A Dislocated Gut Feeling:

An Analysis of Cyborg Relations in Diabetes Self-Care

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Abstract

In this thesis I use Annemarie Mol's method of *empirical philosophy* to analyse the experiences of people with diabetes who use self-measuring devices to continuously monitor their blood sugar. I investigate what happens when technology with its own programmed intentionality intermingles with the human body.

My findings suggest that living with these kinds of machines can alter users' sensations of their bodies in a series of different ways. Some of them experience that the machines help them to better distinguish between different physiological feelings, using the self-measuring devices to *calibrate* their own sensations of the body. Others have the opposite experience, claiming that they lose the ability to feel nuanced bodily variations when these changes are continuously translated into numbers and digits. They *outsource* the act of sensing to the machines. Some get physical *phantom* reactions when they watch the number on the machine display, whether or not this number is connected to a real change in blood sugar levels. Others even incorporate the numerical logic of the machines in such a way that it becomes a disruptive force that *colonizes* their daily lives.

I compare these experiences to two philosophical theories that focus on the human subject and its relation to technology: Michel Foucault's concept of *self-writing* and Peter-Paul Verbeek's updated version of *postphenomenology*. I find that these theories need modifications to be able to relate to and describe machines that are closely intermingled with the physical body, but that still have a strong independent intentionality.

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I also want to thank Ragnhild Elisabeth Burum Eskeland for being the first person to explain and show me the sometimes frustrating other times comical and always profound complexities that follow from living with diabetes and the surrounding technology.

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Most of all I am deeply grateful for the interviewees themselves, who were all willing to talk openly with me about very private parts of their lives. Through our conversations they showed an understanding of their complex situation that in many regards surpasses the insight of the philosophers described in the following pages.

As I have had this group of competent helpers and supporters, any still remaining errors, misunderstandings or mistakes are solely my responsibility.

Askild Matre Aasarød
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Chapter 1 – Introduction

1.1 Introduction: A new gut feeling – A problematic democracy in the body

> I had beaten myself black and blue, but remained myself, indivisible. It wasn't so unusual. Didn't people in the Middle Ages flog themselves? But no one can put himself in my shoes. It's impossible. I can't even say that there are two of me because there aren't.
>
> – Ljon Tichy in Stanislaw Lem's *Peace on Earth*

Ljon Tichy, the protagonist in Stanislaw Lem's satirical novel "Peace on Earth", finds himself in something of a pickle. Through a series of fantastical accidents, he has lost control over the right side of his brain. It now acts as a separate entity within their shared body. It has a strong will of its own, in addition it is arrogant, aggressive, brute and vulgar, all in all almost impossible to negotiate with. Ljon suddenly has to live with the fact that he has two wills in his gut, not just one. It is a highly unsatisfactory situation, as he states it: "I'm not thrilled by the thought of having a democracy established in my head. I want to be less plural, not more". But when Ljon tries to describe his tragic situation to others, he cannot find words. A philosopher he meets, will simply not believe him:

> "Mr. Tichy!" He now yelled in my apartment. "According to logic, you're either singular or you're plural! If your right hand is pulling up your pants and the left hand interferes, it means that behind each stands a separate half of the brain that thinks its own thoughts and refuses to cooperate with the other. Because hands and feet don't go around fighting each other on their own!"

So Ljon is left to try to sort out his internal quarrels alone through writing in his diary. But he falls short: "I interrupted my writing to kick myself. That is, my left foot kicked my right so it wasn't I, or it was only partially I, but grammar simply can't describe this situation."

It is this kind of internal wordless quarrel people with diabetes have to deal with throughout their existence. Quarrels both with their illness, that disrupts their lives through the lack of insulin, and with the many technologies that closer and closer intermingle with, and act on, their bodies to counter this deficiency. In this thesis I will study a specific kind of self-measuring device that is connected directly to the user's bloodstream. These machines become so close to the body that it does not make sense to define them as separate from it. Still they also act independently, even in opposition to the user. But both for persons with diabetes and the people who design the technology,

a good vocabulary for expressing these *cyborgian siamese twins* seems to be lacking.

Therefore I will in this thesis perform an experiment. I will take two theories that in different ways talk about the human subject without falling into the Cartesian subject/object divide, or what Bruno Latour has called "the modernist settlement": Michel Foucault's theory of *self-writing technology* and the theory of *postphenomenology*. I will compare these theories to the experiences of people with diabetes using the technology, as I have documented through a series of extensive qualitative interviews. Foucault's concept is interesting in this situation because the technology he describes shares many traits with the self-measuring devices of diabetics, postphenomenology because it keeps the subject as the core entity in philosophy, even when technology and the world is seen as clearly intermingling with this unit.

This experiment has a twofold objective. *Firstly, I want to test if these theories can handle the human/technology relationship that people with diabetes live with, and if not, I will try to suggest some theoretical alterations.* This is, however, not only to further the perpetuum mobile of philosophical analysis. My personal experience from knowing and talking to people with diabetes who use these machines, is that they are quarrelling, fighting, crying, crushing, hugging, shaping and being shaped by their technologies, but without being able to properly describe their – often existential – struggle. To negotiate a peace with the machines – and through them also the disease – is difficult when they are both so elusive and hard to define. As Anne, one of the participants in my, puts it:

> [I]t's very intriguing to make the [diabetes technologies] into a larger part of me, because it feels so unreal, or kind of...I had such a distance to them. I wasn't very fond of having diabetes, so then I really worked to make it into a part of me. To make it kind of – my own.

Secondly, I hope that my descriptions of the participant's experiences can provide some empirical substance to the complex and often opposing effects that follow from self-measuring technology. I will let their stories be an essential part in the main body of the thesis, and in addition through the

extensive portraits presented in the appendix. I do this because I sincerely believe that presenting their tales in themselves is an important and often neglected task.

1.2 Summary: Finding words for ambivalent body-technology relationships

In the following I present a short summary of the thesis.

1.2.1 Theory: Blurring the human and the world

In this work I analyse two theories that are concerned with the human subject, but in a manner at odds with the classical modern idea of the subject/object divide. Michel Foucault has, in the late part of his philosophical career, discussed how the human notion of selfhood has developed through and with technology into its current shape. He argues that the human being has changed, and will continue to do so, by means of *self-writing technology* (Foucault, 1997)[1]. According to Foucault it was in these kinds of reflective, technologically mediated loops that the modern "narrative of the self" came into being. He specifically describes the *hupomnemata*, a wax tablet used in ancient Greece, as a good example of a self-writing device. These ancient technologies have some striking similarities with contemporary self-measuring technology.

Like Foucault's idea of self-writing, the philosophical school of *postphenomenology* also tries to describe the subject without falling into the old dichotomies of modernity. But postphenomenology aims at creating a language to speak from the perspective of this unpure unit. In attempting this, Peter Paul Verbeek has defined concepts to talk about situations where humans and technology act closely together, through what he calls *cyborgian relations* between humans and technology (Verbeek, 2011). This is a relationship where there is no meaningful way to separate the user and the machine. But there are also relationships outside the human, between different technologies, *composite relations*. Technologies can adjust to each other, without our conscious, constant presence. Verbeek argues that the coincidences and unforeseen consequences following technology constitute what he calls *technological intentionality.*

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[1] For more thorough referencing, see main part of thesis.

1.2.2 Empirics: Inseparable, but still distinct

These two philosophies attempt to understand the relationship between the body and technology as intermingling. But are there classes of human-technology relationships that exist in the grey areas between the different concepts defined by the two theories? To try to search for these subtle and elusive relationships I have used Annemarie Mol's method of *empirical philosophy* (Mol, 2000, 2004, 2008). Her tactic is to find novel concepts through philosophical discussions based on real life examples, instead of working from abstract theories. This method can be helpful in trying to locate real world situations that lack a good vocabulary. So, following Mol's suggestion, I have conducted and analysed qualitative interviews with users of a technology that has a specific and at times problematic relationship to the human body and self: the Continuous Glucose Monitor (CGM), a machine for real-time self-measuring in diabetes care. Through these conversations I hope to see if the theories of self-writing and postphenomenology can handle the complex relationship between this technology and the human.

1.2.3 The new hupomnemata – Being written while you read

The self-writing technologies, as described by Foucault have some striking similarities with the CGM: Both technologies externalize internal sensations, emotions and thoughts, and thereby allow the subject to see him- or herself, and his or her body with an external gaze. But if we go beyond the similarities, there are some essential differences. The user's image of his or her own body grows with the new digital sense data. But this data is partially defined by the machines. The technology presents the user with what Mol calls the *object body,* a body analysed and surveyed as dead matter, unlike the *subject body* the user knows from his or her own bodily experiences. It is through this understanding of the object body that the user is taught to feel his or her disease and flesh. But as

we shall see, different users react in different ways to this. Some use the technology to *calibrate and strengthen their own bodily sensations,* others *internalize the number on the mechanical display* so that this becomes what triggers sensations*,* others *outsource the work of sensing* to the machines, while yet others have their lives completely *colonized by the machine's rhythm and logic*. Common to these different experiences is that the device actively shapes the user's sensations of his or her body, and thereby also his or her self. And the technology's independence from the user also goes further. It *acts behind the user's back*, presenting specific findings and revealing mistakes and secrets to medical professionals.

The CGM is an ambiguous *hupomnemata*. It objectifies the body, splitting its different elements apart. This process can be compared to Charis Cussins' idea of *ontological choreography*, where a person objectifies him- or herself to be able to reach a new subjectivity (Cussins, 1996). But for users of the CGM and pump, the machines play a more active role. It is not, as in Cussins' description, the human who defines the new notion of the self. The new selfhood is moulded through a constant debate with an active and assertive technology. This perspective is not discussed by Foucault's definition of self-writing. His non-modern description of the creation of selfhood seems to still feature some elements of classical modernist ideals in its asymmetrical description of the active human subject using the passive technology.

1.2.4 The Siamese Cyborg: The void between *cyborg* and *composite relation*

Postphenomenology has a different challenge from self-writing: My empirical work suggests that the theory has difficulties handling technologies that can be said to be both a part of, yet separate from the human body.

The relationship between the physical body and the CGM is a *cyborgian relation:* both through the fact that the technology is literally a part of the patient's bloodstream, and through the

way the technology externalizes and reinterprets body, thereby blurring the boarders of the subject. The intermingling goes so far that some users even describe having physical sensations when they see a number on the display of the pump, rather than when the body is in a certain state.

On the other hand it is a *composite relation*, as it acts on the object-body without, even in opposition to, the human subject's consent. The device is clearly a stranger. Making itself separate from the human self through beeps, vibrations and flashing screens is an essential part of the technology's script. The device, and through its display also the users' bloodstream, is very much visible as foreign to the subject. The technology seems to be both cyborg and composite.

1.2.5 Discussion

The CGM is a good example of a situation that the two philosophical theories analysed in this thesis have problems describing. But if the two theories are seen together, it seems that their different viewpoints can supplement each other. *Postphenomenology's* symmetrical view on intentionality, if transplanted into *self-writing* allows this theory to better describe technology with active intentions. This modification is necessary for the self-writing concept to describe what I call the *new hupomnematas*, contemporary self-analysing technology that should not only be seen as passive tools.

And opposite, if we allow the perspective of Foucault's *self-writing* into *postphenomenology*, the latter's problem of not accepting the self as subject and object at the same time, might be more easily handled. If we try our hands at this theoretical bricolage, we can construct a new postphenomenological concept. The human and the technology together shape a conflicting unity, they become what I call a siamese cyborg, or in more theoretical terms, they constitute an unstable *cyborg-composite self-relation.*

Chapter 2 - Theory

2.1 Theory: Beyond the Cartesian divide

Throughout the 20th century the clear theoretical separation between the human subject and the world has slowly disintegrated. Thinkers have moved away from what has been called "the modernist settlement", the division between the self and the world as made famous by René Descartes (Latour, 1999, p. 193). Different schools of philosophy have picked apart what was once the centre of the modern philosophy. The resulting world views can be called postmodern, late modern or even a return to the pre-modern. To avoid this labyrinth of philosophical naming, I will in the following conveniently group different theories that move away from the subject/object divide into what I, inspired by Bruno Latour's fundamental critique of modernity, call *non-modern*.

What I am particularly interested in throughout this paper is how we relate to the notion of the subject in a non-modern ontology. The self is the point from which we all view the world, but how can we talk about it in a non-modern sense, without it dissolving? How do we talk about selves as unpure constructions?

To try to analyse this question I have chosen two philosophical theories that engage with selfhood and the subject without resorting to Cartesian dualism, namely Foucault's concept of *self-writing technology*, and *postphenomenology*, specifically as defined by Peter-Paul Verbeek.

Foucault's theory is particularly interesting in relation to the empirical study in this thesis, as self-writing technology shares many features with the self-measuring devices in diabetes care. Verbeek's concepts are relevant as they attempt to describe all human technology relationships, but it is unclear how well they can handle the situations presented through my interviews.

2.2 Self-Writing: *Autopoesis* through the technologies of the self

According to Michel Foucault, the fundamental question in ethics is not what moral codes we should follow, but what kind of subject we want to be (Verbeek, 2011, p. 17). The question that

naturally follows is: how do we become this subject? Foucault argues that the human subject is not a fixed, essential being. It changes, and will continue to do so, through the way we live and in relationship to our tools and surroundings. In Foucault's early writings, he challenged the idea of the free individual. The gushing powers of the structures in society and nature leave little, if any room for a free subject, he argued. The idea of the self-contained, autonomous self would only exists for a fleeting instance in history: "As the archaeology of our thought easily shows, man is an invention of a recent date. And one perhaps nearing its end" (Foucault, 2002b, p. 422). With time, he wrote, the concept of 'man' will be "erased, like a face drawn in sand at the edge of the sea" (ibid.).

But shortly before his death Foucault reformulated his earlier thoughts. In a series of lectures held at Collège de France he argued that the human subject is able to manoeuvre through the structures of power (Foucault, 1998). Though it is not fixed and unchanging, what he calls the "narrative of the self" is a being that is constructed and moulded through a process of *self-writing*. To explain this complex idea, he tries to reach back to the historical time when the "narrative of the self" surfaced.

2.2.1 Birth of the self

According to Foucault, the roots of *the narrative of the self* are to be found in the ancient Mediterranean societies, through a specific kind of technology, namely writing. More exactly, when writing moved from being purely a tool for the state and religion, to become a technique of the subject. The community of people with the knowledge to write fundamentally changed when they moved their new found skill into their private spheres. Because, as Edmund Husserl also argues, with the influx of writing into society, language itself – and with it the structure of thought – was altered (referenced in Ihde, 1998, p. 42). Foucault points particularly to one specific technological device in ancient Greece: *The hupomnemata*. This was a personal wax tablet you could carry around

as a sort of notebook. It could be compared to a diary, but it served a slightly different purpose than modern versions. It was not a place to express inner thoughts, but to reconfigure the impressions from the outside world. The role of the hupomnemata was to "enable the formation of the self out of the collected discourses of others" (Foucault, 1997, p. 217). You could write down "extracts from books, examples, and actions that one had witnessed or read about, reflections or reasonings that one had heard or that had come to mind" (ibid, p. 209). The user could then reorganise, comment on or adjust these impressions. Through this practice, a space for the individual to speak with itself was created. The hupomnemata helped gather the scattered impressions of the world that the writer experienced. It was "a matter of unifying these heterogeneous fragments through their subjectification in the exercise of personal writing" (ibid., p. 213). The unification widened, and redefined the boundaries of man, as Foucault describes it, partially quoting Seneca: "The role of writing is to constitute, along with all that reading has constituted, a body [...W]riting transforms the thing seen or heard "into tissue and blood." (ibid.).

This process of *self-writing* was developed through Roman times and the early Christian era in letters and journals. But it also slowly changed. The texts turned form being about things 'outside' the person, to being about the self. Instead of describing the world, the self started looking at the physical body, describing the details of existence as a physical being. Health reports became increasingly important in correspondences. Writers described "the bodily sensations, the impressions of malaise, the various disorders one might have experienced" (ibid., p. 217). Through the writing the body was multiplied, giving the writer the ability to look at him- or herself from the outside, a sort of premortal autopsy.

These descriptions of illness and bodily sensations often related to the soul, and the relations between the body and the soul, as exemplified for instance in Augustine's *Confessions* (ibid., p. 253). In his texts Augustine dissected his bodily sensations, and confessed his personal sins.

Through the process of writing the self externalized its inner sensations and quarrels, so that they could be controlled. The text as technology became a way to perform *askesis*, meaning, as Foucault defines it, the training, or surveillance, of the self, by the self (ibid., p. 208).

These processes constitute what Foucault calls *autopoesis*, in Greek literally meaning *self-production*. All the different variations on these techniques were aimed at producing distance to the self, to enable self-analyses, or a form of meta-agency, and thereby control over oneself as an acting body (Verbeek, 2011, p. 87). Since ethics according to Foucault is related to self-shaping, the starting point for moral practice is in this *techné tou biou*, the technology of life (ibid., p. 75).

Later in history, as the self-observation became more prominent, this pre-modern reflective action morphed into the idea of the creative subject that controls itself freely, and that produces new impulses without input from the outside world (Foucault, 1997, p. 249). This marked the beginning of the dualistic world view of modernity. Unlike its predecessor, the *modern* writer did not consider him- or herself as coming into existing through his or her things. Unlike in ancient Greece, the modern self is an island. Foucault's ideas of self-writing can be seen in opposition to the duality of this "modernist settlement" (Latour, 1999, p. 193). The theory of self-writing unblackboxes the 'modern man' and describes the complexities of how the idea of the autonomous self came into being.

2.2.2 Summary: Self-reflective personhood and the mind in the chessboard

Foucault thus presents a theory of the creation of self-reflexive personhood, *autopoesis*, through the use of self-writing technology. This nuanced analysis of the human subject opposes the subject/object divide of modernism. The human subject is not fixed in the fleshly body, but exists also in the self-technology. In this Foucault shares the ideas of Gilbert Ryle. Ryle argues that the subject can also be found in the object she or he thinks through:

> The statement 'the mind is its own place' as theorists might construe it, is not true, for the mind is not even a metaphorical 'place'. On the contrary, the chessboard, the platform, the scholar's desk, the judge's bench, the lorry-driver's seat, the studio and the football field are among its places (Ryle, 1949, p. 51).

In this thesis I want to see what happens when we move this part of Foucault's thinking into the present day. How well does his concept of self-writing work when applied to real life technologies that are more assertive and harder to negotiate with than the passive wax tablets of the past? Through this investigation, I hope to see if the theory works on contemporary technologies of the self, and if not, what modifications have to be done.

There is also another strand of philosophy that attempts to keep the subject/object divide blurry, while still speaking of the individual: *Postphenomenology.* Though phenomenology at times has an uneasy relationship to Foucaultian philosophy, postphenomenology shares many of Foucault's ideas about the subject. But where Foucault tries to find a language to speak about the creation of the subject in a world with blurry boundaries, postphenomenologists such as Peter-Paul Verbeek tries to find a language to speak from the viewpoint of this unpure entity.

2.3 Postphenomenology: Watching the world through technology's eyes

The fundamental aim of phenomenology is to analyse the relationship between humans and our *lifeworld*, meaning our perceptions of the world (Verbeek, 2006, p. 363). Though postphenomenology wants to distance itself from the modern subject/object divide, it still attempts to salvage the perspective of a subject watching an object. Specifically it describes how we receive impression of the world through our tools, the physical technologies we surround us with. The goal of postphenomenology, as defined by Verbeek, is not to create a model mapping out all the different aspects of reality in one theory (Verbeek, 2005, p. 164). Its viewpoint is not a foundational, ontological position, instead it is something slightly more humble (Verbeek, 2011, p. 15).

Though object and subject are not clearly divided, we need to device a language to talk

about these unpure opposites. This is necessary, because this divide is the perspective we as individuals see the world through, it constitutes the human experience. We cannot know anything from outside our bodied selves. As Don Ihde, the man who created the original postphenomenological concepts, puts it: "We can know only what is possible for a bodied being – and this implies an actional, perspectival, and situated kind of knowledge" (Ihde, 1998, p. 42). Since we think, enact and live the subject/object divides, we need a language to relate to this shaky notion. By doing this, Verbeek argues, postphenomenology might contribute to larger systems of thought such as Bruno Latour's Actor-Network Theory (ANT) (Verbeek, 2005, p. 164). ANT views both human and non-human actors – or actants, as Latour prefers to call them – as entities that emerge in the network of relations between objects, they do not have any predefined essence. Instead, they are undefined phenomena that only get their form through the relationship-network (ibid., p. 149). Verbeek believes that the situated view is lost in the perspective where the human/object divide is completely eliminated, and not discussed, even as a rhetorical perspective. He wants to create a "fertile hybrid of postphenomenology and ANT notions" to capture the best of the two worlds (ibid., p. 148).

2.3.1 Don Ihde's postphenomenological concepts

So how does postphenomenology try to conceptualize the human, our technology and the world? To understand it we need to start with its predecessor, classical phenomenology. The phenomenologist Martin Heidegger created two main phenomenological concepts to describe the human-technology relationship. A tool can either be, *ready-at-hand*, meaning that it is not thought of as something outside of the body, but instead performing something in unison with it, as for instance when you use a hammer to drive a nail into a plank. If you miss the nail, and hit your thumb, the hammer painfully stops being ready-at-hand, and drastically becomes what Heidegger calls *present-at-hand*,

it makes its otherness to the body wildly visible (Verbeek, 2006, p. 364).

One way of looking at Heidegger's concepts, is to see technology as something that mediates our relation to the world. Technology makes us able to experience different interpretation of what is out there. This reinterpretation fits well into Heidegger's own definition of the human subject. He defines it, pointing to the Greek root of the word, *hypokeimenon*, as that which gathers everything onto itself (Verbeek, 2011, p. 28). Ihde redeveloped Heidegger's original concepts to fit the mediated view on human-technology relationships (Ihde, 1998, p. 46). As a modification of ready-at-hand, he presents *embodied relations*. This is situations where "[t]echnological artefacts become *extensions of the human body*" (Verbeek, 2006, p. 365).

For instance when we wear glasses, the world is related to us slightly differently, but still closely resembling, our own earlier perceptions of it. It can be presented through this simple figure:

$$(\text{human–technology}) \rightarrow \text{world}$$

Ihde's modification of the present-at-hand concept is slightly more different than the original: In *hermeneutic relations* the technology is giving the user a very specific interpretation of the world. For instance when we read the temperature from a thermometer, the level of the mercury that aligns with a number alongside the thin glass container is far from the sensation of temperature that we feel on our skin. The machine channels one abstract aspect of the temperature, and lets us read it:

$$\text{human} \rightarrow (\text{technology-world})$$

The object itself becomes very much present-at-hand in this process, and plays an important role in defining the world for the user. Still, Ihde's two concepts are not mutually exclusive, but exist as points on the same continuum. So even embodied technologies have hermeneutic qualities.

In addition to the embodied and hermeneutic relations, Ihde has named two other types of human-technology relationships. One class is *quasi-alterity relations*. This is a relationship where

the human is not relating through, but at a technology. This can for instance be when you communicate with a chat-bot on the internet, or when you feel closely connected to a beautiful artefact, a phone, bicycle or a book. The concept shares many of the exterior feature of the kind of alterity relation humans can have to other individuals. But according to Ihde, whose symmetrical view does not go as far as Verbeek's, our relations to things can only partially mimic the connection between two persons (Verbeek, 2005, p. 127).

The fourth concept is *background relations* (ibid., p. 128). This is when technology constitutes or stabilizes our surrounding. For instance air-conditioning that keeps the temperature in a room at a certain level, or the gasoline keeping a car running. This is a form of technology that is seldom thought about until it breaks down.

2.3.2 Technological intentionality

In all these different relationships, technologies shape the way we experience the world. They act not only because an action has been consciously delegated, such as for instance when a police district builds a speed bump to enforce speed laws. Unintended consequences and unforeseen reactions that a technology prompts, is a form of *intentionality* separated from human delegation and design (Verbeek, 2011, p. 9). This definition of intentionality also relates nicely to the original latin term, where intentionality means literally *to direct* (ibid., p. 57). Through this ability to act and direct without a conscious human plan, Verbeek argues, technology can be seen as an independent moral actor:

> [M]ediating artefacts help to determine how reality can be present for and interpreted by people. Technologies help to shape what counts as "real." This hermeneutic role of things has important ethical consequences since it implies that technologies can actively contribute to the moral decisions human beings make (Verbeek, 2006, p. 366).

Verbeek uses the example of genetic science, that not only created a whole new moral dilemma when it made it possible to see who could be potentially bearers of a disease. Those who had earlier

been healthy individuals were by the technology transformed into potential patients. But the technology did not just do this, it also prompted a moral solution to the problematic situation it created: more research into genetic technology. Following this series of events, not continuing research into genetic diseases becomes an immoral act (Verbeek, 2011, p. 57).

2.3.3 Summary: Unintended consequences and technological actors

So technology, according to Verbeek, is as much an actor as a human being. Verbeek is strongly influenced by Latour, who argues that the human and the technology not only act on each other, but become closely interwoven, and therefore act towards goals not set by any of them. When humans and technology act together, they can start to follow a drastically different program, or script, than they had before. So an angry *man* who wants to threaten someone and a *gun*, that alone frankly has no other intention than to follow gravity, form a *gunman,* that together might have a script to kill someone (Latour, 1999, p. 177).

But does postphenomenology's attempt at combining the membraned human individual and a symmetrical view on agency, work? In the analysis chapter I will use my empirical data to see if the theory is able to talk about technology that is both inseparable, defining parts of a humans body, but still very much independent and present-at-hand.

Chapter 3 – Description of technology

3.1 Self-measuring devices for people with diabetes

The Continuous Glucose Monitor (CGM) and insulin pump are machines created to make insulin injections and glucose level management easier for people with diabetes. The machines are two separate entities, but are used in unison by many, but not all users, as the pump software acts on the CGM measurements. Throughout this thesis I will often speak of the two in unison.

The CGM continuously monitors the glucose levels of the user through a needle injected into the skin. It has to be calibrated through manual blood sugar measurements twice a day. Via a transmitter (A) it sends its information to the pump (B) (see figure 1). The pump itself has several functions. It stores the data, but also presents it on its display either as a number, a developing graph or both. In addition 'Bolus Wizard', a software available through the pump, can give the user suggestions on what insulin doses should be injected.

The pump is programmed to alert the user with beeps and vibrations when the CGM reports of specific kinds of changes in the blood sugar levels. In addition the measured blood sugar level is displayed on the screen as a number, ranging from 2, extremely low, to 22, extremely high. Blood sugar levels outside these values are usually not shown. These measurements can be complied to make a detailed overview of blood sugar levels over a period.[2]

All in all the machines are designed to perform the same role as the pancreas does for people who do not have the disease: Distributing insulin into the blood stream so as to let sugar enter into cells throughout the body.

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[2] These continuous, longterm measurements must not be confused with longterm *hba1c* levels, which are onetime measurements of the average plasma glucose concentration in the bloodstream that indicate the blood sugar levels over a certain period.

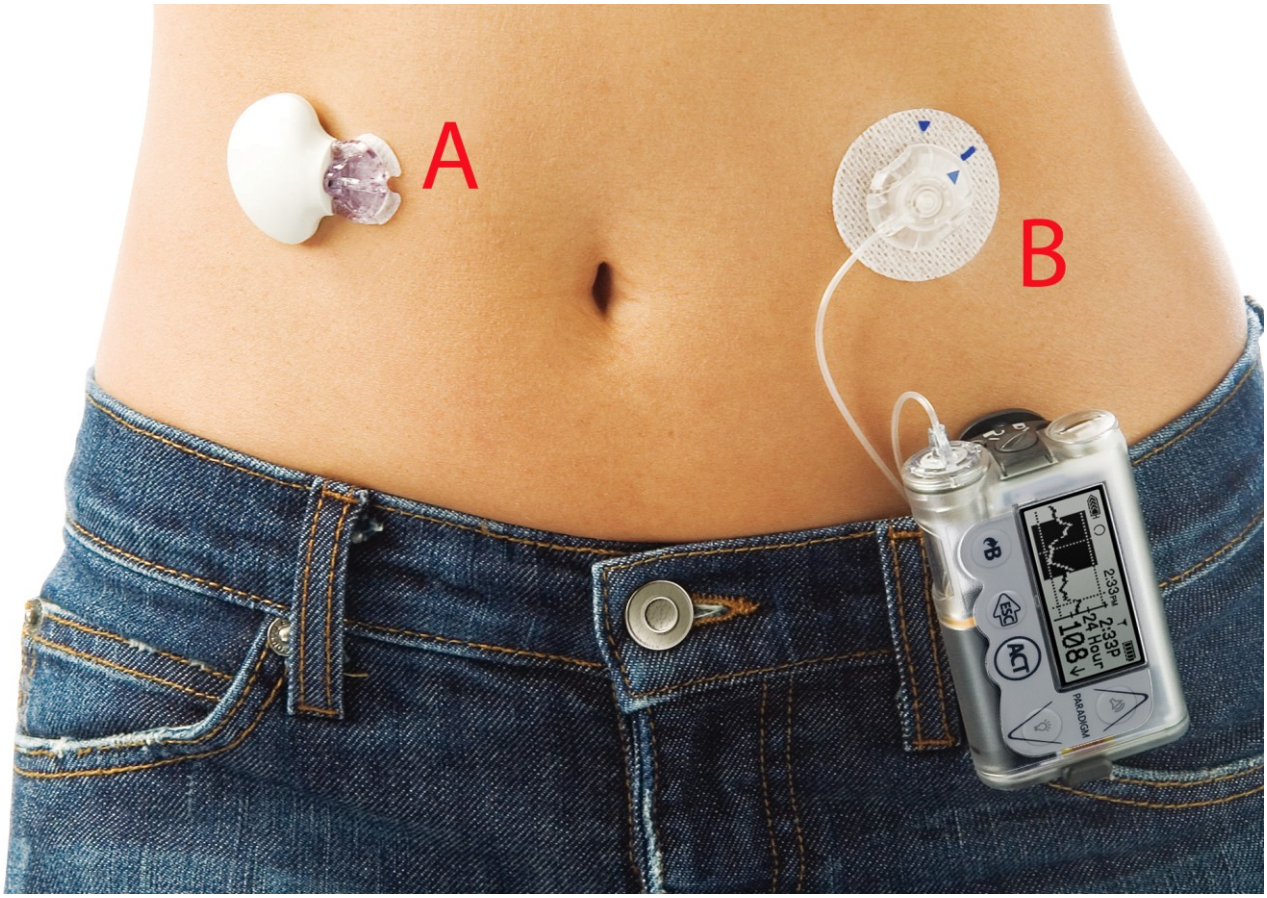

Figure 1: Overview of Continuous Glucose Monitor (A) and insulin pump (B).

Chapter 4 – Method

4.1 Testing philosophical theory by letting it meet the world

The theories described in chapter 2 perform an interesting and difficult form of acrobatics by describing the human subject and its place in the world, without relating to the Cartesian subject/object divide. I believe their role is philosophically important. Still, I wonder how well they are suited to tackle modern human-technology relationships. My concern is therefore to challenge these theories. To be able to do this I conduct a form of experiment. Using Mol`s method of *empirical philosophy* I compare the two theories to real life experiences of people using self-measuring technology in diabetes care.

I have conducted 6 extensive qualitative interviews, 5 with people who have experience with using the CGM, and one with a diabetes nurse who instructs people with diabetes in the use of the technology. This has resulted in altogether 7.5 hours of interview material – 147 pages of transcribed text (see appendix 5) – that I have analysed. In the following I will describe the methodology I have used throughout the empirical work and the following analysis, and the challenges I have faced.

4.2 Empirical Philosophy

Empirical philosophy is a methodological tool that can help connect philosophy closer to real life experiences. Mol suggests that philosophical theories should emanate from concrete examples, instead of peoples experiences only being afterthoughts, added on to a theory when it has already been constructed: "Good case studies inspire theory", she argues. They "shape ideas and shift conceptions. They do not lead to conclusions that are universally valid, but neither do they claim to do so" (Mol, 2008, p. 10).

Mol's philosophy is a modest science; it does not attempt to find big truths and eternally valid theorems. Instead it attempts to describe the experiences of people and tries to see how their

perception of reality is shaped and enacted by their surroundings. She focuses on everyday events and experiences rather than abstract concepts, she privileges "practices over principle" (Mol, 2002, p. 32). So her philosophy is thoroughly grounded in particulars and real life experiences, and this goes further than just presenting real life examples next to theories. She leaves epistemology in the background and allows ethnography into the foreground (ibid., p. vii). As Noortje Marres puts it in a review of Mol`s *The Body Multiple*:

> [I]t seems to me that what makes Mol's philosophical project stand out from others', is not so much empiricism in general, but a very specific brand of it. Many philosophers, after all, have drawn on empirical studies in their work, from Karl Marx to the philosopher of the cognitive sciences Paul Churchland, etc. Mol's project rather stands out because of an ethnographic mode of philosophizing, informed by social theory. Accordingly, her work would be better labelled as "ethnographic philosophy," or "ontological sociology" if these terms were not so ugly (Marres, 2004).

Specifically Mol has allowed the narratives told by people she interviews to become the central pillar of her thinking:

> I do not claim to be proposing something new here, but rather seek to raise the status of 'telling stories'. Rather than a matter of 'merely' sharing private experiences, telling stories is a form of public coordination. It is a part of how we govern ourselves and each other (Mol, 2008, p. 102).

It is this consistent focus on the unpredictable, jagged storylines of real life experiences that I am inspired by in this thesis. I differ from Mol`s philosophy in that I try to use her method in relation to theories that do try to move beyond the particular. Though Foucault's self-writing and postphenomenology do not attempt to find single ontological truths, both theories are part of larger ontological systems. Still, my method in this thesis is heavily indebted to Mol`s modest idea of philosophy, where "ontology is not given in the order of things, but that, instead, ontologies are brought into being, sustained, or allowed to wither away in common, day-to-day, sociomaterial practices" (ibid., p. 6).

Mol does not lay out her method in much practical detail. So to flesh out the method that guides my empirical work, I have turned to *grounded theory*, a methodological tool that shares

much with Mol, but that is described more thoroughly by a large group of theoreticians, amongst others Martyn Hammersley, Paul Atkinson, Steinar Kvale and Svend Brinkmann. This theory also tries to "derive inductively from data a theory that is "grounded" in data" (Merriam, 2002, p. 7). As with empirical philosophy this method does not have as its goal to study cases that are representative, but stories that might nonetheless be of theoretical importance (Clarke, 2003, p. 557).

4.3 Interviews

The interviews are by far the most important source of information in my work. I have spoken to people with type 1 diabetes in the age group 20-45. It is their stories that create the basis for the analysis in the thesis. Therefore I have taken great care in how I have found my interview subjects, and how I have related to them.

4.3.1 Finding the interview subjects

As Hammersley and Atkinson point to, finding and accessing the sources one need for an analysis, is complex, and often filled with negotiations and bureaucracy:

> Gaining access to informants can be quite complex, sometimes as difficult as negotiating access to a setting. Indeed [...] it may even be necessary to negotiate with gatekeepers before one can contact the people one wants to interview (Hammersley and Atkinson, 2007, p. 104).

This has been the case for my thesis as well. The disease, and the technology I have studied, are very private topics for persons with diabetes, both mentally and physically. So I took great caution in the manner I approached the potential participants. I decided to go through some official gatekeepers in the diabetes community. Luckily, these gatekeepers were positive and supportive towards my project. I have reached my conversation partners through two organisations: *Ungdiabetes*, the youth and young adult organization for people with diabetes in Norway, and *Norsk*

diabetikersenter (NDS), a private foundation working with diabetes care, supported by *Helse Sør-Øst*, the government health organisation responsible for specialized health care in the south eastern part of Norway. Two of the people I spoke with, Anne and Bård, I got in touch with through the leader of *Ungdiabetes*, Ida Trældal Rystad, the remaining three I reached through NDS. Aasa Løvfall, the nurse I interviewed, works at NDS and was also my main contact in the foundation.

The group of participants was also defined by the organisations that I reached them through. Ungdiabetes of course got me in touch with young people. NDS has a wider range of patients, but still, the ones that were willing to speak with me were all under the age of 45.

In addition my selection of informants was not random within these organisations, but was dependent on people who actively wanted to talk to me after receiving my invitation through the gatekeepers. Originally I feared that this would mean that only people with relationships to their technology that closely followed the scripts defined by the health professionals would contact me. This turned out to not be the case. My small group of conversation partners ended up consisting of a good mix of people with very different relationships to their technology and their disease. Still, for a larger survey, I would suggest trying to reach a wider selection, as my approach might have prevented me from talking to important and interesting sections of the technology's user group, for instance people who do not feel knowledgeable enough about the machines, and do not want to talk about them, or user who have a more conflicted and turbulent relationship to their health professionals.

4.3.2 Conducting the interviews

My approach to the interviews was inspired by empirical philosophy and grounded theory. Mol consciously has a symmetrical relationship to her interviewees. She asks them to describe exact events and activities, rather than probe them for their abstract opinions. Through this open and

concrete process she allows them to become what she calls "co-researchers" (Mol, 2002, p. 11). I have attempted the same procedure for my interviews. Similarly, Hammersley and Atkinson argue that open qualitative research based on grounded theory should not be narrow down to one specific research design or research category beforehand, but be open to input from the sources (Hammersley and Atkinson, 2007, p. 3).

Based on these assumptions, I have conducted my interviews as what Kvale and Brinkmann call *semistructured lifeworld interviews* (semistrukturerede livsverdensinterview) (Kvale and Brinkmann, 2009, p. 19). Before the conversations I created a thorough interview guide (see appendix 2), but allowed the interviews to be steered by the topics and examples my conversation partners valued. This also fits well with Mol's approach.

4.3.3 Ethics

As mentioned, diabetes and diabetes technology is a private topic. I took several precautions to shield my informants from unwanted attention, to prevent specific details from being connected to specific people and to make sure that the interviewees understood what they were participating in.

In order to conduct my interviews, I had to make an application to *Norsk samfunnsvitenskaplig datatjeneste* (NSD), the Norwegian Social Science Services, in order to have my research approved. The NSD reviews projects that intend to attain and discuss private information from participants, to make sure they are ethically sound. My project was approved (see appendix 3)

But I also had other ethical concerns that were related, not to bureaucratic evaluations, but to the face to face meeting with the participants. As Kvale and Brinkmann argue, ethical challenges typically arise in interview situations because of asymmetrical power relations between the interviewer and the interviewee (ibid., p. 95). The person organising the conversations has both

defined the structure of the meeting, and knows how the information gained will be used.

To try to counter this asymmetry and attempt to get closer to a situation where the informants became "co-researchers" rather than just sources, I started each interview by thoroughly describing the goal of my project to my informants, and explaining that they were allowed to decide which topics they would and would not talk about. In addition, I presented them with a contract that stated that they agreed to take part in the conversations, and that the information gathered would be treated with respect, and most importantly, sufficiently anonymised (see appendix 4).

Throughout the work with the information gathered from the interviews, in interview transcripts, the condensed interview portraits and in the thesis itself, I have at all levels anonymised the informants with diabestes. The nurse I interviewed is presented with her real name. They have all been given new names, and I reveal no exact information about where they live or work. Concerning the specific disease histories of each person, complete anonymity is difficult to attain, as that would drastically diminish the material I collected. Such information might enable health practitioners that know the patient to recognize them. All subjects were informed of this possibility, but still wanted to participate.

Anonymous sources can also be problematic for another reason. As Kvale and Brinkmann point to, it can on the one hand protect the participants, but on the other become an alibi for the scientist, by allowing him or her to analyse the interviews, without the possibility of being contradicted (ibid., p. 91). To avoid this problematic situation, I have added the full transcripts form the interviews to the appendix (see appendix 5, on CD).

4.4 Process of analysis

The material I have collected for analysis in this thesis is vast, and the ways of analysing it innumerable. As this is a qualitative analysis, I have not attempted to find representative patterns

through my interviews, instead I have used what Sharan B. Merriam calls *purposive sampling.* She describes this, by referencing Patton, as a method of homing in on the "information-rich cases", those "from which one can learn a great deal about issues of central importance to the purpose of the research" (Merriam, 2002, p. 12). So what I have been looking for through my material is cases, stories and experiences that might be singular and very specific, but that connect directly to the theoretical challenge I am trying to discuss.

This mapping of a material does not lend itself easily to charts, spread sheets or pattern recognition software. Instead, the analysis has to be an intrinsic part of the interviews themselves, and later a part of the hermeneutic circle between me as reader and the interviews in their transcribed form. This is, as Merriam also points to, one of the prime characteristics of qualitative research: "*[T]he researcher is the primary instrument* for data collection and data analysis" (ibid., p. 5). And as far as the interviewees are co-researchers, the analysis of their experiences can in no way be clearly separated from the data itself. As Kvale and Brinkmann put it, you cannot make any sharp distinction between data and the reinterpretation of this data in qualitative research (Kvale and Brinkmann, 2009, p. 76). This unseverable connection between collecting data, and analysing it, is one of the main pillars of grounded theory, as Adele E. Clarke puts it: "[In grounded theory c]oding begins immediately, and theorizing based on that coding does as well, however provisionally" (Clarke, 2003, p. 557). So my analysis started at the first moment of my first interview, and has continued throughout the writing process.

Though all these academic points hold true, and are important as to how I conducted my analysis, the real life distillation of my research data was also defined by more worldly limitations and challenges. To be able to manage 147 pages of interview text, I had to make choices, and focus on some information rich examples, and leave others out. This distillation process was very much a practical, almost mechanical work. I read, and re-read the transcribed document, marking what I

found interesting. Then re-reading what I had previously marked, distilled the selection even further. Based on these selected parts from each conversation, I wrote portraits of each of the participants (see appendix 1). Through this process of writing, what interested me with the different excerpts became clearer. As a result I could transport the most interesting parts of the conversations into the analysis, where I would directly connect them to the theoretical aspects of the thesis (see chapter 5).

One major hurdle for the analysis and presentation of my data is the fact that all the interviews were conducted in Norwegian, so the quotes had to be translated into English. As the old saying goes, *'traduttori traditore'* – to translate is to betray. Nuances change with translated words, and new sentence structure might alter the original meanings and sentiments of the conversations. To prevent this from affecting my own analysis, I have through the writing process worked with the Norwegian text, and only in the final stages of the writing translated the quotes into English. In addition, I have consciously tried to preserve the original structure of sentences, so that they are closer to the original Norwegian, as long as they grammatically still pass as accepted English.

4.5 A short introduction to the interview subjects

My interview subjects formed a fairly heterogeneous group. As sketched below, their ways of relating to the technology are also very diverse.

Anne

Anne is a woman in her early twenties who has had type 1 diabetes from infancy. She has, following several situations where different insulin injecting machines have failed, grown to distrust technology that act independently on her body. So she refuses to use an insulin pump and even insulin pens. But she was very pleased with the CGM in the period she used it, since it allowed her

to gain more insight into her body, and allowed her to control herself in more detail. Unfortunately, her need for constant knowledge about what her blood sugar was at any time, led to major disruptions of her everyday life. She now no longer uses the CGM.

Bård

Bård is in his mid-twenties, and has a relaxed relationship to his disease. His blood sugar levels have not always been well regulated throughout his youth. Therefore, to better control the condition, he has been using the CGM for some time. But he removes it frequently, so that he does not feel too confined by it. Still, he is also dependent on the machine's measurements, as he uses them to calibrate his own *gut feeling* of what his blood sugar level is. So even when he is not wearing the machine, it affects his life through what he is able to sense in his own body.

Marit

As a woman in her mid-forties, Marit has been following the development of diabetes technology for the last four decades. Marit`s problem, unlike most other people with diabetes I have spoken to, is not that her blood sugar levels are too high, but that they are too low. She also, like Bård, is affected by the numbers derived from the CGM. She can have physical sensations from seeing specific numbers on the display, without them being, necessarily, connected to a body state.

Glenn:

A man in his early forties, Glenn has a turbulent relationship to his disease, and also to the technologies surrounding it. He daily fights and negotiates with them. They wake him at night, and alert him when he does not want to be alerted. His uneasy partnership with the technology results in that he often removes the machines, or turns them off.

Susanne

Susanne is a mother of two and has a problematic blood sugar that fluctuates at night. This stressful situation has made her dependent on the CGM, and overall she has a good relationship to it. She closely, almost subconsciously, follows the machines instructions, but at the same time, can perform adjustments when she feels the machine is wrong.

Aasa

Working at *Norsk Diabetikersenter*, Aasa is one of the nurses who instructs the users of the CGM. She has good insight into the complexities that follow from using self-measuring technology. In addition she has to relate to the fact that the machines can also reveal information to her that her patients might not want her to see.

Chapter 5 – Analysis

5.1 Analysis: Displaced gut feelings

The theories described in chapters 2.2 and 2.3 attempt to, respectively, describe the creation of the self and talk from the perspective of the subject. They both discuss how we are affected by the technologies we relate to. But how do the theories work when applied to contemporary devices?

As I will analyse in depth throughout this chapter, my empirical work suggests a wide range of different, and intermingling, ways that users react to self-measuring technology in diabetes care: Some use the technology to *calibrate* their own sense perception, others *outsource* the job of sensing to the machines altogether, some *internalize* the information from the technology, so that they have sensations related to numbers on the machine display rather than from reactions in their physical bodies, others have their lives completely *colonized* by the machine logic. In addition the machines also have specific displays that, so to say, reveal the users body to other people, the technology *snitches*, to put it somewhat bluntly, to health professionals, revealing what used to be secret and unobtainable bodily states. These different experiences share some traits. They all talk about how sensations that for a person not connected to this kind of technology are simple feelings of a body and a self, become externalized and complicated when the user is connected to the CGM and pump. Their own personal gut feelings become displaced, so to speak.

In the following I will try to see the two theories in relation to this empirical maelstrom. Through this I hope to first of all un-blackbox the technological relationships I have encountered by feeding them through the theoretical apparatus of the two philosophies. Secondly, I will ask what the result of this analysis has to say about the theories, and their aptness in describing the situations.

5.2 New Hupomnemata – The CGM and the pump as ambivalent self-creators

Michel Foucault's concept of self-writing technology provides an elegant and thought provoking account of the genesis of the modern subject. In the loop between a self-writing technology and the

user a room for reflexivity is created, and through this the human can organize the impressions from a chaotic world and the constantly changing sensations and notions of his or her own body.

But if the human self was created through interacting with technology in this manner, that would also mean that 'the narrative of the self' is still in a continuing process of being made and changed in step with alterations in self-writing technology. So how does Foucault's theory work if it is used not on ancient Greek technology, such as the *hupomnemata*, but instead is applied to contemporary technology that perform self-writing? Can it describe present day creations of selfhood?

I will argue that the theory of self-writing in many ways is apt to analyse many contemporary human-technology relationships, but it has problems describing the complexity that follows when technology with a strong intentionality enacts and defines the body of its user. In this respect, there seems to be some elements of modernity present in Foucault's otherwise non-modern concept. In the following I will present this argument through analysing the stories told to me by persons with diabetes, about their relationship to self-measuring devices.

5.2.1 Calibrating the body

At first glance the similarities between the self-writing technology described by Foucault and the ones studied here are striking. As the written texts in ancient Roman and early Christian societies, these machines, through writing the body down and representing it, give its user an externalized gaze of his or her own flesh. They allow a person with diabetes to take the fragmented parts of his or her own corpus, and unify them. They open a room where the person can control and reset the borders of the self.

One example of this process in action can be seen through the story of Bård. He is a person with type 1 diabetes in his mid-twenties who lives with his partner and their dog in a small town in

the southern part of Norway. Bård has been poorly regulated for much of his youth. But with an insulin pump and a Continuous Glucose Monitor (CGM), the knowledge and feeling of his own body has been expanded. He is able to unite and control the quarrelling elements in his bloodstream. Bård has to calibrate his CGM twice a day, so that the values it shows are to be trusted. He takes a manual blood sugar test and plots the numbers into the pump and CGM. But he then again uses the machine's display to calibrate, so to speak, his own gut feeling. This is necessary because he at times becomes confused about whether his glucose levels are high or low. The sensations in his body are too unpredictable and vague. So he needs the CGM to regularly redefine his ability to guess what his levels are.

> **Bård:** Because earlier it has been so that when I had high values, I become nauseous, and maybe even throw up. But lately it has been the other way around. And that has been really, seriously scary. Because I might have had low levels and then barfed. And then I believe that my levels are high, and inject insulin for that. Because I have not been wearing it [the CGM]. And that's the reason I have started using it again now. You need a reassurance on how things actually are, when you haven't experienced such a situation before.

Still, he can feel that the CGM confines him. That is why he sometimes decides to remove it to live without its messages and advice. But even when he is not wearing it, he still has the calibrated gut feeling that he can trust, at least for a time.

> **Bård:** Because I don't walk around with it all the time. Well, the last time I took a break, I went maybe two months without it. To feel free. That is quite wonderful. But then you still have that feeling in the body, and you can sense that 'this is what the levels should be now'.

But after a period away from the machine, he needs a new calibration. Therefore he comes back to the CGM.

> **Bård:** But when you suddenly one day realize that, oh no, now I need a new handle on how this works, or how that sensation is, then it’s okay to connect it again.

The CGM and the pump therefore become a sort of continuous reassurance for Bård. Through its externalization of his blood sugar it creates a mirror outside the body that makes Bård able to better control himself. David Morris has also noted this effect of diabetes technology: "In general one cannot feel one’s glucose levels as reliably as one can feel, say, one’s body temperature or an upset

stomach. Diagnostic devices compensate for these problems with the symptomology: they allow one to interpret moderate symptoms when one feels them" (Morris, 2008, p. 413). Through this Bård's sense-perceptions are expanded and he gets a greater feeling for the border of his own body.

This process is very similar to Foucault's self-writing. Though the pump automatically 'writes' the body, the person with diabetes actively uses this text to expand control over his own bloodstream, and "unify [...] heterogeneous fragments" into one self (Foucault, 1998, p. 213).

The concept of self-writing is as optimistic as Foucault gets. In his theory the self can shape itself, and find a form of freedom within the structures of power in nature and society. But though the CGM and the pump in this specific situation seem to fit well into Foucault's ideas, a closer study of this form of self-writing technology reveals that the differences are also prevalent.

5.2.2 Who is holding the pen?

An interesting aspect with the pump and CGM is that they can become an intrinsic part of the users own sense perception, the way Bård describes. He is allowed to see and then control what has earlier been his body's subconscious processes. In her analysis of the self-control of persons with diabetes, Mol points to the Greek definition of a *free man*. It is defined as someone who is in control of his conscious bodily functions: "As a Greek citizen, you were supposed to train yourself in order to bring your voluntary muscles under ever better command of your will". If you controlled your body from "a decisive centre", you would not become someone else's slave (Mol, 2008, p. 36). Through the self-monitoring technology, the range of 'voluntary muscles', here interpreted as the parts of the body that are consciously controlled, expands, and accordingly so does the self.

But for persons with diabetes this process is slightly more ambivalent than in the stories from ancient Greece. For this knowing of the 'muscles' is not conducted form a decisive centre. Instead it seems as if this enlarged body has two administrative cores: The fleshly and the

mechanical centre. As Peter Sloterdijk argues, being human in a large extent has to do with being in and feeling a body. We get our shape, not just from language, but from corporality (referred in Verbeek, 2011, p. 34). And for persons with diabetes using self-monitoring technology, corporality is defined partially by the displays on machines. So the technology actively takes part in setting the borders of the being. One can frame this through Akrich and Latour's concept of *script*. The technology becomes a co-script-writer, together with the person with diabetes, on the script that defines how the body should be seen and used (Akrich, 1992). The situation for the person with diabetes has similarities with Latour's description of how a gun and its human user together can form a gunman, as described in chapter 2.3.3. But the continuous measuring technology belonging to a person with diabetes, do not become ready-at-hand, a silent part of the human being. It is not a simple tool. In its moulding of the user's life it is very much present-at-hand, an active negotiation partner or adversary. All in all, a question that in relation to Foucault's wax tablet is quite easy, becomes more complex, namely: Who is holding the pen?

Whereas the *hupomnemata* is described as an enabler by Foucault, the agency of the diabetes technology needs to be taken more seriously when concerning self-writing. The effects on the self are disruptive and defining. As Mol – and Verbeek (2011, p. 9) – argues, the best way of looking at this situation is to accept the technology as holding a form of intentionality:

> The blood sugar measurement devices do not just allow for more frequent registering of the facts: they alter the value of the facts. What was 'a proper' blood sugar before the miniature measurement machines, may be 'a high' blood sugar now. Blood sugar regulations is made tighter by self-measurement (Mol, 2000, p. 14).

Through this the machines also alter what the subject is. "Measuring blood sugar levels is not only something that happens from the outside, it may also markedly alter a person's '*intro-sensing*'" [my emphasis] (ibid., p. 17). The patients' sensations of the body is thus changed and augmented following the gaze of the diagnostic devices. The patient is seduced to sense in a certain way (Mol,

2004, p. 50). With this seduction, a new series of tensions arise, tensions that are not attributed by Foucault to the relationship between a writer and his or her text.

5.2.3 Outsourcing knowledge to the other centre

One of these areas of tensions becomes clear if we follow the story of another person with type 1 diabetes who uses the CGM and the pump. Susanne is a woman in her late thirties who lives in a large city in the eastern part of Norway. She was diagnosed with type 1 diabetes late, just when she had turned 20. So she has a vivid memory of living without the disease. Still, during the last 18 years she has been able to adjust fairly well to the illness. But it has been hard to regulate at times, because of unexplained nightly fluctuations in blood sugar levels. Via the pump and the CGM she now keeps tight control.

But though the devices have helped her cope with the diabetes, they have also had different, unforeseen consequences: They have made her more distanced from her body. Unlike Bård, she uses the machines to give her the knowledge she earlier had to feel her own body to obtain.

> **Susanne:** I think that you actually become kind of inattentive. Because before I got the sensor, I really had, really kind of had a competition with myself, that I had to guess the levels I had before I made a measurement. To teach myself to know my body better. But I really stopped doing that completely after I got the sensor.

The sensor gives her a number that defines her glucose values. But the sensation of a specific blood sugar level in her body is much more nuanced, diverse and vague than the digits on the pump screen. It involves the whole body.

> **Askild:** Can you describe the feeling of having a blood sugar level of 10? How does that feel in your body?
>
> **Susanne:** I actually think...that I believe, it's really hard to describe. It's something with the breath and the taste you have in your mouth, whether you are high or low, and when you have low blood sugar, then I quickly start to kind of shake. But if I'm high I become really dry and thirsty. But the thirst comes first, and then I feel at once this kind of acetone smell, if I'm really high.

Since she got the CGM she has spent less time on this kind of internal sensing and manually trying

to understand her longterm blood sugar. This has at times led her to potentially dangerous situations, where the display has shown her the wrong number, and she has gone far too long before noticing that she was high or low.

> **Askild:** So you're saying that really you're worse at that now? That you have given over the work to the pump?
>
> **Susanne:** I have given it over to the pump because the alarm is supposed to give me notice when I become high.
>
> **Askild:** So what if you would have to go back to using syringes or injector pens again [without the CGM]?
>
> **Susanne:** That would mortify me. Hehehe. So...but I have experienced that the sensor has failed. And the people who do the support claim that I must have calibrated the machine just before I have eaten or something.
>
> **Askild:** How has it failed?
>
> **Susanne:** Because the sensor showed in the morning that I was low, so I ate a sandwich, then I felt really shaky. Then it continued to beep when I got to work. So I ate some more. So I thought that this can't be right, because I'm not low. Because then I felt in my body that this had to be high. And then I turned out that I was really at 18 or something.
>
> **Askild:** How long did it take before you said that this has to be wrong? How long did you trust the measurement?
>
> **Susanne:** Three hours I suppose.

In this example Susanne suppressed her own bodily sensations and supplanted them with the machines' numbers. The self-awareness she was seduced to perform by the machines was limited, and highly technologically defined. This switch to letting the mechanical parameters define the body, is not present in Foucault's description of the idealized self-writer in front of the wax tablet. As David Morris argues, "to mediate the experience of one’s body with technology is to boil oneself down to a medical condition summarized by a few numbers. [...T]his leads to a dissociation between oneself and one’s body, to a dualistic objectification of the body" (Morris, 2008, p. 413).

5.2.4 The subject and the object body

The view of the body enacted by the machine moves away from what Mol and Law calls the "fleshy situatedness of our modes of living" (Mol and Law, 2004, p. 2). Instead they present the body

through a *pathological gaze*. This medical view, according to Foucault, became prevalent at the start of the 19th century. Instead of doctors discussing with the patient how the body felt, the subject and its physical being were separated. The medical staff started examining the body without minding the patients' sensations. It was a separation between the *subject* body and the *object* body. With the subject body of the patient removed from the examination, the body was just flesh. As Mark Sullivan aptly describes it, as quoted by Mol and Law:

> [T]he medical subject and the medical object were not two different substances within the same individual, but two different individuals: one alive and one dead. Knower and known are epistemologically distinguished with the physician assuming the position of the knower and the patient/corpse the position of the known (ibid., p. 2).

So with the modern shift in medicine, self-interpretation and self-knowledge was eliminated from the body. As Mol says, the body healed by modern science is not self-aware. With the pathological paradigm a forest of different technologies that were able to look inside the 'dead bodies', sprung up: X-ray machines, ultra sound, MRIs and CT-scans. The self-measuring devices used by people with diabetes can be seen as a continuation of this development. But with the CGM and the pump the pathological gaze was transferred from the medical professionals to the patient him- or herself. The knower and the known are still separate, but the person with diabetes is both. It is an extreme version of the self-autopsy of the ancient writers. This development has diverse effects. Bård has come to understand his body better, letting the view of the object body develop the sensations shaping his subject body. Susanne on the other hand, does not any longer notice the trembling in her fingertips or the dryness in her own mouth when her blood sugar is high.

What the patient can end up with when the machine's pathological gaze becomes internalized, is a view of the body that is a caricature of the Cartesian subject/object divide. Different parts of the flesh are split apart and become distant objects that can be manipulated and controlled by a self that is separate from them. This objectification of the body in medical terms can be seen as a process to reshape a new feeling of selfhood, what Charis Cussins calls *ontological*

choreography. She argues that a person's objectification of his or her body in certain situations can help them configure themselves, and can "bring about desired changes in [his or] her identity" (Cussins, 1996, p. 600). This process is similar to the one presented by Foucault, where writers described and deciphered their "bodily sensations, the impressions of malaise, the various disorders one might have experienced" (Foucault, 1997, p. 217). But in the close human technology relationship between persons with diabetes and their devices, the machines as much as the human defines this objectification, and the patient can lose touch with his or her flesh. Objective findings – as Mol argues, and Susanne's story suggests – can erode the subject's sensations (Mol, 2000, p. 15). So the diabetes technology has an ambivalent relationship to the human user, and who is in control is much more complex compared to older, simpler self-writing technology (Danholt, forthcoming).

For Susanne, the pump and the CGM have for the most part been a blessing, her blood sugar levels are stable. In part because of these machines, she has been able to bring forth two healthy children, something that is not a given for a person with diabetes with difficult to control fluctuations in glucose levels. But the way she feels and controls her body has changed. Before she got the pump and the CGM, she would manually monitor herself, and try to make longterm overviews of her levels. To manage this she used what has been a common companion for many persons with diabetes: a diabetes diary. This is a book where you write down what you eat at different meals, and what your manual blood sugar measurements are. In many respects a classical self-writing device. After Susanne received the CGM, she completely stopped writing in the book. Now the machine takes all the notes.

> **Susanne:** I do see that after I got the sensor, I don't write in those books at all anymore, how much food I have eaten and what my blood sugar was before and two hours after. I did that before.

The notebooks are important because they do not sense on behalf of the user. Mol quotes a diabetes nurse who stresses the importance of these manual books, instead of the automatic machines: "It's easy [to use automatic measuring devices], sure, but maybe it's too easy. Scribbling down a number

is also a way to let it get through to you. To make it sink in" (Mol, 2000, p. 16).

So the self-relation created through the CGM and pump is more complex than the one between the man and his wax tablet as described by Foucault. Who the notetaker is, and what is written is strongly shaped by the technology's intentionality. And the CGM and the pump can also go further. They can completely colonize the way their user lives his or her life.

5.2.5 Overwhelmed and colonized by the pathological view

There are many different ways people appropriate the Continuous Glucose Monitor. Susanne lets it take over some of what used to be the work of her conscious self. Bård uses it to strengthen his own strong centred self. Others move in a different direction, using its enactment of the body to surveil what their 'unconscious muscles' are doing in excruciating detail. Let us analyse the story of Anne. A woman in her early twenties, she is currently starting her higher education. She lives with her parents on the outskirts of a city in the eastern part of Norway. As an infant she was diagnosed with type 1 diabetes, so she has no recollection of an existence before the disease. Throughout her life she has had a turbulent relationship with her illness, and she has tried a wide range of technologies to help her cope with her insulin-dependence. They have had varied and surprising effects on her life. Anne has never been particularly fond of talking about her diabetes. But when I contacted *Ungdiabetes,* the youth organization for persons with diabetes in Norway, to get in touch with someone who had knowledge about using the pump and the CGM, she volunteered immediately. She felt there was a lack of knowledge about the real effects the different technologies have on the user:

> **Anne:** [I]f there was one thing I really missed, that was focus on the aids, the treatment things, kind of. The measurement devices and the pump and the syringes and all that. There was focus on how you were treated and how you... How much insulin you used and such. So I thought to myself, if there is one thing I can contribute with, if that's possible, it's toward change, or focus on the things.

Anne, and her whole family, have always had a very active relationship to the diabetes. Through

Anne's youth, her mother created manual overviews of her longterm values using Office Excel, and they were discussed around the dinner table. Through this conscious struggle with the disease, she was striving towards one ideal: A steady blood sugar. When I visited her at her home, she brought a basket up from the basement. It contained different technologies she had been using throughout her life. It was filled with injectors, insulin pens, monitoring devices and insulin coolers. But perhaps most telling was a small purse for carrying a measuring device that she had used in her early teens. To try to make this hospital looking container more pleasing for a young girl, she had decorated it with colourful markers. Covering the whole front of the bag, in big yellow numbers, she had written "5.5": The holy grail for persons with diabetes, the definition of a well regulated blood sugar level (see figure 2).

Figure 2: Anne's self-decorated container

Unlike many of the other people I have interviewed, Anne's main concern has not been that the machines create a racket every time there are small changes in her bloodstream. It is the other way around. She has never allowed the disease to recede from view and be handled by the technology. For instance she has refused to continue using the insulin pump. One of the reasons for this is that she has had some dramatic experiences with it. Several times it has given her other insulin doses than she has ordered it to. Especially one instance, where her pump started injecting its entire insulin reservoir into her body, has made her distrust machines that act on her behalf. Now she even refuses to use insulin pens. Instead she applies small syringes, that she fills manually with insulin from glass containers. Because the syringes are see-through, she can with her own eyes control the amount of insulin that she injects herself with.

Her distrust of the insulin injecting machine and her goal of attaining a blood sugar level of 5.5, made her obsessive about measuring her disease. At the most extreme, she would manually measure her blood sugar 200 times per day, a rate that immensely interrupts the normal rhythm of any day. So when she was allowed to try the CGM, it was a revelation. With it she felt that she could both have the constant overview that she needed, but also in some ways relax with this knowledge. It was a machine she could negotiate with.

> **Anne:** It was absolutely super. I didn't have to closely feel, I didn't have to concentrate and wonder what my values were, because I knew. Or I knew that, there was maybe a fifteen minute delay on the machine. But then I could see the trend, I could see the curve, and that was more than enough. So if I went down, I could kind of foresee a low blood sugar, or I could see that it was going up. That I really didn't care about that much, because I didn't bring insulin [when I was exercising]. But just the fact that I had the overview, to not have to closely sense. One does not walk around sensing that I am a number, but I have to concentrate and feel the parameters I have in my body in a way. To check if I have the blood sugar that I actually have.

Though the CGM made her need for constant knowledge of her blood sugar easier to manage, her obsession did not change when she started using the CGM. If something it became more prevalent. She had to prick her fingers less often to draw blood for a manual test, but her knowledge of the inside of her body became all consuming, and her life started conforming to the machine’s updates:

> **Anne:** In the end I walked around with it. I never put it down. I never put it in my pocket. I walked around with it in my hand, and checked every 5 minute update.
>
> […]
>
> **Anne:** So it was breakfast, and then I sat there staring at it, really.
>
> **Askild:** So you had it laying on the table as you ate?
>
> **Anne:** It was there [points] and the food was there [points]. Hehe.
>
> **Askild:** You watched it while you ate?
>
> **Anne:** Yes. It became my newspaper so to speak. [...I]t gives you a message when it transcends a certain number. And I sat there waiting for it, that beep, that signal.

While Susanne gave away responsibility to the CGM and the pump, Anne's whole life became defined by how her body was presented through her diagnostic devices. Her attempt at reaching the steady blood sugar level of 5.5 became completely disruptive for her life. How measuring devices in this way can control and confine user's life has also been commented on by amongst other Cristiano Storni, who observed the same effect with a user of a manual blood pressure monitor (Storni, 2010, p. 545). This reaction, Storni argues, is a common reaction to self-monitoring, an effect that does not follow the script from the designers of the technology.

This can all be seen in relation to the earlier mentioned ideas of Mol about how diagnostic devices *perform* a patient's disease through defining its parameters. All things we surround us with, that we mirror ourselves in, contribute to shaping us. But, argues Mol, the diagnostic devices play a more important role as they actively interprets and defines – much more so than a notebook or a hupomnemata – how the disease and body are read: "[I]n this great chain of beings, the blood sugar measurement device is a crucial link. It has altered, and may alter in each patient again, the targets set, the *normal* blood sugar level strived after" (Mol, 2000, p. 14). 5.5, Anne's eternal goal became so important for her life, in part because the machines she regulated her diabetes with talked the language of 5.5.

So this modern self-writing technology becomes a large, acting entity, its intentionality potentially overshadowing the users. But in addition it also brings other actors into the self-writing process.

5.2.6 The body snitch: A machine that gives your flesh to others

The continuous measurements performed by the self-measuring devices are logged in the machines. As long as it is connected to the patient's body, it will write down narratives describing his or her blood sugar, and the actions he or she performs to regulate it. This information can then be used and analysed by the medical professionals. The bodily functions that were before only detected as a vague sensation by the patient, or that one could see traces of in longterm *hba1c* measurements, suddenly becomes a visible and sharable entity.

Aasa Løvfall is a diabetes nurse at *Norsk Diabetikersenter* in Oslo. She tells the story of a 14 year old girl with type 1 diabetes, who has used the CGM for a test period. Her blood sugar levels were very high, and they tried to figure out why. The transcripts of her values, taken from her CGM, showed that she had not been taking insulin at times she claimed she had, either out of fear of low blood sugar, or in an attempt to lose weight.

> **Aasa:** It is very revealing, we do see what you are doing under the covers in a way, so we talk a lot about this with the patients when we upload the information. When I upload this I can see that... She sits here and says 'I took insulin to my food every day, of course'. And then it becomes apparent here that that just isn't true...You kind of have to prepare the patient for this. And say that this isn't because I want to control you, it's because we are going to get this to work, right?
>
> **Askild:** One can say that this is a kind of surveillance in some ways.
>
> **Aasa:** True, in good and bad ways.
>
> **Askild:** Where one both surveilles oneself, but the health personnel also gain this knowledge. Do patients react to that?
>
> **Aasa:** Some say that in this specific period I don't want you to download it. And then there are some that download it at home, and choose for themselves what they will bring and show us.

So as Aasa explains, some patients try to retain the privacy that so easily disappears with the use of

continuous measurement devices. But the machines are not designed for this. Parts of the software created for the pump and the CGM is specifically written to give instructions to the medical personnel, and not to present the information directly to the patient. When the blood sugar values are loaded into a specific software in preparations for consultations, Aasa and the other nurses get the blood sugar developments of a patient shown as a long graph, and in a box underneath this, they get a series of tips and instructions. For instance: "Consider counselling your patient to modify bolus amounts when sensor glucose values are rising (upward arrow is present)" (see figure 3.1 and 3.2). The pump has two different displays so to speak, to two different user groups: The person with diabetes and the health practitioners.

So in the process of transferring the view of the objective body to the person with diabetes, the whole medical system also gets to take part in what was formerly private, internal sensations of the self. In modern self-writing technology such as this, there is not only the human using the text. The machines act independently and also allow other people to enter into the intimate process of shaping the body, and thus the subject itself.[3]

[3] For a different example of technology revealing private information about body states, see appendix 1, page 10.

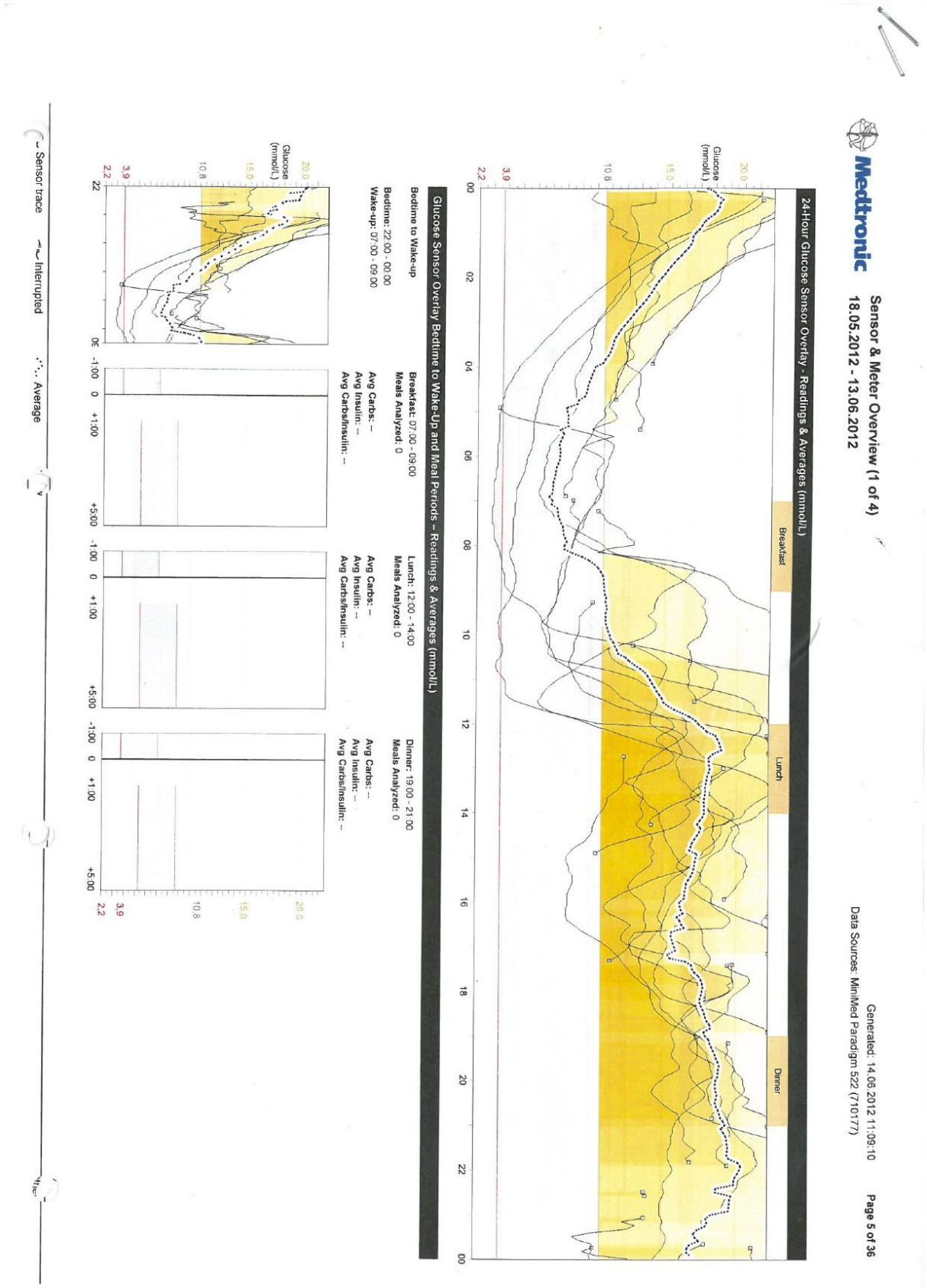

Figure 3.1: Analysis of blood sugar levels from anonymous patient, I

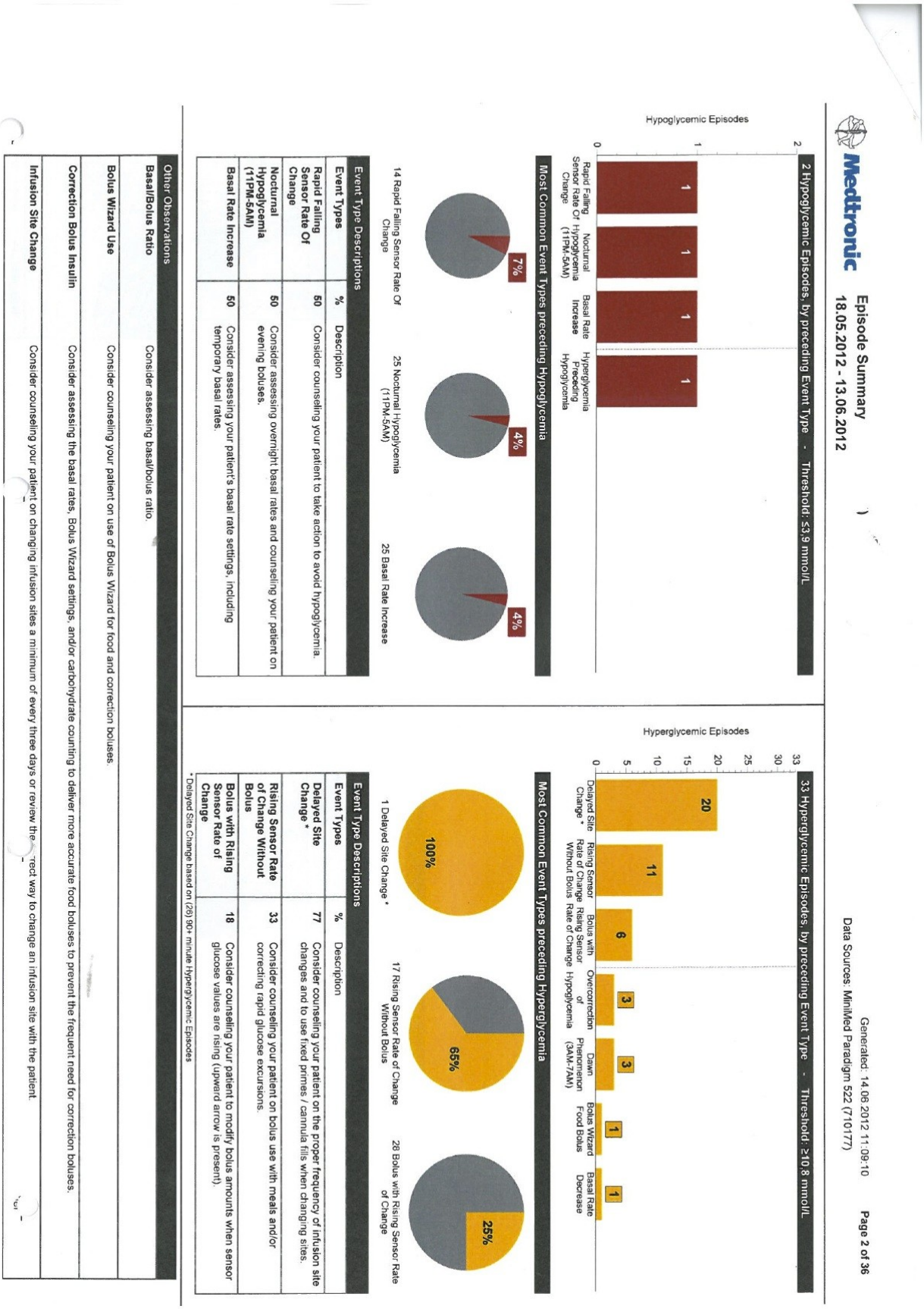

Figure 3.2: Analysis of blood sugar levels from anonymous patient, II

5.2.7 Negotiating identity with the new hupomnemata

Diagnostic devices are appropriated by their users in diverse ways, and the technological intentionalities are complex and hard to foresee. Still, a common trait in the stories told this far is that the devices are active participants, and do not simply follow the commands of the persons with diabetes. This though, does not mean that the user is somehow sedated into the logic of the machines. When the user's and the technologies' plans collide, there is much room for conflict, but also of manipulation and negotiation between the entities, sometimes ending up with de-scriptions of the medical professionals' script for the technology.

Susanne for instance, has learned how to negotiate with the machine, so that it will not bother her with recalibrating at times when she is busy. Instead of making a manual blood sugar measurement, she just plots in the number that is already on the pump screen. This of course puts her in the danger of having a machine that is calibrated wrongly and might for instance lead to her getting an insulin shock. It is against what the medical professionals would recommend. But for the most part it works for her. And she is allowed to keep the rhythm of her life the way she herself plans. She is able to attain control over how her own identity is made.

That diagnostic devices in this manner are used not purely following their medical purpose, but instead to let the user live out and define his or her identity has also been noted elsewhere. Lena Mamykina et al. has described how the persons with diabetes they studied used a type of imaging technology that was scripted to give them an overview over their eating habits, to help shape their own identity. They used the technology not only to document their food intake, but to tell stories about their lives:

> Some of these stories helped individuals address their negative emotions and reaffirm their positive attitude to health management. Other stories helped individuals re-establish their confidence in their competence and ability to manage their health. Yet others helped them to maintain a *consistent sense of self*, and create a link to their lives from before they were diagnosed with the disease. Researchers in social sciences argue that these three driving factors are the essential components of constructing one's identity [my emphasis] (Mamykina, 2010, p. 2).

They were able to see themselves and shape themselves in relation to the being they saw in the technological mirror. They appropriated the technology as a classical self-writing device.

But this kind of digital negotiation can also be a dangerous process. Anne also negotiated with her technology and the disease. But in her attempt to get the diabetes to yield to her, she was still trapped in the framing of the world presented by the CGM and pump's display: The language of 5.5. As most persons with diabetes, Anne dreamt of escaping the constant fluctuations of her disease. She wanted the numbers she was monitoring to stabilize. But unlike others she started scheming with the machine to be able to actually go through with this. And her means of doing this were potentially lethal:

> **Anne:** [I] could never want to let go of the numbers, in the sense that I just let the blood sugar go, and pretend that I do not have diabetes. So my solution, to flee from the diabetes and still fulfil the demands from my mom and dad, was to stop eating, so that it didn't, so that the blood sugar didn't go high and I could stop measuring myself, and I could stop injecting insulin, because I don't need insulin when I don't eat.

She had been able to find a way to negotiate with her disease and her technology in such a way that her blood sugar was at a fine level, constantly close to 5.5, and she did not have to use insulin. But this came at the cost of her physical body's health. In the end, she was put under psychiatric care. And her psychiatric doctor demanded that she should not be allowed to continue using the CGM:

> **Anne:** Then my psychiatrist said that I was not allowed to get it back because at that time I worked so incredibly hard with just measuring six times a day the way I was supposed to. I was completely devastated. Since I had gotten word that it was a possibility for me [to continue using the CGM]. But when I look at it now, when I do have the possibility of having it back if I ask, I don't want to, because I will be too caught up in those numbers, and those curves. And I am afraid that I will go nuts again to be quite honest.

5.2.8 The complexity of the new hupomnemata

Anne, Susanne and Bård's stories describe how complex these negotiations are when they are preformed through and with self-measuring devices such as the pump and the CGM. Bård uses it to learn to know his own body better, thereby allowing the fleshly self to remain centre stage. Susanne

outsources responsibility that she used to have over her body to the technology, thereby diminishing the role of her old centred self. Anne on the other hand, was for a time almost controlled by the logic, definitions and goals of the machines.

Common to all these stories is that the self-writing technology is far from a passive entity. This complexity in the self-creation through self-writing is not detailed in Foucault's original description of classical self-writing, as presented at Collège de France. A theory of self-writing for contemporary technology actively has to relate to this technological complexity.

The self that rises from the uneasy communion of humans and active self-writing technology is different from the 'modern man'. It is a self with many faces, with internal quarrels and discussions, with parts that are both inside and outside the borders of identity at the same time. Not one concrete solid unity, but a unity where the different elements – flesh, brain and digital wires – are clearly showing, and where the gathering of their different intentionalities is a continual, at times frustrating process with many captains at the helm.

Postphenomenology also tries to navigate these uncharted waters. But as I will analyse in the next chapter, the challenges for this theory seems to be slightly different.

5.3 Me, myself and I: Postphenomenology and a subject with many cores

The idea of self-writing has to be nuanced when faced with contemporary technology such as the CGM and the pump. The concept as described by Foucault at Collège de France seems rigged not to talk about situations where the *self* is *actively* written *by* the materials it is written *on*. Postphenomenology on the other hand, does not have a problem with this. It is well suited to handle the ambivalence of non-human intentionality. But as I will argue in the following, the CGM poses some different problems for this school of philosophy: Situations where this technological intentionality is an inseparable part of the human body and self, but still clearly a distinguishable

entity.

5.3.1 Internalizing the machine: Mixing hermeneutic and embodied sensations

Through the hermeneutic display on the pump, what was formerly hidden activities of the body become active parts of the user's lifeworld. Verbeek has described technologies with this kind of body centred sight. He uses the example of ultrasound, and argues, in line with Mol, that such machines have a particularly potent way of altering the moral relations we have to our bodies:

> Such technologies make visible parts of the human body, or of a living fetus in the womb, that cannot be seen without them. But *the specific way in which these technologies represent what they "see" helps to shape how the body or a fetus is perceived and interpreted and what decisions are made*. In this way, technologies fundamentally shape people's experience of disease, pregnancy, or their unborn children. [My emphasis] (Verbeek, 2006, p. 366).

When an ultrasound image shows the fetus as a single entity, with the mother's womb only as background, the machine helps shape the picture of this as an independent being. Similarly, as Anne, Bård and Susanne's stories have told us, body-centred technologies shape the lives and self-perception of their users. The ultrasound machine seems to fit ideally with what Ihde calls a *hermeneutic relation*. The fact that the technology conveys the body, does not seem to complicate matters. At first glance this also seems to go for the Continuous Glucose Monitor and the insulin pump. But a closer scrutiny reveals that these machines cannot be defined as simply parts of a hermeneutic relationship.

My empirical study suggest that certain technologies do not only give input to the human user, the technology itself *becomes* the input through its enactment of the a body or a disease.

An example of this is Marit. She was diagnosed with type 1 diabetes when she was eight. This was back in 1978 long before the modern regimes of frequent measurements. In the beginning her overview of her blood sugar came only from urine samples twice a day. Much has changed since then. She began using manual blood sugar measuring technology when they first became

available in the mid 1980s. Later she was an early test patient for different insulin pumps. So she has tried and experienced the turbulence of early machines. Now she is a consistent and thorough user of both the pump and the CGM. Still there have been troublesome aspects of her illness.

Unlike most other persons with diabetes I have spoken to for this thesis, Marit's difficulties have not been that she has too high glucose counts, but too low ones. At times her *hba1c* has dropped down to 4, the average level for people without diabetes. This has left her in constant danger of getting *hypoglykemia*, or insulin shocks. The reason she is so low has been her fear of late complications because of the disease. Marit was originally given the CGM to make her able to push her blood sugar levels upwards.

> **Marit:** When I see that the blood sugar is on 10-11 maybe, earlier I really couldn't handle it. Now, when I am at *Diabetikersenteret*, and my longterm levels are moving upwards, they ask me if I feel it's okay. No, I doesn't. 'I see that you are satisfied', I say, 'but I don't feel it's okay'.

Since it has been hard for her mentally to allow her levels to go up, Marit has forced herself into a consistent and unrelenting regime when using her technology. She has never allowed herself to take a break from it, and has instead let it actively take part in her body. The pump and the CGM have become such an intrinsic part of her own sense perception that it is the numbers on the display, not the vague symptoms produced by her fleshly body, that makes her sense things. At times she cannot feel whether her values are high or low. But if she takes a glance at the display on the pump, the sensations set in.

> **Marit:** But then you see. If I then look at it and see that now its 15, or if I get an alert. *Then* I feel it.
>
> **Askild:** So then..
>
> **Marit:** Theeeen...
>
> **Askild:** So it opens up something?
>
> **Marit:** Then I feel really bad.
>
> **Askild:** But if you hadn't seen that number, you wouldn't have?

Marit: I don't think so. But I don't know, but I don't think so. So it's really, really weird.

[...]

Askild: So it has changed your sensation of your body a little bit?

Marit: Yes.

Marit's use of the display to trigger physical sensations is similar to Bård's, as analysed in chapter 5.2.1. But there is a difference between the two that I believe is important in this theoretical discussion. Bård used the information defined and displayed by the machines to calibrate his own gut feeling. Marit feels the machine, not her gut. One can of course discuss whether or not the two cases are just nuances over the same relationship between the user's sensations and the machines' enactment of the disease. But the fact that the technology, at least to a certain degree, not only allows the user to feel his or her body in a specific way, but actively becomes inseparable from the thing being felt, points to the theoretical blind spot I am getting at in this analysis. In Marit's case the body and the machines are clearly intertwined.

5.3.2 Allowing the cyborg into a human centred theory

This again leads us to re-examine the question of the "modernist settlement". The attempt to move beyond this simplistic duality defines the philosophy of both Foucault and postphenomenology as described in this thesis. But since postphenomenology has as one of its goals to try to maintain the subject as a meaningful entity to use as a starting point for analysing the world, every infringement on the classical autonomous human subject creates knots that have to be untied. These questions have also challenged postphenomenology's predecessors. The phenomenologist Hubert Dreyfuss, amongst other, argues that a mind and a body cannot be clearly separated. So an artificial intelligence, he argues, a mind created without a human flesh, would not be able to become a conscious subject, because it would lack a body (Ihde, 1998, p. 44). It would not be able to be

intelligent because it "neither perceives, moves, nor acts", as Ihde puts it, channelling Dreyfuss.

The phenomenologist Patrick Heelan is addressing the same question, but from a slightly different angle. He argues that what constitutes a body can also be mechanical. The human and technology blur so close together that when we for instance see the temperature through a thermometer, it should not be understood as an hermeneutic relation, but as a direct perception of the world (ibid., p. 45).

These two seemingly opposite positions can be interesting to see together. The self is hard to separate from the body. Is it the torso? The brain? The basal ganglia? The pineal gland ? The self is made up of an interplay of different parts of our body. And with diabetes technology, this body physically becomes lager. The 'thermometer' of the CGM becomes a part of the flesh and blood.

Let us again take a look at Bård's relationship to his technology. He uses the CGM to train his own gut feeling, but he has also programmed the insulin pump to camouflage itself as a part of his body. He has adjusted his background dose of insulin, so that it automatically goes down every morning, and up after lunch. In this way he can have his own morning and lunch routines without thinking about his diabetes. Bård starts working early, as he is a craftsman, but he does not want to eat breakfast until a bit later in the day.

> **Bård:** So then I have adjusted my dose, so I don't need to eat before nine. My opinion is that it's nice to eat breakfast at work, rather than stress with it early in the morning.
>
> **Askild:** So then you have taken little insulin in the morning, so your blood sugar won't go to low?
>
> **Bård:** Yes. And then after lunch I have turned up the dose again. So that I don’t have to inject insulin, because I often forget that. So it's really nice to have it in there [in the machine].

He has given over some of the responsibility for injecting insulin to the pump and CGM. The hormone levels that the pump and the CGM maintain do not only adjust the mechanical parts of the patient’s body. Lack or surplus of insulin effects the mood, personality and thoughts of the person with diabetes. So when the technology defines and enacts these hormones and glucose values, these

machines are clearly a part of Bård's self. For short periods of time his machines seem to act more in line with what a pacemaker does. As with Marit, technology becomes a complete part of the human body, not only something displaying it. But unlike a pacemaker – or such a simple thing as food – the technology still remains present-at-hand and external, while it becomes intertwined with the body.

At this confusing junction, postphenomenology stands face to face with the c*yborg enigma*. The cyborg, this monstrous unclean, unbordered entity, is famously defined by Donna Haraway as "a kind of disassembled and reassembled, postmodern collective and personal self" (Haraway, 1991, p. 163). Haraway is not interested in the attempt at keeping the human subject as the starting point for understanding reality. At least not through the ideal or 'centred self'. She instead sees its dissolution and mutation as a fascinating development, and the old notion of the one-centred being as conservative and destructive:

> The boys in the human sciences have called [the] doubt about self-presence the "death of the subject" defined as a single ordering point of will and consciousness. That judgment seems bizarre to me. I prefer to call this doubt the opening of non-isomorphic subjects, agents, and territories of stories unimaginable from the vantage point of the cyclopean, self satiated eye of the master subject (Haraway, 1988, p. 586).

The idea of the humans as an uncertain node, something constantly changing, nothing and many things at the same time, should defeat the old cyclopean human ideal. She is interested in the human without a pure centre, existing in what Susan Leigh Star calls the *high tension zones*, the in-betweens, therefore always subversive to the power systems that define and organize (Star, 1991 p. 45).

Verbeek has tried to counter the problems that phenomenology faces when meeting the cyborg, by partially accepting Haraway's premise.

5.3.3 Postphenomenology 2.0: Cyborg and composite relations

Based on this acceptance, Verbeek has tried to further develop the post-phenomenological concepts. In addition to Ihde's four terms, he has added two more: *cyborg* and *composite* relations. These are concepts that focus on meeting points between man and technology that question the subject's privileged role. They are either very close, or decidedly separate from the human.

The *cyborg relation* describes situations where the human technology bond goes further than embodied relations, where there is no meaningful way to separate the user of a technology and the tool itself:

> When microchips are implanted to enhance the vision of visually impaired people, when antidepressants help to change people's mood, or when artificial valves and pacemakers help to make people's hearts beat, there is no embodiment relation anymore – at least, not a relation which could compare to wearing eyeglasses or using a telephone. True, in both cases it is an association of a human being and a technological artefact that experiences reality, but in the "bionic" or "cyborg" association there actually is no association of a human and a technology anymore. Rather, a new *entity* comes about [my emphasis] (Verbeek, 2008, p. 391).

Two formerly distinct units have merged together until their combined view of the world is inseparable. It is "a new experiencing entity" (ibid.). Verbeek describes this concept with this figure:

(human/technology) → world

If *cyborg* relation is an extreme version of *embodied* relations, *composite* relation builds on the *hermeneutic* connection. In line with his attempt to move postphenomenology closer to the symmetrical view of ANT, Verbeek has created a concept that describes how technology relates to other non-human actors, without direct human interference. As mentioned above, the intentionality of technology allows for a world of action that is theoretically not different from human acts. To – from the human perspective – be able to understand this external form of actant, postphenomenology needs to break free from what has formally been its only perspective, the human subject, and also start to relate to the viewpoint of the technology:

> There is a double intentionality involved here; one of technology toward "its" world, and one of human beings toward the result of this technological intentionality.[...R]ather than putting these intentionalities in the service of human relations to the world – as is the case in Ihde's hermeneutic relations – they explore technological intentionalities as relevant *in themselves* (ibid., p. 393).

This is a natural conclusion following from Verbeek's acceptance of objects' intentionality. Technology can be situated towards its world, the same way humans are situated towards our lifeworld. Verbeek describes this *composite relation* through this figure:

human → (technology → world)

With Verbeek's two new concepts, room is made for a more nuanced analysis of how humans and technology react and live together. But there are technological grey zones that undermine Verbeek's clearly defined borders between the different worlds.

5.3.4 The unified cyborg

It is important to note that the cyborg-concept as defined by Verbeek is different from that of Haraway. And Verbeek also uses it differently in specific contexts throughout his own writing. What he calls cyborg *intentionality* he uses to describe any situation where a relationship of human and technology act together to coshape what ends up being a common intention, be it through an embodied, hermeneutic, (quasi-)alterity, background, composite, or cyborg relation. So cyborg *relations* is a subgroup under the concept cyborg *intentionality*. It is, as above defined, a relation where the boundaries between man and the machine do not only blur together. They merge to form a new uniform entity. It is this idea of the cyborg that I analyse in this thesis.

Unlike Haraway's cyborg, this being is still similar to the old idea of the subject, described in the Cyborg Manifesto as "the cyclopean, self satiated eye of the master subject" with its "single ordering point of will and consciousness". To describe his cyborg relation Verbeek uses the examples of a person equipped with a pacemaker or using an anti-depressant drug. It is a cyborg

consisting of many parts but still with a decisive centre. A person on a prescription for Prozac is changed by the pill, but he or she does not become many.

And opposite, in Verbeek's definition of the *composite relations*, the human and the technology have two clearly separate intentionalities, "one of technology toward "its" world, and one of human beings towards the result of this technological intentionality" (ibid., p. 393). Reality though, does not come with such neatly defined borders.

Let us take the example of one of my interviewees, Glenn, who has a very turbulent relationship to his illness. He was diagnosed with type 1 diabetes in his teens, and quickly rebelled against it:

> **Glenn:** I really have to honestly admit it, and say that diabetes, is a living hell, to be honest. I think it is bothersome, completely fucked up. Yes. If there was a way to operate it away I would have done it at once. Even if it had cost me money, then I would have sold my apartment and had it done. I have to honestly admit that. That would have been my first priority. I don't wish diabetes on even my enemies. I can live with it. There is no doubt about that. But it's a living hell. You have to prick yourself. And to have that crap in your body all of the time. It's not cool.

Now in his early forties, he uses both an insulin pump and a CGM, but he still argues ferociously with them, and the disease. He is dependent on the machines, and allows them to perform a lot of the calculations and regulation of his glucose values, the same way Bård and Marit does. Still, he often grows frustrated with them and the way they make themselves and the diabetes constantly present. The pump and the CGM tells him when his values surpass 10, and when they drop below 4. This means that he receives a steady stream of beeps and vibrations.

> **Glenn:** I think it's ridiculous that it beeps when the levels are going up, and when they are going down. I really find that ridiculous. It's okay that it tells me when it's on its way down, and then be done with it. But when it goes up, and then beeps every half hour, that I find ridiculous. It is supposed to do that, so then it's okay, I guess.
>
> **Askild:** What do you do about it?
>
> **Glenn:** I turn it off. I can't do anything else about it. Because the levels are going up. And I have given insulin, and I can't give more insulin because then I will be sick [...W]hy is it beeping now?! It's because it's too high, or because it has fallen too quickly so the [calibration] contrast is wrong. Then I just turn it off. And it turns itself off as well sometimes. It's ridiculous. It should be a lot better at keeping shut, instead of howling and beeping all the time.

Glenn and the technology are far from being one simple unit. Neither are they two separate entities. They fight and negotiate with each other. In addition they fight and negotiate with the disease in the object body, both together and on their own. It is a messy situation, comparable to Stars *high tension zone*, a place where forces meet and react, but are not defined properly by the prevailing systems of definitions or standards (Star, 1991, p. 45).

Another example of one of these in-between situations can be told by Susanne. Since she constantly wears the self-measuring technology it has become a very intrinsic part of her life, and even her mind. She has incorporated the communication from the pump and the CGM, so that she often does not even notice that she acts upon them. The clearest example of this is when the machines wake her up at night with commands. She reacts to the information, almost without noticing it:

> **Askild:** Is it so that you can remember it the morning after, or does it happen completely automatically?
>
> **Susanne:** Automatically. Like now, I can't remember that I did it last night.
>
> **Askild:** You saw it now when you looked at the pump? How can you...how do you sleep? Do you have the pump by your side, and then it vibrates, and you wake up?
>
> **Susanne:** Most likely it has been beeping. But most likely it has been beeping several times, with 10 minute intervals, if I haven't heard it the first time. So then I have my partner, who hears it and wakes me up.

But even in these more or less subconscious interactions with the pump, Susanne does not only follow its commands.

> **Askild:** So then you press OK for its suggestion?
>
> **Susanne:** Yes. Or really I just plot it in. It says that I for instance have hight blood sugar levels, for instance 15.2, so then I plot in to Bolus Wizard 15.2 and then he suggests insulin.
>
> **Askild:** So then you have to press OK for Bolus Wizards suggestion?
>
> **Susanne:** Yes. But what I have really learned...if he suggests something at night I should subtract a little from it, or I will go down and end up having low blood sugar.

She seamlessly floats between letting it be a part of her body, and actively using it as a foreign lens

to see her body through. One could argue that her self therefor is scattered and opened up, but still a subject. Mol also points to this decentralisation of the self in diabetes self-treatment:

> [W]ith measuring and feeling, the boundaries of the body-in-practice are partially permeable. An active body incorporates bits and pieces of the world around it, while its action may be shifted out of the body, excorporated (Mol, 2004, p. 12).

The technologically enlarged body switches between being a part of the self, and being a dead object. It flickers between what in classical phenomenology was seen as the "rich lived world of intentional stances" and the "absolutely inhuman" object world (Latour, 1999, p. 9). The relationship between the machines and the user is neither cyborg, nor quite composite. It is embodied, but still somehow hermeneutic. Like a radio set between two stations, the CGM and the pump, exists in two different realms at the same time. It is a state that current postphenomenological concepts do not seem to handle.

5.3.5 Postphenomenology's flaws

Parts of this theoretical deficiency has also been mentioned by others. Latour has dismissed phenomenology in its entirety, arguing that its only possible use is as a sort of theoretical cadaver that ANT can salvage some aspects from. He argues that no matter how much the theory tries to avoid it, phenomenology, and its different theoretical offspring, will always reinforce the subject/object divide inherent to its structure:

> Phenomenology jettisoned the two poles of pure consciousness and pure object and spread itself, literally, over the middle, in an attempt to cover the now gaping hole that it sensed it could no longer absorb. Once again the modern paradox is taken further. The notion of intentionality transforms a distinction, a separation, a contradiction, into an insurmountable tension between object and subject... The phenomenologists have the impression that they have gone further than Kant, Hegel and Marx, since they no longer attribute any essence either to pure subjects or pure objects. They really have the impression that they are speaking only of a mediation that does not require any pole to hold fast. Yet like so many anxious modernizers, they no longer trace anything but a line between poles that are thus given the greatest importance. Pure objectivity and pure consciousness are missing, but they are nevertheless – indeed, all the more – in place (Latour, 1993, p. 58).

This, Latour argues, also hold for postphenomenology (Latour, 2007, p. 61). Through trying to

cover the grey area between humans and nonhumans, the theory is cursed with reinforcing the abyss between the two. This might be the reason why the theory seems so clumsy when trying to relate to technology such as the insulin pump and the CGM. Latour's ANT and Mol's empirical philosophy, do not have a problem moving back and forth between the two realms. ANT does not particularly care for analysing the human subject, and Mol avoids the subject/object enigma by not talking about *being* at all, and instead chooses to study how diseases, technology and humans are *enacted* (Mol and Law, 2004, p. 7). Postphenomenology on the other hand constantly has to awkwardly negotiate the chasm.

The theory's overzealous focus on physical entities instead of acted entities, has also been criticised by *pragmatists*, a philosophical school that phenomenology shares many traits with. Larry A. Hickman, who can be labelled a neo-pragmatist philosopher, points his finger at the heart of the problem I have analysed in this chapter. He picks apart one of Ihde's example of how technology's mediation shapes and defines the world view of its user. Ihde puts up a distinction between western style technology for navigating at sea, and the "perceptual navigation system", used by pacific natives. When westerners explorers encountered the navigation techniques of the natives, consisting of the reading of minute weather and current signs, they could not understand it, because they assumed "that instruments must mediate controlled interactions with nature". But through this reading, Hickman argues, Ihde commits postphenomenology's recurring sin. He unwittingly divides clearly between human world and the object world. When Ihde's argues that the western sailors could not fathom navigation not mediated through technology, he himself also fails to see the natives' knowledge as what it is: their navigational technique can be read as technologies, albeit *mental* ones:

> In these cases there is more than just "perception." There is a (cognitive) deployment of conceptual tools and techniques – instruments – to achieve certain goals. For [the philosophical pragmatist John] Dewey, the distinction would not have been between the instrument and the non-instrumentally perceptual, but between instruments of different functional types: those that are relatively exterior to the organism and those that are not (Hickman, 2007, p. 1).

So pragmatist philosophers would just define the pump and the CGM as a specific functional type, not as part of the body or not. The machines are not different from say a mnemonic device used by a person with diabetes to organise his or her life.

These critiques share much with what I have found in my analyses. Its difficulty of moving between dead matter and living subjects, makes postphenomenology a clunky theoretical tool. But still, as I will argue in the next chapter, I see its perceptive as a fruitful way of speaking of the human subject's technology relation where the technology's own intentionality is put to the fore.

Chapter 6 – Discussion

6.1 Discussion: "To make it kind of – my own"

In this thesis I have analysed the theories of self-writing and postphenomenology by comparing them to the real life experiences of people using contemporary self-measuring technology. The meeting between stories told by the interview subjects and the two theoretical frameworks reveals some interesting areas of friction. My empirical work suggests that the idea of *self-writing* needs modification to handle such new self-writing technology as the CGM. Foucault's concept does not relate to an active technology, instead there seems to be left over elements from modernist, dualist thinking in Foucault's concept. *Postphenomenology* as described in this thesis has a different problem with the subject/object divide. It does not undermine non-human actors in its theoretical framework. Its problem is that it does not talk about multi-centred actors: The human on antidepressants is one entity, the human and the blood sugar monitor are two entities. Reality is more complex.

The following question naturally arises: Can one loosen these theoretical knots? In the following I will present possible ways the two philosophical perspectives can be enriched through exchanging concepts with each other.

6.1.1 The new hupomnematas: The wax tablet writing the man

The reading of Foucault's concept of self-writing in this thesis might seem unfair to the thinker. Few philosophers have focused more on how we are shaped by external forces and factors. Still I think it is fruitful to read Foucault's lectures on self-writing from Collège de France without this implied, unmentioned, context. It forces us to try to find a language to *actively* connect this concept to the non-modern tradition, and to contemporary technology that is more complex than for instance the hupomnemata.

The self-writing devices Foucault describes from the Greco-Roman and early Christian

societies, are pure tools, not entities that can act without human scripts. He describes how the self through these technologies and techniques takes the many impressions from the outside world, and our own bodies, and shapes them into one identity, as a choir consisting of "tenor, bass and baritone voices, men's and women's tones" (Foucault, 1997, p. 214) that together become one harmonious whole. But the voice of the machines themselves is not discussed as a part of the choir.

Postphenomenology's concept of technological *intentionality*, as inspired most notably by Latour and ANT, allows us to describe such technologies as something more than dead matter. Therefore I suggest that to make room for a description of *new hupomnematas* – technologies of the self for our time – this form of intentionality must actively be brought into the concept of self-writing. With more active, attentive technologies the notion of the self becomes more porous, closer resembling Haraway's multi-centred hybrid being. I argue that allowing this idea into Foucault's concept, is just a natural continuation of the un-blackboxing of the modernist idea of the human individual that prompted Foucault to describe the concept of self-writing in the first place. Seen in relation to the rest of Foucault's work, this reading of self-writing seems natural. It makes self-writing closer connected to for instance the idea of *governmentality,* another of the concepts Foucault defined late in his life. This theoretical construct also blurs the boundaries between man and the world, and sees the subject as at the same time shaped by and shaping the structures of power (Foucault, 2002a).

6.1.2 The Siamese Cyborg: Postphenomenology and the human in the wax

Trying to suggest amendments to the theory of postphenomenology based on this thesis' empirics is a bit more complicated. Unlike the self-writing concept, this theory seems to have more working against it.

As described at the end of the previous chapter, the theory has been heavily criticised by

writers from several different schools of philosophy. They question its ability to breach the subject/object gap. Still, these apparent weaknesses do not mean that the theory is without merit. Verbeek specifically states that it is a philosophy that does not claim to draw one big ontological system (Verbeek, 2005, p. 164). Its worldview is definitively human centred, even after Verbeek added the concept *composite relation*. And this perspective, I argue, is in itself an important contribution to non-modern theory. In the advanced musings of Haraway and Latour, the perspective that we all see the world through in our daily life has been neglected. But just because this view is not an essential, foundational concept of reality, does not mean that we should not analyse the world through this perspective. Rather, it seems like a good starting point to try to understand how we should live as selves, what we as shaky and unpure subjects should be. Without such a first person viewpoint, the image of man might just slowly be "erased, like a face drawn in sand at the edge of the sea", as the young Foucault feared (Foucault, 2002b, p. 422). The clunky and difficult negotiation that postphenomenology performs, plays a role in seeing the human as not only theoretical points in a network or an unbordered collection of functional types, but as units that we can actually live as.

But if we are to continue to use postphenomenology to analyse the world, what changes have to be done to its structure to counter the flaws that I have discussed? Again it might be helpful to borrow concepts from another theoretical tool kit. Unlike postphenomenology, the concept of self-writing easily allows external objects into the body, and the body out into objects, without the two entities having to be seen as one cyclopian unity. As Foucault says:

> The role of writing is to constitute, along with all that reading has constituted, a "body" […] And this body should be understood not as a body of doctrine but, rather – following the often-evoked metaphor of digestion – as the very body of the [writer] (Foucault, 1997, p. 213).

Cussins' concept of *ontological choreography* shares many similarities with self-writing in this respect. As mentioned in chapter 5.2.4, Cussins argues, through her study of women trying to

become pregnant with the help of infertility clinicians, that objectification of the body is not necessarily the same as loosing subjectivity. Instead the objectification allows the self to better manage itself, it can be a movement on the road to a new wanted feeling of selfhood (Cussins, 1996, p. 600). As the interviews presented in this thesis show, the self seen in the laboratory light of the self-measuring devices naturally splits up into many fragments. If we allow the perspective of Foucault and Cussins into postphenomenology, its problem of not accepting the self as subject and object at the same time, with potentially opposing intentions going on simultaneously, might be more easily handled.

How can we then describe the many-kernaled subject, with different elements floating between being a part of the subject and exterior to it? It is not a cyborgian entity, at least not in Verbeek's interpretation. The human and the machine instead form a relationship more similar to that of siamese twins. If we should try to draw a figure to describe this constellation within the existing framework of postphenomenology, we would end up with this constellation, almost resembling an Escher painting:

$$\text{human/technology} \leftrightarrow (\text{technology} \rightarrow \text{human})$$

The human/technology, in an unstable *cyborg relation*, watches itself through the technology's *composite relations* to the body. And the other way around the machines reading the body, watch and define the borders of human/technology. This multi-centred subject exists within what I, building on the postphenomenological concepts, choose to call a *cyborgian-composite self-relation,* or more simply put: it is a *siamese cyborg*.

This complex and many kernelled being performs a continuous internal discussion, or dance if you will, with itself. For a person living with both diabetes and the machines, the boundaries of the self are constantly redefined. And it is in this choreography that they have to live. The unique

technologically enhanced insight presented through the technology, allows the user to control what used to be unknown parts of his or her body. But it also pushes many people with diabetes into problematic relationships with themselves, and their self-building technologies. The sensations of their bodies and selves, their gut feelings, are hard to place. Their struggle to negotiate a peace between the elements that constitute their identity is a lifelong one, and one that lacks a good language to be described. For the most part, the person with diabetes is forced to travel without any maps or directions, alone through an unknown terrain on their journey towards a wanted subjectivity. Once again Anne's description is apt:

> [I]t's very intriguing to make the [diabetes technologies] into a larger part of me, because it feels so unreal, or kind of...I had such a distance to them. I wasn't very fond of having diabetes, so then I really worked to make it into a part of me. To make it kind of – my own.

I hope that I through this thesis have given a small contribution to the mapping of this difficult landscape.

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Appendix

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Appendix 1: Portraits of interview participants

In the following I present portraits of each of the participants I talked to for this thesis. All the texts are based on the interview transcripts (see appendix 5), and in large parts consist of direct quotes. These texts are in no way necessary to read to understand this thesis, but they bring more depth to the descriptions of how using self-measuring technology affects the users' lives.

"It became my newspaper, so to speak"

On the distrust of mechanical injections and the problems following constant self-surveillance – an interview with 'Anne', 26.05.2012

Anne is in her early twenties and currently starting her higher education. She lives with her parents on the outskirts of a city in the eastern part of Norway. At age one she was diagnosed with diabetes, so she has no recollection of an existence before the disease. Throughout her life she has had a turbulent relationship with her illness, and she has tried a wide range of technologies to help her cope with her insulin-dependence. They have had varied and surprising effects on her life. Anne has never been particularly fond of talking about her disease. But when I contacted the organization *Ungdiabetes* to get in touch with someone who had knowledge about using a Constant Glucose Monitor (CGM), she volunteered, because she felt there was a lack of knowledge about the real effects the different technologies has on the user:

> **Anne:** [I]f there was one thing I really missed, that was focus on the aids, the treatment things, kind of. The measurement devices and the pump and the syringes and all that. There was focus on how you were treated and how you, how much insulin you used and such. So I thought to myself, if there is one thing I can contribute, if that's possible, it's toward change, or focus on the things. (1.00)

Anne's relationship to the different technologies has changes drastically through her youth. The way she today controls her disease is quite unusual, and it has come about partially because of her experiences with different diabetes technologies, especially the CGM.

From an early age Anne tried to negotiate and de-scribe her technologies. She tried to redesign them, both their looks and their function. For instance, she was troubled by how large and inconvenient the early manual blood sugar monitors were. She tried to combine the monitors and the needle that she used to prick her fingers before a blood test, so that they could become one tight device. She also made her own, smaller containers for her blood sugar monitors and insulin pens, that looked less like medical machines, and more like what a young girl would want to be seen with. She painted the containers with markers, drawing flowers and heart. On one she has written 5.5 in big yellow numbers, the ideal standard blood sugar level (see figure 2).

> **Anne**: I was sewing my own tiny containers, that were a lot smaller then these [the old container], because these containers were twice the size and they took a lot of unnecessary space. So the big measurement devices ended up fitting in my pockets. That was really nice. (3.48)

She even opened the machines up, to try and make them smaller, but this of course often destroyed them.

> **Anne**: I remember that I removed the plastic covering once. To see if I could make what was inside take less space. It all resulted in that I destroyed it and got the batteries to fall out.

Her attempts at redesign did not go any further then opening up the machines, redecorating them and creating new containers for them. But when she became older the process of becoming less alienated from the technology remained an important, but also frustrating task.

> [I]t's very intriguing to make the [diabetes technologies] into a larger part of me, because it feels so unreal, or kind of...I had such a distance to them. I wasn't very fond of having diabetes, so then I really worked to make it

> into a part of me. To make it kind of – my own. (2.37)

She always made these modifications and attempts at de-scription by herself, hidden away from others. She wanted the technology to slide into the background, and not make itself, and the disease visible to others. Therefore she loathed the time it took for the old manual measurement devices to reach its conclusions about her blood sugar. It led people to notice her diabetes and look at her while she was being evaluated by the machine:

> **Anne:** [I] remember that I was irritated by how long it took. An embarrassing process. When it counts down from 25, I just...!
>
> **Askild:** That was after you had conducted a blood sugar measurement?
>
> **Anne:** Yes, it takes 25 seconds. That I remember...hehe. It was kind of, you did manage to gather a rather large audience in those 25 seconds, and then you got the result, and then: FAIL. Hehehe.
>
> **Askild:** So did you walk away when you were supposed to measure? Or how did you do it, if you had to measure at school for instance?
>
> **Anne:** I always did it in hiding, because I was so embarrassed. I didn't identify with being a diabetic at all. (6.16)

Injection technology – an untrustworthy middleman

Annes close relationship to the CGM is related to her distrust of other technologies. She does not trust machines that are supposed to make calculations for her, or even just perform simple commands that she has given them. She is especially suspicious of machines that are responsible for injecting insulin. From here experience, she has taken that she cannot trust that a technology performs this task. Her first meeting with a technology that was supposed to act on her behalf, a so called *injector*, an insulin pen where you do not have to physically push the insulin into your own body, shaped her view:

> **Anne:** I have a problem with trusting technology, the kind that control something as untechnological as the body's blood sugar. In addition to that I have some experiences that haven't been that good. At one time a new [insulin] pen was introduced. It was a mix between a pen and a pump. So you plotted in the number of units you were supposed to have, and then you didn't need to click on it, or anything. You only set it into your skin. You just plotted in a number, and it was about this big [10 centimetre], and you set it into your skin, and then it showed on a little screen that the insulin was injected. So you just waited, and it counted down 5,4,3,2,1. And then you could take it out. That was pretty...it was the first technological independent entity I had met. I was really pleased with it, it was really cool. You only gave it the numbers and it did all the rest. I could do it while blindfolded. But twice it injected a double dose, that is at least what we have understood afterwards. I injected such small units. I injected between 2,3,1, I could even take half a unit. So double of that was quite drastic. So I collapsed both times. And after that I stopped using it.

Later on Anne moved on to use an insulin pump. She used this machine from she was around 9 til she was 14. Though she today can see that the pump helped her stabilize her blood sugar, she was never able to get used to it at the time. The cords were constantly ripped out, and again, she did not trust the pumps ability to inject insulin according to her wishes. She had too many experiences with the machine failing. Again, some concrete experiences would make her distrust machines being middlemen between herself and her body. In her early teens she was playing in a football tournament. She had just put in a new ampul with insulin into her pump. Before connecting the pump to your body, the machine should be put into what is called 'prime mode'. This means that insulin is flushed out of the pump cord, to clear the tube of air. But at this specific instance, Anne

forgot to turn off the primer, so the pump just continued to inject large amounts of insulin after she had connected it to her body.

> **Anne:** And that dose went up to 10 units. And the most I had injected my entire life was 4,5. And my unit dose was between 0.5 and 2 units.
>
> **Askild:** So it continued to inject it?
>
> **Anne:** It did. And if it had gone to 10, the I...I don't think that would have gone very well. I realized it because I by change went to the bathroom with two friends just then. And I heard the clicking sound, from when the pump is working. It sounded so familiar, but I knew that I wasn't injecting insulin. I only used the pump for small doses. My basic dose. I recognized the sound and thought, are there more people than me wearing a pump here? And I look at the pump and I see the display, 'prime 5.6, 5.7, 5.8, and I realize that I am injecting my own insulin chock. [...] So I tear it out, with the bandage and everything, and throw the pump into the wall, in pure frustration. And my friends both begin to laugh. And I just stand there crying and howling, and I don't know what to do. I fear for my life. It doesn't sound like a lot, 6 units. But for me it was more than my maximum dose my entire life. I was so scared, I had been exercising all day, and hadn't eaten in a long time. So I knew I had 15, maybe 20 minutes, it works really quickly when you exercise a lot, and when it's hot. And it was really hot. So I called mom, and she was on her way home from the cabin, and I tell my coaches, who didn't understand shit, and gave me a Pepsi Max, because it does not have any sugar in it.
>
> **Askild:** Oh my.
>
> **Anne:** And I stand there and I see everything in slow motion. And I think: 'Ok. Then that means insulin chock then, here and now'. Hehe. I didn't have any money either, but a smart mother realised that I was really stressed out, so I got a bottle of Fanta. And my mom called the ambulance. So it all went well. But I still had time to black out, and go and hide behind a tree, and just lay there. I can't remember any of this. But someone found me. So I got intravenous nutrition. So it all went well. But it completely freaked me out. And what scared me the most was the thought that....if I hadn't gone to the bathroom. When you are young, it's really limited how strong an insulin chock you can handle. […] It was kind of, the fear got ignited in me again. I had no control. In reality I didn't know what was happening to me. I knew that I had 3ml [of insulin] connected to me at all times. And in theory all of it could be injected. So it became an irrational fear, a fear of having too much insulin.

This shaped her distrust of the machine performing on her behalf. And made the services the CGM could provide more alluring.

CGM – increasing conscious control

So having the conscious knowledge of, and control over, what was going on in her body was an important goal, not only for Anne, but for her whole family. Both before and after she got the CGM they spent time manually visualizing her blood sugar, to understand it's fluctuation and changes.

> **Anne:** [W]e were writing these spread sheets ourselves, or mom did it for me. So she filled out these forms every day, where blood sugar was displayed the same way as on the small CGM. So, yes, I used it quite a lot. But we did it manually. Mom on excel and the whole nine yards. (1.02.22)

Also as a part of this control of her own blood sugar, Anne constantly trained to better feel the bodily sensations that followed from different blood sugar levels.

> **Anne:** That is something I have been practising my whole life. And dad was very conscious about that: 'Guess what your levels are, before you can see them, so that you can guess when you are not sure'. But when I am out exercising things are different. Now for instance, I can feel that I am between 10 and 15, and that fits well with the measurement I did half an hour ago, where I was a bit high. But I can feel it on my body. And I feel low blood sugars easily. But not before it is at 3. (27.54)

And in this self-training the blood sugar monitoring devices, unlike the devices that were supposed to inject insulin for her, became close partners. In the end, too close.

Anne's relationship to blood sugar monitoring is very complex. She has used many years to try to come to terms with how much she is supposed to measure. As a part of this she was one of the earliest patients who were allowed to use a Continuous Glucose Monitor, one that was not connected to a pump, but that could be used in combination with manual insulin injections. This device consisted of a sensor connected to her body, and a separate display that looks much like an insulin pump, just without the cord. Suddenly she could access her blood sugar without the humiliating and time consuming process of constant manual measurements.

> **Anne:** I was sold at once! I thought that it was big and ugly. But it was nice, because it showed my blood sugar all the time. And I really identified with that. Because I had a period where I was measuring manually, I was completely obsessed with it. I have always measured myself often, like 10 times a day, or 12, which is within normal limits. But it developed so that it became 30, then 60 and then 100. Finally 200. The only thing I did was measure myself. Every minute. Just to get that number. It had no real value. That was the reason I got the CGM. Because my doctor thought it wasn't very constructive to use so many strips [used for manual measurements]...They are kind of expensive. And he thought it would help me. So that I didn't have to go around feeling the compulsive need to measure. (8.52)

For Anne the CGM had the opposite effect of the pump and the injector. Instead of performing actions on her behalf that she could not completely control, it gave her more knowledge to control her own body. With the CGM she felt that she could both have the constant overview that she needed, but also in some ways relax with this knowledge. She still kept on calibrating it more then was suggested, but it was a machine she could negotiate with.

> **Anne:** It was absolutely super. I didn't have to closely feel, I didn't have to concentrate and wonder what my values were, because I knew. Or I knew that, there was maybe a fifteen minute delay on the machine. But then I could see the trend, I could see the curve, and that was more than enough. So if I went down, I could kind of foresee low blood sugars, or I could see that it was going up. That I really didn't care about that much, because I didn't bring insulin [when I was exercising]. But just the fact that I had the overview, to not have to closely sense. One does not walk around sensing that I am a number, but I have to concentrate and feel the parameters I have in my body in a way. To check if I have the blood sugar that I have. (27.54)

The new machine also had more wide reaching and ambivalent effects. It made its real-time presentation of the composition of Anne's bloodstream available to the rest of her household, making the constant control a common task she had to share with the rest of her family.

> **Anne:** [I] was no fan of the fact that it could be lying on the kitchen bench behind me – where it often ended up, because I tried to get some distance to it – and then dad could come along and say, 'Anne, your levels are way to high now! You have to do something'. He was also kind of obsessed with those numbers. So having high blood sugar was a disaster. The fact that he could see them wasn't easy.

Though the CGM made her need for constant knowledge of her blood sugar easier to manage, her obsession did not change when she started using the CGM. If something it became more prevalent. She had to prick her fingers less often, but her knowledge of the inside of her body became all consuming, and her life started conforming to the machines updates:

> **Anne:** In the end I walked around with it. I never put it down. I never put it in my pocket. I walked around with it in my hand, and checked every 5 minute update.
>
> […]

> **Anne:** So it was breakfast, and then I sat there starring at it, really.
>
> **Askild:** So you had it laying on the table as you ate?
>
> **Anne:** It was there [points] and the food was there [points]. Hehe.
>
> **Askild:** You watched it while you ate?
>
> **Anne:** Yes. It became my newspaper so to speak. [...I]t gives you a message when it transcends a certain number. And I sat there waiting for it, that beep, that signal.

She was at this time performing sport at a high level, and spend large amount of her days exercising, running and swimming. The CGM gave her an unprecedented freedom, but it also made her life centre around the graph and numbers on the display.

Many people with diabetes through frustration with the disease try to escape it. Pretending not to have it, they refuse to relate to their blood sugar levels, and stop using insulin. Anne also ended up trying to rid herself of the disease, but in a drastically different manner then many other people with diabetes.

> **Anne:** [I] would never want to let go of the numbers, in the way that I just let the blood sugar go, and pretend that I do not have diabetes. So my solution, to flee from the diabetes and still fulfil the demands from my mom and dad, was to stop eating, so that it didn't, so that the blood sugar didn't go high and I could stop measuring myself, and I could stop injecting insulin, because I don't need insulin when I don't eat.

She had been able to find a way to negotiate with her disease and her technology, in such a way that her blood sugar was at a fine level, close to 5.5, and she did not have to use insulin, but at the cost of her physical body's health. In the end, she was put under psychiatric care. And her psychiatrist demanded that she should not be allowed to use the CGM:

> **Anne:** Then my psychiatrist said that I was not allowed to get it back because at that time I worked so incredibly hard with just measuring the 6 times a day the way I was supposed to. I was completely devastated. Since I had gotten word that it was a possibility for me [to continue using the CGM]. But when I look at it now, when I do have the possibility of having it back if I ask, I don't want to, because I will be too caught up in those numbers, and those curves. And I am afraid that I will go nuts again to be quite honest.(10.05)

Manual technique – controlling all aspects of insulin injection

Now several years on, she is able to prevent the numbers from taking control. She has an impressive analytical and contemplative view on her own problems with her disease and the diabetes technology. She also has interesting thoughts about the prospects of finding novel ways for constant measuring devices to interpret a patient’s blood sugar so as to discourage obsessive attention.

> **Askild:** Do you have any wishes for how the technology should look, so that it works better for you? So that it does not put you in danger of becoming obsessive with the measurement?
>
> **Anne:** Hm...I have thought a lot about that. But number are so concrete, and if there is something you need it's to be concrete, when it comes to treatment. We do have decimals for a reason. They are maybe not so important....well they are kind of important. Hehe. So, no. I think that colour codes, everything like that, would replace something very important. So I have accepted that it is my relationship to numbers in general that I have to work with. And not the blood sugar that has to adjust to me. (30.03)

She also has a deep understanding of the fact that the technologies only conveys interpretations of what her real inner body is. Still Anne finds the elusive idea of actually having real-time insight into these hidden processes, intriguing:

> **Anne:** What I am doing now is in some ways theory. I regulate based on some parameters from my everyday experiences. But there is no correct answer that can tell me if the choices I have done are correct, except that my blood sugar is kind of okay.

Anne has conquered her paralysing need for constant knowledge about her blood sugar. But she has kept her distrust of technologies that are to perform actions on her behalf. She is one of the few people with diabetes who still use syringes to inject insulin. Each time she needs an injections, she fills these small syringes, no longer than 7 cm, with insulin from small glass containers, and injects herself. She has her own routine, that she almost, but only almost, performs subconsciously. She walks me through the process:

> **Anne:** These [syringes] are really nice and simple. First I have to... ease the pressure [hits the glass with a finger] then I have to put it in....
>
> **Askild:** Mhm...
>
> **Anne:** ….like this... Just to get the air out [hits the syringe with her finger]. I can do this blindfolded. It has become very much my standard. Then I pull back the syringe, now I need 4 units. Mmm [looks closely at the amount of insulin she has pulled into the syringe]. And then it's just.... [Puts the needle into her thigh, and injects it]. I need to keep it there...so that I know that it has all come in.

On every step of the process she herself controls the different aspects. From how much insulin is in the syringe, to checking that no insulin escapes during the injection. But this manual technique is not only a way of having complete control over all the different actions in the process of injecting insulin. It is also something that points back to what she had always dreamt about: Diabetes equipment being as small as possible. Wherever she goes, she now only needs to carry a small pouch, the size of a wallet with her manual monitor, her insulin containers and her small syringes. The rest is in her head.

"[When] I need a new concept on how this works, or how the feeling is, then it's okay to reconnect"

Calibrating the machine, and calibrating the body – an interview with 'Bård', 28.05.2012

Bård was diagnosed with diabetes in 1992 when he was four years old. He has no clear recollection of living without the disease, but many of his early memories are of stays in hospitals. The first type of technology he started using was the simple syringes that you had to manually fill with insulin, but he quickly moved on to pens. And now he uses a pump constantly, and a CGM most of the time.

Bård lives in small town in the eastern part of Norway with his partner and a dog. They have just bought a large rundown villa that Bård is currently fixing up personally. He is a skilled handyman, but he is slightly less comfortable with digital technology. He has had the pump since 2001, and the CGM for well over a year. He has created his own tricks and routines for managing life with the pump and the CGM. He uses the pump actively to teach himself to feel his own blood sugar level. But he also refuses to let the machine define his average day or his life, and gets annoyed by its constant beeps and vibrations. So when he has had a specifically exhausting quarrel with the CGM, he can decide that he wants to be alone, and can take the device off, and go for months without it.

> **Bård:** What can I say. I have never been particularly good with my diabetes. I can be honest about that. I am very – no matter if I have a pump, or syringes or whatever – very listless.
>
> **Askild:** How exactly?
>
> **Bård:** When it comes to measuring my blood sugar and things like that. So it's often high, and I have some high hba1c counts and stuff like that. What should I say. It helps...that's why I got the measuring device, or the CGM, or whatever it's called.

Both the pump and the CGM has helped him to monitor and lower his blood sugar levels. But to what extent Bård listens to the advice form the CGM and the pump varies. He has found ways to negotiate with the technology, so that it does not disturb him when he does not want it to. For instance if he is spending a night on the town, a situation that is a minefield for most persons with diabetes.

> **Bård:** If one goes to a party for instance, one might be a bit more prepared to turn it of maybe, so that the levels won't go to low.
>
> **Askild:** So then you turn it off?
>
> **Bård:** I just stop it. And then the levels become high. But then you don't have to worry about low blood sugar.
>
> **Askild:** But then what you are saying is that you consciously...
>
> **Bård:** You stop it, or you can go into the background dose, and turn it down for some hours.

He has experimented with this form of adjustment for many years, with mixed results. He has ended up in comas, and blacked out in his bed. These experiences has made him most comfortable with

turning the pump completely of, or giving himself much less background insulin then the CGM suggests, if he is going out for a drink. And he is still experimenting to see how his blood sugar, as displayed on the pump, reacts in different circumstances.

> **Bård:** At times I have eaten, and then not taken insulin, just to see how my body reacts. That gives you a better overview. It's almost scientific. Trial and error.

He has also adjusted his background dose of insulin so that he can have his own morning routines. Bård starts working early, as he is a building craftsman, but he does not want to eat breakfast until a bit later in the day.

> **Bård:** So then I have adjusted my dose, so I don't need to eat before nine. My opinion is that it's nice to eat breakfast at work, rather than stress with it early in the morning.
>
> **Askild:** So then you have taken little in the morning, so your blood sugar won't go to low?
>
> **Bård:** Yes. And then after lunch I have turned up the dose again. So that I don't have to inject insulin, because I often forget that. So it's really nice to have it in there [in the machine].

So he has given over some of the responsibility for giving him insulin after he has eaten to the pump and CGM. They give him a predefined boost so he does not have to remember it.

Bård is not one of those people who constantly watches the number on the pump display. Sometimes he prefers to not be able to get the blood sugar information that is available to him. But the way the pump displays his levels has none the less prompted him to start a small competition with himself. The visualization of the blood sugar on the pump, shown as a continuously evolving graph, has a line running horizontally through it, symbolizing a blood sugar level of 10. During the day he competes with himself to, as he says "hold the line", meaning keeping his levels under 10. Still Bård refuses to see this game as exiting:

> **Bård:** Well, I don't know if exciting is the word. Hopefully it is the same every time. If something is wrong, then at least you get an explanation for why you have felt the way you do. Because you do walk around all the time feeling your body, am I feeling well now, or am I feeling shitty. So then you often know what your blood sugar is when you are wearing it. Then you can see that, yes it fits with the sensation I have in my body.

Calibrating himself

Bård has to calibrate his pump twice a day, but he then again uses the pump to calibrate, so to speak, his own gut feeling. At times he becomes confused about whether he is high or low. He needs the CGM to regularly redefine his ability to guess.

> **Bård:** Because earlier it's been so that when I had high values, I become nauseous, and maybe even throw up. But lately it has been the other way around. And that has been really, seriously scary. Because I might have had low levels and then barfed. And then I believe that my levels are high, and inject insulin for that. Because I have not been wearing it. And that's the reason I have started using [the CGM] again now. You need a reassurance on how things actually are, when you haven't experienced such a situation before. (46.37)

Still, he can feel that the CGM confines him. Therefore he sometimes decides to remove it to live without its messages and advice. But even when he is not wearing it, he still has his own gut feeling that, at least for a time, he can trust.

> **Bård:** Because I don't walk around with it all the time. Well, the last time I took a break, I went maybe two months without it. To feel free. That is quite wonderful. But then you still have that feeling in the body, and you can sense that 'this is what the levels should be now'.

[...]

Askild: When you take such a break, why do you choose to do it? Is it conscious or does it just happen?

Bård: Many times it just happens, other times it is a more conscious choice. Often in the weekends, it can be okay to not wear it, to have some time off, kind of.

But after a period away from the machine, he needs a new calibration of his gut feeling. Therefore he comes back to the CGM.

Bård: But when you suddenly one day realize that, oh no, I need a new handle on how this works, or how that sensation is, then it's okay to connect it again.

The pump therefore becomes a sort of continuous reassurance for Bård.

Bård: It gives you a sort of reassurance, that you have someone who is looking after you, and saying that, 'no, now you are kind of high, so please, inject some insulin'. In that way it's really convenient. But for a period only, until you grow tired of the nagging. And you also constantly try to learn how the body feels as well.

Letting the machines hold the fort

Even though he feels the machine can make him recognize his own blood sugar levels more precisely, Bård is also worried the technology might make him less attentive to his disease. He dreams of more advanced technology that can calculate and adjust what doses of insulin he needs so that he does not have to think about it. But he is not sure outsourcing more of the diabetes treatment to the technology would be good for him. He needs to watch the numbers consciously.

Bård: As I said, I would love to have something that could say, 'this is how you are now, this is what you must inject'. But then I would just be more lazy then I am now I think. So it's good to have something, to have to look at the numbers, and see if they are going up or down.

On the other hand, he has never felt comfortable with keeping close overview of the food that he eats, and he does not care for counting calories. So instead of doing calorie math when he eats, he again trusts his gut feeling and experience.

Bård: No, I have never been counting calories, and I never will. So in that sense I am a part of the old school. I think it's the new ones who begin doing that, the way I understand it.

Askild: What do you do if you get a plate of food, at a restaurant for instance. What thoughts do you do on how much you should inject? How do you reach that number?

Bård: it's experiences, 'this was how much I needed the last time, so then I'll try that'. Then it works, or it doesn't. If it doesn't you just have to inject a little extra. And it's okay for the most part.

Askild: So you perform a sort of balancing act?

Bård: Yes.

Askild: Do you remember, or is it more of a gut feeling?

Bård: Mostly it's a gut feeling. 'it's *smk* [puts finger in the air] about there'.

Askild: But has the gut feeling changed after you got the CGM?

> **Bård:** Well, yes. It has, I have become better at understanding it. It is easier to see that 'damn, that thing that I thought didn't raise my blood sugar much, suddenly had a large effect.

As a part of his ambivalence against the measurements the CGM performs, Bård does not particularly care for seeing the longtime view of his blood sugar that the machine enables. He thinks it's more than enough to know how his levels have been the last 24 hours. But he would want the doctors and nurses to have the overview, so that he does not need to. Again, Bård does think it would be nice to give away some of the responsibility to others, be they doctors or more advanced machines. He relates to the pump and CGM, and feels he has a descent balance in the way he uses them. But he does not watch the number and line on the screen that much, and the sensor annoys him at times. And if he could choose, he would really want to be able to live without them.

> **Bård:** I'm not the kind of guy who....I don't think it's that interesting to look at it. At times it isn't interesting at all. It is mostly to get a confirmation that I use it, a confirmation on what things are and how I feel. I want to live without.

"If I look at it, and it's 15, or if it alerts me. *Then* I feel it."

Understanding how the body varies from day to day, and letting sense perceptions be defined by the number on the screen – an interview with 'Marit', 31.05.2012

Marit was diagnosed with diabetes when she was 8. This was back in 1978 long before the modern regimes of frequent measurements. She measured her blood sugar levels form urine samples twice a day. Much has changed since then. She began using manual blood sugar measuring technology early on. And in the mid 1980s she was an early test patient for different insulin pumps. So she has tested and experienced the turbulence of early machines.

Unlike the other persons with diabetes I have spoken to for this thesis, Marit's problem has not been a too high *hba1c* count, but a too low one. At times it has dropped down to 4, which is as low as the average level for non-diabetics. This has been because of her fear of having a too high blood sugar lever. So she was given the machine to be able to push herself upwards.

> **Marit:** When I see that the blood sugar is on 10-11 maybe, earlier I really couldn't handle it. Now, when I am at *Diabetikersenteret*, and my longterm levels are moving upwards, they ask me if I feel it's okay. No, I don't. 'I see that you are satisfied', I say, 'but I don't feel it's okay'.

It has now been a couple of years since she received the CGM, and she has been able to integrate it almost seamlessly into her daily life the same way she has with the pump. To integrate technology into her life and her self-image has been a conscious process on her part, since she first got the pump. When she was younger, she even tried to make it a part of her style.

> **Marit:** it's a difference between being 19 and being an adult, like I am now. So I got a guy who could sow these leather pouches to make some for me. He made them so that they could be connected to my pants waist, because [the pumps] are quite big to have laying in your pocket.
>
> **Askild:** So you designed it yourself?
>
> **Marit:** Jepp.

After receiving the CGM, her view on her disease changed. Unlike earlier, she can now see exactly how much insulin she uses every day. She can also see how her need for insulin varies from day to day, something that was impossible to notice actively before.

> **Marit:** [I]ts useful for me. My insulin needs varies not just in relation to what and how much I have eaten, but because days are just different. My body isn't the same every day. Even if today is identical to yesterday, my body has different needs. I don't know why it's like this, nobody has explained it to me. But thats the way it is.
>
> […]
>
> **Askild:** But if the days otherwise are identical, can you feel if one of them is different from the other in your body?
>
> **Marit:** No, I can't.
>
> **Askild:** But do you feel it later?

> **Marit:** I do see that from my blood sugar levels, that what I did yesterday won't work today. I am a person with strong habits. So I do try to notice it as early as possible. But it dosn't always work.

This close monitoring is very important to Marit, especially since she has problems with sensing her own blood sugar, specifically low levels. So instead she lets the pump feel them for her.

> **Marit:** I am not able to feel the low ones just yet. But that might be because I am alerted by the pump when it is around 4. But I don't think I can feel it in my body, I don't.

Feeling unwell when the display tells you that you should

An interesting aspect of her use of the pump and CGM is that it has become an intrinsic part of her own sense perception. The numbers on the display makes her feel things that she otherwise would not.

> **Marit:** But then you see. If I then look at it and see that now it's 15, or if I get an alert. *Then* I feel it.
>
> **Askild:** So then..
>
> **Marit:** Theeeen...
>
> **Askild:** So it opens up something?
>
> **Marit:** Then I feel really bad.
>
> **Askild:** But if you hadn't seen that number, you wouldn't have?
>
> **Marit:** I don't think so. But I don't know, but I don't think so. So it's really, really weird
> [...]
>
> **Askild:** So it has changed your sensation of your body a little bit?
>
> **Marit:** Yes.

These numbers though they convey something personal, it not something Marit guards and keeps to herself. She would even like people that are close to her to be able to see the information when they want to.

> **Marit:** My sister wishes that she could push a button so she could see what my levels are.
>
> **Askild:** Because she is worried about you?
>
> **Marit:** She was worried about me, she was. So...and I understand that. I think that if she could do that, or some of the ones I live with now could see my levels, then I would have liked it.

Though Marit has such a close control with her diabetes, and feels she needs it to live her life the way she wants, she does not let it control her life. If, for instance, she has a course in SPR that needs her to stay in a pool for hours on end, she lets this be a test to see if the CGM can take it, rather than backing out. So she would rather let the technology stop working, than let it work her.

"It was always 10. 10, 10, 10, 10"

On hating your disease and having to live with technology that always reminds you of it – an interview with 'Glenn', 01.06.2012

Glenn was diagnosed with diabetes in the early 1980s when he was 15 years old. So the disease is something that massively disrupted his life. This has made it difficult for him to accept his disease. So when he describes it he does not hold back.

> **Glenn:** I really have to honestly admit it, and say that diabetes, is a living hell, to be honest. I think it is bothersome, completely fucked up. Yes. If there was a way to surgically remove it, I would have done it at once. Even if it had cost me money, then I would have sold my apartment and had it done. I have to honestly admit that. That would have been my first priority. I don't wish diabetes on even my enemies. I can live with it. There is no doubt about that. But it's a living hell. You have to prick yourself. And to have that crap in your body all of the time. it's not cool.

After he was diagnosed he quickly moved from using the syringes to pens, and in 1988 he was given his first insulin pump. But the first pump did not help him much.

> **Glenn:**[I]t was orange of course. Everything was orange for diabetics. So that was terrible. But I stopped using it because it just became too much. I couldn't bathe, I couldn't do this I couldn't do that. So it just became terrible. And the blood sugar just went up, up, up.
>
> **Askild:** When you used the pump?
>
> **Glenn:** With the pump an everything.
>
> **Askild:** Was it because of the pump? Or do you know why?
>
> **Glenn:** No. It was because I didn't care about it. I am still a bit lazy. But I have become a lot better at it. But, I forgot to take insulin when I ate, and all that crap. I have to confess that. I am a lot better at it now, but still. I have always been kind of lazy when it comes to that. When I am hungry, I eat. Then I will just have to measure the blood sugar afterwards.

Outside the standard limits

Glenn wanted to have as little as possible to do with the fluctuations in his blood sugar. Diabetes was not to define his life. So he became quite poorly regulated. Both the manual measurement devices, and later the CGM, which he received in 2009, were constant reminders of this. He often had levels that were so high or low that the pump would not even say what they were, only alert him thoroughly.

> **Glenn:** [The display] was flashing, and it still does that today. But it flashes when it's to high, because it can't give me any number.
>
> **Askild:** Because you are off the charts?
>
> **Glenn:** Yes, far off the charts. I'm really good at that. I can still do that today. But still, I don't become sick from it.

So Glenn used to have a very distanced relationship to measurement and the disease. He had no plan for how to regulate his blood sugar, and he would only half-heartedly try to control the disease.

Askild: When you first got it, how did you relate to the numbers you received from the censor?

Glenn: I took 10 units. *Thysh* [imitates injection]. When my levels were 20, 10 units. When they were 12, 10 units. When they were 15, 10 units. It was only 10 units.

Askild: As long as your levels were high?

Glenn: Then it was 10 units.

Askild: How did you define 'high'?

Glenn: I was at around 15 and up all the time, so then it was 10 units all the time. And I had a scheduled doses every night. It had been decided by the nurses at Diabetikersenteret, me and Jack Hjervel [doctor and expert on diabetes]. So that was that. It didn't matter how high the blood sugar levels were. *Thysh*.

Askild: So you injected 10 no matter what. And the night doses was predetermined?

Glenn: It was always 10. 10, 10, 10, 10.

This way of handling the illness changed when he got in his mid twenties and he started working regularly. Then his *hba1c* started falling somewhat, and the 10 rule became dangerous to use because it caused sudden low blood sugar levels. So he had to learn how to adjust his levels more accurately. Today he does this by relying heavily on the calculations from the pump and the CGM.

Glenn: Now I relate to the Bolus [Wizard], on my machine. Because it says how many units I should take. If my blood sugar is so and so high, I just enter into [the machine]. And then it depends on how much rice, and how many potatoes I have eaten. And then I might enter 120 grams. So I type that into the machine. And it tells me to inject so and so much.

Askild: So you don't calculate on your own. You do it together with the pump?

Glenn: With the pump and the censor. If I was to do it alone, it would be a lot of '10s' again. As I have said, I don't want to have diabetes. I have to admit that. I have always said that. it's the worst thing I know. To have to sit there and calculate.

Constant stream of messages

Now the pump keeps close tabs with how Glenn's blood sugar is. It tells him when he surpasses 10, and when it drops below 4. This means that he receives a steady stream of messages.

Glenn: I think it's ridiculous that it beeps when the levels are going up, and when they are going down. I really find that ridiculous. it's okay that it tells me when it's on its way down, and then be done with it. But when it goes up, and then beeps every half hour, that I find ridiculous. It is supposed to do that, so then it's okay I guess.

Askild: What do you do about it?

Glenn: I turn it off. I can't do anything else about it. Because the levels are going up. And I have given insulin, and I can't give more insulin because then I will be sick.

Because of this, every three weeks or so, he takes the CGM off, so he can be alone from its constant attention. But when he is using it he usually trust the machines calculations, even if he sometimes does not care to adjust for high levels. And if the machines advises him against take more insulin, even though Glenn would like to take some more to hurry the lowering of his levels, he usually

listens to them. His experience is that if he tries to take more than it advices, he goes to low.

But the pump does not understand his body completely. It mistakes many of his fast changes in levels with technical malfunctions, and instead of accepting them, asks for a recalibration.

> [...W]hy is it beeping now?! it's because it's too high, or because it has fallen too quickly so the [calibration] contrast is wrong. Then I just turn it off. And it turns itself off as well sometimes. it's ridiculous. It should be a lot better at keeping shut, instead of howling and beeping all the time.

And Glenn is especially frustrated by the fact that the pump is ordered to wake him when his levels get high at night:

> **Glenn:** it's okay that it tells my when the levels are low. But it doesn't have to tell my when they are high. Because that isn't dangerous. It isn't dangerous to me. You can get late complication a guess, or whatever. But you can also get late complications when you are tired in the morning and fall asleep behind the wheel.

He has tried to adjust for this by taking more insulin right before he goes to sleep, but then again he puts himself in danger of going too low. So in the end, to get the sleep he wants, he has asked his girlfriend not to wake him if she notices he is low.

> **Glenn:** it's kind of like I am shaking at night. 'You were shaking and kept me awake again tonight' [my girlfriend tells me'].
>
> **Askild:** Do you wake from it?
>
> **Glenn:** No.
>
> **Askild:** So you always sleep through it?
>
> **Glenn:** I used to be good at that: When I got low blood sugar, I went to bed. Then you won't be in so much pain. The muscles won't become so stiff.
>
> **Askild:** Because you were asleep when the body went through it?
>
> **Glenn:** Because when you sleep, you relax a whole lot more. And when you have been laying and shaking, and had cramps. If you sleep it lets goes faster.
>
> **Askild:** Okay. So you are the one who is shaking! I thought I was the pump! But it was you! But your levels must be very low for you to start shaking!
>
> **Glenn:** Yes...1,01.
>
> **Askild:** So your girlfriend doesn't wake you up?
>
> **Glenn:** She isn't allowed to.

So he is willing to sleep through insulin shocks to avoid the annoyance of detailed regulations of his disease.

Constant adjustments also annoy him at work. This might be because Glenn's work day does not leave much room for constant management of the blood sugar. His job has to do with heavy physical labour, and his lunch breaks don't give much room for taking a clean blood test to calibrate the machine. This is one of the situations where he at times forgets to regulate himself at all.

> **Glenn:** Then at might forget to take insulin. it's because I only have half an hour. So then I wash my hands and

stuff. And I won't care to measure my blood sugar.

But even though it often annoys him, he has been able to adjust to using diabetes technology when it comes to more intimate parts of his life. For instance in bed.

Glenn: I have this strap around my leg with this container, or pocket, for the pump, that I got with the pump.

Askild: So you have this pocket for the pump around your thigh?

Glenn: Yes, it's nice. it's fantastic. It works really, really well. So, yes. I take it of when I have sex off course. it's not so cool to have it there then.

Askild: How would that work [to remove it]. Wouldn't it start howling and making a racket again then?

Glenn: No, I just throw it in the bed.

A technology that is hard to negotiate with

So the physical aspects of the pump and CGM are not too bothersome. But he does not dear to toy around and experiment with the machine, he is too afraid of destroying it, and having to go to the emergency room. He instead prefers using the mechanisms he has been taught.

Glenn: I'm no computer nerd. I can connect a PC and stuff like that, as long as I know how to do it. I am good at putting up loudspeaker and stuff like that. But to push and organize these programs, I really can't do it. And I won't experiment with it. Because if it stops it's most likely in a weekend, and then you become sick, and have to go to the emergency room. And they won't understand a thing. The people there are idiots.

Askild: So just finding your way through trial and error isn't an option?

Glenn: No, no. That isn't an option. Not with the pump, because I only have one. If I had two that might have been simpler.

Askild: Then you could have tested and pushed some buttons on one of them...

Glenn: Yes, then I could have. I could have seen if one of them worked with new settings. And then I could have tested it several times, to see if I could manage. And then I would have learned to know the machines better.

But Glenn is upset because he feels he has not gotten enough information about how the pump works.

Glenn: No, the only thing I want to say is that I want more training in how to use them. As I have said, I don’t have any knowledge about computers. But when I went to a PC-cource, I learned quite a lot about the computer. Not only how to type in 'hello' and sex.no. Do you see what I mean? And I think our training should be a lot more about the pump, and a lot more training about what you can use it for. Get instructions that ask 'do you use it this way, do you know this?'.

One more thing that worries Glenn is that the machines are not customized to only fit to his body. He fear other persons with diabetes can take his machine by accident, or that the CGMs of others may affect his pump. He wants the machine and the pump to be specifically tied to his body.

Glenn: Yes, you should be able to connect it to you. It should know your body. It should know what my blood type is. [Noticing that this] is me, kind of. It is my DNA.

Glenn is skeptical towards the idea of an independent technological entity that can take choices for him. So he would not trust a machine to choose and inject insulin into his body without his consent. But what he would want the machine to do without his interaction, is be able to stop injecting insulin.

> **Glenn:** [I]t could stop to give me insulin, and start again when the blood sugar has gone up again to a certain level. That I believe in. But not that it injects me with insulin. That only makes you lazy.

But still, some kinds of automation he would really like. So that he could forget about following every small change in his disease. He compares the technological competence he would like his machines to have to Apple-devices, and how they automatically understands when there are software updates or other changes that are needed for the device to adjust to the world.

> **Glenn:** I think it would have to be smarter. You don't need all that noise that tells you that you 'have to calibrate that, and enter this'. It works on my computer clock and on iTunes. There [on computers] the clocks automatically get set, to the correct time of day.

These automations would allow Glenn to leave the diabetes more in the background, so that it would not affect his life in such a substantial way as it otherwise does. He refuses to let the disease be a defining feature of who he is. But still he admits it shapes him to some extent, wether he wants it to or not.

> **Glenn:** I have been really conscious about not letting the diabetes change me. Because I want it to go away. My dream is that when I am 50, diabetes don’t exist anymore. At least not for people like my [people with type 1 diabetes]. I have to admit that. So my identity is the same, no matter what I am wearing on my body. But when I started using the pump I slowed down my life. Because I had to carry it.

"I realize that after I got the sensor, I never write in those books at all anymore"

Making patterns visible, losing touch and closing the diary – an interview with 'Susanne', 04.06.2012

Susanne is a is a woman in her late 30s, she was diagnosed with type 1 diabetes late, just when she had turned 20. So just like Glenn she has a vivid memory of living without the disease. During the last 18 years she has been able to adjust well to the illness. Via the pump and the CGM she keeps close control with her blood sugar levels. She has gone through two successful pregnancies, and is currently trying to get pregnant again.

But though she now has a balanced and healthy relationship to diabetes, she has also had challenges. One thing that has been hard to cope with is the fact that she fears the invasive syringes and pens that are used to inject insulin.

> **Askild:** What is it that you fear, if you were to describe it?
>
> **Susanne:** I don't know. it's this rather silly notion I have, that my stomach is a balloon, and to try and puncture it with a syringe might make it burst.

This fear caused her to not be able to correct her blood sugar levels in a sufficient way. Because of her strong disliked toward syringes and pens, she would delay setting corrective doses of insulin if her blood sugar levels were high.

> **Susanne:** So yes, If I had measured and hadn't injected the right dose, I would wait until the next time I ate. [...T]hat could be 4 hours. So I was high for 4 hours, before I compensated.

So she delayed taking insulin so she would have to perform as few injections as possible. After she got the pump this changed.

> **Susanne:** When I got the pump, and had used it for a while, I swore that I would never go back to syringes.

Discovering patters and losing touch

But still her disease was unstable. It turned out that she had some unexplained fluctuations in her blood sugar levels at night. So to prevent her from having to wake up at 2 am every night, she was given the CGM to learn how her nightly level changes occurred. The continuous measurements also revealed other strange level changes. Two days after a training session, her blood sugar dropped drastically. With the CGM she can counter these variations.

But receiving the CGM also made her more distanced from her disease. Having the machine gave her the knowledge she earlier had to focus on and feel her own body to obtain.

> **Susanne:** I think that you actually become kind of inattentive. Because before I got the sensor, I really had, really kind of had a competition with myself, that I had to guess the levels I had before I made a measurement. To teach myself to know my body better. But I really stopped doing that completely after I got the sensor.

The feeling of a blood sugar lever is much more nuanced, diverse and vague then the number and line on the pump screen. It involves the whole body.

Askild: Can you describe the feeling of having a blood sugar level of 10? How does that feel in your body?

Susanne: I actually think...I believe, it's really hard to describe. it's something with the breath and the taste you have in your mouth, wether you are high or low, and when you have low blood sugar, then I quickly start to kind of shake. But if I'm high I become really dry and thirsty. But the thirst comes first, and then I feel at once this kind of acetone smell, if I'm really high.

Since she got the CGM she has spent less time on this kind of internal feeling and manually trying to understand her longterm blood sugar. This has at times led her to potentially dangerous situations, where the display has shown her the wrong number, and she has gone for way to long before noticing that she was high or low.

Askild: So you're saying that really you're worse at that now? That you have given over the work to the pump?

Susanne: I have given it over to the pump because the alarm is supposed to give me notice when I become high.

Askild: So what if you would have to go back to using syringes or injector pens again [without the CGM]?

Susanne: That would mortify me. Hehehe. So...but I have experienced that the sensor has failed. And the people who do the support claim that I must have calibrated the machine just before I have eaten or something.

Askild: How has it failed?

Susanne: Because the sensor showed in the morning that I was low, so I ate a sandwich, then I felt really shaky. Then it continued to beep when I got to work. So I ate some more. So I thought that this can't be right, because I'm not low. Because then I felt in my body that this had to be high. And then it turned out that I was really at 18 or something.

Askild: How long did it take before you said that this has to be wrong? How long did you trust the measurement?

Susanne: 3 hours I suppose.

Writing the disease down versus having it written for you

Before she got the pump she would manually monitor herself, and try to make longterm overviews of her levels. To manage this she used what has been a common companion for many people with diabetes: a diabetes diary. This is a book where you would write down what you ate at different meals, and what your manual bloods sugar measurements were.

Susanne: You had this notebook that you could get at the pharmacy or at Norsk Diabetikersenter, where you were to keep control with how your blood sugar was.

Susanne never actively used this book, but after the CGM, she completely stopped writing in it.

Susanne: I do see that after I got the sensor, I don't write in those books at all anymore, how much food I have eaten and what my blood sugar was before and two hours after. I did that before.

But though she has outsourced much work to the pump and the CGM, Susanne does not follow their instructions blindly, she can even fool them into following her daily rhythms. For instance she might lie to the technology when it demands a calibration at an unfitting moment.

Susanne: If I'm in the middle of something, and it asks me to calibrate, I usually just take the value on the pump screen and plot that in. And then I take a control measurement later on. And most of the time...90 percept of the time, it's correct when I measure later.

Askild: So the pump asks you to perform a control measurement, but you trick it by...?

Susanne: Yes.

Susanne has a relaxed relationship to the measurements, and does not look much at the display except when she is prompted to, or before she eats. She does not use the more advanced features of the pump, but instead relates to the most basic mechanisms.

Susanne: I use the simplest things. I plot in what I use, how many units [of carbohydrates] I have eaten. Or I plot in how much I am about to eat, and it calculates how many units I should take. Thats what I use it for mostly. I really wish I could use the other [parts of the machine and CGM]. But I don't really feel competent at that.

Between conscious and subconscious

Wearing the pump and the CGM constantly has made these technologies a very intrinsic part of Susanne's life, and even her mind. She has incorporated the messages from the pump and CGM, so that she often does not even notice that she acts upon them, for instance when the technology wake her up at night with commands.

Askild: Is it so that you can remember it the morning after, or does it happen completely automatically?

Susanne: Automatically. Like now, I can't remember that I did it last night.

Askild: You saw it now when you looked at the pump? How can you...how do you sleep? Do you have the pump by your side, and then it vibrates, and you wake up?

Susanne: Most likely its been beeping. But most likely it's been beeping several times, with 10 minute intervals, if I haven't heard it the first time. So then I have my partner, who hears it and wakes me up.

But even in these more or less subconscious interactions with the pump, she does not only follow its commands.

Askild: So then you press OK for its suggestion?

Susanne: Yes. Or really I just plot it in. It says that I for instance have high blood sugar levels, for instance 15.2, so then I plot in to bolus wizard 15.2, and then he suggests insulin.

Askild: So then you have to press OK for Bolus Wizards suggestion?

Susanne: Yes. But what I have really learned...if he suggests something at night I should subtract a little from it, or I will go down and end up having low blood sugar.

"It is very revealing, we see what you are doing under the covers in a way"

On making the body into shared knowledge and being able to control the disease without understanding it – an interview with nurse Aasa Løvfall, 14.06.2012

Aasa Løvfall is one of the health professionals who help train of persons with diabetes who are given the CGM and the insulin pump. She has worked with diabetes patients for 20 years and has followed the development in the medical technology closely. In this conversation we talk about how, in her experience, different patients react to living with the pump and CGM. In addition to this she explains how the medical staff use the information that they retain from the machines.

Aasa explains that the first continuous monitors they started using were for short term testing of blood sugars, usually a bit less than a week. These devices did not have screens, so the only way one could see the information it collected was to print it out after the test period. This was mostly used to try and understand what happened to patients that had unstable blood sugar levels at night. In addition it was used as a rhetorical device to teach uses the effect of postponing the injection of insulin in relation to meals.

> **Aasa:** It was a test, especially to see if you had high or low levels at night. If you awoke with high levels, what had happened during the night? You might have measured the levels before you went to bed, and maybe at one or two. And a lot might have happened in-between. There is much information that needs to be mapped during a night. And this was a way to make the user conscious about injecting insulin before he ate, and not wait until after.

As the machines have become more widespread, many people now want to start using them. But some of the willing users don't understand the work that follows with the technology. Therefore nurses like Aasa spend much time making the potential users aware of this.

> **Aasa:** The technology sound enticing. 'I can just see what my levels are', many think. But it is also demanding. Thats what we use time to explain [at Diabetikersenteret]. That firstly you need to calibrate it. And you need to understand the curve [on the display], understand that there is a delay in the information. 10 minutes, 15, half an hour, depending on how fast your levels go down or up. And you need to understand where on the curve you are. Are you going up, or down? What should you do? So we use quite a bit of time on that.

When the body becomes shared knowledge

If the patient gets the pump and CGM, his or he relationship to the disease changes drastically, and what has earlier been private or unmonitored knowledge of how the disease was handled becomes shared. Aasa uses the example of a 14 year old girl who had used the CGM for a test period. The transcripts of her blood sugar levels show that she had not been taking insulin at times she claims she has, either out of fear of low blood sugar, or in an attempt to lose weight.

> **Aasa:** It is very revealing, we do see what you are doing under the covers in a way, so we talk a lot about this with the patients when we upload the information. When I upload this I can see that... She sits here and says 'I take insulin to my food every day, of course'. And then it becomes apparent here that that just isn't true...You kind of have to prepare the patient about that this isn't because I want to control you, it's because we are going to get this to work, right?

> **Askild:** One can, this is kind of a form of surveillance in some ways.
>
> **Aasa:** True, in good and bad ways.
>
> **Askild:** Where one both survailles oneself, but the health personnel also gain this knowledge. Do patients react to that?
>
> **Aasa:** Some say that in this specific period I don't want you to download it. And then there are some that download it at home, and choose for themselves what they will bring and show us.

So as Aasa explains, some patients try to retain the privacy that so easily disappears with the use of continuous measurement devices. But the machines are not designed for this. Parts of the software created for the pump and the CGM is specifically written to give instructions to the medical personnel, and not to present the information directly to the patient. The information displayed to the patient through the technology is something quite different from what the nurses and doctors get. When the information is loaded into a specific program, for instance in preparations for consultations, Aasa and the other nurses get the blood sugar developments of a patient shown as a long graph, and in a box underneath this, they get a series of tips and instructions. For instance, for the 14 year old girl Aasa mentioned: "Consider counselling your patient on bolus use, the means for correcting rapid blood sugar drop". So the pump has two different displays so to speak, to two different user groups: The person with diabetes and the health practitioner.

All this information also means that persons with diabetes have much more to talk about on their consultations then they did just some years ago.

Managing the disease without understanding it

Another effect Aasa has noticed is that the technology can let people with diabetes that do not have a particularly good insight into their disease start to regulate it way better, without necessarily understanding that much more of it. Aasa explains with the example of one specific patient that has gotten a drastically lower *hba1c* after she was given the CGM. This patient does not have a very planned and active relationship to her disease.

> **Aasa:** But when she sees it [the print out of her CGM measurements], she understands. […] She lacks some understanding of her disease. But she can count carbohydrates. She eats mostly the same, more or less. So we have made a chart that tells her that for potatoes she is to take this much, because she loves potatoes. And then she can manage. As you can se [from the charts] it works excellent. It has revolutionized her hba1c. And it's because the machine does much of the work.

But though Aasa believes the machine can be trusted in many situations, she is also critical towards some of the ways the pump convays information. Its use of numbers and decimals creates a fake feeling of accuracy.

> **Aasa:** We are very much against it being commas [in the blood sugar measurements], for instance that you have 7.2 in blood sugar. It indicates that this is very precise. If instead it said 7/8 or 9/10, you wouldn't think that it was so precis. So we don't want those commas. But they came [with new machines] a couple of years ago, and they are here to stay.

Addiction, repulsion, or something in-between.

In Aasa's experience patients react very differently to being able to access the information that the pump and CGM present. Some want as much of it as possible, others try to avoid it.

> **Aasa:** There probably isn't any simple answer. Some say 'I become completely addicted. I try to take it off, and then I become so uncertain that I couldn't sleep at night, and I don't have my safety net out'. And some become kind of baffled by all you have to control, push and do. So it takes a lot more room. Those are the two extremes. Then there is the ones in-between. There has been done studies that suggest that 75% is the ideal amount of time you should wear the censor.
>
> **Askild:** So you suggest to people to take it off in some periods?
>
> [...]
>
> **Aasa:** If you have an usual daily routine, 9 to 5, then I recommend that you take breaks. But the ones who are in the group who might become addicted, they take shorter breaks. And then we have those who just leave it in the drawer.

When the nurses try to teach the patients how to use the machine, they focus on the CGM as something that the person with diabetes should consult and argue with, and not an infallible master of blood sugar control.

> **Aasa:** We talk a lot about it, that this here is a machine. And when you use Bolus Wizard you always get a suggestion, arrows pointing up or down. You are the one who decides. Because of all of this information from Bolus Wizard, the consultations take more time. So we always go through [how it works for them]: 'Are you satisfied with the Bolus now? Is it correct?'. The different factors we have put into [the machine], should they be adjusted?' So in a way we force a repetition and a control of these things.

So there is more information available, but the effect this has on the patient varies, according to Aasa. Some patients use the information to know and feel their own blood sugar levels better, also when they are not using the machine, the way it is for instance for Bård. Others again stop trusting their own gut feeling.

> **Aasa:** Some, I think, become more uncertain. They don't dare to trust themselves, and some are, it's difficult to say how many, but I know a couple who are very eager to know their blood sugar, and it training... So I suggest that before you look at what your levels actually are, take a couple of seconds and think, 'what have I got now?'
>
> **Askild:** Yes.
>
> **Aasa:** So, then you can train yourself, to feel your body. Am I thirsty? Maybe I'm 10, maybe 11.

In Aasa experience a lot more people then she would originally expect are frustrated by all the work and negotiation that follow using the CGM and the pump. Having technology that you have to argue and discuss with so close to your body takes its toll, whether you constantly argue with it, or trust it completely.

> **Aasa:** 'What is this? What the heck have you forced me to use?!' [some user say].What we have to do then is, again, to spend some time on it. [As if talking to a patient]: 'You have taken part in the calibration and programming of the machine: It has an alarm that will sound when the levels are at 2.5 or 3. Doing this is it's job.' So we have those sorts of conversations. That is what has surprised me the most [how much people react to the alerts from the machines]. And then there are those who trust the machine blindly. […] There is something I try to say: Bolus Wizard is a reasonable conversation partner.
>
> **Askild:** Mm.
>
> **Aasa:** You can argue with it. But it's always you who leave the discussion.

Appendix 2: Interview guide

Askild Aasarød

Intervju-guide: Type 1-diabetikeres hverdag med insulinpumpe og kontiuerlig glukosemåler

Muntlig informasjon til intervjusubjektene:

«Som en del av min masteroppgave i teknologi- og vitenskapsstudier (Science and Technology Studies) ved Århus Universitet og Universitetet i Oslo, ønsker jeg å gjennomføre et utvalg åpne, grundige intervjuer med type 1-diabetikere som har erfaring med insulinpumpe og kontinuerlig glukosemåler (CGM).

Jeg vil undersøke hvordan disse teknologibrukerne tilpasser og justerer livene sine til apparatene, og omvendt, hvordan de tilpasser og justerer apparatene til sin hverdag. Blant annet lurer jeg på om det er samsvar mellom antatt og reel bruk av maskinene. Samtalene har som mål å undersøke hvordan brukere selv definerer og justerer maskinene, og hva de oppfatter som viktig i forholdet til pumpen og CGM. Håpet er at vi bedre kan forstår hvordan denne typen teknologi bør designes.

Interjuet er svært åpent, og vil i stor grad ledes av tanker og temaer du selv mener er viktige i forhold til pumpen og CGM. Så ikke være redd for å bruke tid på å beskrive konkrete detaljer og eksempler du synes er viktige.»

Å lære å bruke maskinene

- Når ble du diagnostisert med type 1 diabetes?

- Hvorfor begynte du å bruke insulinpumpe?

- Når begynte du å bruke kontinuerlig glucosemåler (CGM)?

- Hvordan var opplevelsen med den første tiden du brukte CGM?

- Hvordan lærte du å bruke CGM og pumpe?

- Var det noen spesiell utfordringer med å bruke teknologien?

- Hvilke instruksjoner fikk du fra helsepersonell?

- Hva fikk du ikke instruksjoner om?

- Er du enige i instruskjonene? Hvorfor/hvorfor ikke?

Hverdagen med maskinen

- Kan du beskrive en vanlig morgen med CGM og pumpe?

- Hvordan forholder du deg til pump go CGMens beskjeder?

- Hva gjør du om pumpa melder om en blodsukkerendring når du er opptatt? Skjer det noen

Askild Aasarød

spesifikke situasjoner?

- I løpet av en dag, hva ser du på som de største utfordringene ved å bruke pumpe og CGM?

- Hva konkret gjør du for å forholde deg til disse utfordringene?

- Hvor ofte ser du på blodsukkernivaet på pumpedisplayet?

- Hvordan forholder du deg til det tallet?

- Har du på både pumpa og CGM hele tiden?

- Når tar du den eventuellt av?

- Hvordan forholder du deg til loggføring av pumpeinformasjonen?

- Hvordan sover du med pumpa og CGMen? Kan du beskrive det?

- Hva gjør du når pumpa og CGM vekker deg om natta?

- Hva er den største forskjellene mellom livet før og etter at du fikk pumpe?

- Hva er den største forskjellen mellom livet før og etter at du fikk kontinuerlig glukosemåler?

- Hvordan har du justert hverdagen din etter pumpas krav? Har du noen konkrete eksempler?

- Hvordan justerer du pumpa til din måte å leve livet på? Har du noen triks?

- Er det noen spesielle hverdagsituasjoner som blir påvirket av CGM og pumpe?

- Hvordan forholder du deg til venner og familie når det gjelder pumpen og CGM?

Tanker om pumpa og CGM

- Følger du alle instruksjonene du har fått til hvordan pumpa skal brukes?

- Følger du alle instruksjonene pumpa gir deg i løpet av en dag?

-Hvis ikke, hva velger du å ikke gjøre?

- Hvordan er det å forholde seg til en maskin som gir deg beskjeder på den måten?

- Er det deler av måten pumpen er laget på som du undrer deg over?

- Har du måter å bruke pumpa på som du tror er anderledes enn designerene har tenkt?

- Hva synes du fungerer godt med pumpa og CGM?

Askild Aasarød

- Hva fungerer ikke så godt?

- Er det noen egenskaper du savner på pumpa?

- Er det egenskaper du skulle ønske pumpa ikke hadde?

Appendix 3: Confirmation from *Norsk Samfunnsvitenskapelig Datatjeneste*

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

NSD

Harald Hårfagres gate 29
N-5007 Bergen
Norway
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Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Sissel Myklebust
Senter for teknologi, innovasjon og kultur (TIK)
Universitetet i Oslo
Postboks 1108 Blindern
0317 OSLO

Vår dato: 01.06.2012 Vår ref:30640 / 3 / KH Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 07.05.2012. Meldingen gjelder prosjektet:

30640	*Me and my Buddy: An Exploration of the uncertain Boundaries between the Self, the Body and self-monitoring Devices: The Case of Constant Glucose Monitors (CGM)*
Behandlingsansvarlig	*Universitetet i Oslo, ved institusjonens øverste leder*
Daglig ansvarlig	*Sissel Myklebust*
Student	*Askild Matre Aasarød*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/forsk_stud/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://www.nsd.uib.no/personvern/prosjektoversikt.jsp.

Personvernombudet vil ved prosjektets avslutning, 01.10.2012, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Vigdis Namtvedt Kvalheim

Kjersti Håvardstun

Kontaktperson: Kjersti Håvardstun tlf: 55 58 29 53
Vedlegg: Prosjektvurdering
Kopi: Askild Matre Aasarød, Skt. Anna gade 41
8000 Århus C
Danmark, -1 UKJENT

Appendix 4: Contracts with interview subjects

Samtykke til bruk av intervju

Jeg gir samtykke til at intervju med meg kan brukes i Askild Matre Aasarøds masterprosjektet om type 1-diabetikeres forhold til insulinpumpe og kontiuerlig glukosemåler.

Forutsettningen er at informasjonen fra internvjuet/ne blir behandlet med respekt og tilstrekkelig anonymisert.

Dato: [redacted]

Underskrift: [redacted]

Appendix 5: Full transcripts on CD

The full transcripts are available in Norwegian on attached CD.