems could only be understood and changed"* if the research subjects themselves are included in the process of knowledge production (Brydon-Miller et al., 2013).

Lewin (1951) was the first who developed the method which included iterations of phases with six stages. They were (1) analysis, (2) fact finding, (3) conceptualizations, (4) planning, (5) implementation of action and (6) evaluation (Ibid). The model can more roughly be translated into two stages, (1) the diagnostic stage, where the situation and problems are studied by the researcher and the subjects and hypotheses are created, (2) the therapeutic stage, where experiments are created and designed in collaboration, then carried out and finally the effects of these are examined (Baskerville & Wood-Harper, 1996). (Fig.5)



(Fig. 5. show the iterative process of action research, and how the diagnostic and the therapeutic stage are intertwined and affect each other continuously)

AR is a repetitive and continual process connecting theory and practice where the stages listed above are repeated over and over again during the course of the project (Ibid). Additionally, AR cannot be understood as a fixed set of methods, theories and research approach, rather it is *'an orientation to inquiry'* where joined actions backed by research constructs new knowledge (Reason & Bradbury, 2008; Andersen et al., 2014)

However, AR presents various challenges for a social scientist who has chosen this approach of knowledge research, but it seems these challenges do not differ considerably from the conventional challenges of doing social science (Baskerville & Wood-Harper, 1996:240). Baskerville and Wood-Harper point out some of the critical underpinnings which includes the *impartiality of the researcher* arguing that it is *consulting* not research and the issue of generalization of the research findings is *context-bound* (Ibid). The opponents of AR often argue that as a research approach, AR lacks validity as carried out experiments often are hard to replicate as in natural sciences, thus making the approach less scientific (Cheeckland & Howell, 1998). Moreover, as the phenomena of study are not homogenous over time, it might it difficult to replicate the experiments (Ibid).

For the researcher to handle the aforementioned challenges they need to constantly reflect during the process and can seek help from the following guidelines by Baskerville and Wood-Harper (1996) and Checkland & Howell (1998) to determine the validity of the research approach. Checkland and Howell (1998:18) suggest that the researchers should be able to enact formerly declared methodology, which then would strengthen the *recoverability* of the course if the research should fail under critical scrutiny. Creating a process as transparent as possible in order to increase the recoverability should be one of the main concerns when performing AR.

For the sake of *'achieving scientific rigor'* Baskerville and Wood-Harper (1996:244) suggest creating a clear and *'ethical client-system infrastructure and research environment'*, planning and documenting their collection of data, support subject learning through observing the iterative cycles of formulating theory, planning action, taking action and lastly evaluating action. More, the AR practitioners are able to make certain generalizations that are *'based on the theory and learning';* however for that to happen, the researchers need to disseminate the scientific knowledge produced to make it possible to conduct future research (Baskerville & Wood-Harper, 1996, p.244).

Avoiding the pitfalls and abiding by the suggested guidelines AR, can prove to be a valid method for making scientific claims, yet researchers need to be aware of the limitations of such claims (Checkland & Howell, 1998, p.20).

Action research as a method allows me to gain insights into what ICD patients, who are equipped with a Fitbit tracking device, experience throughout the course of the study, since I intervene with the patients on a level where the patients themselves act as important roles in the positive democratic change in their environment. Furthermore, it allows for me to build trust with the patients involved, as I collaborate closely with them throughout the process, which is significant to the empirical insights I gathered. As mentioned earlier, action research is an improvement process and the improvement I seek to foster in the participating patients is an improvement of their health literacy, while leaving space for the explorative aspect. This means that during the process of the study, I hope for the health literacy of the patients to improve but at the same time it is not a fixed goal of the study, as I cannot predict if they accept or reject the technological intervention. As the project proceeds, I continuously reiterate my approach to the patients to adapt their developing relations to the technology and leave space for the unpredicted. Furthermore, I emphasise that I do not seek to make any scientific claims for ICD patients or self-trackers.

But when conducting action research there is always a chance that it might seem that the process lacks validity. I try to make my research process as transparent as possible by describing and documenting my empirical process as thorough as possible.

5.2 Semi-Structured Interviews

The main objective was to create and keep an open atmosphere with the participating patients. This was crucial throughout the duration of the project as it helped to maintain an open dialogue where the patients could share their experiences while I could set a fluid agenda for the meetings.

As mentioned above, I conducted the interviews based on the interview theory by Kvale & Brinkmann in their book “Interview: Det kvalitative forskningsinterview som håndværk”. The semi-structured interview has its focus on the experience of the informant of a given subject (Kvale & Brinkmann, 2015, p.47). Furthermore, the semi-structured interview is conducted like an everyday conversation but the approach secures the focus of the interview is around the themes which are included in the interview guide. At the same time, it provides the interviewer with the possibility to follow other relevant themes that might occur during the conversation (Ibid, 2015, p.51). Kvale & Brinkmann describes a person as a ‘*good interviewee*’ as one who is willing to cooperate, is motivated, has knowledge about the relevant phenomena, appears truthful and acts consistent while answering (Ibid, 2015, p.222). Moreover, they state 12 factors which can affect the qualitative interview:

- Everyday life
- Meaning
- Qualitative
- Descriptive
- Specific
- Deliberate naivety
- Focus
- Ambiguity
- Change

- Sensitivity
- Interview Situation
- Positive Experience

(Ibid, 2015, p.50-51).

These factors act as a guide and help the interviewer to attain a qualitative comprehension of the phenomenon (Ibid).
An important note is that different interviewers can have different sensitivities towards a phenomenon, which means that if the interviewer has previous knowledge or experiences related to this phenomenon, it can affect the way the interviewers conduct the interview - and vice versa if the interviewer has none or very little former knowledge of the subject (Ibid).

The interview guide for the first session of meetings was divided into five categories and ended with the patients being asked to perform three small tasks.

The five categories were:

- Information regarding the study (including signing a statement of consent).
- Participation (questions regarding why they agreed to participate and what their expectations were).
- Process, health and everyday activity (questions regarding why the patients have an ICD, their current health perception and how physically active they are daily).
- Symptoms and transmissions with ICD (questions regarding symptoms in relation to their heart disease and when they last experienced any symptoms related to a transmission).
- Activities (questions regarding connection between their heart disease and physical activities and if they involving clinicians or next of kin related to these connections).

Three small tasks were:

- What do you experience with the Fitbit tracking device (e.g. screen dumps or manual logging)

- Symptoms (log a symptom in the ‘symptom diary’, look at the Fitbit app, note experiences and connections)
- If there is a transmission from the ICD (look in the Fitbit app, note experiences and connections)

The last two sessions of interviews were outlined as the first but were also adapted individually to each of the patients in order to ensure I followed the guideline, as elaborated above, by Kvale & Brinkmann. The interview guides were adapted to match the everyday life, focus and sensitivity of each of the patients as their situations were quite different in terms of technical and health literacy. But at the same time, it was shaped by the insights I gathered from the first session.

6. Theoretical approach

In the following section I focus on post-phenomenology as my main theorem for this thesis. I describe the origins of post-phenomenology and the theory of mediation by Peter Paul Verbeek. Next I focus on Critical theory of Technology by Andrew Feenberg, which is my second theorem which will support my analysis. I describe some of the central elements, but focus mostly on the aspect of social relations, where Feenberg draws upon the work of Georg Lukács. The two theories complement each other since Peter Paul Verbeek's mediation theory mostly focuses on the relations between the human and the technology which is in this project is the patients and their relation to the Fitbit. Andrew Feenberg's Critical theory mostly focuses on the socio-political relations which, in this project, are manifested by the patients' hope that their knowledge can become a part of future clinical practice.

6.1 Post-Phenomenology

6.1.1 The Origins of Post-Phenomenology & Mediation Theory

The two main contributors to Peter-Paul Verbeek's work on human-technology relations are Don Ihde and his post-phenomenology, and Bruno Latour with his actor-network theory (Verbeek, 2016). Even though post-phenomenology and actor-network theory are often viewed in a disagreement with each other, Verbeek manages to intertwine these two theoretical approaches in his framework of technical mediation. Verbeek argues that Latour's perspective on mediation of actions and Ihde's understanding of mediation of experience can be combined into a new concept of mediation, a concept where both action and perception are important roles of the relationship between humans and technologies. Furthermore, Verbeek states the argument that both post-phenomenology and actor-network theory attempt to leave the subject-object divide in the same ways, as they both suggest that mediation cannot happen between subject and object.
Verbeek however, claims that subject and object co-shapes mediation (Verbeek, 2005, 130).

Verbeek states, *'When technologies are used, they inevitably help to shape the context into which they function'* (Verbeek, 2011. P. 4), which delineates that when a technology is used it creates relations between its users and the world in which the technology is used. This ultimately results in specific experiences and practices. These relations and experiences between users and their world shape the basic understanding of human-technology relations that act as the essential principle for Verbeek's perception of human-technology interaction (Verbeek, 2015. p. 28).

However, a more comprehensive understanding of technology is needed rather than just perceiving it as the sheer existence of artefacts which naturally linger in and affect our lives. And do to so, Verbeek suggests three aspects of conceptualising the understanding of human-technology relations; *technologies as extensions of the human*, *the dialectics between humans* and *technologies and the hybrid relation* (Ibid).

Technologies as extensions of humans distinguish technologies as means to facilitate human experiences and practices, here the technologies are understood as morally neutral (Ibid).

The dialectics between humans and technologies situates around the interaction between human users and the technology. However, here the technology takes over the physical and cognitive capacities of the human users to a certain degree. This then enables the technology to acquire a degree of cognitive function which serves the humans in their way of thinking, reflecting and experiencing (Verbeek, 2015, p.29).

Verbeek presents a central problem with the first two aspects, since it puts humans and technologies in two separate spheres, which fails to perceive the complex, tangled relationship of the two. In order to fully grasp this complexity Verbeek suggests a different approach where we examine human-technology relations in a more hybrid form.

The hybrid relation is the notion that the interaction between humans and technologies help them shape each other. Every aspect of human existence develops in close relation with the surrounding technologies. And these technologies mediate the human understanding of the world, thus linking these two directly in the world they exist in (Ibid). Based on this notion Verbeek has built his mediation theory through which he seeks to address and explore the hybrid relation between humans and technologies.

6.1.2 Mediation Theory

Mediation theory consists of three dimensions in the human-technology world, (a) *Relations*, (b) *Points of Contact*, (c) *Types of Influence*. The notion of (a) *Relations* originates from Don Idhe's work on the different human-technology-world relations;

- Embodiment relations: (Human-Technology) -> World
- Hermeneutic relations: Human -> (Technology-World)
- Alterity relations: Human -> Technology (World)
- Background relations: Human (Technology/World)

(Verbeek, 2015, p.29., Verbeek, 2011, p.143)

Embodiment relations are when technologies form a unity with a human being, and then this unity is oriented towards the world. We speak to one another through the telephone, we do not speak to the telephone and we look *through* microscope instead of looking at *it* (Verbeek, 2015 p. 29).

Hermeneutic relations are where we interpret what technologies presents to us. The example of the MRI scan representing brain activity shows us exactly that. Rather than human being using technologies, here they form a unity with the world. Humans are directed towards the manner of unity in which technologies represent the world (Ibid).

Alterity relations are where humans connect with technologies with the world in the background of this interaction. Examples of this is getting money from an ATM or through various human-robot interactions (Ibid).

Background relations are the fourth and last of Ihde's relations, and is when technologies become the context for human experiences and actions. The notifications from cell phones, the noise an air conditioner makes and the warm air from heating installations are all examples of how technologies are a context for human existence instead of being experienced themselves (Ibid).

Verbeek contests these relations as he deems them insufficient to correspond to how present day technologies have developed and suggests an expansion which better suits more modern configurations:

- *Cyborg relations*: Human/Technology -> World
- *Interactive context*: Human <> Technology/World
- *Augmentation*: (Human-Technology) -> World + Human -> (Technology-World)

(Verbeek, 2015, p.29-30)

Cyborg relations are when the technology becomes more than embodied, it merges with the body of the user thus creating a hybrid of the two. A brain implanted microchip for Parkinson patients or a pacemaker are such technologies (Ibid).

An *interactive context* is when a technology becomes more than just a background for our existence; it interacts with our presence, by e.g. through facial recognition or behavioural feedback, to determine how we behave in certain situations (Ibid).

The last of the three new configurations is *augmentation* which is when an embodied relation is combined with a hermeneutic relation thus resulting in a bifurcation of the human-world relation. Google smart glasses are an example of how the embodied relation of the technology can mediate an experience of the world but on the other hand provide a representation of it at the same time (Ibid).

The next of the mediation dimensions is, (b) *Points of Contact*. This dimension alludes to the connections between humans and technology. Verbeek is joined by Dorrestjin and Van der Voort, who all present their product impact model which consists of four zones that all represent distinctive points of contact:

- *Before the Eye*
- *To the Hand*
- *Behind the Back*
- *Above the Head*

(Dorrestijn et al. 2014, 287).

Before the Eye represents technologies that influence our choice of life through *guidance*, *persuasion* and *interference*. The intervention of these technologies can be interpreted as an attempt to affect the human decision-making process; cognitive manipulation (Ibid).

To the Hand is a more bodily or physical oriented zone, where *coercion* is the main notion. Speed bumps on highly trafficked roads are used as an example, where the technology physically affects humans (Ibid).

Behind the Back is where environmental factors alter the behaviour of humans, e.g. surveillance that has twofold possibilities, either to enforce people's notion of feeling safe or induce a feeling of violation in terms of privacy. This provides an interesting example of how technologies can create conflicts in their intended designs, which is referred to as *environmental conditioning of subjectivity* (Ibid).

Above the Head is the most abstract zone of the four. It addresses philosophical allegation on the impact of technical hybridity on society. An example is the *dystopian* fear the technologies will eventually take over society and cause massive unemployment, but also the *utopian* belief in progress through technology (Ibid).

The third and last of the mediation dimensions is (c) *Types of Influence*, and here Verbeek is joined by Tromp and Hekkert. Together Tromp, Hekkert and Verbeek (2011), further determine two ways through which the role of mediation of technology can be assessed, *Salience* and *Force*. Through salience and force, technologies can present influence on humans between the *Hidden* or *Apparent* on one side, or the *Strong* or *Weak* on the other. When you take the subway and the turnstiles force you to buy a ticket before you can enter the train is an example of a strong and apparent technology, as is the example of the car that will not start before you put the seatbelt on. This influence is referred to as *coercive* and is a representation of a *hidden* and *strong* influence (Tromp et al., 2011). More moderate variations of technical influence are referred to as *persuasive* and can be seen in dashboards in cars or battery levels on smartphones or wearable technologies that displays energy consumption which is a representation of *apparent* and *weak* influences (Ibid).

The last two configurations consist of, first, a *hidden* and *weak*, which is referred to as *seductive* and presents itself in milder and more non-cognitive ways, e.g., the placement of coffee machines in order to promote social interaction. The final configuration is a *hidden* and *strong* technological influence. Buildings without an elevator is a powerful example of such a technological influence and is this is referred to as an *implicative* influence (Ibid). These three dimensions help us as human beings shape our experiences and practices and through these they, instead of being external to us, help to define what we, as humans, are. Furthermore, technologies assist us in developing our knowledge of the world and even more importantly our moral actions and decisions (Verbeek, 2015, p.30).

By applying Peter-Paul Verbeek's' Post-phenomenology and his concept of mediation theory it allows me to unfold how the technology is mediated through the users but also helps to unfold how the relationship between the user and the technology appeals for behavioural changes in the everyday life of the patients and the clinical practice of the clinicians.

Through the approach of mediation of technology theory, I am able to understand and explore how the patient-Fitbit relations are of significance in the everyday life of ICD patients and how the technology mediates knowledge and experiences from their world. By investigating the experiences of an ICD patient wearing a Fitbit self-tracking device, I can help to clarify how they perceive their illness in relation to the data the Fitbit presents them. Moreover, I will be able to investigate whether the technology initiates behavioural changes in the life of the ICD patients as their understanding of the data develops throughout the study.

6.2 Critical Theory of Technology

6.2.1 The Origins of Critical Theory of Technology

In this study, Critical Theory contributes through the notion of critical reflexivity and how to re-evaluate technological progress via the concept of emancipating humans from the confinement of technology and foregrounding values that 'ought to be' (Rexhepi and Torres 2011, 689). More importantly, it states that the socio-political implications of modern technology cannot be separated from the development process it has undergone, thus it must be considered connected to the socio-material casualties it may invoke through interconnections amid various research disciplines (Ibid, p. 689).

Critical theory designates from what is known as the Frankfurt School, which is comprised of German philosophers and social theorists who developed the theory in the 1930s (Feenberg, 2002, p.13). However, to this day, by combining the philosophical and social sciences it is still being developed further, which allows for a perspective to become morally specific in a practical sense rather than instrumental (Bohman, 2016.)

Feenberg describes technology as a '*two-sided phenomenon: on one hand the operator on the other the object. Where both operator and object are human beings, technological action is an exercise of power*' (Feenberg, 2005). He argues next that technologies function as the organized center of societies and societal power in its fundamental form is presented as '*technological power*'. This power is performed by designs that reduce the significance of the normal functioning of the technology and what depending institutions might exist. This reduction affects the format of experience and will ultimately result in '*human suffering and damage to the natural environment*'(Ibid). The demonstration of technological power will then introduce a new intrinsic resistance of the technical system, ultimately those who are not involved in the design process will undergo the unwanted consequences of technologies and object (Ibid). By performing design through a democratic lens negative feedback loops can be avoided and by commencing to a broader spectrum of interests and concerns less resistance a technology would face (Ibid).

6.2.2 Social Rationality

Feeberg presents in his article 'Modernity, Technology and the Forms of Rationality' the concept *social rationality*, which refers to the work of Georg Lukács and his term *reification* (Feenberg, 2011). The concept of *reification* seeks to bridge boundaries between social relations into what appears as separate objects such as institutions and commodities. Individual attributes of human conditions are eliminated through a conceptualized understanding of the social world. *Reification* thus separates objects' social manner from their individual content making these attributes a *second nature,* which are to be studied as a dimension of facts and rules perceived through the lens of natural science and disciplined by technologies.

However, *reification* shapes the relations and objects it conceptualizes compared to natural science which only observes (Ibid). But *reification* is not a mere theoretical approach but also, as Feenberg describes it, a '*practical relationship to the world*' which forms the world into collections of things determined by laws that are explicit to the various domains that all together make society (Ibid). Here the point is that subjects, when subdued to institutions of reifications, limit their knowledge and behaviour due to the manipulation of technology. Activities become restricted to minor objective manners of assessment with no regards for human relations and implications and ultimately a cause for *reduction of function* (Ibid). Under these conditions, meanings come to ignore the importance of significance and affiliation which objects have in the world they are a part of; food becomes more than just a source of calories but is closely connected culturally to established rules. This is to be understood as the complex cultural associations tied to food are connected to its perceived reality as a source of energy, which is its basic functionality. Such cultural understandings are lost if its functions are dissociated through *reification* (Ibid).

Feenberg states that this notion is valid throughout many aspects of social life but he also acknowledges that it has allowed for great progress in society and that '*nation states and cities depend on the generalization of social rationality*' (Ibid, p.866). The approach of social rationality can be of relevance in various discussions regarding technology in society, as many often jump to the conclusion that bad people make negative usage of negative instruments. However, according to Feenberg, the common-sense rationale is disrupted by the nature of the systems that act as the foundations for this rationale, which in more detailed description is the acknowledgement of what is understood as facts of life. The reified organisations of society abide by individuals as the necessary form of their own experience (Ibid). Furthermore, Feenberg states that it is only in modern societies that instrumental activity is free from the essential concerns which then conceive a complete technical system that '*embraces human beings as well as things in accordance with arbitrary plans*' (Ibid, p. 868). This delineates the opposition to technology suggested by critical technology as the critique of effects of technological progress, that various human aspects of reality are ignored. However, we cannot return to premodern stages and therefore must initiate '*unprecedented solutions*' (Ibid).

Feenberg refers to Herbert Marcuse who argued that inherent normative legitimacy is to be found in all human experiences, such as perceptions of healthy and sick, and tasteful and vulgar (Ibid, p.870). Marcuse also stated that these perceptions can surface as disagreements and might never be solved but this is not important in a democratic context. He witnessed how the environmental movement through public debates and voting gave an '*operative content to normative categories*' which lead the development of technologies to new possibilities. This notion would ultimately lead to politically expressed changes in the technological development and would no longer be motivated exclusively by power and profit (Ibid). Marcuse' take is unique as one of the classic critics of technology, since he does not ascribe regression to previous states but acknowledges the flexibility of technology and the potential reconfiguration it holds under different social circumstances (Ibid). The manner of rationale and its connection to meaning act as the bridge to the dimension of modern social studies of technology. Feenberg describes it as '*the key insight to the new field of technology studies*' which is the introduction of social actors in the design process of technologies and technological systems and hence restore human determination in the technical field (Ibid).

Feenberg then points to Weibe Bijker (2012) and the '*social construction of technology*' as a case of modern theoretical framework of technology studies. This kind of approach converts social demands into technical design norms and thus become responsible for social content in technical form. Furthermore, if such an approach can draw related conclusions to what Marcuse has presented then they can propose that technological design reflects society and '*embodies a new way of life*' without political and philosophical influence (Ibid, 871). As a supplement, Feenberg acknowledges the concepts presented by Marcuse through a dynamic scope that links the transformation of technology to a continuous process which is intensified as technology precedingly presents a number of issues to where answers must be found in the present (Ibid).

This development contains two sides, a negative and a positive. The negative side roots in the technical rationale which perceives technology in its unspoiled form of materials separated from its natural background. The unexpected side effects of such systems appear important as they develop and ultimately act as a reason for protest. When exposed to such negative feedback the system is modified to reflect a better realistic comprehension of the complexities at hand, thus creating raised attention towards the hybrid character of technology (Ibid). The other and positive side is established in the colonisation of users who pursue personal fulfilment by improving technology to better fit their needs. And through this unfold complex potentialities, unanticipated by the initial designers. The development now provides new forms of sociability along with creative opportunities for the general public where individual sudden developments of technology present feedback toward the original design and cause reflection of the usage and form of the technology in relation to complex human aspects (Ibid, p.872).

The effect of the dynamic interaction of technical disciplines and the public intervention is the causality of present day society and results in an improvement of the technology. Feenberg argues that modernity has unleashed technology by constructing conditions for independent rational systems to develop, thus making social rationality a constructive yet cryptic feature of modern society (Ibid).

Feenberg writes '*The ultimate test for technology is public acceptance since the public must deal not only with each particular technology in its ideal setting but all of them together in the chaotic world of daily life*' (Ibid, p.872).

How Feenberg presents technologies and how these affect societies today, functions as the overall framing of human-technology relations and their significance thus representing the extensive philosophical context in which this thesis operates.

Moreover, by applying Critical Theory of Technology I compliment my analysis and explore how the technology possibly connects the socio-political practice in which these individuals, as patients, are situated and the social relations that are present. This means that as the development of self-tracking technologies and the use of self-tracking expands, I can use critical theory of technology to analyse what the patients state about their future expectations in relation to the data they produce. In addition, I apply critical theory of technology to elucidate how the patients improve their illness perception through the use of the Fitbit device. And to illuminate how the increased use of patient-generated health data, which is part of the public debate regarding health 2.0, that shows the patients wants to be more involved in their own treatment, is something the patients find interesting and useful (Buccoliero et al., 2016).

6.3 Summary of Theories

Through this framework I can evaluate the way in which the technology in this study exerts its influence on the users and how this influence affects their perception of daily routines and their relationship to the technology. This will be seen through the performed interviews. It is a practical way of structuring the empirical material and provides a conceptualisation of the individual insights of each patient. Verbeek's post-phenomenology and mediation theory allow me to go in depths with the relational crossroads of the patients and the intentionalities of both the technology and the patients. Feenberg's critical theory supports the analysis by examining these relations and intentionalities on a socio-political level by discussing the findings and consequences on a more societal level. Likewise, action research lets me familiarize myself with the patients and reflect iteratively on the research process.

7. Literature Review

The following section consists of a literature review of the concept of patient-generated health data, to create an understanding of what this concept is. Next I describe what the community 'Quantified-Self' is, and what the main reasons are for people get involved in this practice. Then follows a section regarding self-tracking where I draw upon selected relevant articles that describe different modes of self-tracking

Lastly I will briefly touch upon the discussion of ethics within these subjects to gain insights on what dilemmas one should be aware about.

7.1 Patient-Generated Health Data

According to Deborah Lupton, we stand on the brink of a revolution where the patients themselves bring most of the information in terms of self-monitoring through healthcare apps and self-trackers (Lupton, 2013b). Lupton is supported in her statement by Gregory Abowd, who said at AMIA 2011 (American Medical Informatics Association) *"within five years, the majority of clinically relevant data (…) will be collected outside of clinical settings"*[7].

The office of the National Health Information Technology defines patient-generated health data (PGHD) as "*health-related data created, recorded or gathered by or from patients (or family members or caregivers) to help address a health concern*"[8].

Another definition stated by Shapiro (2011):

> "*PGHD are health-related data - including health history, symptoms, biometric data, treatment history, lifestyle choices and other information - created, recorded, gathered or inferred by or from patients or their designees (i.e., care partners or those who assist them) to help address a health concern. PGHD are distinct from data generated in clinical settings and through encounters with providers in two*

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[7] https://www.amia.org/amia2011/keynotes

[8] https://www.healthit.gov/policy-researchers-implementers/patient-generated-health-data

> *important ways. First, patients, not providers, are primarily responsible for capturing or recording these data. Second, patients direct the sharing or distribution of these data to health care providers and other stakeholders. In these ways PGHD complement provider-directed capture and flow of health-related data across the healthcare system. PGHD are not new phenomena; many patients record and share information on their health and wellness with care providers. However, the proliferation of Smartphones, remote monitoring devices, application development platforms (e.g., iPhone and iPad apps) and ubiquitous networks are enabling massive growth of PGHD. Increasingly, PGHD will be created, recorded, and shared electronically*" (Shapiro et al. 2011).

Shapiro et al. (2011) divide the concept into four types of data which are relevant to be acquainted with in relation to self-tracking as there are similarities in the terminology and how the concepts are addressed.

- The first type of PGHD is what he calls 'patient or proxy' measures such as vital signs recorded by the patient through a device, both digital and analogue, automatically or manually.
- The second type is 'self-reported' which can be logged by the patient or a family member and consists of lifestyle data such as diet, amount of calories consumed, how much water the patient drinks etc., and is typically logged manually.
- The third type is about 'perceived quality of life', and regards mood levels, sleep, social relations etc. and is also typically recorded manually.
- The fourth and last type of PGHD is 'data other than health-related' which allow the provider to identify the patient on a more personalized level.
  (Ibid).

The data can be structured or unstructured and come in various forms, thus also collected through a range of differentiating methods and digital tools which all have the potential to help the patients becoming more engaged in their own care ([9]; Shapiro et al 2011).

Hartzler et al. (2016) explains that there has been done much work in the digital measurement and gathering of patient-reported outcomes (PROs), but not enough effort and work has been put into how this data is visualised and presented in clinical settings (Hartzler et al., 2016). Furthermore, she states that communicating collected data through visualised patient-facing dashboards displays potential for shared decision making (Ibid).

Since it is the patients themselves who are the ones who now generate data on a much bigger scale than previously, new ways of including the patients in their own treatment follows. Through these ways of patient involvement healthcare providers are now provided with new possibilities of gathering information regarding the patient's condition, since it has been shown that PGHD can provide insights which might have been missed in verbal clinical visits (Zhu. Et al, 2016).

Furthermore, especially for patients who suffer from a chronic condition it appears to be an extra and heavy burden to bear to collect the data and the sharing of data can be viewed as extra troublesome (Ibid).

PGHD have been used in medical treatment for decades, and as a technology it is rapidly developing and becoming a deeper integrated part of self-care among patients. (Nunes et al, 2015; Shapiro et al, 2011)

As mentioned, the information generated by the patients can potentially lead to new medical insights regarding the patients' condition and thus has the potential of affecting medical practices in a positive manner. These insights might otherwise have been missed, if not for the patients gathering and passing this information on to the clinicians during clinical visits (Zhu et al. 2016).

However, as Pols describes, there is also the possibility that the knowledge and experiences produced by patients is viewed quite differently (Pols, 2013). She explains it where the knowledge is *'romanticised'* and thus making the knowledge irrelevant. Pols further argues that '*voicing the before unvoiced'* can create complications since they

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[9] http://www.mobihealthnews.com/content/patient-generated-health-data-can-be-used-improve-patients%E2%80%99-health-%E2%80%93-here%E2%80%99s-how,

belong to a group of individuals who comprehend '*true experiences*' and not factual knowledge and thus ultimately creating a division between medical science and the humanities (Ibid). Moreover, Pols claims that the voice of the patients may be hard to argue with since it represents feelings and emotions which can be hard for those who act as the listening actors to grasp, she writes "*The sufferers present true experiences, not contestable knowledge*" (Ibid).

7.1.1 Values & Benefits of Patient-Generated health Data

To understand the benefits of PGHD, I draw upon an article by Chung et. al (2015), where the research team wanted to understand how data collected through digital tools, such as a mobile application, have the potential to support clinical care. Through their study they ended up with five major goals of clinically supported benefits of reviewing the tracked data of patients who suffer from irritable bowel syndrome (Chung et al. 2015).

- *Supporting diagnosis*
- *Personalizing treatment*
- *Increasing motivation and accountability*
- *Learning about patients*
- *Facilitating discussion and managing visits*

(Ibid)

Supporting diagnosis is when healthcare professionals within multidisciplinary teams rely on patient-generated data gathered over time to regulate and alter patient treatment in order to optimize treatment outcome within chronic disease management. It is also when the medical staff uses this data to determine when to involve other disciplines (Ibid).
By reviewing self-tracked data clinicians are equipped with better opportunities to *personalize treatment* and through learning about patients' preferences and routines they can better shape individual needs (Ibid).
Increasing motivation and accountability by directing patients to take up self-tracking work for a great number of patients. However, there are still some who struggle with motivation. Here Chung et al. states that reviewing the data with the patients seem to be rewarding

and can lead to better engagement both to the tracking aspect but also "*with the overall treatment plan*" (Ibid). They further explain that this is especially true when the patients cannot make sense of the data themselves and need guidance to do so, and the process of tracking symptoms but not feeling that it betters their situation is another obstacle which can be discouraging (Ibid).

Learning about patients through patient-collected data proves to be beneficial for clinicians as they *'get an idea of what's going on in their life'* which can help them to understand unspoken patient values. By understanding these values the healthcare providers can develop better social relations with the patients thus keeping them more motivated and involved in their treatment (Ibid).

By having access to patient-generated data prior to patient visits, clinicians can better '*manage visits*' as they can plan the agenda around the data or it can '*facilitate discussion*' when the patients find it hard to explain how they feel (Ibid). Furthermore, the clinicians can use the data to create notes in the patients' medical journals as it provides the patients with an idea that their work help the clinicians to better keep an overview of their condition (Ibid).

7.2 The Quantified Self

The Quantified Self is a community consisting of a growing group of individuals who all share the same passion for self-tracking. When you visit their website it states "*the Quantified self – self-knowledge through numbers"*, this tells us that it is not only the passion for tracking oneself but it is the seeking of knowledge about oneself through the process. The data the self-named Q-selfers seek can consist of various measurements such as what food you ingest, how many calories the food consists of, what mood you are in, sleep habits, arousement levels, blood pressure, exercise habits, how many times a day you sneeze - the list is only limited by your imagination. The data are often concrete and precise numbers, like the time and distance of a run or pulse but other measurements are much harder to quantify, how often you feel sad or depressed or how fresh you feel in the morning. The measurements can of course be translated into numbers but they are still the assessment of an individual and therefore will not be a concrete read of the body which makes it harder for comparison with other self-trackers[10].

However, it is important to note that comparison of data is not the purpose of the Quantified Self, they meet up and discuss methods of gathering, tracking or collecting the data, not the results. A variety of methods exist, from manual journaling with pen and paper or using a huge variety of self-tracking technologies, like smartphones applications or tracking devices, such as Fitbit or Garmin. (Zhu. Et al, 2016).

The reasons for self-tacking can vary almost as much as the methods, they can be born of pure curiosity, health related issues or self-improvement goals in sports or at work (Ibid).

The community was founded in 2007 by Gary Wolf and Kevin Kelly, and the goal from the start has been to explore what self-tracking tools are good for and to create an environment where all questions could be asked and explored on a human level, as explained above[11].

In an article in 2012 from the Economist it is mentioned that the Quantified Self started out as a blog which then lead to regular meetups and today the community is connected through Quantified Self Labs in more than 50 different countries where they organize conferences, produce guides to self-tracking, exchange experiences, share ideas and help each other to reach all their individual goals. But it is not only the individual aspects of self-tracking that are being discussed; the more societal, sociological, social and research related subjects are also part of the agenda (The Economist, 2012).

In an article in The Times in 2010, Gary Wolf describes four of the main reasons that self-tracking has had its breakthrough in the late 2000s.

The first reason is the technological development of trackers; they are now much smaller and much easier to wear when going about your everyday.

The second being that ever since smartphones became prevalent, it made it much easier for individuals who did not own a specific tracker device to start tracking, also the usage of smartphone applications made it more intuitive for the user.

The third reason is the increased popularity and usage of social media to share who you are, and the more people want to share the harder they search for something to share.

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[10] https://qsinstitute.com/about/what-is-quantified-self/

[11] https://qsinstitute.com/about/what-is-quantified-self/

The fourth and last reason described by Gary Wolf is the concept of ‘cloud computing’, which is a technology that makes it possible to automatically store data *“in the cloud”*. Practically, this ensures quick and easy storage of data with less work for the user and more time to explore the data. But common to all four reasons, as briefly described, is the fast technological development which is premise to the expansion of certain practices (Wolf, 2010).

7.3 Self-Tracking

This growing number of health-related apps and the fast-growing market of self-trackers that can monitor various activities such as sleep, activity and heart rate to name a few, is beginning to be an integrated part of both self-care and clinical treatment (Lupton, D. 2013b).

But it is important to identify the reasons for self-tracking and what these reasons entail for the users. This becomes relevant in this report as the following section will explain five different modes of self-tracking and what these modes mean for the user and the initiator. I draw on the article “Self-tracking as communication” by Lomborg & Frandsen, they propose to conceptualise self-tracking as a communicative phenomenon along with three dimensions (Lomborg & Frandsen, 2016). This will be supplemented by five modes of self-tracking in the article “Self-Tracking Todes. Reflexive Self-Monitoring and Data Practices” by Deborah Lupton (2014).

Understanding self-tracking as a communicative phenomenon correlates to understanding what self-tracking and the involved technology mediates for the users, which can influence the empirical data collected from the users. Lomborg & Frandsen emphasis that the visualisation aspects of self-tracking becomes a core dimension since the accumulated inputs from the users is turned into feedback. This feedback acts a mirror of the data since it reflects the way the users tend to perceive themselves through the collected data (Ibid). They introduce the concept of the ‘*data double’* by Ruckenstein (2014), which describes the *auto-communicative* relationship between the visualisation of tracking activities and the self-trackers. The data double indicates *“the conversion of* *human bodies and minds into data flows that can be figuratively reassembled for the purposes of personal reflection and interaction"* (Ruckenstein, M. 2014, p.68). So the data double converts the detailed measurements into clear and understandable information for the user who can then interact and react to in order to comprehend themselves better. Yet in order for the user to associate self-tracking with the self it seems that the type of data visualization is important. Lomborg & Frandsen here point out two reasons for why. The first is how visualization provides the self-trackers with tools of reflections and understanding of their bodily habits, the second reason being that the rhetorical manner of visualisation links tracking with science and thus seriousness and passion regarding oneself (Lomborg & Frandsen, 2016).

I now move on to describe how different mode of self-tracking according to Deborah Lupton can influence the self-tracker and what these modes are.

7.4 Modes of Self-Tracking

As described above, there can be various reasons as to why individuals take up self-tracking or self-monitoring; however, I also find it is important as well to explain the differences of how the self-tracking is initiated. In order to do this, I will draw upon the article "Self-Tracking Modes: Reflexive Self-Monitoring and Data Practices" by Deborah Lupton (2014). Lupton develops a typology of five modes of self-tracking (See below). And even though they overlap, they are also noticeable different e.g., if the self-tracking is voluntarily initiated or forced and what the purpose of the process might be (Lupton, 2014).

- *Private self-tracking*
- *Pushed self-tracking*
- *Communal self-tracking*
- *Imposed self-tracking*
- *Exploited self-tracking*

(Lupton, 2014)

The first mode is *Private self-tracking*, where the purpose is to create more self-awareness and improve the life of the users through the data and knowledge they obtain. It is undertaken solely for personal reasons and the data is kept secluded and only shared with a few chosen others. This is the main reason for, as mentioned earlier, the members of the Quantified Self movement, and can be viewed *"as a selfish activity which is a result of a personal motivation"* (Ibid). They talk about what they have tracked as individuals, and chose among themselves what data to collect and how to interpret it. Furthermore, as this represents individuality it may not be as relevant for others; however, inspiration might be found (Ibid).

The second mode is *Pushed self-tracking* which differentiates itself from private self-tracking as the initial motivation for committing to self-tracking comes from an external actor. Pushed self-tracking is often *"patient self-care, health promotion and preventive literature medicine"* (Ibid). The purpose is to achieve behavioural change within target groups in order attain better health or to increase knowledge in various areas. The data is generated from self-tracking processes which can encourage patients with chronic illnesses to reduce their medical consultations with clinicians or other people involved their treatment (Ibid). Lupton describes how the workplace is becoming a significant place of pushed self-tracking as "*financial incentives and 'team spirit' and productivity may be offered for participating"*, and they turn to digital tools to help them in the process (Ibid). Another important point Lupton makes is that wearable technology producers, such as Fitbit or Garmin, are facilitating and make *'deals'* with employers to retail their tracker devices and the data analytics software as part of certain wellness programs. The employers and insurance companies then use these wellness programs to promote health among their employees in order for them to lower costs (Ibid). Another tendency is that insurance companies are starting to incorporate self-tracking data in their way of calculating risks and subsequent premiums that they offer to customers (Ibid). This raises a lot of questions towards the ethical aspects of how data is being used, and who owns what of the self-tracked data.

The third mode is *Communal self-tracking*, which sort of question the very nature of the words self-tracking, because it focuses on the fact that a lot of self-trackers view themselves as part of communities. The self-trackers use social media platforms and other platforms which are specifically designed for relating and sharing individual data sets (Ibid). Here the Quantified Self is mentioned again as one of the main online communities that facilitates both offline and online meetups. They organize seminars and encourage self-trackers to share and talk about how they collect their data in order to be inspired by each other. For the communal self-trackers, it is not only the gathering of information regarding their own life, body, habits and so on, but by sharing they get a sense of contributing with new knowledge (Ibid). What is interesting here is how users actively contribute with minor data sets into major ones, small data become big data suddenly for the data to become more meaningful. Lupton explains how some of the Q-selfers start to refer to themselves as the Quantified Us but still with focus on the individual's process (Ibid). Next Lupton introduces another aspect of how the communal self-trackers are being used in other discourses "*on citizen science, environmental activism, healthy cities and community development*" (Ibid). These concepts make use of the data collected by individuals, such as air pollution, transportation levels and so on in order to promote health in the conceptions of 'smart cities' or 'healthy cities' to encourage healthy ways of living (Ibid).

The fourth mode, *Imposed self-tracking* is when self-tracking is initiated by another agent than the self-trackers themselves, primarily for the benefit of the external agent. Lupton uses the example of how an increasing number of workplaces are imposing self-tracking for their employees for them to analyse habits and work practices to increase work efficiency. Furthermore, she mentions that some companies force their employees to wear badges with sensors that monitor movement, sound and geo-location (Ibid). Another example is the use of imposed self-tracking in educational systems, where students are required to wear devices that monitor heart rate in order for the teachers to know if the students are fully participating in certain exercises, and she emphasises that students rarely have a choice in these types of situations (Ibid). The last example she draws upon is in law enforcement and family law. Here the situation can be related to a monitoring the location of certain individuals or the use of urine or blood samples to monitor drug use. The use of digital tagging to ensure that criminal offenders do not leave their residence is also an example of how imposed self-tracking is being used (Ibid).

The fifth and last mode is named *Exploited self-tracking* and relates to some of the previously mentioned modes, as here the data collected by self-trackers either for personal, pushed or imposed reasons the data is picked up and repurposed mostly for commercial benefit of others (Ibid). Lupton explains that the perception of personal data as a product is often seen in commercial groups, this provides the companies with opportunities of using the data as valuable information regarding user habits and behaviour. There are tendencies within these companies where they develop mobile applications to monitor the users, through the products they have bought. "*For example market research companies use self-tracking apps issued to their research subjects to gauge their habits and responses to brands"* (Ibid). Furthermore, these types of companies mask the monitoring of users, as if the questions are meant to be beneficial for the individual's usage but they sell the information about the data to other companies. This data can be extremely valuable for companies as customers purchasing habits can provide them with insights of how to target the users more with offers and advertisement (Ibid).

7.4.1 How the Modes of Self-Tracking Overlap

As Lupton argues there are several places where the five modes of self-tracking overlap. The private mode can be combined with the communal mode creating a focus where the goal is to encourage people to improve within communities or similar mutual goals by self-tracking data. The mode of reflexive self-tracking is still a part of this, if it involves sharing data with others, however a number of communities include manners of '*participatory democracy, citizenship and community*' (Lupton, 2014). Lupton makes the example of online platforms where the intersection becomes more apparent. The purpose of such online platforms is to facilitate communication between patients and create a forum where they can swap experiences and help each other (Ibid).

The mode of exploited self-tracking surfaces when the data generated on the platforms are used by third-parties, which can be both medical or pharmaceutical research companies. However, as Lupton points out, sometimes the involvement of third-parties might benefit the patients; e.g. research that might result in new ways of treatment or therapies. But other cases show that the only ones who gain something from third-parties using the data, are the third-parties themselves (Lupton, 2014c).

Lastly Lupton states that pushed and imposed self-tracking are very close to each other as '*some elements of self-interest may still operate and a discourse of 'choice' may be employed, people have little option of opting out*' (Lupton, 2014). The reference to the wellness programs of some companies, where some employees are giving the option of wearing a device, thus permitting the employers to examine their data the self-tracking is imposed. The employees are presented with an illusion of freedom of choice, if they do not comply, the consequence can be an increase in their insurance premiums, which is why it becomes imposed (Ibid).

7.5 Ethics: A Critical Perspective.

Throughout the various articles presented in this section, several critical perspectives are presented on self-tracking and the usage of PGHD in clinical settings. To end this chapter I elaborate on some of these as the ethical and critical evaluations are important to discuss.

7.5.1 Privacy

Privacy is one of the main topics in the discussion regarding self-tracking and the question of who owns the data, as I briefly touched upon. Chung (2016) explains that even though patients start to track their health and symptoms it is not in every case that they are interested in sharing this data, not only with next of kin, other patients but also not even healthcare providers (Chung, 2016). However, she argues that it relates to the importance of how the self-tracking is initiated, but even if the process is '*provider-initiated*' some patients will still not gladly share their data, as they do not wish to be judged or they alter their behaviour thus making the data less credible (Ibid). Ruckenstein (2014) explains that the participants in her study also gave examples of how privacy issues played a part in the dialogue. But the participants did not associate the supervision of data with a threat to their privacy but it was at the same time something they realized could become an issue (Ruckenstein, 2014). Lomborg and Frandsen also point out that users of self-tracking technologies often have little or no knowledge of who benefit from the data. Thus, the users are subjected to very little transparency of these issues, which can result in distrust (Lomborg & Frandsen, 2014).

7.5.2 Data Selection & Relevance

Zhu et al. (2016) point out that some of the interviewed clinicians expressed that they were worried that some of the data the patients would track and present would be irrelevant and thus take up more time than it would help, and how to communicate this to the patients could turn out to be another issue which would require their time (Zhu et al. 2016). This could ultimately result in disharmony between the patient and the clinician as the healthcare needs could be subject to discussion due to different opinions of what is

important. Furthermore, clinicians together with a few patients stated that they were worried that clinicians would be '*overwhelmed by raw PGH*' and that the clinicians would not know how to react to all the data they would receive (Ibid).
Moreover, patients can be affected by the data they collect. It can create an awareness that the patients did not have before, which can be a both positive and negative influence. "*Even motivated patients can be hindered by awareness of the disease, the scattered nature of self-tracking tools, and data collection burden, making PGD hard to collect, and thus share*" (Zhu et al, 2016).

I end this section with an argument stated by Lomborg and Frandsen, whom claim that there is a risk that some of the individuals who track themselves are subjected to "*... an objectivation of human subjects as entities that are defined by, augmented by and may be controlled through their numbers*" (Lomborg and Frandsen, 2016). Which means that self-tracking comes with the risk that the self-tracker might feel compelled to let the data take control over their lives, and in the case of patients blindingly trusting a technology can potentially have severe consequences if the presented data turns out to be wrong due to a technical malfunction.

This literature review provides the reader with insights into what patient-generated health data are and what some of the values of PGHD are. These values can be of importance both for the patient, but also for the future use of PGHD in clinical settings. Furthermore, it provides us with a basic understanding of the history of self-tracking, at least from a Quantified-Self perspective is. The different modes of self-tracking provide me with understanding of what significance and implications that might hold for a patient when agreeing to participate in this study. Also, it provides me with background knowledge for reflection of what consequences the different modes can have for both the participating patient but also for the data they produce, which I will elaborate further on in the discussion section of this thesis. The aspect of comprehending self-tracking as a communication phenomenon relates to Verbeek's mediation theory, which will be described in this analysis, as the patients react towards the feedback the Fitbit gives to them.

7.6 Summary

By elaborating on the concept of patient-generate health data I present a manner to comprehend both what the concept is but also how the gathering of these data can occur. In addition, I also provide a basis of understanding of what values patient-generated health data can deliver, the importance of ‘voicing the unvoiced’ and that patients who suffer from a chronic condition, such as ICD patients, do carry an extra and heavy burden (Zhu. Et al, 2016). This states the relevance of patient-generated health data in clinical contexts. By presenting self-tracking as a tool of communication I allow for the reader to understand what the purpose of self-tracking is and what aspects of self-tracking are important for this study. The modes of self-tracking provide insights into what a provider needs to consider and how this can affect the process for both parties involved. Furthermore, the modes of self-tracking acts as the basis of questioning the future of self-tracking in healthcare and what it might implicate for future patients. Lastly, the two dilemmas of privacy and data selection are a few of many of ethical controversies that correlate with the themes of this thesis as the patients are exposed to both throughout the process.

8. Empirical Material

In the following section I demonstrate my empirical material by presenting the patients and a short analysis with the mediation framework presented by Peter Paul Verbeek of the ICD. I perform this short analysis to emphasise that the patients in this project do indeed have prior experiences with technology and more importantly one of the most intense relationships that patients can have with technology: The relation of the cyborg as stated by Peter Paul Verbeek.
This chapter is concluded with a brief review of how I will structure my analysis in the following chapter.

Patient #1: 52-year-old woman. She has had an ICD for nine years and has been part of the SCAUT project since June 2017. She has agreed to participate as she feels very lucky because she has could get all the help she has needed regarding her condition. Moreover, she wants to be able to pay something back and help future chronic cardiac patients. She does not have any prior experience with self-tracking devices other than her ICD.

Patient #2: 45-year-old man. He has had an ICD for four years, but due to complications and malfunctioning issues he is on his fourth ICD. He has been part of the SCAUT project since May 2017. He has agreed to participate since he is curious about his condition and would like to gain more insights in his sleep habits. He knows what an activity tracker is but has no practical experience using one.

Patient #3: 59-year-old man. He has had an ICD for 16 years and has been part of the SCAUT project since May 2017. He would like to participate in the project as he, like patient #1, would like to ‘give something’ back. He has prior experiences with self-tracking, as he has been tracking himself for 7-8 years to improve his general health.

8.1 The Cyborg

The cyborg relation is the fifth technology relation which has been discussed in section 6.1.2 and is precisely the relation which can be used to analyse the nature of the patients in this project before we dive into the relation they have to the Fitbit device.

Instead of the Fitbit where the data is mediated and thus needs to be read and interpreted, the intentionality of the ICD is situated beyond the patient (Verbeek, 2011:144). The relation can be understood as such:

(Patient/ICD) -> World

The idea of the embodiment is no longer existing, as the intentionality of the patient does not matter for the ICD to exercise its own intentionality. If the heart of the patient stops, the device will act as it is programmed and shock the heart, thus making it beat again. As Verbeek states "*But in embodiment relations a distinction can still be made between the human and the technological element in the mediated experience, while in cyborg relations this is no longer possible*" (Ibid:145).

8.3 Data Processing

Based on the knowledge basis gathered through the ethnographic fieldwork and literature review I gained insights into how self-tracking technology mediates knowledge and experiences, and speculated how this fits into the socio-technical practice of the patients.

I will divide the analysis into two main parts, the first focusing on the significance of the initiation process, where I will draw upon Feenberg and the concept of social rationality. The second part of the analysis will focus on the concept of mediation by Peter Paul Verbeek, and I will explain what the Fitbit technology mediates for the participating patients. This part will be divided into three subparts and will result in correlations and controversies.

- The first part will focus on what preconceptions and experiences the patients had to self-tracking in general and what expectations they voiced.

- The second part will be based on what immediate experiences the patients got throughout the first two weeks of the project.
- The third, and last part is similar to the second with focus on experiences and what thoughts the patients have regarding the future usage of self-tracking devices related to their illness.

9. Analysis

9.1 Initiation

Based on the five modes of self-tracking and the term ‘data double’ by Lupton (2014), which is presented in the literature review, I can elaborate on which modes the patients involved in this project are situated and what this implies in the socio-political space of self-tracking data in healthcare. Furthermore, the ‘data double’ can serve as the connection to the patients’ perception of data.

9.1.1 The importance of Initiation of Self-Tracking

The patients are subjected to the second of the five modes of self-tracking presented in the literature review by Lupton (2014), *pushed self-tracking*. This mode aligns with the designed intentionalities of the Fitbit as the purpose is to achieve behavioural changes with the users, in this case the patients. Furthermore, this mode of self-tracking is already a notion the patients are familiar with from both their use of the SCAUT platform but also their ICD. And as patient 3 has stated, he has self-tracked for years. Through both these technologies the patients generate and help to remote monitor their condition to promote their treatment or care. As one patient states about his perception of the SCAUT platform:

> Pt.2: *“I think it’s positive. I think that it is very positive that I can receive messages through it. And I also think that it is very good that I am told through the app when my home monitor box has sent. There happened to be a day where it had sent something, and then I was told. That was nice.”*
> I: *“Do you find it interesting in relation to your condition?”*
> Pt.2: *“Yes very much so”.*
> (Pt.2:1)

For the Fitbit, the purpose is not only to facilitate changes in the daily life and routines of the patients but also to increase their health literacy, which affects their illness perception. And through the increased knowledge gain regarding illness perception or body awareness, they develop certain coping strategies to possibly better lead the life they want to. The Fitbit and the process of self-tracking becomes a tool for the patient to master their disease as the analysis will show.

9.1.2 The 'Data Double' & Social Rationality

The patients generate data, their 'virtual you' or 'data double' as mentioned by Lupton (2014), which becomes a black box mediated by the technology. This perception of the patients' selves is processed by a third-party, that changes the contextual significance of the data as the data can be manipulated to serve different purposes. The 'virtual you' is shaped by the patients' reflections and what toolset the technology brings to feed into the process, but as a third-party takes power of the patients' 'virtual you' they are in danger of becoming an oppressed group within this socio-technical configuration. By applying Feenberg's aspect of social rationality, I show the patients' way of perceiving their world with and how the technological boundaries entangled in this practice (Feenberg, 2011). Following the position of Feenberg, the Fitbit creates a perceptual framework of self-reflection where the patients can act on the features of the technology in their daily life in order to perceive their condition differently and to achieve different purposes. This notion is inherent to their social rationality regarding the influence of the technology, as they describe that they do change aspects of the way they live or reflect over their life. But the fact that a third-party is 'watching' them does not play a significant role until one of the patient realises during an interview that he is indeed being 'watched', which is interesting as he had been informed during the on-boarding meeting.

I: "*How do you feel that I am able to see all your data?*"
Pt.2: *"I'm a bit shocked, but okay…"*
I: "*Shocked how?"*

Pt.2: *"Well I didn't realize that, but I know that when I'm wearing this and I have agreed to it, then it's fair enough".*
(Pt.2:2)

If we are to follow Feenbeg's notion, the boundaries for grasping and understanding the phenomenon of the Fitbit are constructed through the rationale demonstrated by the patients. This relates back to his element in social rationality '*reification*', which essentially helps shape the relations and objects it conceptualizes (Feenberg, 2011:866). But in order for this concept to help me understand the way the patients practice self-tracking I need to recognize that the patients' attitude towards the socio-technical relations and reflections are influenced by the technology itself. And as Feenberg states, it is important not to surrender to '*reduction to function'*, which does not mean that the new conceptualized features of the technology can be directly transferred to a new way of life for the patients, as it will create new boundaries from which the implicated relations will influence (Ibid). This means, that even though the patients experience behavioural changes in their daily lives in terms of increased activity and focus it does not necessarily means that these changes will be made permanent, despite that being what they hope for.
As patient #1 explains, that she does not believe that she is active enough throughout her every day and hopes that the Fitbit can help her:

Pt.1: *"Yes I think that it could help and remind me that I should do something, and we have a rowing machine in the basement so there is no excuse (…) I do move and such but I don't necessarily break a sweat".*
(Pt.1:1)

The hope was that through the time the patients wore the Fitbits, I could understand the underlying aspects of the human-technology relations, as Feenberg states that the common-sense rationale is corrupted by its own nature (Feenberg, 2011:866). Understood as such, the fact that the patients' daily lives are affected by this technology, the technology then comes to shape their attitudes toward the understanding of what values are significant of those who designed the Fitbit. The patients are then manipulated by these values and act on them as they inform us. One patient even states that after an accident where she hurt her knee, she still tries to reach the 10.000 steps a day stated by the Fitbit. This is an example of the aforementioned manipulation.

I: *"Do you have anything new and exciting to tell?"*
Pt.1: *"Sunday the 11th of February I was out skiing and twisted my knee. So that's the reason why I haven't been that physical active. I have tried to maintain to reach the 10.000 steps a day, but I have been wearing this big brace and got home by ambulance and all that".*
(Pt.1:3)

The presence of the Fitbit entwined in the daily life of the patients comes to shape their subjective assessment of what is normative behaviour in this regard when the Fitbit comes to represent a contextual feedback on the lack of activity and insights in sleep and heartrate. More so, it could be argued that the technological mediation, even as it not a physical coercion that forces the patients to act and move when the Fitbit suggests that they should, will be a derivative effect that guides them to mediate new intentionalities into the technology. By accepting this notion, I follow Feenberg's statement that these mediations are derived from the unexpected complexities of the world that it reveals itself through (Feenberg, 2011:872).

I now proceed to elaborate on the abovementioned intentionalities and mediations by unpacking the patients' experiences and insights through the dimensions of Verbeek's mediation theory.

9.2 Three Sessions of Meetings & Interviews.

What the technology mediates is situated knowledge, meaning that the specific technology gives access to a certain type of information. Because of the Fitbit, the individual practice reactions through the feedback the patient receives via the device. These mediated experiences of practice are what I will analyse in the following section based on the interviews I have conducted.

9.2.1 Session 1: On-boarding & Introduction

The first of the three sessions of interviews revolved around on-boarding and introduction. It created a foundation for the participating patients, as they could state their expectations, previous experiences and questions regarding the process.

9.2.1.1 Reason for Participation – A Personal Gain

As Verbeek states

"*Human intentionality is mediated by technological devices*" (Peter Paul Verbeek, 2011:56).

However, this intentionality can also intertwine between the technology and humans. In this case, intentionality appears as the patients express their expectations for participating in the project, and their personal gain. Even though the patients state they participate to *give something in return*, the individual objective functions as main motivation. One states:

"*I look forward to be technologized*".
(Pt.1:1)

This is based on her expectations to the functionalities of the Fitbit. The patient intends to receive a physical outcome based on the Fitbit. The intentionality becomes what Verbeek calls '*composite intentionality*', which is a hybrid form of the two intentionalities, they merge as the intentionality of the technology interferes with the intentionality of the patients (Verbeek, 2011:144-145). The technology is directed at the patients, with its nudging features and rewarding responses, but this is at the same time a shared intentionality with the patients as we see in the quotation above. They are aware of the technological functions and features of the Fitbit and they expect this to affect them in a positive manner. Another patient specifies that the intentionality of the technology can potentially act as a supporting tool.

Pt.3: "*In general, I like to participate in these kinds of things, if I in some way could improve a few things for myself or others. That is the primary reason".*
I: "What do you expect regarding yourself?"
Pt.3: "At the moment I am in the midst of this clarification, I would like to be able to breathe and run like I used to. I used to run for the B national team and used to be talented. But one gets older, that's for sure, I will be 60 this year but physically I would like to be able to run the entire time and not needing to walk. So that is what I would like to gain from training in general".
(Pt.3:1)

Verbeek's *composite relation* differs from Ihde's *hermeneutic relation* in that it compels us to augment the initial understanding of Ihde and intentionality becomes double. The first intentionality is of the Fitbit which is directed at the Fitbit's world and the intentionality of the patients, which is directed at the result of intentionality of the Fitbit (Ibid:146).

Composite relation: patient ->(Fitbit->world)
(Ibid).

9.2.1.2 Influence Through Persuasion & Interference

The patients' awareness of 'someone' reviewing their data is what incites them to change their behaviour (Verbeek, 2015:29).

The Fitbit is an embedded contextual feature of the patients' daily life and they interpret the feedback in a certain way, that attempts to persuade the patients to perform certain actions. The mere presence of the Fitbit entwined in the life of the patients co-shapes their subjective understanding of what normative behaviour is in this respect, since the Fitbit represents contextual feedback. It can also be argued that the technological mediation, even though it is not physical coercion that forces the patients to act, it is a derivative effect which leads them to abide by the intentionality of the technology; the intentionality of behavioural change.

On this note I refer to the second dimension of mediation, *points of contact*, where Verbeek is joined by Dorrestjin and Van der Voort and their four zones. The patients are situated in the first zone *before the eye*, as the Fitbit influences their choice in life through persuasion and interference (Dorrestijn et al. 2014:287).

> "*Sometimes when this one beeps I get up, walk down the stairs, through the yard and back up again. Simply just to get some exercise. Otherwise I just sit here all day…".*
> *(Pt.3:1)*

The dimension of *point of contact*, not only relates to the patients being asked to state their expectations and what they hoped to gain from participating in the project. As one patient stated:

> "*But more when you are wearing an activity tracker that you subconsciously move more…".*
> *(Pt.1:1)*

The dimension also relates to the patient's expectations to increase her level of activity, where the interference of the Fitbit becomes an expected intervention. The Fitbit mediates action, as the patient react to the nudging reminders to move, thus receiving the satisfactory “Nice” or “Well Done” response from the device. Which will be elaborated further during the analysis of the second and third session of interviews.

9.2.2 Session: Novice User Impressions

The second session had the purpose of gathering the immediate insights the patients had based on the relatively short period they had worn the Fitbit. The interview also had the purpose of answering any questions the patients might have encountered.

9.2.2.1 The Fitbit Mediates Feelings: Positive & Negative

A consequence of the composite intentionality of the technology is that the patients experience different feelings when they examine the data the tracker presents. One patient feels guilty when he cannot comply with one of the designed intentions of the Fitbit, which is to influence the users to become more active. Both because he cannot reach the number of steps the Fitbit signals the users should reach to receive the digital 'fireworks' the tracker rewards its user with. But also, when he reviews his data from longer periods.

I: "*How has it been to wear the Fitbit?"*
Pt.2: *"It has been okay. It gives me a feeling of guilt, that I don't exercise as much. Otherwise then…"*
I: *"Is that because of the reminders?"*
Pt.2 "*Yes, among other things, but also when I review the data and see how inactive I really am but I have had a long period where I've been really tired and have felt a bit off. And related to my condition, then I never really know when I am sick because of my reduced immune system".*
(Pt.2:2)

Here we see a combination again between the *hermeneutic relation* between the *composite intentionality* of the patient and the technology of the Fitbit. The patient reads and interprets the data he the device presents but simultaneously he reacts with negative emotions towards the data. The patient connects the data to this condition but does not gain anything from this connection as his condition affects him in ways which confuses him more than it clarifies anything.

But not being able to reach the goals stated by the Fitbit does not only demonstrate feelings of confusion or guilt. As a patient states, she feels inspired to reach the goals and therefore the technology mediates the feeling of competition. And in this example the mediation results in direct behavioural influence through digital persuasion.

Pt. 1*: "(…) but I've had a few difficulties reaching my goals"*
I: *"When you say goals, are the goals determined by the Fitbit?"*
Pt. 1: "*Yes, it is, to try to see if I can reach the number of steps it says to be active, 5 days in a row. So, there is this competition between me and the app".*
(Pt. 1:2)

Pt.1: *"(…) it is that inner competition, I would like that little "shock" right? When I reach those 10.000 steps, and that is a cool feeling, and that's why I think that I might as well go for a walk. And I have probably done that more than I used to, so it has helped me to get-going a little".*
(Pt.1:2)

Patient #3 also explains how he embraces the reminder functionality of the tracker as he due to his job sits down most of the day.

Pt.3: "*(…) Then it is something about me sitting down all day not being active at all, and instead of calling or emailing my co-workers I go and talk to them. And then you get a reminder too "it is time to move chubby boy" and then I go for a walk. It it's really cold, then I go down to the big conference room and walk around the table. Simply just to reach my number of steps".*
(Pt.3:2)

This illustrates how far patient#3 takes the nudging of the Fitbit, but only in the sense that he knows that it is good for him, and not that the technology controls him. Which I will elaborate on further in this chapter.

9.2.2.2 Do I feel What I feel – The Fitbit as a Supporting Tool

Patient #3 further explains how he uses the Fitbit to determine whether he indeed feels what he feels. Furthermore, the tracker has acted as support in terms of him contacting the clinicians because he felt bad one day he was out running. Again, the intentionality of the device merges with the intentionality of the patient thus resulting in the composite intentionality combined with the hermeneutic relation, as the Fitbit mediates a reaction which influences the patient to take action and contacting the clinicians.

> Pt.3: "*I have contacted the clinicians because of my tracker, this was before I had the home monitoring box. I was out running and then I felt bad, and then I called them the day after. My heartrate is visible on my tracker and if I sense something in the forest, I have a look at it and if there is a connection then I relax to lower the heartrate (…) So it is a way for me to say "do I feel bad, well is it true?"*".
>
> (Pt.3:2)

As this quotation shows there is a certain state of morality imbedded in the technology, as it causes the patient to make a moral decision if he is going to contact the clinicians, it changes the way he sees the world. The mediated knowledge from the Fitbit is a direct cause of action towards the world around the patient.

Patient #2, as patient #3, also uses the data mediated from the tracker to determine whether what he experiences matches the reality around him. As one of his expectations was to gain knowledge about his sleep habits and patterns, he seeks assurance regarding how he sleeps. He has been using a sedative in order to ensure that he gets the sleep he needs, which he would like to not be necessary. However, despite using medication he still does not feel he is fully rested when he wakes up, and he hopes the insights from the Fitbit will provide him with clarification. But correspondingly, if he sleeps well and feels fully rested, the tracker can assure him that he indeed has slept well.

> Pt.2: *"Well I can feel when I wake up if I slept well, and then I can subsequently see that it is true. And if I have nights where I don't sleep well, then I can also see that, that is true. I like that. Sometimes you can think "Wow, I barely slept", and then you can look at*

the data and see that you almost slept an hour, even though you don't feel like you slept at all. So it is nice to see how it works".

(Pt.2:2)

The Fitbit ensures him that his perception of sleep is not a part of his imagination which ultimately provides him with a feeling of safety and self-efficacy; that he can sleep well without the help of medication. The moral assessment of the Fitbit reveals that even though the intended mediation of the sleep analysis feature is to ensure that the user get the desired amount of sleep, it now serves the function of assuring the patient that what he feels is truly real. The feedback from the tracker becomes even more a tool for him to experience himself in his own world. As Verbeek states "*The various moral issues do not need to be used as given criteria to assess technologies, but rather are the dimensions in which technologies play out their moral roles – mediating freedom, democracy, responsibility and the like, rather than possible threatening them"* (Verbeek, 2011:118).

9.2.2.3 Future Expectations

Patient #1 does also use the sleep feature of the Fitbit, but has another approach since the device has confirmed her thoughts; that she does not get enough sleep. By making sense of the presented data she realizes that she would like for the device to help her reaching her own goal. She wants the Fitbit to become an assistant which can tell her when to go to bed, but at the same time interprets the feedback it has provided her and connects different reasons as to why she does not:

Pt.1: "*That the sleep feature can tell you if you have slept enough or "remember to sleep more hours"*

I: "But do you think that it also should be a goal for you?"

Pt.1: "*Well then it should be something like a healthier lifestyle and get the habit of going to bed earlier".*

(Pt.1:2)

> Pt.1: *"Well I do think that I should get more rest, so I don't keep watching that movie that is so cozy to watch. But it's also a mental thing which I believe I need more of. But then I should think like that I need my rest more. To allocate the resources better".*
> (Pt.1:2)

As patient #1 states, she relies on the persuading feature of the Fitbit to make her to go bed, thus getting a healthier lifestyle, and in that sense the technology mediates action. The technology becomes an interactive context for Pt.1, as she would like for the Fitbit to be 'something' that just tells her to go to bed without her having to make the decision herself. It is a combined relation of the hermeneutic relation, since she must read and understand what the Fitbit tells her, as it mediates the action of her going to bed, which she states that she could gain from. The reason why it becomes an interactive context is, as Verbeek (2015) states that it interacts with the patient based on behavioural feedback data from the technology: the sleep analysis stages.

The notion of the technology exercising power over its users, by telling them that they should go to bed can be interpreted as just that: control. However, all the patients express their attitude towards the notion of being controlled by a technology. As Pt.3 states:

> Pt.3: *"Well I only let it control what I want it to control, movement. But it doesn't control when I am going to bed, in no way what so ever. Yesterday I went to bed at 21.15 and I don't have to sit there and wait for it to say I have to go to bed at 22.00. But in relation to movement I say that I have to go and feed my Tamagotchi, then people know that I'm just going to go for a short walk"* (Pt.3:2)

So, the notion of control refers to what type of influence the Fitbit has towards its users and can be interpreted as an intention of power. But this power is definite, as pt. 3 states, he does not live by what the technology tells him. In a situation where the Fitbit attempts to exercise its power the user is still capable of not obeying, as he only obeys the Fitbit when it benefits him, from his perspective. Then the functionalities and features of the technology are now perceived in a different way. The patient's state of mind, how busy the patient might be, is also a determining factor as to whether the influence is strong enough to cause behavioural change.

Patient #2 shares a similar belief when it comes to the idea of control. He is not influenced in such a way that he deems it necessary to follow what the Fitbit tells him to do in a strict manner, but even though it appeals to his conscience in a negative way he still appreciates the insights that the technology provides him when he wears it. Furthermore, patient #2 also states that he believes that most other people should do the same.

> I: *"Do you feel like the Fitbit has any control over you and what you should do?"*
> Pt.2: *"No I don't but it is nice to be able to keep up. Because when I'm wearing it, then I am reminded. And I think that people in general should. But as I am reminded, then I also reflect more"* (Pt.2:2)

The question of control then reveals that the technology becomes a cause of reflection for the patient. And as patient #2 previously has stated, it affects his conscience, again the moral influence of the technology becomes more evident as it more integrated in the human-technology relationship. Mediating reflection is both an intention of the patient, as patient #2 expected to gain knowledge and insights of his condition even though he states that it is regarding his sleep habits, but also a designed intention of the Fitbit.

Patient #1 is clear in her standpoint on control and describes her perspective in details as she outlines the boundaries of the idea of control. She is the first to mention the concept of optimization, as technology can mediate a perception of making oneself better as a human. As she during the first interview described how she is looking forward to be 'technologized', the idea of transhumanism and post-humanism comes to mind. Instead of using the word *control* Verbeek (2005) uses the term *taming* when he refers to Peter Sloterdijk's "Rules for the Human Zoo" (Sloterdijk, 2009). He then uses the example of the obstetric ultrasound to show the important implications technology can have for the moral reflection when engaging with it (Verbeek, 2011: 38). Through technologies we, as humans, can determine various elements of our lives which we would not be able to do without such technologies. The idea of the Fitbit *taming* the patients through its influence regarding daily activity, sleep and reflection is a solid example of how the users of a technology are making moral choices based on the mediations of it (Ibid).

I: *"What is the limit?"*

Pt.1: *"When it is total surveillance with how many vitamins, how much fluid you intake then I might think "too much""*

I: "*Is there something else you would want to know?"*

Pt.1: "No because then I think it would control me too much. Then it becomes the thing where you should be as optimal as possible. Then you seek to optimize something, which I do not think is health. There needs to be space for you to do nothing. And have a cake Sunday".

(Pt.1:3)

9.2.3 Intermediate User

During the third session of interviews the focus was similar to the second sessions, but as more time had passed the patients had more time to adapt to and adopt the Fitbit. It became more relevant to ask the patients if their expectations had changed and how the sharing of data affected their perception of the technology and the process.

9.2.3.1 Making sense of data

As described above, more time had passed and the more acquainted the patients are with the Fitbit. As patient #2 expressed earlier, he expected that the Fitbit would be able to help him identify problems and gain knowledge regarding his sleep habits, as he sometimes felt it necessary to use medication for him to sleep. Furthermore, he stated that the Fitbit would appeal to his conscience in a negative way, yet still acknowledged the feedback he got. When asked how it was to wear the Fitbit for a longer period, almost two months, he answered that he had indeed identified the pattern he was searching for and he has started to meet with a psychologist.

Pt.2: *"I think that it has been okay. Firstly, as we have discussed earlier, about the number of steps then I feel like "well I should" but also regarding my sleep. Because, as I have said* *before, then I don't feel like I sleep well. I don't feel like I get a proper night's sleep. I do sometimes, because I use medication which does that I can sleep. That has troubled me, because now I can see the pattern via the Fitbit".*

(Pt.2:3)

Moreover, when asked if he feels that his sleeping pattern has changed during the time he has worn the Fitbit he replies:

Pt.2: *"No, but by looking at the Fitbit data then I know what I feel is correct".*

(Pt.2:3)

This is an example of how the composite intentionalites of the Fitbit and the patient result in positive findings and the patient now has a too which he can use to determine whether he gets the rest he is seeking.

Patient #1 stated during the second interview that she was curious regarding her resting heart rate, but not enough to make her seek more information. However, during the third interview she explains that she indeed has sought supplemental information. She has taken to the internet to gather more information. In this case the Fitbit has mediated curiosity which next leads to knowledge regarding her condition, as she correlates her data with her condition. For patient #1 it is important to not be abnormal, as she states:

Pt.1: *"Well last time I got curious then I went home and googled it and found out that I am not abnormal. I might not be in the good end but neither am I in the bad one. So I have to accept that, that is okay (…)"*

I: *"So you can actually see that your resting heart rate has decreased over time"*

Pt.1: *"Yes that is good".*

(Pt.1:3)

Another aspect of her life where she uses the Fitbit and the data is in relation to sleep. When asked if she has reviewed any of her data, she replies that she has tried to examine the sleep data, but she is not pleased with the results. Even though she sleeps more, she is not satisfied with what the tracker tells her. She becomes more detailed in her expression, as this seems to bother her a lot. Again, this is an example of how the Fitbit can mediate reflection over her current lifestyle and it provides it with insights into why she is feeling as she is. Moreover, this also shows that the Fitbit is a technology with a sense of morality. The reflections patient #1 makes, plays a moral part in the choices she makes both in terms of sleep and daily movement.

Pt.1: *"I have been able to see that no matter how hard I try to sleep more evenly, well maybe I do within the last three days, but it doesn't give me the effect that I feel more rested. It doesn't. And I have been able to see that the times where I have taken a nap, that I spend more time in deep sleep than otherwise. And that gives me things to reflect upon, because I'm thinking "when will I ever have time for that, except for the weekends?"*
I: *"Do you feel any difference the following day, or is it just because you can see it on the Fitbit?"*
Pt.1: *"No I feel more rested. And the Fitbit has helped me to gain insights in this. And I love it, because it actually measures, I examine it several times a day, and based on what I see then I push myself more".*
(Pt.1:3)

However, it is not every time that that this interpretation has an outcome which the patients are happy with. As patient #3 describes he does not always agree with the data the Fitbit shows him. Instead of, as in the prior examples of how the data makes sense and supports a moral decision, patient #3 copes with the situation differently. His approach towards the Fitbit data is more critical in the sense, that if he does not feel any symptoms and the tracker shows an increase in his heartrate, he does not panic.

Pt.3: *"If I cannot feel a change, like if I feel dizzy, start to sweat or something odd. Then it is just this one* (the Fitbit) *that acts up".*
(Pt.3:3)

In this case, the power of the Fitbit is not final as he knows his condition well and still relies on his own judgement regarding how he should act. Here we see an example of the type of mediated influence the technology has towards its users, as an apparent and weak influence (Tromp et al., 2011). He realizes the Fitbit presents him with the apparent data, and interprets it as he does in the hermeneutic relation but as he does not feel any changes or symptoms he chooses not to act and considers it as a malfunction.

> Pt.3: *"Well if there is a connection between what I feel in my body and what the tracker shows then I react. But if it is like the other day where the tracker shows something and I don't feel anything then I perceive it as a IT malfunction".*
> (Pt.3:3)

This creates a situation of data mistrust contradicting to the other examples of the patients trusting in the data and afterwards reacting towards it. Thus, the technology serves different purposes in different situation as it enacts the individual patients' needs and as Verbeek states "*technologies have "intentions" and thus they are not neutral instruments but play an active role in the relationship between humans and their world"* (Verbeek, 2011:9). Furthermore, as we see over and over through the analysis, the Fitbit is an example of what Verbeek refers to as Ihde's concept of *multistability*. The Fitbit has several attributes which are created through the different relations and understandings it mediates for the patients (Ibid). In the following section I illuminate how the Fitbit shows its multistability through mediating how the patients make sense of the data by acting on it.

9.2.3.2 When the Sense-Making of Data Results in Action

As patient 2 explained during the first interview, he often experiences rapid heart rhythms and is used to experiencing minor episodes every now and then (Appendix 10). However, when asked if he purposefully examines his Fitbit data during the third interview, he replies that he has been interested in his heartrate. He then explains how he sometimes believes that when he is having the feeling of increased heartrate, it is something he is imagining.

> I: *"What was the purpose of your examination?"*

Pt.2: *"I tried to find the heartrate. To find out how it was, because sometimes when I get the feeling that my heart beats faster, then it might be my imagination. Because I can experience a few seconds where I'm thinking – was it something I felt or was it something I imagined? Then I could check my heartrate, and it was high".*

(Pt.2:3)

Patient 2 uses the Fitbit to consult himself, as he is in doubt regarding his condition. Not only is he questioning himself but the Fitbit mediates a role of emotional support but letting him know, that he is not imagining what he is experiencing. He then uses the Fitbit to consider whether he should make a transmission based on what he experiences. This is a strong reaction based on the Fitbit, as he first uses it to confirm what he feels, and the if he deems it necessary to inform the clinicians. Which he in this specific situation did:

I: *"Did you make the transmission right after?"*

Pt.2: *"Yes, I am just laying down waiting for a few minutes and if it carries on for more than five minutes then I dial 112, but it was only 3-4 minutes. And then I made the transmission".*

(Pt.2:3)

Another example of how a patient acts based on what he feels and what he experiences via the Fitbit is when patient 3 explains that sometimes when he is out running, he can get symptoms or a feeling that something is not right. He then consults his tracker, and if it does not show anything unexpected he reacts simply by laying down on the forest floor and then relaxes. When he feels better he gets back up and continues running (Appendix 13). However between the second and the third interview, he experienced a new type of symptom which he is not used to and reacts by making a notation in the SCAUT app. He consults his Fitbit, but as it measures a heartrate of 172, and he does not feel that his heart is racing as he expects it would, he settles for the notation. He explains that he has experienced it a couple of times previously but has not been able to make sense of what he feels nor the tracker data.

> Pt.3: *"(…) but I have written something on SCAUT, because I felt a little weird during, I had chest pain. (…) I have actually experienced this a couple of times before, and then you kind of think thrombosis but after a couple of minutes it disappeared again. And I cannot see anything on any of the trackers (…)".*
>
> (Pt.3:3)

This emphasises that the Fitbit is indeed no neutral instrument and it does indeed have intentions and these intentions can be viewed as multistable as the intentions change through different relations between the patients and their world. It also highlights that the Fitbit mediates moral choices which affect the daily life and routines of the patients but also the clinicians if these choices result in patient-clinician interaction.

9.2.3.3 Device pleasing

I end my analysis by demonstrating how an activity tracker mediates actions that do become an integrated part of the life of an ICD patient. As patient 3 explains during the first interview he has been an avid self-tracker throughout the last 7-8 years and has now made the tracker's step objective a part of his life. This illustrates that the tracker can mediate permanent behavioural changes in at least single case.

> Pt.3: *"I have made it kind of a sport to reach my steps and even though I go to Fitness and bike 15 km every day, which do not count as steps, I still want to get my steps".*
>
> (Pt.3:3)

As demonstrated throughout this analysis the many ways the Fitbit influence the patients lives come to show. Some of these insights are connected and others contradict each other more. I believe this to be a realistic perspective on how the life of an ICD patient is individual and a self-tracking technology, such as the Fitbit, can act as a multiple tools with several different purposes. Moreover, that these purposes can change over time and that the chronic condition of a patient also plays a part in how they enact and practice self-tracking. I my conclusion I will demonstrate how the insights are linked but also conflict.

10. Discussion

In this section I seek to critically question possible implications of solely relying on data in healthcare and the probable consequences of patients become managers of their own health, as the risk of self-tracking technologies risk becoming self-diagnostic tools in the daily life of patients. Furthermore, I will critically discuss various aspects of what the Fitbit mediates through the daily lives of the patients, drawing on perspectives presented throughout my thesis. To end this chapter, I briefly touch upon framework of *praxiography* by Annemarie Mol to show how another approach to this investigation could have been applied.

10.1 Data Doubles in Healthcare

Firstly, I discuss the increased use of mHealth and clinical data in the chronic healthcare practice. Next, I argue the problems of using a quantified representation of the patients, both patient-generated but also clinical data, in self-management of chronical patients. I draw on arguments presented by Andersen et al. (2011) among others to reason that the continuous relevance of emphasising cooperation between clinicians and patients, as the use of ICT and mHealth technologies are increasingly being implemented in the healthcare system.

As humans, in this case patients and healthcare providers, interact with self-tracking technologies and the data produced to form meaning about a condition, they engage in a reflexive connection with a '*data double'* (Ruckenstein, 2014:69). The term data double derives from the field of surveillance studies and illustrates a '*surveillant assemblage'*, where human bodies are conceptualized from their local settings and are divided into a series of flows which then create the *data double*. Thus, the data double is a representation of a human in extracted and decontextualized form, composed by sets of information created with the intention of analysis, and in this case of self-tracking the intention of behavioural interpretation and influence (Ruckenstein, 2014:70). However, as

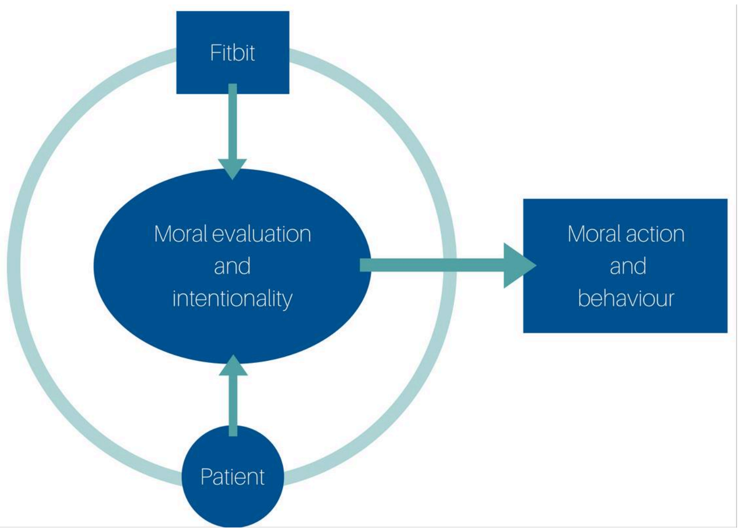
demonstrated in this thesis, the virtual representation of the human can be influence by many different aspects of the individual's life, but also, what the individual patient choses to acknowledge as valid and useful data, proves in this case to be an important aspect of the process of self-tracking
Although the data double derives from the field of surveillance, it has been used in the field of self-tracking as a means to understand the interaction between users and their own data (Ruckenstein, 2014; Lupton, 2014a; Lomborg & Frandsen, 2016). However, as these studies mostly reply on the reflexive interaction between the users and their self-tracked data, not many engage in the critical aspects and the suspicion within the analysis and conclusions created with the use of data doubles. Therefore, I find it relevant to discuss what might happen when patients extensively rely on their data double, as there are examples of in this study. A question also hinted at by Lupton (2012) through her study of mHealth and web 2.0 technologies, as she ends her paper by speculating "*Will the 'objective' measurements offered by mobile devices take precedence over the 'subjective' assessments offered by the senses of the fleshly body?"* (Lupton, 2012:242).

To begin this discussion, I return briefly to the current situation of ICD patients. As described earlier in section 2.1, telecare and remote monitoring is becoming increasingly implemented in healthcare practices regarding ICD patients as a means to decrease the number of in-clinic visits and ease the process for the patients (Skov et al., 2015:829). Replacing the in-clinic visits, the healthcare provider is able to remotely monitor the patient by examining data from the ICD, in other words the *data double*. However, there is a risk that the patient might not be represented fairly through this process. The condition is divided from the context of their body and is mediated through various forms of hermeneutic representations (Andersen et al., 2011:114). The consequence of the de-contextualization of the patient might be that the clinicians will have to rely solely on these hermeneutic interpreted representations to make sense of the patient's condition and context (Andersen et al., 2011:114). And as we see throughout section 9, the patients make use of their data double for various purposes. Not only do the patients use their data double to ensure that they are indeed feeling the way they are, they also use it as a supporting tool to cope with the reality they are faced with on an everyday basis (section

9.2.2.2 – do I feel what I feel?). And as Verbeek states, in the hybrid relation it is the interaction between humans and technologies that help them shape each other (Verbeek, 2015:29). Thus, the data double, to follow Verbeek's notion, helps the patients to perceive who they are, as without the representation through the Fitbit, they are not able to make the moral choices they do based on the feedback they receive. So, a question could be, how will the clinicians communicate with the patients when they are already, as seen in this thesis, embracing their data double?

10.2 Mediation of the Fitbit

Through this illustration (fig. xxx) I show how the theoretical aspect of mediation and intentionality apply to the representation of the Fitbit.



(Fig. 6. shows the implicated aspects between the patients and the Fitbit, and how the interpreted intentionality affects the outcomes for the patients *how do I react to the data the Fitbit presents?)*

The patient's reason for reacting to the data is based on the presumptions of how he or she interprets the data (intentionality) and in what context the data is perceived and acted upon (moral evaluation). It is important to note that the moral evaluation and the intentionalities are interdependent, as these aspects are overlapping, thus affecting the moral understandings and perceived intentionality of the Fitbit. As the patient interprets the data presented by the Fitbit in accordance with the aforementioned aspects, it influences the choices related to his reality. As we understand from the analysis, these interpretations vary from patient to patient and context to context. The Fitbit can act as a representation of various feelings, such as guilt but also increased level of activity through motivation. As the patients are situated mostly in the hermeneutic relation with the Fitbit it requires a certain experience and expertise for the patient to understand the choice they make. For instance, they are of the understanding that as they are chronic heart patients, daily activity is even more important for them as a consequence of their condition, as patient 2 states:

> Pt.2: *"(…) because I have to get started. There is no doubt about that. I don't question that the more I gain weight, the more fat sticks around the heart and the harder it is for it to pump. But again, it is a mental thing, I have not been able to get going".*
> (Pt.2:3)

This is based on knowledge that the patient has regarding his own condition which leads to a mediated intentionality of the technology. He makes a moral assessment of the situation he is in and decides if the Fitbit can act as a tool which will help him to get going. As he used the Fitbit to reach the conclusion that it is not because he cannot but because he has been struggling mentally. It is reasonable to assume that the designed intentionality of the Fitbit is to motivate and persuade the user to take action towards the situation of the patient; however, as mentioned in the case with patient 2, it mediates negative responses even though he initially expected to gain insights. The aspect of guilt is important to reflect upon if implementing such a technology in healthcare processes.

The technology by itself does not differentiate between patients, and the risk of the Fitbit mediating negative memories regarding a patient's situation and condition should be considered. More so, the differences of perceived intentionality can be found in the perspective of the patients regarding how the technology can be used and for what purpose. As described, they primarily use it to assess the situation they are in and to facilitate activity through the reminder and 10.000 steps objective. In relation to the data they generate, they state that the main reason for participating is two-fold, as they want to give something back to the system, which has helped them but also to gain insights about their own situation. The notion of who initiates the process is important to acknowledge as it can have potential consequences. The Fitbit can become a burden for the patients, as they can reach a point where they have gathered all the insights they are interested in, thus losing interest in the self-tracking practice. In short, if the patients reach their 'goals' then the perceived intentionality of the technology can change once again as patient 3 states in section 9.2.2.1.

By following this notion, we can examine the technology as having a role in the treatment and care plan of patients with ICDs. I also find it important to ask the question, what part will the technology then play in this process? Does self-tracking technologies then overlap the role of the clinicians as facilitators of knowledge regarding a medical condition, and how do patients best understand the human-technology relations they are situated in regarding with their conditions. What role does the Fitbit play, and what possible role could wearable technologies play in the future? Will it be a supplement for the clinicians or just for the patients?

> Pt.3: *"So it is a bit for my own curiosity, do I gain anything from this?"*
> (Pt.3:1)

10.3 Praxiography by Annemarie Mol

The framework of praxiography originates from Annemarie Mol's book "The Body Multiple: Ontology in medical practice" (Mol, 2002), in which she studies the disease atherosclerosis, which can be viewed both as a theoretical framework but simultaneously leans closely to a methodological approach. Mol presents and argues that praxiography is a method through which ethnographers can study practices via various events, activities and physical environments, among others, and that knowledge is found within these forms of practices (Ibid). Mol further defines praxiography as a descriptive approach where knowledge is composed and claimed through qualitative methods where interviews, observations and visualisations help the ethnographer to tell stories of different practices (Ibid). Within praxiography the focus is not on understanding human perspectives on objects but attempt to connect and explain objects as things which are manipulated in practices. In short, praxiography parts with focusing on objects and instead foregrounds the surrounding practices and aims at investigating how objects are handled (Ibid).

As Mol's research is on atherosclerosis and how it is *being done*, she draws on Judith Butler's view on gender identity and that identity is not something which is given; it is performed (Mol, 2002:37). Using this as a foundation, Mol tells the story of one of her informants, and how his body is being done in practice how this presents valuable knowledge for the ethnographer. "*But in telling about the way he lives with his painful legs, Mr. Gerritsen also presents us with insight into the events that happen to someone with an impaired body"* (Mol, 2002:14). Through the story of the informant, and by letting Mr. Gerritsen tell it himself the researcher collects insights about his everyday life and how he is affected by his impaired body and what concrete and material adaptions he makes in his daily life.

This framework or approach to informants, in my case patients, could additionally have been a motivating and explorative method to apply in this thesis. By letting the patients tell their stories and using their narratives to show how they enact the technology differently, but also at times similarly it shows that all these enactments are intertwined in a network and are not to be seen as fragmented events related to the phenomenon – *"there is one more than one – but less than many"* (Ibid:55). This notion corresponds with what I have shown throughout my analysis, and is what Mol calls *multiplicity*. And it is within the framework of multiplicity that praxiography attempts to explain, divide and illustrate how a phenomenon is enacted through various practices.

11. Conclusion

In this project, I have investigated what experiences and understandings a self-tracking technology such as the Fitbit Alta HR mediates for patients who suffer from a chronic heart disease. I have explored what knowledge and experiences the Fitbit mediates and how these insights affect the everyday life of the participating patients. Moreover, I have examined how the data from the Fitbit affect the illness perception of the three participating patients and how they make sense of it. I have unpacked how the patients experience the different types of influences the technology exerts and how they react to the data they generate. Lastly, I have examined how these data are mediated in a clinical and organizational context, in this case the through the SCAUT platform.

I conclude how the insights of the patients create certain dilemmas based on their experiences. As more of the patients use the data from the Fitbit to create meaning of their situation, they now trust the data. However, the interpretation of these data can also create an impression of mistrust as the analysis shows, the data alone can create a situation where the patients do not agree with the presented data.

The Fitbit mediates different moral choices. Purpose change over time according to the knowledge and experiences which change as the patients view their health from a different perspective. Not only because they can “read” themselves through their *data double,* but also because the tracker mediates interaction between them and me. The analysis shows that the patients do not disapprove of a third-party collecting and examining their data, but do at the same time express where their limit is.

The patients react differently toward experiencing behavioural changes in their daily level of activity. Some are more compliant than others and even though they do not always follow through on their intentions, the Fitbit still mediates consideration and reflection towards their moral choices and thus towards their health perception. The patients are subject to various behavioural changes, such as an increased of daily activity which to some degree becomes a competition for two of the patients as they embrace the influence the Fitbit exerts. However, a contradictory example is that the Fitbit also appeals to a patient’s guilt, when he is unable to comply with the intentionalities of the technology.

I have argued that the Fitbit offers a composite intentionality, as the intentionalities of both the patients and the technology merge. Thus, the perceived intentionality of the Fitbit and the corresponding enactments are therefore linked to the hybrid rationale. This shows that if it is used by other patients, the perceived and mediated intentionality would be affected by the individual nature of these which makes it impossible to ensure that the outcome is the same as the one demonstrated in this thesis.

12. Recommendations

My research indicates that the participating patients embrace self-tracking as a positive method of gaining insights to their own health and disease. They use the Fitbit for different but also similar purposes and all believe that by contributing and participating they help other patients suffering from the same condition. My recommendations are based on the insights gathered from the patients combined with the insights from the literature review.

12.1 Using the Fitbit As a Tool of Empowerment

The use of the Fitbit stimulates the patients to obtain new knowledge regarding their condition. I believe that using self-tracking technologies the patients enter a realm of information which can help them to develop coping strategies in relation to their health. As demonstrated in this investigation, the patients use the Fitbit to learn about themselves in situations where it can be difficult to understand what the body tells them. By introducing them to a technology as the Fitbit, they are provided with a tool that empowers them to cope with these types of situations. Furthermore, it shows that two of the patients become motivated by the technology and do become more active on a daily basis. However, as patient 2 expresses the notion of guilt when he reviews the data, it is evident to consider patients individually as it would be morally wrong to advocate guilt in such a situation.
As described in section 7, patient-generated health data and self-tracking are both ways which make it possible to involve patients more in their own treatment. This investigation shows that patient 2 uses the Fitbit as a tool to clarify whether he feels what he feels. Maybe the use of the Fitbit lead to a quicker self-realization for the patient, that what he was experiencing physically also was influenced mentally.

12.2 Making More Sense of Data

As my research suggest the patients all make sense of the data in some way. This maybe also related to the section above, however my point here is that when including patients, it is necessary to ensure that the data is perceived correctly. And this creates a dilemma, which is stated in section 7.5.2. The data needs to be of relevance if presented to clinicians or any third party. And the fear that the process could result in disharmony is necessary to consider, as stated by Zhu et al. (2016). However, as each patient present a data double which is unique they also have different perspectives of what is relevant to them. This means that even though one patient finds it interesting to obtain more knowledge regarding sleep habits, the next might not. And as one might embrace the step reminder, another might feel irritated. This interpretation and making sense of data will continue to change, as the investigation shows that the purpose of participating changes over time, as the patients gain more knowledge and feed their curiosity. The notion of The Quantified Self is another example of how individual self-tracking can be, and I do believe that there are many positive angles in such a community. I end this section with a recommendation to invite a group of heart patients to a workshop and asking them the question of what they would find relevant and interesting, both in terms of what to track but also how to do it. I believe that by letting the patients discuss among themselves, and not answering questions asked by a researcher could provide with even deeper insights to how they make use of the technology.

13. References

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