Interacting Bodies: Posthuman Enactments of the Problem of Diabetes

Relating Science, Technology and Society-studies, User-Centered Design and Diabetes Practices

Peter Danholt

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Peter Danholt

Computer Science
Department of Communication,
Business and Information Technologies
Roskilde University
P. O. Box 260
DK–4000 Roskilde
Denmark

Telephone: +45 4674 3839
Telefax: +45 4674 3072
Internet: http://www.ruc.dk/dat_en/
E-mail: datalogi@ruc.dk

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Preface and acknowledgements

This dissertation constitutes an attempt to study diabetes practices in a performative manner, which means that I have attempted to study how people with diabetes go about their business of treating and living with diabetes by intervening in those practices. I have done so in order to be able to understand the problem of diabetes in a manner that does not simply repeat the obvious fact that people with diabetes prefer to be without the condition and that since they have the condition are, in this respect, in a state of deficiency and in need of support. My research is thus explicitly concerned with producing knowledge that can inform us *differently* about the problem of diabetes, than in a manner that legitimizes all sorts of attempts to aid people with diabetes. Immodestly put, but meant seriously, I attempt to contribute to how diabetes is *realized* concretely and conceptually. In this respect the dissertation constitutes a contribution to people with diabetes, healthcare practitioners in diabetes treatment and people interested in technologies for chronic disease management, not by presenting a concrete solution to diabetes practices but by re-figuring the problem of diabetes and technologies for those practices.

Writing is difficult whereas talking is easy. When talking you can leap from one contention to another relying on and assisted by those you talk with. They help and direct you by employing you to go on or by slowing you down, but continuously assisting you in formulating your argument regardless of whether they agree or disagree.

When writing no one and thus everyone speaks. Your contention is constantly disrupted by or associated with contentions in other writings and discourses. Potential counter arguments emerge through the engagement with the argument you are trying to formulate derived partially from yourself and from others.

The frustrating sensation I have experienced during the writing of this dissertation is that the difficulty is not what to write but what *not* to write. Every sentence seems to be like the archetypical crazed teenager depicted in American college movies that wants to throw a party and invite every other sentence it knows, and I, the author, must be the strict prohibitive parent identifying and excluding the unwanted.

Throughout the writing process the clear and concise argument is challenged and outnumbered by an ongoing mumbling of points, phrasings and sentences pressing to be included and the author has to close off this mumbling in order to achieve coherency and clarity. Then a new state of clarity and coherency may emerge only to be disrupted by yet another roar of mumbling voices. Nevertheless, any text is conditioned by this mumbling and therefore it is welcomed although a constant source of frustration.

From indistinct mumbling to distinct, personified, and to me clear, voices, that I would like to thank. People who have been generous and pleasant discussants enabling me to formulate arguments present in the text. And as they say, those people are not in any way responsible for the inadequacies of the text, only I am.

The PhD grant has been provided by Computer Science, Roskilde University and I have been enrolled in the research school program "Design and Management of IT" (DMIT). I have been a member of the research project Healthcare IT (HIT), which counts senior and junior researchers from Roskilde University (RUC), The IT University of Copenhagen (ITU) and the Technical University of Denmark (DTU) and The University of Copenhagen. Former as well as present members of the HIT research group have constituted one audience to whom I have presented my work throughout my doctoral research and have been generous to comment in constructive ways. These are senior researchers Finn Kensing, Peter Carstensen, Kjeld Schmidt, Jørgen Bansler, Erling Havn, Morten Hertzum, Jesper Simonsen and Dixi Strand Henriksen and junior researchers Joakim Halse, Hrönn Sigurdardottir, Maren Fich Granlien. Thanks to Magnus Nilsson as a fellow PhD. student and struggling companion.

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Last, thanks to my beloved children Linemarie and Asbjørn for being, well my children, but mostly, my heartfelt thanks and gratitude to Trine, who is there in every part of my life and has offered me crucial resistances, encouragement and support.

Dansk Resumé

Kroniske sygdomme og deres behandling udgør en helt central problemstilling i den vestlige verdens samfund, hvorfor det synes oplagt at udvikle løsninger til dette problem. Det overordnede epidemiologisk definerede problems evidens kan således uden videre legitimere diverse løsnings tiltag. Men det overordnede problem beretter ikke om, hvordan kronisk sygdom lokalt og i praksis udgør et problem for personer med kronisk lidelse. Min afhandling tager derfor afsæt i spørgsmålet: *Hvori består problemet med kronisk lidelse, konkret diabetes?* Medfølgende dette bevidst naive spørgsmål er min forståelse af behovet for at forstå problemet med kronisk sygdom på en måde, der rækker udover de åbenlyse forhold; at det er en gene at have en kronisk lidelse; at man åbenlyst hellere var fri og at løsningsforslag der søger at lindre og støtte er velkomne. Afhandlingens formål er således at bedrive forskning, der muliggør en forståelse af problemet vedrørende kronisk lidelse, som rækker udover den umiddelbare, gængse og allestedsnærværende forståelse af problemet. Med dette forehavende for øje tager afhandlingen afsæt i en række problemstillinger:

Den første problemstilling omhandler inddragelsen af mennesker med kronisk sygdom i udvikling og design af teknologiske løsninger rettet mod 'chronic disease management' og det forhold, at de i en sådan rolle ikke blot er lægmand eksperter, men også må antages at være afgørende prædisponeret for at være positive overfor sådanne løsninger. Dette er gunstigt fra et snævert design perspektiv med interesse i udvikling af teknologiske løsninger men udgør et metodisk og videnskabeligt problem.

Den anden problemstilling består i forståelsen af at forhåbningen om 'empowerment' af patienter er en ambition, der på den ene side forstår patienten som en central og handlekraftig figur i behandlingen, men på den anden side antager at diverse 'empowerment' tiltag modstandsløst adopteres af patienten. Præmissen for denne antagelse er forestillingen om det handlekraftige, rationelle subjekt, der aktivt søger et godt liv og helbred. Men denne antagelse er grundlæggende asymmetrisk. Hvorfor skulle 'empowerment' tiltag ikke også være i

hænderne på brugerne på måder, som forandrer, oversætter eller forkaster disse tiltag?

Den tredje problemstilling knytter sig til ambitionen om og karakteren af et bidrag indenfor IS forskning. Ambitionen om f. eks. at udvikle en prototype eller et 'proof-of-concept' beror på tilsidesættelsen af forståelsen af teknologi-som-netværk; som en virksom association af menneskelige og ikke-menneskelige aktører (socioteknisk ensemble, teknologi-som-praksis) i ønsket om at kunne præsentere noget, der fremstår som teknologi i en traditionel optik, som en neutral, selvopretholdende genstand. 'Proof-of-concept' er en lokal bedrift, der beror på en række aktørers bidrag, som søges generaliseret og derved overses at det som realiserer 'the proof-of-concept' er en lokal, situeret begivenhed.

Det er ikke afhandlingens ambition at løse disse problemstillinger, de udgør derimod dens præmis. Afhandlingen tager dem alvorligt som grundvilkår, der sætter nogle rammer for, hvad jeg som forsker kan håbe på at udrette. At nære ambitionen om at løse dem synes ikke blot ubeskedent, men også at være en forglemmelse af deres substantielle karakter.

Således tager afhandlingen afsæt i forståelsen af videnskab og teknologi som performative praksisser igennem hvilke viden og teknologi produceres som et produkt af kæder af menneskelige og ikke-menneskelige aktører som udtrykt indenfor Science, Technology and Society-studies (STS). I relation til videnskab betyder det at den polære modsætning mellem forskning som 'biased' og 'un-biased' opløses. Ingen viden er 'un-biased', a-historisk, neutral eller objektiv i en STS optik. Ej heller giver det mening at tale om forskning som mere eller mindre 'biased' eller at forskeren refleksivt søger at redegøre for sin bias. Det bliver i stedet relevant at tænke i baner af, hvordan forskeren muliggør forskningens genstands mulighed for at italesætte sig således, at den potentielt yder modstand til forskerens forståelser og/eller etablerede forståelser i samfundet. I posthuman STS er 'det konstruerede' og 'det virkelige' ikke modsætninger som i en modernistisk videnskabsforståelse, de er derimod hinandens forudsætninger.

I mit feltarbejde har jeg bl.a. etableret et eksperiment, der introducerede en teknologi til 8 personer med type II diabetes. Teknologien, *Onetouch® Ultrasmart*™ er et integreret blodsukker måleapparat og digital logbog til at opsamle anden diabetes relevant data udover blod sukker målinger (motion, medicin, kost og generel helbredstilstand), data, der lader sig repræsentere af Onetouch gennem diverse snit og diagrammer. Onetouch er således markedsført som et informations- og beslutningsstøtte værktøj for folk med diabetes, der kan hjælpe dem til at få overblik og kontrol med lidelsen. Mit eksperimentet havde flere formål: 1) at skabe en situation der ikke tog afsæt i antagelsen om et veldefineret problem (kronisk sygdom) med fokus på at udvikle en løsning til dette problem. Omvendt tog eksperimentet afsæt i en konkret løsning som drivkraft for at undersøge problemet forbundet med kronisk lidelse og derved 2) give deltagerne mulighed for at afvise Onetouch og udpege deres egne løsninger og/eller argumentere for hvorfor Onetouch ikke er relevant for dem og på den vis informerer mig om problemets karaktér. 3) At give deltagerne mulighed for at realisere Onetouch som løsning og Onetouch muligheden for at blive realiseret som relevant.

Den empiriske del af afhandlingen indeholder, udover et introducerende kapitel der præsenterer eksperimentets performative aspekter, seks kapitler, der hver repræsenterer én af deltagernes måde at praktisere sin lidelse på. Fælles for disse historier er, at de viser, hvordan deltagerne aktivt medvirker til konkrete tilblivelser af diabetes. Historierne viser, hvordan kompetence kan være årsag til inkompetente handlinger; hvordan ønsket om at komme under en standardiseret grænseværdi kan være en central drivkraft for personen på trods af, at grænseværdiens vigtighed nedtones af lægefaglige praktikere; hvordan diabetes praktiseret som et privat, personligt forehavende både er forbundet til og forskelligt fra, hvordan der undervises i diabetes på diabetesskolen; hvordan det kan være vanskeligt at tro på diagnosen, når man ingen tydelige fysiske gener har; og på den anden side hvordan diabetes kan være en særdeles legemliggjort lidelse, der fordrer tæt bevågenhed og dog på trods opleves som ukontrollérbar; og sidst hvordan diabetes kan være noget, der skal gennemgå en tilblivelsesproces for, at personen med diabetes kan blive i stand til at tage vare på lidelsen. En tilblivelsesproces der indbefatter, at man inkluderer andre mennesker, praksisser og teknologier.

Disse historier danner tilsammen belæg for afhandlingens to sidste kapitler. Det første argument omhandler en re-figurering af Onetouch fra informations- og beslutningsstøtte system til registrerings praksis. Onetouch lanceres som informations system og udtrykker problemet om diabetes som et spørgsmål om at opnå overblik og kontrol. Dette er en forståelse, hvor praksissen med at indsamle data negligeres. Ligeledes viste eksperimentet at deltagere i brugen af Onetouch søgte at undgå omstændelige eller unødvendige registrerings praksisser. Registreringspraksissen med Onetouch er således i både markedsføringen af Onetouch og dens praktiske anvendelse praktiseret som omstændelige og marginaliseret. I modsætning hertil står en posthuman STS forståelse, hvor praksis ikke blot betragtes som afgørende for at enhver teknologi bliver funktionel og virksom, men også hvor praksis i sig selv er produktiv, da den indvirker på og producerer kropslighed og forståelser. Med afsæt heri udfoldes et argument for Onetouch som registreringspraksis snarere end som informations- og beslutningsstøtte. Dermed re-figureres Onetouch og gives en anden supplerende eksistensberettigelse. Et sådant argument udgør en multiplicerings praksis, hvor Onetouch ikke overskrides som teknologi gennem konkret re-design, men ej heller bevares i sin oprindelige form. Argumentet udgør i stedet en intervention og en tilføjelse til virkeligheden.

Det sidste kapitel søger at besvare spørgsmålet om problemet ved diabetes. Med de seks historier som baggrund kan problemstillingen vedrørende diabetes siges at bestå i håndteringen, ikke af en lidelse, men af *relationen* til en lidelse. En sådan posthuman betragtning af problemet forstår problemet som bestående i den gensidige 'enactment' af diabetes lidelsen og diabetes personen/subjektet. Diabetes er således ikke et givet objekt, der skal styres, men et *praktiseret* objekt. Således forstået handler diabetes problemet om opnåelsen af en affektiv relation og produktionen af en krop og en identitet, som er følsom og 'tilgængelig' for diabetes, således at diabetes kan blive tilgængelig for personen med diabetes.

Når vi betragter problemet således har det betydning for, hvad der kvalificerer som et relevant bidrag til diabetes praksisser. Det bliver kun delvist relevant at forfølge en ambition om at sætte folk i stand til at overvåge og følge deres lidelse, eftersom det forudsætter og viderefører en forståelse af et diskret objekt, der kan kontrolleres. I stedet er det centralt at følge og intervenere i hvorledes diabetes *gøres* og realiseres i situerede praksisser. Et bidrag består derfor i at cirkulere forståelser og beskrivelser, der gør det muligt at forstå og praktisere diabetes som relation. At forstå problemet således indskriver personen med diabetes - ikke som en der behersker en genstand mere eller mindre - men som en der er uløseligt impliceret i diabetes og lidelsens udfoldelse. Ligeledes bliver det vigtigt at cirkulere forståelser af teknologier som praksisser, formulere argumenter der støtter forståelser af teknologiske genstande som nogle der sætter én på arbejde med det sigte at blive forandret. Hvor omstændelige praktiske aspekter forbundet med at opnå virksom teknologi ikke italesættes som aspekter der skal søges minimeret af hensyn til brugeren (og i sidste ende teknologiens interessenter), men som en praksis hvorigennem kroppe, forståelser, behov og begær transformeres. Et bidrag består derfor i at operere med og udbrede en ontologi, hvor kroppe og forståelser, objekter og subjekter ikke er givne, men mulighedsrum. En ontologi der gør det attraktivt og oplagt at tænke sig selv, andre og verden som foranderlig og hvor man kan påvirke og påvirkes gennem materielle praksisser. En sådan posthuman forståelsesramme er således at betragte ikke blot som en metodisk tilgang, men som en virksom og interventionistisk proces.

Summary

Chronic diseases and their treatment constitute a central problem in western societies and accordingly it seems obvious to try and develop solutions for this problem. The evidence of the general epidemiological defined problem may thus immediately legitimize diverse solution initiatives. But the general problem does not say anything about how chronic disease locally and in practice is a problem for people with chronic conditions. This dissertation therefore begins with the question: *what constitutes the problem of chronic disease, concretely diabetes?* Accompanying this deliberately naïve question is my understanding of the need for understanding the problem of chronic disease in a manner that goes beyond the obvious aspects: that it is unpleasant to suffer from chronic diseases; that one obviously would prefer not to suffer from chronic disease and that solutions that attempt to ease the suffering and be supportive are welcome. The aim of dissertation is thus to conduct research that enables an understanding of the problem of chronic disease that goes beyond the immediate, common and pervasive understanding of the problem. With this purpose in mind the dissertation is premised by a set of problems:

The first problem relates to the inclusion of people with chronic disease in the development and design of technological solutions for 'chronic disease management' and the fact that they in such a role are not only laymen experts, but also must be regarded to be decisively predisposed to be affirmative towards such solutions. This is advantageous from a narrow design perspective with an interest in the development of technological solutions but constitutes a methodological and scientific problem.

The second problem consists in the understanding that the wish for 'empowerment' of patients is an ambition, which sees the patient as a central and active figure in the treatment on the one hand, while presuming that various empowering initiatives are adopted without resistance from the patient on the other hand. The premise for this assumption is the understanding of the capable, rational subject, who actively seeks the 'good' and healthy life. However, such an assumption is generally asymmetrical. Why should empowering initiatives not also

be in the hands of the users in ways that transform, translate or reject such initiatives?

The third problem relates to the ambition of and the character of what might constitute a contribution to Information Systems research. For instance the ambition of developing a prototype or a ’proof-of-concept’ is premised by the abandonment of seeing technology as network, that is as an association of human and non-human actors (sociotechnical network, technology-as-practice) in order to be able to display something that qualifies as technology in traditional view, that is as a neutral, discrete entity. ‘Proof-of-concept’ is thus a local situated achievement based upon a range of actors’ contribution, attempted generalized and thus the local, situated achievement is overlooked as constitutive of the ‘proof-of-concept’.

It is not the ambition of the dissertation to solve these problem, they merely constitute its premises. The dissertation considers them as basic conditions that frame and constrain what I as a researcher can hope to accomplish. To hold the ambition of solving these problems seems not only somewhat immodest but constitutes also a disregard for their substantial character.

Hence the dissertation is premised by understanding science and technology as performative practices through which knowledge and technology is produced as an outcome of chains of association of human and non-human actors as it is expressed in posthuman Science, Technology and Society studies (STS). In relation to research this implies that the conception of a dichotomous opposition between biased and un-biased research dissolves. No type of knowledge is ’un-biased’, a-historical, neutral or objective in the optics of STS. Neither does it make sense to speak of research as more or less biased or the researcher’s attempt to reflexively account for her biases. Instead it becomes pertinent to think in terms of how the researcher enables the object of study’s ability to articulate itself so that it may potentially resist the researcher’s assumptions and/or established understandings of the object. In posthuman STS ’constructed’ and ’real’ does not stand in opposition as in a modern perception of science. On the contrary they are mutually constitutive.

In my empirical fieldwork I have among other things conducted an experiment that consisted in the introduction of a specific technology to eight persons with diabetes type II. The technology, *Onetouch® Ultrasmart*™ (hereafter Onetouch) integrates a blood sugar measurement device and a digital logbook for recording other diabetes relevant data than blood sugar measurements (exercise, medication, food, general health condition), data that may be represented and associated in various ways. Hence Onetouch is promoted as an information- and decision support system for people with diabetes to support them in keeping track of and managing the condition. My experiment had several purposes: 1) to create a set-up that was not premised by the presumption of a well-defined problem with a focus on developing a solution. Inversely the experiment employed a concrete solution (Onetouch) as a catalyst for investigating the problem of chronic disease, specifically diabetes and thereby 2) to provide the participants the opportunity to reject Onetouch and demonstrate their own solutions and/or argue for why Onetouch is not relevant to them and thereby inform me of the character of the problem. 3) To provide the participants the opportunity to realize Onetouch as a solution and Onetouch the opportunity to become realized as relevant.

The empirical part of the dissertation includes, beside an introductory chapter on the performative aspects of the experiment, six chapters each referring to one of the participants' ways of practicing his or her condition. These stories have in common that they show how the participants actively contribute to concrete *becomings* or enactments of diabetes. In particular they show how competence can be considered as causing incompetent actions; how the wish to become below a medical standardized limit value may constitute a pivotal motivation for the person with diabetes, despite the fact that the importance of adhering to the limit value is downplayed by the healthcare practitioners; how diabetes practiced as a private, personal matter is both in accordance with and in contrast to the teaching at the diabetes school; how it may be difficult to believe in and thus take the consequences of the diabetes diagnosis serious when one has no significant physical symptoms; and in contrast how diabetes may be a considerable embodied condition, that demands close attention and yet can be experienced as unruly; and last how diabetes may be something that needs to undergo a process of becoming in order for the person with diabetes to become able to manage the condition, a process of becoming that involves the inclusion of other people, practices and technologies.

These empirical stories together form the premise for the last two chapters of the dissertation. The first is about the re-figuring of Onetouch as primarily an information- and decision support system to Onetouch as a recording practice. Onetouch is promoted as an information system and expresses the problem of diabetes as a matter of being able to overview and manage the condition. This understanding is one where the practice of recording data is neglected. Moreover, the experiment with Onetouch showed that the participants in their use of Onetouch sought to avoid tedious and 'unnecessary' recording practices. The recording practice with Onetouch is thus both in the promotion of Onetouch and in the concrete use practice of the experiment enacted as tedious and marginalized. In contrast hereto stands a posthuman STS understanding, where practice is not only considered as pivotal for any technology to function, but also where practice in itself is considered to be productive, since it affects and produces bodies and perceptions. Premised in this manner an argument for Onetouch as a recording practice rather than as information- and decision support system is formulated. Thereby Onetouch is re-figured and is provided a different supplementary reason for existence. Such an argument constitutes a multiplication practice, where Onetouch is not transgressed as a technology through concrete re-design, but neither simply preserved. The argument is instead an intervention in and addition to reality.

The last chapter attempts to answer the problem of diabetes. On the basis of the six stories the problem of diabetes can be articulated as a matter of managing not a condition, but a relation to a condition. Such a posthuman perception of the problem sees the problem as consisting in the mutual 'enactment' of the diabetes condition and the person/subject with diabetes. Hence diabetes is not a given object to be managed but a *practiced* object. Perceived like this the problem of diabetes is about establishing an affective relation and producing a body and an identity that is sensitive to and available for diabetes so that diabetes may become available and sensitive to the person with diabetes.

When we consider the problem of diabetes in this manner it is consequential for what qualifies as a relevant contribution to diabetes practices. It is only partially relevant to follow an ambition of enabling people to overview their condition, since it assumes and continues an understanding of a discrete object to be controlled. Instead it is important to follow and intervene in how diabetes is *done* and enacted in situated practices. Hence a contribution consists in circulating understandings and descriptions, that enable us to perceive and practice diabetes as a relation. To consider the problem thus construes the person with diabetes, not as someone who more or less controls the condition, but as inherently entangled with diabetes and its becoming. Moreover, it becomes important to circulate understandings of technologies as practices, formulate arguments that support understandings of technological artifacts as inducing work with the purpose of transforming the user; where tedious practical aspects related to accomplishing functional technologies are not immediately articulated as aspects to be minimized for the sake of the user (and in the last instance the stakeholders of the technology), but as a practice through which bodies, understandings, needs and desires are transformed. Hence a contribution consists in applying and dispersing a posthuman ontology, where bodies and perceptions, objects and subjects are not given, but potentialities. An ontology that finds it desirable and obvious to consider oneself, others and the world as transformational and where one may affect and be affected through material practices. Hence a posthuman disposition is thus not only a methodological approach but also an agential and interventionist process.

Introduction:

Interacting Bodies and Researching the Problem of Diabetes

Interacting Bodies

This dissertation is entitled *Interacting Bodies: Posthuman Enactments of the Problem of Diabetes. Relating Science, Technology and Society-studies, User-Centered Design and Diabetes Practices* and is about the practice of how people with diabetes manage their condition and how to study this practice. The central understanding is that diabetes can be viewed as a practice and as a site of *interacting bodies*. For people with diabetes, life can be considered as a continuous process of interacting with a range of bodies; the disease as a body that resides inside and affects their human body; the person with diabetes as a body that through actions and other bodies such as food, medication, movement of the body (exercise) affects the condition; treatment as interaction with healthcare practitioners, medical knowledge and technologies that in different ways relate to and interact with the person-body. These interactions may 'break down' the person-body into other bodies such as blood or urine samples that become objectified and externalized in order to give testimony about yet other bodies such as blood sugar, cholesterol, ketone bodies, lipids etc. Thereby, complicated relations of bodies, as both inside and part of other bodies as well as outside and separate to those bodies, are formed. Consequently, in this view what a body *is* depends on how it is related to other bodies. Bodies considered as such are thus relational and multiple; they are not well-defined, discrete and unified and how these bodies come to matter for other bodies is contingent. Importantly, diabetes considered as such entails that no-body fully determines how other bodies emerge, but no-body is not without affective consequences for other bodies either. This is the principle of irreduction implied when seeing diabetes as a site of interacting bodies.[1]

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[1] The french philosopher and sociologist of science and technology Bruno Latour proposes the principle of irreduction that states that "nothing is either reducible nor irreducible to anything else" (1988b), which I consider to mean that everything is connected in affective relations and thus consequential for other things, while at the same time nothing is only and fully the same as something else. Isabelle Stengers applies the principle in her work on the

Moreover, to study diabetes as a site of interacting bodies is in itself a matter of interaction. The researcher, as a body, interacts with the participants in the study, bringing concerns and materials into play through questions and trials, a practice that again can be perceived as bodies interfering and interacting with other bodies. Thereby bodies are affected and potentially transformed in subtle or substantial ways. To think of diabetes and researching diabetes in this manner is *performative*. What it entails to consider diabetes as a site of interacting bodies will be unfolded in this dissertation, and how it is consequential for diabetes, treatment and chronic disease management technologies is the central concern.

This introduction may also be conceptualized as a site of interacting bodies since I here present and discuss how and why I have conducted my doctoral research. My doctoral research has been driven by concerns relating to the problem of chronic disease, doing action-research, empowerment of patients, researching the practices of people with chronic disease in relation to design of information systems and technologies. This introduction thus motivates my research by rehearsing my concerns produced through interaction with concerns elicited in design and constructivist understandings coined in Science, Technology and Society (STS) studies.

Chronic diseases and the problem of diabetes

Chronic diseases are considered to be the greatest challenge in contemporary Western healthcare. Specifically, the World Health Organization designates that diabetes has reached epidemic proportions (WHO 2002, Dept. Of Health 2001). The Danish National Board of Health (DNBH) has issued several initiatives on chronic disease, one is: “Chronic disease: patient, healthcare and society” (Sundhedsstyrelsen 2005).[2] In this report the DNBH poses the problem of chronic disease accordingly: 1.5 million people, or approximately up to 1/3 of the adult

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relation between science and politics. She refuses to consider science as neither reducible to politics as when holding that ”science is merely politics” but equally she wants to avoid the crude oppositional alternative, namely that science transcends politics as if the two were two inherently different enterprises, a view that leads to the common understanding of science as rational and ’apolitical’ and politics as ”arbitrary, tumultuous and irrational waves of human controversies” (Stengers 2000: 16). See also Latour 1999, Jensen 2004a, Gomart & Hajer 2002.

[2] Title in Danish: ”Kronisk Sygdom: Patient, sundhedsvæsen og samfund – forudsætninger for det gode forløb”. See also Regeringen 2002, Sundhedstyrelsen 2005, 2006

Danish population suffers from chronic diseases. Longer life rates caused by improved living standards, but also healthy living, efficient healthcare and medical technologies, have led to a societal condition where chronic diseases constitute the predominantly greatest challenge for healthcare. It is estimated that app. 80% of the healthcare expenses in Denmark is spent on treating chronic diseases (ibid).

Healthcare providers, decision makers and researchers have realized that treating chronic diseases is inherently complicated. These diseases have multiple causes; suffering from and treating them is a continuous activity. Chronic diseases are lasting, irreversible and often multiple through their interrelation with other conditions. Chronic diseases demand lasting attention and treatment (2005, 31-32). Treatment is thus a complicated task that demands the coordination of a range of actors. Because treatment is an ongoing activity, the active, participating patient is considered of great importance for successful treatment. (WHO 2002, Sundhedsstyrelsen 2005, Wagner 1998, Dept. of Health 2001, 2004).

These are the epidemiological facts – the general problem. The DNBH employs a model to understand the problem and improve things by. This is the Chronic Care Model (CCM) developed by the MacColl Institute, Seattle, USA (Bodenheimer 2002, Wagner 1998). The CCM is a holistic model that pictures improving treatment of chronic disease as resting on three factors: the patient, the health system and the society.[3] Further specified, the model counts six aspects: self-management support (the patient), resources and policies (the society), organization of healthcare, decision support, delivery system design and clinical information systems (health system). The outcome of these factors should be an "informed, activated patient" and a "prepared proactive practice team" able to engage in mutual "productive interactions". The CCM stresses the importance of evidenced-based medicine and care. Every aspect of the model rests on medical knowledge of best practices and evidence for treatment, rehabilitation and

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[3] Talcott Parsons often considered the father of medical sociology, proposed the three concepts illness, disease and sickness as referring to three different perspectives on disease namely the individual, subjective experience of being ill, the objective understanding of the disease represented by medicine and the social and societal effects of being sick and the stigma and differentiation it involves (1951). These three categorical perspectives are obviously reproduced in the CCM and are widely accepted as a meaningful way of thinking about and ordering disease. For a critique of Parsons see Mol 2002. For an understanding of CCM as a technology and ordering device see Danholt 2006c. For the work exercised and executed by disease categories see Bowker & Star 2002. See also Foucault 1973, 1991.

prevention of chronic diseases. The overall purpose is to secure that patients are offered effective and evidenced-based healthcare (Sundhedsstyrelsen 2005: 38).

Similarly, the research program my doctoral research is a part of: Healthcare IT (HIT) is also concerned with the patient. The primary focus in the HIT research proposal is empowerment of patients (Bansler et al. 2003). The active participating patient or user of healthcare services is considered a key actor in HIT. Consequently, HIT seeks to address the aspect of collaboration and communication between healthcare providers and patients ultimately and primarily for the benefit of the patient. To be concerned with developing healthcare services, that place the patient at the centre of attention, is generally a primary concern today among decision makers, healthcare providers, patient organization and researchers. This patient-centred focus is difficult to consider as anything but sympathetic and relevant.

However, when articulating the problem of chronic diseases in this manner we also address the problem from a specific point of view; we address it as a societal problem, and as such our concern is how to organize society so that the problem of chronic disease becomes solvable. However, my research has been premised by being inherently uncertain with regards to *what constitutes the problem of chronic disease*, and therefore the objective of my research has been to define or invent the problem, rather than solve it.

My research has been premised in this manner, instead of simply accepting the general, epidemiological, societal problem of chronic disease as legitimizing attempts to solve the problem, for two main reasons. First, in order to avoid contributing to the production of what may turn out to be petty, irrelevant solutions on the basis of a poorly understood problem, which, as I will argue, there might be a considerable risk of doing in relation to chronic disease management. Second, I take my clue from the French poststructuralist philosopher Gilles Deleuze's reading of another French philosopher Henri Bergson. Following Bergson, Deleuze argues that we should not be content with only solving problems, but also claim the freedom to define them.

> "We are wrong to believe that the true and the false can only be brought to bear on solutions, that they only begin with solutions. This prejudice is social (for society, and the language that transmits its order-words [mots d'ordre], "set up" [donnent] ready-made problems, as if they were drawn out of "the city's administrative

> filing cabinets," and force us to solve them, leaving us only a thin margin of freedom). Moreover, this prejudice goes back to childhood, to the classroom: It is the schoolteacher who "poses" the problems; the pupil's task is to discover the solutions. In this way we are kept in a kind of slavery. *True freedom lies in the power to decide, to constitute problems themselves*." (Deleuze 1991:15 my italics)

Bergson's (and Deleuze's) central concern is that problems may be "badly stated" (ibid. 18) and thus poorly grounded, and therefore lead to equally badly proposed solutions. Since problems and solutions are related, problems stated properly may dissolve and thereby bring about their own (dis-)solution. Or they may bring about a more sophisticated formulation of the problem that calls for different solutions than immediately assumed. Since problems may be "badly stated" we should be both rigorous and free to engage in the definition of problems, rather than simply to accept general definitions of them, and thereby implicitly support and re-produce the prevailing understanding of them as well as the view that problems are pre-existing, universal entities not particular, historical and crafted entities.[4] Conseqeuntly my concern is the particular one: *for whom and how is chronic disease a problem*. This is an important concern since what constitutes a problem for people with chronic disease must be regarded as consequential for how and why they employ specific solutions.

In contrast, had I raised the research question: How can IT support treatment of chronic disease?[5] then I would have embarked on research

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[4] Problems must be constructed; the general epidemiological problem of chronic disease thus rests upon a whole range of actors, procedures, technologies, knowledges, on a society that collects and computes data in highly specific and sophisticated manners (Foucault 1991). Symbolic interactionist Joan Fujimura has described how a problem becomes 'do-able' in cancer research. A problem needs to be 'do-able' in order to be addressed. She shows how this is achieved through the alignment of different levels of work organization (Fujimura 1987). The point is thus that a problem needs to be set up in a specific, concrete manner in order to be addressed, and that a problem from the outset has a dubious quality, or even that we are unable to consider it a problem before it has been constructed as such. A problem is thus not a preexisting entity but must be ordered and related to other entities in order to become a problem. This understanding is similar to the understanding of a fact in Science, Technology and Society Studies (STS) as having a history, a genealogy rather than simply something discovered. See the argument that follows later in the introduction.

[5] In comparison, in the HIT research proposal the research questions posed are: 'How can IT applications support communication between care providers and patients? 'How can IT applications support the interactive nature of healthcare work and enable the patient to take more control over his or her own health? 'How can IT applications support knowledge sharing among patients and provide tools for building patient communities?' (HIT p. 1). (See http://www.healthcareit.dk/program.html accessed November 2007).

attempting to solve the problem, and would thus have accepted the general problem of chronic disease. My concern has been to particularize the problem empirically and be deliberately uncertain with regards to what constitutes a problem. In the words of the Belgian philosopher of science and chemist Isabelle Stengers I have attempted to be an idiot:

> "[The idiot] is the one who always slows the others down, who resists the consensual way in which the situation is presented and in which emergencies mobilize thought or action… [the idiot] demands… that we don't consider ourselves authorized to believe we possess the meaning of what we know." (Stengers 2005: 994-5)

In relation to empowerment my concern has thus also been to be uncertain with regards to the need for empowerment and abstain from the inclination to empower people through diverse solutions, technical, organizational etc., and thereby implicitly disempower them.[6] Instead I immanently empower people with chronic disease by initially abstaining from assuming that they are in need of diverse solutions; by not assuming that they are in a state of lack and deficiency[7]. This reluctance to presume people with chronic disease as in a state of lack qua their condition and thus in need of empowerment, relate to an argument that constitutes a central motivation for how I have conducted my research. It relates to what I consider the asymmetrical assumptions intrinsic to the ambition of patient empowerment, and what may constitute a contribution in action-oriented design approaches.

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[6] I am reluctant to argue for the empowerment of patients simply because to do so is first and foremost to render them disempowered. They are disempowered by the assumption that they need to be empowered. Similarly, the French actor-network theorist and Michel Callon has stated: "to speak for others is to first silence those in whose name we speak" (Callon 1986: 216)

[7] Sociologist of technology Jessica Mesman has studied the aspect of patient safety in clinical practices with a concern of abstaining from understanding failures in clinical practices through a "deficiency model". Her work considers instead how uncertainties in clinical practices are managed through "resources of resilience" and is thus able to recognize and appreciate the immanent patient safety practices already at work in clinical practices. See Mesman 2007.

Translation, Technology as Network and Nominalism

As argued extensively in relation to chronic diseases, patient empowerment literature and medical informatics the patient plays a central role in the treatment (Dept. of health 2001, 2004, Kuhn et al. 2003, Segal 1998). Evidently this means that the person with the condition is a powerful agent with regards to employing the various technologies and treatment procedures. But if the active patient is considered to have great importance in the treatment of chronic diseases arguably s/he must also play a central role in the acquisition of empowerment. However, the ambition to empower patients seems premised by a determinist view that considers e.g. technological devices, educational programs, or a plethora of combined initiatives as 'realizing' the patient as active and empowered. The patient thus plays a decisive role in treatment as somebody who makes a substantial difference in relation to the condition. But why should the patient not make a similar difference when it comes to acquiring empowerment? Why should he or she simply become empowered as intended by those who seek to empower them? The patient is thus in one regard considered an active agent with crucial importance for treatment, while s/he, when it comes to becoming empowered, is a docile, passive body unresistingly shaped and structured by empowerment. My contention is that patients are always active, and their actions consequential both with regards to their condition, but equally with regards to the various technologies, knowledges and practices of treating their condition. They *translate, negotiate and transform* what is passed on to them by healthcare providers, nurses, physicians, technology manufactures and designers, decision makers, teachers etc. rather than simply adopt it. The point is thus that the success of a specific technology, procedure, knowledge, understanding is always in the hands of its users. The French sociologist of science and technology and actor network theorist Bruno Latour has designated this the principle of translation and opposes it to the principle of diffusion. Latour defines translation thus:

> "To designate this thing which is neither one actor among many nor a force behind all actors transported through some of them but a connection that transports, so to speak transformations, we use the word *translation*... a relation that does not transport causality but induces two mediators into coexisting." (Latour 2005: 108)

The principle of translation holds that every message, technology, fact is always through its use and dissemination susceptible to be transformed and translated. Accordingly it means that an entity relies on actors and network for its dissemination, nothing has force or inertia in itself to become disseminated. From a translational perspective it is to be expected that messages are corrupted and technologies transformed since this is intrinsic to the process of being put to use. In contrast the principle of diffusion assumes that a message or a technology possesses an initial force that enables it to travel so far through a medium depending on the medium.[8] The principle of translation implies that people with chronic disease must be regarded as being *equally* influential and active when it comes to their condition as with diverse empowering initiatives. The principle of translation constitutes the non-determinist premise of my doctoral research. The principle of translation has mattered substantially to my doctoral research? In order to unfold this I will situate myself further.

Besides being a member of the HIT research group mentioned above, I have been enrolled as doctoral student in a PhD research school program named "Design and Management of Information Technology" (DMIT). In the DMIT program it is stressed that design and management should be understood broadly, in order to avoid the potential rationalist and positivist connotations that come to mind when information technology is articulated as manageable in a strong sense. DMIT stresses the importance of participation in the design of technology and is related to the Scandinavian design tradition (Bjerknes et al. 1987, Bødker et al. 2004, Greenbaum & Kyng 1991, Kensing et al 1998). The part of the program that relates to "Information systems and human computer interaction" is concerned with "design of information systems", "evaluating system usability", "users' interaction and experience", "the intricate interplay between IT and

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[8] Bruno Latour and Michel Callon and Actor-network theory is inspired by the French philosopher Michel Serres and his work on communication-theory. Serres considers noise as the premise for any message. Hence, communication is premised by a parasite logic where any message in order to be a message and be received as such implies channels of communication that translate it. Without channels and noise there is by definition no communication only sameness. See Serres 1982, 1983, 1995. For an excellent introduction to Serres see Brown 2002. See Latour 1986, 1999, 2005. The principle of translation also owes much to Michel Foucault's work and his insistence on "cutting off the king's head", see the argument later in this introduction. See also Law 2002, Danholt & Bødker 2005, Markussen & Olesen 2007 and Olesen & Markussen 2004 for applying the principle of translation.

organizations."[9] Stressing the emphasis on participation, the program advocates empirical studies of practices and action-research. During my doctoral education at DMIT I have often encountered the understanding that emphasizes the importance of research as contributing to 'real-world' practices. Now, it seems difficult to disagree with this ambition. Who would not want to contribute to the 'real-world' practices that one studies?[10]

However, provided a translational understanding what may constitute a relevant contribution is in the hands of its future users and is thus highly contingent. It constitutes an ambition to contribute, but it cannot be considered a given outcome of doing action-research in a 'real-world' practice. Provided a translational understanding one becomes doubtful, as a researcher, as to whether his or her intervention will in fact in the end constitute a contribution. It might just as well end up being an interference and a waste of time and resources for the practice one seeks to contribute to. This seems to me to be a reasonable doubt and modesty one must have as a researcher. Simply to advocate for action-oriented intervention in practice seems to me to harbor some somewhat problematic and reductionist understandings of research as by definition being able to contribute with the necessary expertise for a given practice.

Hence my understanding is that intervention in a 'real-world' practice might just as well lead to disaster as well as success (and more accurately it probably always leads to transformation including successful as well as disastrous elements). If one accepts this understanding then abstaining from certain types of interventions is not simply 'ivory-tower', 'theoretical far-from-practice-and-thus-irrelevant' research, but might just as well be done out of a consideration for the practice and modesty with regards to one's potential contribution. For instance, if we accept the principle of translation and acknowledge, as is widely accepted in Information systems research (IS) and in Science, Technology and Society-studies (STS) that technologies are always in the hands of their users and are thus employed, used and abused, betrayed, abandoned, configured, changed etc. in and through the practices of use, then a functioning technology is by no means a trivial

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[9] See the website for the DMIT research school at http://ruc.dk/ruc_en/research/PhD/natsc/design/ accessed October 2007.

[10] Obviously, to talk of 'real-world' practices implies a somewhat sharp distinction between 'real-world' and 'academic, theoretical knowledge' which is problematic in many ways. I will discuss this further in Chapter 1. However, the point I wish to make here is another.

task (Bijker 1997, Bijker et al. 1992, 1993, Greenbaum & Kyng 1991, Kling et al. 1982, Latour 1999, Monteiro et al. 1995, Orlikowski et al. 1991, Oudshorn et al. 2003, Walsham 1997, Scacchi 2004, Truex et al. 1999, Woolgar 1991). On the contrary, to realize a given solution, whether technological or other, as functioning, depends not solely or primarily on the intrinsic qualities of the technology, its design or technical qualities, but on a network of actors. A well-functioning technology is in this light the construction and alignment of a network of human and non-human actors.[11] In relation to my doctoral research this means that to e.g. attempt to develop, design and evaluate, say a prototype of a given technology through action-research, requires the alignment and enrolment of a whole network of actors. Considered with the above argument in mind such a project is by no means simply an innocent test or proof-of-concept that does nothing to the practice. On the contrary it is a time- and labour consuming activity

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[11] The Dutch STS scholar and IT-consultant Marc Berg has elaborated on diverse essentialist understandings of technology (Berg 1998, see also Mackenzie et al. 1985, Bijker et al. 1992). Berg speaks of technology determinism and social essentialism. Technology determinism sees technologies as a force that forms society and sociality in a causal manner. The degree of determinism may vary, but central to it is the notion that technologies can be means of domination (Winner 1986). Technology determinism may come in technophilic and technophobic guises, the former conceiving technology as resulting in prosperity, progress, liberation etc. while the latter see technologies as deskilling, alienating, enslaving etc. Social essentialism, on the other hand, views technologies as neutral tools that are shaped and determined by their users. Both sets of understandings are essentialist and determinist since they attribute to one party the power over the other. Latour's (1999) famous argument on the controversy between proponents and opponents of the liberal gun legislation in the U.S. illustrates the limitations of essentialist and determinist understanding of technologies. The slogan articulated by opponents to the liberal gun legislation in the U.S. is that "Guns kill people" to which the proponents respond: "Guns don't kill people – people kill people". Latour's argument is that both of these slogans are inherently reductionist, since they both refer all the power to one actor, either guns or people kill. Latour argues that both are equally flawed, since it is the hybrid person-with-gun that kills. The hybrid person-with-gun consists in the co-constitutive addition of gun and person that makes killing a lot easier for the person than without a gun, and makes a gun function as a gun due to the human actor firing the gun. Each part of the hybrid makes an important addition to the other, and this constitutes the actual 'real' problem that neither the proponents nor the opponents address properly. And sadly, by insisting on their essentialist positions, no progress in the controversy can be expected; both proponents and opponents rely on a "badly stated" problem. Latour, Berg as well as other researchers in technology studies thus subscribe to an understanding of technology-as-network or as practice, which entails that a well-functioning technology (or a scientific fact) is an outcome of association of human and non-human actors in a stable, aligned network. Consequently, technology is a performative achievement of many rather than a stable, singular entity. With the understanding of technology-as-network technologies emerge in and through the practices they are embedded in. They are inseparable from practice and receive their qualities in practice just as they in return shape those very practices in emergent, non-determinist ways. See also De Laet et al. 2000, Haraway 1991, Henriksen 2003, Jensen 2004a, 2004b, Nielsen 2005, Svenningsen 2003.

that obligates and requires a whole range of actors and resources. Admittedly, I have been affected by such understandings in my research. I have considered it unrealistically ambitious, and accordingly inherently immodest to even consider it likely that I, as a doctoral researcher, although potentially supported by fellow senior researchers, should stand even a slight chance of actually contributing to what we, in this case, could call the practice of chronic disease management, by some sort of technological prototype or device. I consider it much more likely that such interventions would exploit and disturb a whole range of actors for my sake rather than theirs. Is this a somewhat saddened, disappointed position? Maybe? But I think rather it is a reasonable, reflective and considered one.

Moreover, when technologies are considered accomplishments of a network and thus that technology *is* a network, then a well-functioning technology in a design project is also the achievement of a *particular local* design practice. This means that to generalize and produce a proof-of-concept is immediately to substitute the understanding of this local achievement and event in which the technology was successful for an understanding of technology as an entity with specific intrinsic qualities that can be exported to other use contexts. The nominalist view (not to mistake particulars for universals, and thus not to mistake a local achievement of a network for a general intrinsic quality of a technology) significantly disrupts the idea of "proof-of-concept". The idea of "proof-of-concept" explicitly bears on the assumption that what has proven successful in one place may thus be so in another. Proof-of-concept is thus distant from the central understanding of technology as network, and thus as in practice a local achievement - an event. Instead it relies on a reductionist and positivist understanding of technology as a technical, discrete and de-contextualised entity that may be exported to other use-contexts. In this view "proof-of-concept" is more appropriately a rhetorical action that increase the possibility of the technology for broader adaptation by drawing on the positivist and obviously sometimes preferred understanding of technology as a de-contextual, technical object and importantly *not* a network and a local achievement. I prefer to hold onto to the non-reductive understanding of technology as network and, accordingly, the idea and ideal of proof-of-concept is abandoned.

The principle of translation, the understanding of technology as network and nominalism, thus together means that I consider, say, a successful prototype developed in action-oriented design research to be a local phenomenon that relies on a whole network of actors. An engagement one (as a researcher) should not take lightly and assume is by definition in the best interest of the practice (which would be a pompous self-assured position). And last, with these concerns as a central disposition of mine what would it matter to develop a concrete device if in 'real' practice it is not picked up and used? So what in the eyes of some would qualify as a concrete, hands-on product of action-oriented research and design, a 'real contribution', I consider mostly to be a staged, local event paid for mostly by the practices it involves.

The concern with the practical implications and whether the actual end product will be useful is pertinent in relation to chronic disease management and technologies for the support of people with chronic diseases, since, as I will argue now, one can be quite concerned with how people with chronic diseases are predisposed to participate and act when included in projects with the obvious intend to create solutions for their support. I will discuss this in the following by drawing on an experience from my graduate research that involved the evaluation of prototype technology for chronic disease management for people with diabetes.

The evaluation of the diet diary: predisposition and emergence

In the winter of 2000-2001 two of my fellow graduate students at Information- and Media Studies, University of Aarhus and I, evaluated a prototype of a mobile technology we had invented, named the diet diary.[12] The diet diary was a mobile technology envisioned to support people with e.g. diabetes to keep track of what they were eating in an easy manner. 17 persons with type 2 diabetes, recruited and treated at the dept. of Endocrinology, Aarhus County Hospital, tested the diet

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[12] The diet diary was a mobile computer (PDA). The idea was conceived during a graduate course on design. We, the designers(tudents), envisioned a mobile technology that could assist e.g. people with diabetes by offering them an easy way to register what was eaten in situ, inform them about food while shopping, and provide an overview of what they had eaten over a period of time. The Diet Diary could register food through barcode reading or by using a simple database or simply by writing/drawing on the screen of the PDA The Diet Diary was developed with support from the Alexandra Institute A/S and Dept. of Computer Science, Aarhus University. My fellow students were Henrik Helsinghoff, Thorkild Hansen and Caroline Meldgaard Pind. See Danholt 2002a, 2002b, 2005a, 2005b.

diary. The qualitative evaluation of the diet diary showed that all but one participant was generally pleased with the diet diary. The majority of the participants considered it to be a tool that probably would be helpful to many people with diabetes. However, many of the participants did not recognize themselves as the primary users of it. One participant, a woman in her sixties, even though she had failed completely in using the diet diary herself (she recruited her husband to do her recordings and interact with the device in her place) did not hesitate to applaud the device saying that it was smart and could do everything, only she was unable to use it. So in general the device was approved of, and from an evaluation point of view it was a success. The majority of participants considered the diet diary to be a reasonable and good tool. Obviously, it seemed that the evaluation deserved further scrutiny when it produced accounts where a participant is sympathetic towards a device that she cannot use. We may have conducted a good evaluation for the diet diary while having conducted poor research.

But as mentioned, one participant resisted. A woman in her thirties discarded the diet diary. She did not experience any need for such a device. During the test period she had no troubles using the device, but she just did not experience any need for it. She did not experience the need to be able to record and assess her food. She offered us an alternative strategy. Her strategy consisted in avoiding sweets, sugar and fat meals, and, as she added, she had lost 15 kg. in a year, which has a considerable effect on one's condition as a person with diabetes. She resisted the diet diary and offered us an alternative strategy than the one proposed by the diet diary.

It occurred to me that we were evaluating a device that was so obviously intended to help people with diabetes, and as such this technology was quite suggestive; it constituted a performative actor that prefigured the participants' responses importantly (Danholt 2005a, 2005b). It seemed equivalent to be studying the behavior of, say, a pack of baboons in a small confined habitat and consider their stressful violent behavior to be their 'natural' behavior and not a product of the confinement (Strum & Fedigan 2000). It seemed unlikely that the participants would articulate principal skepticism towards the diet diary since by doing this they would put themselves at risk of being understood as uninterested in being aided and supported by such technologies, and consequently they would be at risk of being understood as irrational or self-destructive with regards to their condition. Moreover, to be affirmative towards such technologies is also to enact oneself as an active, rational human being interested in managing one's condition and leading a healthy life. Last, why should one want to be skeptical towards a preliminary technology? Even though one might not find it relevant, it might be relevant and useful to others and why exclude them from the opportunity?

However, as noted the trial also produced one account that wholly discarded the diet diary. The thirty-year old woman offered a resistance that constituted a wholly different way of thinking about the problem of diabetes. To her it was not a matter of keeping track of what she was eating in an easy and efficient manner; to her the problem was quite simply to avoid fat and sugar. But importantly the diet diary provided an occasion for her to articulate her diabetes practice. In this sense the evaluation of the diet diary constituted a *productive* event where a novel understanding emerged, where we as researchers were offered an alternative understanding of the problem of diabetes than the one proposed by the diet dairy. Viewed in this light I have since come to consider how many of the responses made by the participants in the evaluation could be viewed as resistances. The woman who could not use the diet diary, but nonetheless considered it to be a relevant and smart tool thus constituted a substantial resistance by her obvious perplexity.

The diet diary evaluation thus produced two decisive understandings for me, the first being that the participants of such trials are significantly predisposed to act as interested, active proponents of the proposed technology.[13] This

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[13] Polemically put we might consider this in relation to design projects that include potential future users; in general: How do we expect people to respond to not yet realized technologies in design projects when invited and treated as experts and where the actual technology possesses a quite immaterial status in the form of cardboard models, post-it notes and hand drawings? Moreover, in a contemporary society where the widely accepted perception of technology is determinist, meaning that they are considered 'means to an end', and as in the discourse on human centered technologies, something to support the user in non-intrusive, transparent ways? Or in contrast, how do we expect future users to be skeptical, critical, resistant and able to express their skepticism about things not yet realized, and that everyone involved has every good intention in realizing as a technology that makes things easier and better? How is it possible in such a context to produce an argument that is not easily refuted as pessimist, reactionary, 'resistant to change' or straight forwardly speculative? To argue that it is equally easy and possible to express skepticism as to be generous and supportive in design projects, is predicated by the understanding that one is able to treat 'what is' and 'what may become' completely symmetrically, which would

obviously constitutes a problem for user oriented design approaches that rest on an understanding of the user experience as authentic and genuine. The second understanding, nonetheless, is that such trials have the potential to produce resistances and the production of novel understandings of problems and practices; however, this requires that one as a researcher is interested in these resistances.

The performative and representational aspects of design

From the experience with the evaluation of the diet diary it seems more than likely that people with chronic diseases may not only be considered as layexperts in relation to their condition, but also be significantly predisposed to favor a solution and act as interested and appreciative of the attempt to construct solutions. The predicament that emerges can be designated as residing in the difference between *performative* and *representationalist* aspects of design.[14] On the one hand, design, at least user-centered design approaches generally honored in design research today is considered to be a performative, emergent process where the end result is not predicated by either users or designers, but an outcome of the process.[15] On the other hand, as mentioned above a fundamental premise of user-centered design is representationalism. The user and use practice is considered to hold important knowledge and expertise crucial for the design of functional technologies, but is accordingly also considered as pre-existing the design process. In relation to a representationalist understanding it obviously constitutes a problem if people with chronic diseases are significantly predisposed to consider technologies for chronic disease management relevant; if they are considerably biased towards appreciating such initiatives.

It constitutes a problem in at least two ways. First, from a strictly pragmatic and somewhat conservative point of view, it constitutes a problem if technologies are designed and developed, but not actually used afterwards. This is obviously a plausible consequence of a design practice where participants, during

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entail that one was gifted with foresight and few people, however bold they may be, will claim this.

[14] A distinction offered by the British sociologist of science and technology and physicist Andrew Pickering in relation to science. See Chap. 1.

[15] This constitutes a central understanding in sociotechnical design and Participatory Design. See Asaro 1998, Bødker et al. 2000, Floyd 1984, Greenbaum et al. 1991, Kensing et al 1993, Mogensen 1992, Scacchi 2004, Schuler et al. 1993.

the design process, are predisposed to appreciate the technology under design, but then when left to their own devises may be disposed differently. Second, it constitutes a methodological problem since the design process is then configured merely as a matter of designing the technology and as consequence the question of the relevance of a technological solution is sidestepped. Does what we consider to be a problem deserve a technological solution, or may the whole idea of a technological solution to the problem of e.g. diabetes, the concept, the problem imagined and thus inscribed in the design, be fundamentally contested as the woman in the evaluation of the diet diary did?[16]

Premised by the understanding that people with chronic disease seem not only to be layexperts, due to their lived experiences with chronic disease, but also significantly predisposed to appreciate design projects aiming at creating technologies for their support, I have attempted to create a different set-up with a different concern. My concern follows and appreciates the performative, suggestive aspects of design as an important dynamism. But I am inherently skeptical of the representationalist aspect. The problem as it has been realized in science studies is that when insisting on a representational ideal of science, the performative aspects of science *in practice* are bracketed out or downplayed, although the material, tangible practice of science is exactly what produces knowledge and facts.[17]

Accordingly, a central tenet in Science, Technology and Society-studies (STS) is with the production of knowledge. In contrast to the classical concerns of epistemology: “What is knowledge?”, “how do we certify that we know something?” (Smith 2005: 54), STS is concerned with “how is what we consider as knowledge produced.” STS is thus not grappling with the quality of knowledge but

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[16] The MUST method, developed by a group of Danish IS researchers, stresses that designer’s initial concern should be to consider whether a particular problem has or deserves a technological answer. Evidently, such a design ethics, at least when having to do with functional technological design and not aesthetic design, seems critical. Designers, as doctors and pharmaceutical companies, should, I will argue, have an interest in making themselves obsolete and thus postpone the inclination to see problems. See Kensing et al. 1998, Bødker et al. 2004.

[17] On the basis of anthropological fieldwork in a laboratory Latour & Woolgar (1986) describe the processes by which a fact is elicited, purified and produced through the practices and machines (inscription devices) of the laboratory. They show how these practices in the accounts given of the fact are 1) bracketed out from the fact, a ‘splitting’ of the practice and the fact and 2) how the process by which the fact is produced is inverted so that the fact is considered as coming before the practice of enabling it to be elicited, although the fact would not have been possible to stand out as a fact if not for the laboratory practice. See also Fleck 1977, Knorr Cetina 1981, Law 2004, Hacking 1983, Olesen 2003, Pickering 1995.

with accounting empirically for the practice of knowledge production. STS treats science as an object of study and thus in the same manner as science treats its object of study by observing and following it in order to be able to depict its qualities and attributes. What follows from STS is that science is a constructivist, performative practice where what comes to constitute a universal fact is an achievement of a range of human and non-human actors tied in chains of associations. A fact is thus not referring to a singular objective entity, but is a heterogeneous assemblage of actors. It is a network.[18] The shift following from STS is from understanding science as (ideally) a representational, positivist endeavor that *depicts* and *discovers* facts to understanding science as a performative, constructive practice that produces knowledge through intricate networks of human and non-human actors. That is not to consider scientific knowledge to be the product of scientists and science collectives, which would be

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[18] This understanding has been attacked by some scientists and proponents of a realist, positivist and representationalist views of science as internalist, that is as having privileged access to nature qua its methods. Representationalism is premised by "the belief in the ontological distinction between representations and that which they purport to represent; in particular, that which is represented is held to be independent of all practices of representing." (Barad 2003: 804). The science wars, as they are popularly referred to, revolve around arguments 'for' or 'against' objective reality and diverse scientists' and 'science critics' relation to reality (Sokal et al 1998, Smith 2005). The constructivism of STS has been strenuously refuted and scorned by some scientists and philosophers of science as 'postmodernist', 'social constructivist' nonsense and (mis)interpreted as suggesting that scientists construct knowledge in the sense that they 'make up' knowledge. Whereas the point widely accepted in STS is rather that nobody specifically constructs, in the sense of fully determines what turns out to be the product of science, but that it is a conglomerate of 'social' and 'natural' causes (Callon 1986, Latour 1987, Pickering 1992, 1995). But what the science wars also eminently exemplify, is the difficulty in considering science as neither objectivist and thus as merely representing reality, or subjectivist and socially constructing reality, as if on the one hand reality exists completely separated from human intervention or is simply a blank surface upon which 'culture' inscribes meaning (Butler 1993, Barad 2007). The constructivist position associated with actor-network theory and posthuman STS is concerned with avoiding the Scylla and Charybdis of this nature-culture dichotomy and reconceptualizing it. A dichotomy, although widely resisted today with reference to Descartes, still reproduced through the dichotomy between humanist qualitative and natural science quantitative research methodologies. Moreover, the relativism of STS has by its critics been interpreted as 'anything goes' and 'everything is equally good' and thus as potentially quietist, whereas the relativism of STS properly understood is not that 'everything is equally good' but that nothing is a-historical and transcendent. Every piece of knowledge, fact, entity is related and embedded historically and is thus influenced by the present, economically, socially, politically, culturally etc. For a rigorous discussion and exposure of the poor intellectual accomplishment by some proponents of a realist, positivist perception in their critique of central understandings of constructivism, see Smith 2005. For an argument for a posthuman orientation in qualitative research see Jensen and Lauritsen 2005.

the *social*-constructivist version of constructivism[19]. With a performative understanding of science one as a researcher becomes differently disposed. The sharp distinction between biased and unbiased dissolves, since an 'unbiased' scientific practice, in the sense of strictly non-interventionist, representational, objective depiction of a given phenomenon, constitutes in a performative view an idealist fantasy. However, this does not mean, as critics might assume, that everything is then equally good, anything goes, that scientific knowledge is merely subjective and any type of knowledge is as good as the other (Smith 1988, 2005). On the contrary, if we take the performative, constructivist understanding of science serious, we become sensitive to the production of knowledge and to the apparatuses whereby knowledge is produced. This means that we become inclined to consider how we produce knowledge. In short, without the guarantee provided by an internalist understanding of science as per se privileged through its methods, we have to become active in constructing what may qualify as knowledge. Arguably, my concern is that it seems inherently problematic to engage in a design practice where it is very likely that the participants are significantly predisposed to appreciate the design process. It matters how we relate to our object of study, it matters for the knowledge produced and for how the object becomes more widely represented and circulated.

Design and having an interest in resistance [20]

Inspired by the event where the one woman who participated in the evaluation and resisted the diet diary, my concern was to create another way of relating to and including participants. Instead of creating a generous milieu for design premised by a deliberate disregard of predisposed participants, I wanted to create

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[19] The so-called epistemological chicken debate between Collins & Yearley on the one side representing a social constructivist position associated with Sociology of Scientific Knowledge (SSK) and Callon & Latour representing a constructivist position associated with actor-network theory that holds that we should be generally symmetrical with regards to how knowledge is produced, both human and non-human agency contribute to the making of facts. This position although in no way unproblematic or undebated ideally attempts to follow how knowledge is an outcome of the association of 'materiality' as well as 'sociality' and thus works to escape essentialist understandings of both nature and culture. See Callon et al. 1992, Collins et al, 1992 Pickering 1992, 1995. Notable references to SSK are Barnes et al. 1982, Bloor 1976, Collins 1983. For a review in Danish see Olesen 2003, 2007.

[20] The argument made in this section is methodological. The argument is further substantialized and unfolded in Chap. 2 and obviously some points are redundant.

a different set-up. I wished to provide the participants with the opportunity to resist a particular device imagined for and promoted as a chronic disease management technology, Lifescan's Onetouch® Ultrasmart™ (hereafter Onetouch).[21] By introducing Onetouch I provided the participants the opportunity to present me with their ways of handling their condition in contrast to the one being suggested by Onetouch. However, symmetrically concerned I also considered the experiment as providing the participants the opportunity to realize Onetouch as a solution and Onetouch the opportunity to become realized as relevant.

So instead of embarking on design oriented research, working from a problem towards a solution, I inverted this process. I started out by introducing an already existing solution, not in order to assess this technology or come up with suggestions for refining or re-designing the technology, but in order to come to understand the problem of chronic disease. My hypothesis was that through concrete interaction with such a technology the participants would be able to articulate how they relate to their condition, how it is a problem to them, and what are their concerns. In short, instead of starting out from the general problem as authorizing design for solutions, I started out with a solution in order to become able to understand the problem.

But as already suggested in the discussion of the diet diary evaluation, it is not simply a matter of providing the participants with Onetouch and then observe what happens; more is needed. As with the evaluation of the diet diary, if we had simply accepted the testimonies given by the participants in terms of positive and negative experiences with the technology and suggestions for re-design, then the 30-year old woman who resisted the whole concept of the diet diary might simply have been asserted as rejecting the device, and we might have concluded that the diet diary was just not right for her. However, more critically concerned and through the appreciation of a performative understanding of science, I came to consider her account as 'interfering' with the basic assumptions of the diet diary. Her resistance towards the diet diary *contested the problem of diabetes as it was inscribed in the diet diary*, namely that the problem of diabetes is to 'keep track' of the condition. Her suggestion was that avoiding fat, sweets and sugar solves the problem of diabetes. She did not just reject the diet diary she *proposed an*

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[21] Onetouch will be elaborately presented in Chap. 3.

alternative technology. She proposed not a concrete device, but a way of thinking about and relating to diabetes that constituted a solution for her and in that sense it was a technology. It relates to and acts upon diabetes just as the diet diary mediates a relation to diabetes. It is a technology since it is functional; it does something. It is a technology in the same way as the body, a protocol, a specific procedure or action may be considered a technology (Foucault 1988, Haraway 1991, Hayles 1999, Willems 2000). My point is thus that the woman in the evaluation of the diet diary was not simply arguing against a specific technology, but rather she presented a technology to us that constituted an alternative to the diet dairy.

However, we can only come to consider her testimony as presenting an alternative, competing technology if first we accept a very broad definition of technology as mentioned, but also if we are *interested*, not in the success of the technology proposed by us, but in alternative solutions as potential opportunities to transform our understandings of the problem.

Luckily, such an inclination is possible when one is situated in academic research. Obviously, if one were a systems designer occupied in industry, although probably claiming otherwise when addressing customers, one's primary interest would ultimately be to market and sell technologies. However, when occupied in academia and interested in design research, one can and should, I think, cultivate a different interest in technology. In fact, one can be more pragmatic, more utilitarian, functionalist and cynical. One, as an academic, can be utilitarian in a manner that industry cannot, since one may sacrifice the concepts and inventions one proposes in the service of knowledge. We may consider our devices as vehicles and means for understanding instead of as ends in themselves. Hence, one does not need to be interested in the success of, say, prototypes such as the diet diary as marketed products, instead one can be interested in them as *experimental* devices. In fact I would argue that it constitutes a problem if one as a researcher in academia mistakes the interest in the success of a given technology for the interest in the understandings it may bring about as a vehicle and catalyst for novel understandings of a problem. The problem is when interest is invested in the success of the technology little incentive to appreciate when participants resist it seems to exist. Or their resistance comes to constitute a design challenge that calls for further design and refinement rather than as a substantial re-configuration of the problem. Thereby, a self-affirmative logic, whereby problems and resistances support rather than stop the process of design, is created.

If, in contrast, one is interested not in the success of the design/concept/technology, but in the articulations and understandings, then one is not confined to think narrowly about what qualifies as a solution. Instead one can appreciate when people articulate and present their own technologies that compete with the proposed ones, since they thereby offer us problems and solutions that we had not imagined. Therefore, to my understanding it constitutes an inherently important and contributive event when somebody resists what is suggested by the designer/researcher. The woman who resisted the diet diary dissolved the problem inscribed in the diet diary. She did not *just* refuse to use the diet diary; she articulated that what we imagined the problem to be was not how she experienced the problem. Recalling Bergson and Deleuze, she stated the problem in a whole different manner, and thereby our problem definition was crucially contested or dissolved by her account. This, I think, ought to occupy one as a researcher, beyond the simple affirmation that she just did not experience a need to use the diet diary. This understanding has constituted a crucial concern in my research. The crucial point here is that to be able to appreciate how participants may contribute to novel understandings is premised by abandoning an interest in the device, the technology, the proof-of-concept, and instead become attuned to see the participant's responses as articulating solutions and problems as responses to our proposal.

Attuned and interested in this manner, our concern is no longer with a specific technology; we follow instead the understanding of technology as network and thus as multiple and not simply a specific, demarcated object. Research by means of a concrete device, whether a prototype or an already marketed product like Onetouch, is thus primarily concerned with the articulations it enables, and therefore, and maybe somewhat surprisingly, its concern is with utility, what works, acts and functions. The concern is not with realizing the technology, but with what the technology realizes, what it makes people do and articulate. So when people reject the technology they offer, in some way or other, an alternative solution, or they erode and transform what constitutes the problem; their solutions thus provide the researcher with an understanding of the problem at hand, that enables him/her to discuss the solutions they propose. So a refusal is not, with this understanding, an invitation to re-design or segmentation. Instead what they are saying is 'what you propose cannot compete with the technologies I already employ'. As a researcher one is thus not presented with problems but with existing solutions, technologies, with what already functions and works. Ultimately and trivially this means that attuned to think in this manner we (researchers) increase our possibilities of becoming sensitive both to the intricacies of living with and treating diabetes, but also that this can be done in multiple ways through a multiplicity of solutions and ways of practicing diabetes.

The crucial point is that we must be interested in the problem, staying with the problem, postpone our inclination to offer solutions to it, and provide those we study and ourselves a due process to potentially dissolve the problem. In contrast, evidently design is immanently interested not in the dissolution and destabilization of problems, but in their immediate and general affirmation since problems authorize solutions. I argue that design ought to have an interest in the destabilization and dissolution of problems as an intrinsic part of its concern, since dissolution of a problem through scrutiny, discussion and argument from a strictly utilitarian and pragmatic point of view *in itself* constitutes a solution. Moreover, it probably constitutes a 'better' solution than the development and design of a concrete technological solution initiated and legitimized by a badly stated, ill-conceived problem. Arguably, this is how STS and constructivist thinking constitute an important challenge to design, since these understandings can work to sophisticate or dissolve ill conceived problems.

Uncertain and free

My initial concern in my doctoral research has thus been to be uncertain with regards to the problem of chronic disease, in particular diabetes, which is why I have been reluctant to simply accept the immediate articulations of the problem, either as a epidemiological problem, or by including people with diabetes in design processes to develop potential solutions.

The French historian and poststructuralist Michel Foucault has often been considered as detailing out the all encompassing aspect of power as exercised through discourse, epistemes, knowledges, structures of modern society, buildings, etc. For some this may seem inherently pessimistic: "Is power pervasive? Are there no refuges, places or instances free of power?" However, such a pessimistic reading is predicated by the somewhat classical understanding of power as inhibiting and constraining subjects. Power stands in opposition to freedom and autonomy in such an understanding. But Foucault did not see power as in opposition to freedom. On the contrary, he considered power to be a productive rather than inhibitive force. Power produces subjects. The optimist reading, which is how Foucault himself thought of – or at least came to think of – his work, was that he through his work actually exhibited the fragility of power by showing how power always has to be exercised and executed practically – that power was practice and depends on a plethora of devices to be exercised. As he expressed it, he was concerned with 'cutting off the king's head', meaning to do away with a reductionist determinist understanding of power as possessed by and flowing from a particular source, and thereby ordering and structuring subjects in an almost effortless move. So what Foucault did was detailing how power has to be performed and reiterated continuously in order to function, and thereby he fleshes out, materializes and particularizes power. By implication he offers us means to realize this and, accordingly, presents us with the continuous possibility of resisting power specifically and locally. Thereby we may potentially realize that we, as human beings, are in fact "much freer than we might feel".

> "My role – and that is too emphatic a word – is to show people that they are much freer than they feel, that people accept as truth, as evidence, some themes which have been built up at a certain moment during history, and this so-called evidence can be criticized and destroyed. To change something in the minds of people – that's the role of an intellectual." (Foucault in Martin et al. 1988:10)

Following Foucault, my concern can be designated as a concern with claiming the freedom to partake in defining and inventing problems instead of being satisfied with the role of trying to solve them. Problems may be approached and dissolved in multiple ways, which is why they deserve to be destabilized and particularized. Claiming the freedom to think that design may not only refer to concrete technological and/or organizational, social change, but may just as well be conceptual and a matter of how we approach and scrutinize a given problem. And, ultimately, that to live with and treat diabetes can be practiced in multiple ways, and that we may intervene in those practices by how we address the problem.

Structure of the dissertation

The dissertation is structured in three parts. The first part *Resources and Problems* consists of two chapters.

Chapter 1: *Relating Design and STS* presents, discusses and juxtaposes central understandings of User-Centered Design (UCD) and Science, Technology and Society studies (STS). I argue, counter to the often articulated difference between ISD and STS as consisting in the former being interventionist, whereas the latter is descriptive and by implication of slight utility value, that the difference consists in that STS refuses to accept the same set of presumptions central to design. The crucial point being that this is done for the purpose of methodological rigor, and the consequences following a deliberate anti-essentialist and performative understanding of the world result in an extensive array of possible interventions.

Chapter 2: *Posthuman Devices for Studying Diabetes Practices* could be considered methodological. Here I present insights from STS, primatology and ethology on experimentation, and how the experiment I have conducted as part of my fieldwork is inspired by these insights. The importance of an anti-essentialist and performative understanding of diabetes practices is stressed. The chapter concludes with a description of the fieldwork I have conducted during my doctoral research.

The second part of the dissertation: *Particularizing the Problem of Diabetes* includes seven chapters. The first *An Agonistic Relation* discusses how Onetouch enacted and negotiated the experiment in a manner that lead to what I have designated an *agnostic relation* between me and the participants, which is a relation not of hostility but of interest. Moreover, Onetouch and diabetes is presented as a disease and a technology designed to support people with diabetes. The remaining six chapters present six of the participants' stories. Each story exemplifies an interesting and peculiar aspect of how the participant relates to and manages diabetes in practice, and how the problem of diabetes becomes particularized and concretized. They show how diabetes as a disease and the persons with diabetes are mutually implicated and formed through mundane practices, knowledges, materialities, technologies and treatment. Central to these chapters are that the peculiar yet reasonable and active strategies employed by the participants, configure the problem of diabetes specifically, and enable them to become persons with diabetes in specific ways. Last, these stories tell of particular problems and solutions in diabetes that enable me to reflect on and develop ways for thinking about the participants' diabetes practice in posthumanist performative terms.

The third part of the dissertation: *Implications* consists of two chapters. The first *A Performative Re-figuring of Onetouch* discusses how practice is diminished in both the promotion of Onetouch and in the participants' use practices. However, through a posthuman performative understanding with its emphasis on practice, I argue that devices such as Onetouch can be importantly re-figured. Such a re-figuring practice constitutes an addition to the present state of Onetouch rather than a transgression of it. Onetouch is thus neither transgressed not preserved but multiplied.

The second and concluding chapter: *Managing a Relation.* Here I recapitulate and discuss the participants ways of enacting diabetes and argue that we may consider the problem of diabetes as being a matter of managing a relation between oneself and the condition instead of being about the management of diabetes as an object. Hence, I argue for the productiveness of having an ambiguous and uncertain relation to oneself and the condition as a premise for engaging in an affective, interested relation with the condition.

Resources and Problems

Chapter 1:

Relating User-Centered Design and Posthumanist STS

> "How can we present a proposal intended not to say what is, or what ought to be, but to provoke thought, a proposal that requires no other verification than the way in which it is able to "slow down" reasoning and create an opportunity to arouse a slightly different awareness of the problems and situations mobilizing us?" (Stengers 2005: 994)

The mythological quality of technology

Information technology is generally regarded a powerful tool of great potential almost it seems applicable for any purpose and problem in contemporary western societies. But information technology is also associated with great risk and disaster. This combination offers an almost mythological status of technology as endowed with high promise and catastrophe. It has become a critical concern of researchers, decision makers and laymen in daily life to control technology. Technology, it seems, has thus acquired a similar status as nature during enlightenment and modernity as what should be resisted and dominated for the good of mankind. The IT scandals are many, and the concern with the 'technological disasters' seems to be an almost obligatory concern in research and politics. But I am doubtful of whether the mythological status of technology is adequate and in the last instance productive. What seems to be perpetually reproduced by such a myth is the idea of progress that awaits us if we are brave, cunning and well armed. But as the Belgian philosopher and chemist Isabelle Stengers asks above how may we be differently occupied with "the problems and situations mobilizing us" in relation to information system development than in terms of 'what is' and 'what ought to be'. The former is premised by the belief in the possibility of making unequivocal, unambiguous descriptions of reality, the latter by the belief in the possibility of actually being able to produce intended outcomes. Both of these positions seems idealist, reductive, naïve and immodest.

In this chapter I will present and juxtapose two approaches to technology namely Information Systems research (IS) and specifically User-centered Design (UCD) and Science, Technology and Society studies (STS). I will argue that the former is premised by some essential, dichotomous understandings and thus includes a degree of certainty with regards to 'what is' whereas the latter is inherently anti-essentialist and thus uncertain with regards to 'what is', but this also implies that what constitutes an intervention and a contribution can come in many forms.

Both UCD and STS are concerned with information technology: however, one immediate perception is that they are differently occupied with the subject. UCD is concerned with designing and constructing these technologies while STS is concerned with understanding the transformative aspects of technology. In this light UCD is prospective and interventionist while STS is retrospective and descriptive. Accordingly, STS has been criticized for having little practical relevance and for being politically 'quietist' (Winner 1993, Radder 1998). Some STS scholars have accepted this critique and argued that STS scholars should explicitly engage in the constructive effort of e.g. designing healthcare systems (Timmermans & Berg 2004). Others do not accept the premise of the argument: a clear-cut distinction between 'interventionist', 'action-oriented' and 'representational', 'descriptive', since it bears on an idealist understanding of science as representational and a-political. In contrast normativity is part and parcel of scientific practice through how research is conducted and framed. In this light normativity is not something employed after the 'facts' are settled. (Mol & Mesman 1996, Haraway 1991, 1997, Harding 1986). This has led to accounts of STS scholars' experiences in the field and with how STS can be argued for as contributive and 'action-oriented' (Vikkelsø 2007, Markussen & Olesen 2007). Or how to be action-oriented in specific circumscribed ways e.g. by facilitating the implementation of a technological system might in fact constitute a waste of resources (Jensen 2007).

If we accept the dichotomy between intervention and representation as designating the difference between UCD and STS, STS acquires a status of having little practical relevance for information systems design. In my doctoral research, fellow researchers and peers, specifically in relation to design of information systems, have posed this critique of STS to me. However, although I generally concur with the omnipresent understanding that relevance is a desirable outcome of research (it seems absurd to hold the opposite), I consider this critique of STS to harbor an understanding of 'practical relevance' as quite circumscribed. Practical relevance, I would argue, may come in many forms. Is It practically relevant e.g. to partake in realizing a well functioning system? Or contrarily, might 'practically relevant' constitute preventing the implementation of a given system? Can 'practically relevant' mean to describe an implementation of a system as a contingent history of associating actors and translating interests, thereby sensitizing the implementation practice in thinking about the realization of system as a matter of interesting others? (Danholt & Bødker 2005). Can a catchy way of phrasing a problem, a flashy power point presentation, a text or a book not be practically relevant? (Vikkelsø 2007). Is the coverage of a design project in public media not practically relevant for the project when it might contribute to 'the spirit' of the project? How do you decide what in a given research or research practice was practically relevant and what was not? The central point is that what might at some point prove to be relevant is historically contingent.

Consequently, I will propose another difference between UCD and STS that does not hinge on a crude dichotomy between intervention and representation. The crucial difference between UCD and STS is that *STS, in the posthuman version I relate to, is defined by a skepticism of the presumptions that are constitutive of UCD*. The difference, we might say, is that in UCD the challenge is defined as to control technologies and have technologies become tools and not actors (in the sense acting by themselves), whereas in STS the concern is with how to exist with technologies as actors, how to be reconciled with an emergent, lively reality that always has surprises in store for us. However, I consider the ambition of STS and UCD to be concordant, namely to partake in forming what Donna Haraway has referred to as 'livable worlds' emphasizing democratization and participation (Haraway 1991). However, how and what that might mean concretely differ significantly between STS and UCD.

In the following I will review and discuss central concerns in UCD more specifically in relation to the Participatory Design tradition. I do that because I consider the focus on user involvement and participation that emerged with PD as being a central tenet in UCD. Afterwards I will present central understandings of STS and contrast them with UCD.

A dichotomy emerges

What was once considered a minor, radical revolt against established practices in systems development is today generally a well-established tenet in design research, namely the inclusion of potential end users and use contexts in the design of technological systems. UCD is rooted in the Scandinavian design tradition that emerged with union supported projects in Norway in the early 1970s..[22] Internationally the Scandinavian tradition has since become renowned as Participatory Design (Greenbaum & Kyng 1991, Kensing & Blomberg, Bjerknes et al.). The tradition emerged in resistance towards what the Danish IS researcher Jørgen Bansler has named the system-theoretical tradition, which was the rationalist approach to systems development that considered development of technology a technical engineering task in order to design the most rational and technically sophisticated system (Bansler 1987).[23] The central critique of the system-theoretical approach posed by the emergent Marxist inspired Scandinavian approach was in the words of Dutch sociologist of technology Marc Berg:

> ”[T]he rationalistic tradition commits a category mistake by conceiving both work practice and technology to operate according to the same instrumental logic; to inhabit the same domain. Traditional system design, in other words, mistakenly sees human work as describable by the logic that belongs to the realm of technology: as consisting of clear-cut, well-circumscribed tasks, executable in a predictable and predesigned sequence.... In this depiction of human work practices, humans are themselves just cogs in the wheel of the larger technological system, whose work tasks are precisely describable and fit perfectly in an authoritarian chain of command. Traditional systems design does not see that work is performed according to a

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[22] I use the term user-centered design as a generic term to broadly encompass design approaches that consider involvement of the user and the use context as essential for designing computer-based systems. I hereby lump together approaches such as Participatory Design (Bødker et al. 2004, Schuler et al. 1993, Kensing et al. 1998, 2004), Cooperative Design (Bødker & Grønbæk 1991, Greenbaum & Kyng 1991, Grønbæk et al. 1997), Computer Supported Cooperative Work (Schmidt et al. 1992, Berg 1997a, 1997b, 2000, Bowker et al. 1997), Contextual Design (Beyer & Holtzblatt 1997) and Human Computer Interaction (Norman 1988, Baecker et al. 1995) Substantial differences in scope, methods and practice exist between these various approaches. One point for instance is that cooperative design and PD is by some of its prominent representatives considered to be, ”more than props and background to create ”user friendly” systems. Rather we see the need for users to become full partners in a cooperative system design process where the pursuit of users’ interest is a legitimate element.” (Greenbaum & Kyng 1991: ix). Whereas HCI for instance is more concerned with human factors, cognitive and embodied, as premises for interactions with systems and thus tends to prefer a more scientific approach to the human actor than a humanist or social-constructivist one.

[23] Bansler (1987) in his account of system development in Scandinavia refers to three traditions: “the system-theoretical”, “the socio-technical” and “the critical” where “the critical” emphasizes the aspect of workplace democracy and the “socio-technical” the design of well-functioning systems.

> fundamentally different logic: a logic of fluid interaction, of situated action, of local circumstances." (Berg 1998: 467-68)

The Scandinavian approach challenged a reductionist understanding of work and introduced a central difference between technology and human work practice. This meant that to develop functional systems, became more than a merely technical concern. With the Scandinavian approach, humanist and social science understandings entered design. In the book *Design at Work* that includes writings by central PD researchers the humanist social constructivist heritage of the approach is stressed.

> "In general, these theories can be grouped under the philosophical heading of social construction, which sees our understanding of the world as generated by people (through their social interactions) rather than as a set of fixed, immutable facts. In contrast with the rationalistic tradition of computer science, social constructionist theory veers away from rigid poles like "objective-subjective," and steers toward understanding different, pluralistic perspectives of how we think and act." (Greenbaum & Kyng 1991: 12)

In accordance with social constructivism PD employs a non-reductive understandings of work practices and a central tenet consists in "taking work practices seriously" by studying and experiencing them. Work practices are situated, contextual and inherently social (Ibid, 4, Suchman 1987). Likewise, design processes are rich with complexity and contingency, which is why it is important that designers in order to be able to develop functional technologies come to understand the work practice in depth by: "examining the context and paying close attention to the situations in which computers will be used" (Greenbaum & Kyng 1991: 15). It is also held that computer systems inevitably will change the context in which they are introduced because systems are "not static entities, but rather systems that adapt as they are used." (Ibid. 15). Hence designers should: "design for ongoing change" (Ibid. 15).[24] Therefore design cannot be conducted in a rigid step-wise manner (the waterfall model), but must be iterative. Last, the poltical manifesto of PD is that designers should design for increasing the skills and knowledge of workers, rather than decrease it (Ibid. 15).

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[24] This constitutes a central concern and predicament inherent to design that has occupied among others the Swedish Design researcher Pelle Ehn. Ehn (1988) expresses it as the paradox between tradition and transcendence.

Conclusively, PD refuses reductionist understandings of work and considers the design process as dynamic and emergent. Designers need to be sensitive to users and use contexts. It is also materialist by emphasizing that technologies influence the work practice and the social interactions of work. Technological systems and social work practices affect and depend on each other:

> "A computer system is not merely an assembly of silicon chips ordered to solve a particular problem. As all who have used computers in the workplace or at home know, their usefulness depends on the fragile relationship of the person, the working environment, and the computer technology itself." (Greenbaum & Kyng: viii-ix).

The borders between system and its context of use are blurry and permeable in this view, an understanding that is concordant with the understanding of technology in actor-network theory and Social Construction of Technology (SCOT) (Bijker 1997, Bijker et al. 1992, 1993, Lauritsen 2007).

By emphasizing the difference between technological logic and human work practice, the heritage of Heidegger's phenomenological thought on the rationalization of 'being' embodied by technology is reproduced. The difference evoked challenges reductionist assumptions about the convergence of technology and human practice and institutes a dichotomy between the two.

Waves and determinism

Berg has argued that one type of determinism is shifted out by another during what has been considered the two waves of the Scandinavian design tradition (Asaro 2000, Bjerknes et al. 1987, Greenbaum & Kyng 1991).[25] The first wave was coined as the 'Collective Resources approach' (Ehn & Kyng 1987). The Collective Resources approach originated as cooperation between the Norwegian Computer Centre and the Norwegian Iron and Metal Workers in 1970. The intention was to educate the workers on the impact of technology on the work practice. The approach sought to mobilize the resources of the collective (workers, union and intellectuals, specifically computer scientists) in order to improve the bargaining and co-determination powers of workers with regards to purchase of technology

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[25] For historical accounts of the Scandinavian design tradition and PD see Clement & Besselar (1993) and Floyd et al (1989).

and work-organization. The Collective Resources approach owed much to Marxist criticism of capitalist society that holds that machines and technology serve capitalism and alienate workers through automation, deskilling, centralized managerial control, division of labor etc. Technology was thus perceived as a determinist, rationalizing tool of capitalism, an understanding that was forcefully presented by critics such as David Noble (1997) and Harry Braverman (1974). Hence this first wave was not concerned with actual design of technology. The work setting of iron and metal workers working with heavy 'inflexible' machinery did not afford such considerations. The main focus was to create a strong collective bargaining power.

The second wave also referred to as the socio-technical approach (Asaro 2000, Mumford 1987, Bansler 1987) of the Scandinavian tradition was explicitly concerned with the design of technology. In various projects computer-based systems were designed together with their intended end-users. The UTOPIA-project in 1981 is referred to as the first project that included end-users in the design of a specific technology. UTOPIA was a Danish-Swedish project where newspaper typographers and designers developed a software product for skilled graphics workers. In the socio-technical wave the focus on technology had shifted. Technology was not per se endowed with alienating, deskilling forces employed in the service of rationalist capitalism. Instead technology was conceived of as plastic not determinist. It was possible to regard technology as designed and shaped for use practices that upskilled instead of deskilled workers. In this wave technology becomes a material shaped and formed by human designers, and technology determinism was shifted out with humanist or social determinism, implying that technology was provided its qualities through design and use (Asaro 2000, Berg 1998, Svenningsen 2003). Greenbaum and Kyng epitomize this understanding in this manner: "Computer systems are *tools,* and need to be designed to be under the control of the people using them. They should support work activities, not make them more rigid or rationalized" (Greenbaum & Kyng1991: 2).[26]

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[26] The problem, according to Berg, is that both technological and humanist determinism do not adequately represent the relation between technology and human practice. What is unsatisfactory is that regardless of which type of determinism one subscribes to, it delegates all agency to one pole, either the human or the technological. The dichotomy also replicates a dichotomy between social science and natural science where the latter is considered as being concerned with objective brute quantifiable facts and the former with the complexity

The dichotomy between technology and human practice that grew out of a critique of traditional systems development also laid the ground for categorical understandings of technology as either determinist (the collective resource) or as plastic and determined by designers and social work practices (the sociotechnical approach). Hence, with the non-reductive understanding of human work practice it became important to understand those work practices for designing technological systems. This meant that anthropological disciplines such as ethnography became relevant for design.

Ethnography in design

The concern with real world practice, as a focal point of interest for design and a premise for designing technological systems for work practices, inevitably raises the concern with how to understand and represent practice.[27] With the turn away from rationalism and the natural sciences' perception of design and towards social science and the humanities, ethnography becomes relevant to design. Work practices must be experienced in their actual context in order to provide profound understandings of this practice. The natural setting of a given practice thus became opposed to the confined laboratory or the merely theoretical conception of a work practice. Hughes, Randall and Shapiro define the importance of ethnography to design in the following way:

> "A key virtue of ethnographic studies is their focus upon the rich and varied 'real world' sociality recovered through a fieldworker's participation in the social life of some setting. Directed toward system use and system design, this implies placing an emphasis on studying the functionalities of a technological system as they evolve from their incorporation into the socially organised work activities of those who use them; rather than, as in many cases, functionalities as the system's designers might imagine them to be." (Hughes et al. 1992:124)

In this citation ethnography is presented as a means to "recover the rich and varied 'real world' sociality" and ethnography is thus represented as a representationalist discipline to uncover and represent human and social practices.

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and intricacy of subjective, interpretive social interactions. See Introduction, Berg 1998. Mackenzie and Wajcman 1985.

[27] A special issue of the *Scandinavian Journal of Information Systems* (SJIS) is dedicated to the debate on ethnography in design and contributes to the discussion and reconceptualization of the problems related to the relation between ethnography and design. See Pors et al. 2002, SJIS vol. 14(2)

In the American ethnographer of design Jeanette Blomberg et al.'s *Ethnographic Field Methods and Their Relation to Design* (1991) ethnography is not endowed with the same representationalist qualities as in Hughes et al. In Blomberg et al. it is stressed that ethnographic accounts constitute an ethnographers' interpretation of a social world setting and that there are multiple vantage points from where to represent it and various ways to do it (e.g. "observer participant" or "participant observer"). Blomberg et al. are careful not to articulate ethnography as 'hard science', and stipulate its relative, interpretive nature. However, when pointing out the strengths and weaknesses of the different ways of doing design-oriented ethnography the ambition of "getting as close as possible to an insider's view of the situation as possible" (Ibid. 127) is expressed. This ambition harbors the classical ideal of representationalism, namely to achieve correspondence between represented and representation. So although an ethnographical account is a situated, subjective, interpretation, the representational ideal is still constitutive. But moreover, and in this respect in accordance with Hughes et al., Blomberg et al.'s present central virtues of ethnography (natural settings, holism, descriptions, members point of view) in order for ethnography to contribute to UCD. The text seeks to educate and sensitize designers to ethnographical virtues and thereby enable them to do ethnographical inspired studies of practice.[28] However, this raises concerns about whether ethnography can be *instrumentalized* and deployed in this manner?

The concern is if ethnography in design does not rely upon a reductionist understanding of ethnography as representational and depicting the reality of the social world of others. Critical concerns in ethnography reject an understanding of ethnography as representationalist (Strathern 1991, 2005, Clifford et al. 1986). In the words of Lucy Suchman:

> "Representational practices, including those of ethnography, are shaped historically, materially, rhetorically, institutionally, and politically...Critical ethnography rejects the notion that we can somehow innocently write descriptions of others, whether in the service of understanding or of intervention. Instead, both the terms "we" and "other" are opened up to question... recent anthropology proposes a view of ethnography as an encounter between actors

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[28] The text thus contributes to the debate on the problem of translating rich ethnographical accounts into design suggestions. See Simonsen & Kensing 1997, Shapiro 1994, SJIS 14(2).

> differently embedded within particular social/cultural milieus. On this view, culture is always relational. Rather than describing attributes of a population from some neutral position outside the field of view, accounts of cultural meanings and practices are inevitably created from particular standpoints that set up the lines of comparison and contrast between the speaker/writer and the persons and practices described. The representations ethnographers create, accordingly, are as much a reflection of their own cultural positioning as they are descriptions of the positioning of others." (Suchman 1995: 61-62)

Ethnographical accounts along with every other type of knowledge thus cannot be detached from the practice of producing it. It is embodied and situated in specific ways (Haraway 1991). The epistemological ideal of representationalism is thus challenged and instead Suchman suggests that representations should be viewed not as representations of a practice but as objects for interrogation and negotiation:

> "Once we recognize that representations are artifacts constructed from particular social locations and within specific forms of practice, we can expand our concern with the adequacy of representational forms to include ongoing dialogue and debate regarding the various places of representations in work and system design." (Suchman 1995: 63)

The reductionist understanding of ethnography in design as representing the 'real world' practice thus constitutes a substantial challenge to ethnography in design. In contrast to these problems PD researchers emphasizes collaboration with work practice over ethnographical accounts of it, as I will turn to in the next section. But before doing this let me briefly present a last point about the relation between design and ethnography. The problems of bringing design and ethnography into relation suggest that the idea of drawing on other scientific disciplines as resources for other disciplines is not unproblematic. In the field of Information Systems (IS) it is, however, a central concern to include and draw on reference disciplines in order to develop IS as scientific discipline (Keen 1980, Benbasat et al. 2003). Such preoccupations imply that disciplines such as ethnography are considered consistent practices and toolboxes that can be transported and incorporated into other disciplines, more or less unproblematically. Furthermore, in order for ethnography to become a resource for design, a reductionist treatment of ethnography is required. It entails that ethnography is conceived of and practiced as a toolbox that uncovers the 'real world' practice of others. Hence in order for ethnography to *work* for design the complexities and concerns from ethnography, the critical, reflexive concerns of ethnographers in ethnography must be (partially) ignored. Ironically, in order for design to consider itself equipped to account for and become sensitive to one practice e.g. a particular work practice by employing ethnography, it require that it treats the concerns and problems that occupy the insiders of the discipline it seeks to instrumentalize, namely ethnography, superficially and reductively.

Design as bridge-building

The problems discussed above, relating to ethnography and design, do not, according to some PD researchers, pose considerable problems to PD. In contrast to the representationalist and epistemological problems that follow ethnography in design, PD is often considered as circumventing these problems entirely. Accordingly, the central tenet of PD approaches such as Cooperative Design (Greenbaum & Kyng 1991) is not to make adequate representations of work practices, but to *cooperate* with users through the entire process of design. Work practices and users can thus speak and act for themselves during the process, instead of somebody representing them or their work practices. Work-practices do not need to be translated or interpreted by ethnographers and further translated into recommendations for design, they should simply just included as participants in the design process. However, as I will argue, this implies another set of problematic assumptions. I will exemplify and discuss this by drawing on the Danish computer scientists and Participatory Design researchers Finn Kensing and Andreas Munk-Madsen's text *PD – Structure in the toolbox* (Kensing & Munk-Madsen 1993).

Kensing and Munk-Madsen argue against a simplistic understanding of communication in design and propose an alternative one. They consider the understanding of communication as a message traveling through a tube between sender and receiver to be a reductionist understanding of communication. Kensing and Munk-Madsen suggest that:

> "[D]esign is bridge-building, since something new is created from two separate things. Design is based on two domains of discourse: the users' present work and the technological options… These domains

> typically reflect the users' and developers' knowledge and understanding prior to entering the system development process. At the outset the users have some knowledge of their present work and of organizational options. The system developers have some knowledge of the technical options with regard to hardware and software. At the outset this is all they need to know." (Ibid. 79)

The authors argue that the design process is about constructing a third discourse, as a product of two existing ones. The initial discourses are socially produced in and furnished by the social world of a given collective. In this case the two preexisting discourses refer to the use practice and the designers. Such an understanding considers reality to be socially constructed and refuses the understanding of an all-encompassing universal, objective notion of reality. Reality is negotiated and created in social practice and production of meaning. Hence Kensing and Munk-Madsen consider the design process as an inherently social practice. The authors thus also articulate a central difference between ethnography in design and PD and contribute to the understanding that we should not try to represent the social work practice comprehensibly through ethnographical accounts and assume that such accounts can simply be transported between actors or domains. In contrast design is a translational practice. A realist understanding of depicting a practice is at stake here, and the authors argue against such an understanding and in favor for an understanding of design as 'world-building' through the collaboration between users and developers. With an understanding of social worlds and communities of practice, design, as the authors put it, becomes a matter of "bridging the gap" between 'social worlds'.

But when we consider a third discourse as an outcome of two existing ones, we make certain assumptions. What is implied with a social world perspective is exactly that social worlds are considered relatively stable, consistent and homogeneous. It thus assumes a particular collective, a social world, a paradigm, as structuring the discourse, practices and modes of thinking of the individual members of the collective. (Clarke 1991, Kuhn 1962, Strauss 1978, Bossen et al. 2007). The problem, however, is that such a perspective tends to prefer what binds the collective together and thus what makes it into a homogeneous social world. Consequently the many heterogeneities of the social world constitute blind spots for this perspective. Moreover, social world perspectives have difficulties in explaining and accounting for transformation or erosion of social worlds other than retrospectively.

Accordingly, the problem I identify in Kensing and Munk-Madsen's account is that they ascribe considerably stability and homogeneity to the practice that will persist at least long and consistently enough during a design process. Kensing and Munk-Madsen's argument, I argue, thus hinges on the presumption of a consistent social world, that is not affected from the mere introduction of the idea of a design project but continues to be homogeneous and stable throughout the process and thus constitutes a consistent counter discourse to the design discourse. On the contrary, I would argue that the social world of the practice is stirred up and becomes heterogeneous from the moment that the idea of organizational design is articulated. The social world is thus in such a view not a stable entity that persists and interacts with other social worlds as an individual actor, but in practice continuously formed and dissolved through interactions with other actors and consequently cannot be presumed as the authors argument rely on.

Moreover, Kensing and Munk-Madsen imply an egalitarian understanding of the interaction between the social world of the practice and the social world of the designers. When design is the construction of a third discourse, then it is implicitly assumed that this is an outcome of the interaction of two equal parties. The egalitarian concern is central to design. An egalitarian concern is different from a concern with equality; the latter is concerned with leveling out differences, the former holds that we are all different, but competent (Borch et al. 2003). The view of different competences supplementing each other is generally accepted in participatory design approaches. The egalitarian understanding can be related to contemporary pedagogy and learning theory.[29] Just as with UCD, these learning

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[29] In the work of Niklas Luhman we find the understanding of the subject as an autonomous self-referential system that although able to be influenced or irritated by its surroundings, cannot be changed or taught by others than itself (Luhman 1995, Borch et al. 2003). Learning is internalized with these system theoretical approaches. In learning theory this has resulted in the understanding of 'learning as the responsibility of the self' and the teacher's role has been transformed from being somebody who conveys knowledge to pupils to a coach that facilitates the individual pupils' conditions for learning. This creates an interesting doubling of the subject as both finished and unfinished. It is finished and a priori as a self-referential system with its own specific competences and expertise, but unfinished with regards to the 'life long project of learning' that is implicated by these learning theories. An important difference between this doubling and e.g. Haraway's posthuman understanding of the subject as cyborgian is that in a posthuman understanding the subject is not assumed to be a distinct, finished and somewhat unified subject as implied by learning theory from the

theories have been able to attach themselves to both the political left and right by their emphasis on individual emancipation and contribution to the collective as knowledge society, where competences and knowledge are the primary commodities and center of competition.[30]

These learning theories hold that the subject or the social group is competent in its own right and thus consistent, while on the other hand it is always prone to optimization through 'life long learning'. When design considers a practice as a social world that is competent in its own matters then the practice is by definition equipped to negotiate on an *equal* level with the social world of designers. The concern with influencing, coercing, enacting, framing the use practice in specific ways through the design process is thus not a pertinent concern. The competent, expert user or collective is thus disassociated from the understanding of a practice constructed and influenced by a design agenda. (Markussen 1996)

In relation to the discussion above on ethnography, PD's emphasis on cooperating with users and thereby escaping the concern with representationalism, is thus, I argue, premised by an humanist a priori definition of the competent collective able to argue for itself (consistently and homogenously). In Kensing and Munk-Madsen the social world perspective thus implies that the practice and the designers as two collectives are constituted as two homogeneous actors able to engage in a equal dispute. The uncertainty in ethnography as to whether the user or the use context is adequately represented is thus through the egalitarian premise dissolved. In its place is a steadfast belief in the parties' ability to speak for themselves and thus as inherently consistent, self-aware and unified. This is in the last instance an inherently realist understanding of a subject or a collective as transparent to itself. The concern with correspondence between representation and represented is thus overmatched by a realist conception of the users and use context.

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outset, but is considered to be inherently heterogeneous and composed of a range of disparate effects.

[30] Foucaults' concept of biopower epitomizes this convergence between the interest of the state and the interest of the subject. In the perspective of biopower the subject is not governed by the state explicitly; governing is internalized in and exercised by the subject himself (Foucault 1991).

The premises of design

As I have argued design implies certain presumptions premised by its concern with the design of technology. Design holds that technology and human work practices are inherently different (Suchman 1987). Hence sociotechnical design holds that the technical and the social constitute two different realms that need to be 'fitted' to another in order for a technological system to function. Design insists on the natural setting of work as the site for understanding and designing technology as opposed to a rational or theoretical understanding, implicitly the laboratory setting is contrasted to the 'real world'. Hence design is concerned with the reality of the practice either through ethnographical fieldwork or participation. In the following I will consider how posthumanist STS is premised by a reluctance to accept the set of presumptions that constitute the premises of design. To my understanding STS constitutes an attempt to engage differently with the world and reality that is not premised in the same way as design, and, consequently, it offers considerable leeway for what intervention might mean and how it might matter.

Our posthuman condition

> "In the posthuman view… conscious agency has never been "in control". In fact, the very illusion of control bespeaks a fundamental ignorance about the nature of the emergent processes through which consciousness, the organism, and the environment are constituted. (Mastery through the exercise of autonomous will is merely the story consciousness tells itself to explain results that actually come about through chaotic dynamics and emergent structures)…. In this account, emergence replaces teleology; reflexive epistemology replaces objectivism, distributed cognition replaces autonomous will, embodiment replaces a body seen as a support system for the mind; and a dynamic partnership between humans and intelligent machines replaces the liberal humanist subject's manifest destiny to dominate and control nature" (Hayles 1998: 288)

As explicated by N. Katherine Hayles in *How We Became Posthuman,* posthuman designates the de-centering of the human subject. The autonomous subject that emerged during enlightenment and modernity as the centre and observer of the world is challenged in a posthuman ontology. Posthuman de-centering implies that both our 'insides' and 'outsides' and their borders are not solely up to us, but are outcomes of interacting forces. In a posthuman ontology, we are neither disembodied intellects observing the world, nor are we the authors of history and nature that through language and the creation of meaning gives flesh to a material world inert and passively awaiting our inscriptions (Deleuze and Guattari 1987, Barad 2007, Haraway 1991, Hayles 1998, Latour 1993, Pickering 1995). A posthuman ontology is thus skeptical of Cartesian rationalism and the positivist understanding of a singular reality that can be empirically discovered and humanist thought found in social constructivism, linguistics and language philosophy.

Posthumanism, although a recently coined term, however, runs through the history of ideas and enlightenment and is found in the works of e.g. Friedrich Nietzsche and Benedict Spinoza. Nietzsche proclaimed that reason is the self-imposed illusion of a mind attempting to evoke order and lawfulness, because of its preferences for such contemplations. Spinoza, a contemporary of Descartes, questioned the Cartesian dichotomy, not in the same manner as in humanist thought and phenomenology as reductionist and disembodied; Spinoza questioned its plausibility (Brown et al. 2001). Spinoza found it unlikely that the mind could actually acquire control of the body as the Cartesian understanding assumes, if body and mind were completely separate and of inherently different matter (one being matter and the other being spirit). Spinoza, in contrast, suggested a *parallelism* between body and mind where they are both 'bodies' not separate but able to affect each other, a parallelism that obviously conflicts with Descartes' categorical and rationalist separation between mind and matter. However, for Spinoza it leads to his joyous philosophy of affective relations and his famous expression: "Who knows what a body can do?" What the body or the mind (equally a body) can do is an open question, since it relies on the affective relations the particular body is able to engage in. Spinoza considers what constitute "good, joyful" relations that enable the body to be "composed" with other bodies and become strong, and accordingly what may be considered "sad relations" that destroy or "decompose" the body (Deleuze 1988). The acclaimed inability to know what a body is, destabilizes the seemingly obvious and commonly shared phenomenon which may seem simpleminded or archaic. However, if we consider our relations to the body today, and the fact that novel relations to the body through e.g. medical technologies and knowledge of the body is and does continually seem to be produced, then Spinoza's 400 years old question is not far-fetched, but seems increasingly pertinent.

We find spinozism in Donna J. Haraway's exclamation: "why should our bodies end at the skin?" and embodied in her Cyborg figure that designates the heterogeneous assemblage of organism and machine and in her present concern with engagements and mutual co-constitution of "companion species" as "significant others" epitomized through human – dog relations (Haraway 2003). The cyborg constitutes the transgression of three categorical dichotomies in modernity, namely between human and animal, human-animal and machine, and between physical and non-physical (Haraway 1991). These dichotomies are borders that have 'imploded' and become destabilized by and through technoscience. Technoscience is characterized by the entrepreneurial performativity of science and technologies that associates and mobilizes networks of actors without respect for allegedly well established ontological categories (Haraway 1997, Latour 1987, 1999).[31] What constitutes human or machine, animal or human, physical and non-physical etc. is continually challenged through the practice of technoscience. Technoscience is thus cyborgian or spinozist since it continually produces novel existences and bodies.

> "Technoscience provokes an interest in zones of implosion, more than in boundaries, crossed or not. The most interesting question is what forms of life survive and flourish in those dense, imploded zones?" (Haraway 1994: 62)

Hence technoscience does not, as humanist critiques of science see it, disenchant reality and nature but is an inventive and active construction of novel naturecultures, dense imbroglios of technologies, materiality and conceptualizations. Posthumanism implies a deliberate uncertainty with regards to what constitutes a body whether human, technological, conceptual etc. which constitutes an opening to and an interest in the formation of novel bodies and existences.

Associations of humans and non-humans

Accordingly, the dichotomy between human and technology that emerged in the Scandinavian tradition is contestable in a posthuman understanding. This is the position of the French STS scholar Bruno Latour. Latour refuses the dichotomy as

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[31] See also Stengers (2000a) for a discussion of technoscience.

categorical and a priori and instead he suggests that we are inherently intertwined with technology. The social is technological and the technological is social:

> "Consider things, and you will have humans. Consider humans, and you are by that very act interested in things. Bring your attention to bear on hard things, and see them become gentle, soft, or human. Turn your attention to humans, and see them become electric circuits, automatic gears, or softwares. We cannot even define precisely what makes some human and others technical, whereas we are able to document precisely their modifications and replacements, their rearrangements and their alliances, their delegations and representations. Do technology, and you are now a sociologist. Do sociology, and you are now obliged to be a technologist." (Latour 1991)

In Latour's understanding and vocabulary non-humans and humans have always, ever since the earliest uses of tools and techniques, been mutually implicated. Tools and techniques are concrete ways for humans to interacting with their surroundings that have 'shaped' our actions and existence. Similarly, materiality and technology have been 'socialized' into human society (Latour 1999). This pragmatogony – "genesis of things" as Latour calls it (Ibid.: 176), thus consists of a long series of "crossovers" or "chains of associations" between humans and non-humans that in turn has shaped the other. Arguably, posthumanity is thus not a new or forthcoming phenomenon as some might suggest[32], but rather what we have always been.[33]

Society and social relations are dense with materiality. Materiality exercises politics in many ways; cars, doors, keys are artifacts where politics are not 'merely' socially inscribed; these artifacts are manifest political actions that

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[32] If one googles "Posthuman", one mainly encounters the imaginary known from mainstream science fiction of the enhanced human being soon to be realized, an evolutionary step that will take mankind (or presumably a few exemplars of mankind living in the Western part of the world) to a new level and become some sort of superhumans. Such imaginaries are interesting and humorous for many reasons, however they presume that what it means to be human is a well-defined and stable matter that can thus be meaningfully considered as transgressable. Some of these accounts draw on the somewhat trivial and to my understanding misinterpretation of Nietzsche's philosophy. See e.g. www.posthuman.com or http://www.maxmore.com/becoming.htm

[33] This is the central argument of Latour's book *We Have Never Been Modern*. He argues that we have never been modern, since the world has never 'actually' been separated into two realms of social beings and material objects as conceived in modern thought; we have only been modern by believing in such a separation as actual and not a preferred and convenient way of thinking about the world. See Latour 1993.

embody specific “programs of actions” (Latour 1991, 1995, 1999). Consequently, in a posthuman ontology it is not a settled matter or settable matter what it entails to be ‘human’ or what ‘technology’ is. Posthumanism is inherently anti-essentialist but interested in the emergence and *becoming* of bodies. Hence, the demarcation between social work practices and technological rationalism central to design constitutes not a premise but an outcome in posthumanism. This is not to say that posthumanism prefers the system-theoretical position that offers no differentiation. The point is that technologies and humans act in closely knitted relations. Technologies may show anything but predictable, automated behavior, and act unexpectedly just as humans may act in very automated and predictable ways. What we *are,* humans and technologies, is a relational situated product. Essences are thus an empirical matter not a priori given.

The ‘real-world’ laboratory

The anti-essentialism of posthumanism is also found in relations to science. A central vocation in posthuman STS is the permeability between science, technology and society. These realms do not exist separate from each other, but are mutually implicated. Science is not internalist, having privileged access to an a-historical reality. The concerns and knowledges produced in science are interwoven with contemporary concerns and interests. Equally, science contributes to the formation of societal concerns, problems and solutions. (Fleck 1977, Haraway 1997, Smith 2005).

The divide between ‘laboratory’ and ‘real-world’ is thus equally one that demands more consideration than simply to assert that the lab. is ‘theoretical’, distant to practice, reductionist and ‘ivory-tower’, whereas the ‘real-world’ is complex, messy and offer genuine, concrete problems. Obviously, the laboratory may construct settings that restrain the object of concern considerably and thus lead to poor understandings of it, but so may so called ‘real-world’ settings. In relation to design the mere fact that designers often consider and refer to themselves as allies of the use practice cannot but affect the relation between designers and practices e.g. in a manner that makes controversies about the need for change and the relevance of the presence and suggestions of the designers less prone to be articulated (Howcroft & Wilson 2003a, 2003b). Equally, the air of construction, change and problem solving, which is an essential part of design projects, must also be considered as impeding skepticism and critical concerns of the design (Markussen 1996, Danholt 2006a).

Moreover, a categorical dichotomy between a 'docile laboratory' setting and a 'wild, unruly real-world' setting seems to be lacking much empirical detail. STS offer many empirical accounts of laboratory settings that are anything but orderly, docile settings. Rather, laboratories are sites where 'unruly' and 'incorrect' behavior is the order of the day, and it is executed equally by materiality and scientists (Knorr Centina 1981, Latour 1983, Latour & Woolgar 1986, Law 2004, Pickering 1995). What for some constitutes 'theoretical ivory-tower' knowledge is to others a practical, concrete problem.

With STS the laboratory is just as much part of the 'real-world' as so much else, since it is a practice of knowledge production like others, distributed throughout multiple sites (Serres & Latour 1995). It is about conversing with materiality and other actors and trying to make this knowledge relevant through circulation (Latour 1987, 1999). When the distinction between laboratory and 'real-world' is destabilized as it is in STS, then simply being in a 'real-world' setting does not guarantee the production of genuine, relevant knowledge and/or interventions. Instead, again, by considering science practices, the Belgian philosopher and chemist Isabelle Stengers has argued that what constitutes a good scientific practice (as well as a good democratic one[34]) is its *interest* in the object of concern. An interested scientific practice entails risk. It is risky since it seeks to maximize the ability of the object of study to resist the questions/propositions raised by the researcher (Stengers 1997, 1999, 2000a, Despret 2004b, 2005, Latour 2004).[35]

> "Every time one in the name of science ensures that those interests, demands and questions that could have problematized the relevance of a given proposal, are silenced, we face a double short circuit: a short circuiting of democratic concerns and a short circuiting of the risk that provides scientific knowledge with its reliability. In other words our

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[34] Isabelle Stengers states: "The production of knowledge, to the extent that it is reliable, and the challenge a truly democratic society encounters, are not in any way in opposition or tension, but tied together in a crucial way. Reliable scientific knowledge depends in the absolute upon that the propositions posed are put to the test, that is, that there is interest for what may falsify them." (Stengers 1999: 69 My translation)

[35] The aspect of interest will be further elaborated in Chapter 2.

> modern societies, where the prevailing argument is to refer to science or objectivity when identifying what actions or decisions should be taken – have the science they deserve." (Stengers 1999: 70 my translation)

In short, we might say that by contesting the demarcation between laboratory and 'real-world' STS construes the problem of constructing knowledge or relevant actions as being a matter not of being situated in a specific place, but of how one contributes to the enactment of the site (Despret 2004a, Winthereik et al. 2002).

Posthuman performativity

The notion of performativity is central to STS and Andrew Pickering designates a dichotomous understanding of how we may see the relation between science and the world in terms of a *representational* and a *performative* understanding:

> "The representational idiom casts science as, above all, an activity that seeks to represent nature, to produce knowledge that maps, mirrors, or corresponds to how the world really is." (Pickering, 1995: 5).

In contrast hereto stands a performative view:

> "One can start from the idea that the world is filled not, in the first instance, with facts and observations, but with *agency*. The world, I want to say, is continually *doing things*, things that bear upon us not as observation statements upon disembodied intellects but as forces upon material beings." (ibid.: 6)

These two ways of thinking about science and the world are consequential for science practices in the following ways. The representationalist understanding constitutes the traditional modernist and epistemological version of science. In this view science is about discovering the facts and laws of the world and represent them in a manner so that represented and representation corresponds truthfully. Practices and technologies of science are considered merely neutral tools for uncovering nature.

In a performative understanding science constructs knowledge and facts in an open-ended, risky manner where the outcome cannot be anticipated. Knowledge and facts have a history, a genealogy. They emerge at particular times due to a plethora of interrelated aspects that stems form contemporary conditions 'inside' of those science disciplines as well as 'outside' of them in society at large. The posthuman aspect of performativity entails that knowledge is produced through practices that includes a range of human and non-human actors. Which means that specific apparatuses, instruments, technologies, techniques as well as existing theories and conceptualization are all an intrinsic part of the fact or knowledge produced. With a performative understanding of science the focus is on the practices through which knowledge is produced instead of with the epistemological concern about the quality of knowledge. Performativity is equivalent to material practice.

In poststructuralism, performativity takes on another although not incompatible meaning. In poststructuralism performativity is the processes through which materiality and meaning mutually co-construct each other and are thus not considered as adhering to two distinctively separate domains, one of words and another of things. Performativity, according to the American poststructuralist and feminist scholar Judith Butler designates the continuous process of subject and bodily formation through discursive practices.[36] Bodies thus *materialize*, not determined by, but inextricably interwoven with how they are represented. This does not mean that language and processes of signification produce bodies and materiality. In the words of Butler:

> "To claim that discourse is formative is *not* to claim that it originates, causes, or exhaustively composes that which it concedes; rather, it is to claim that there is no reference to a pure body which is not at the same time a further formation of that body." (Butler 1998b:77 my emphasis)

Moreover, in the words of Karen Barad:

> "Performativity, properly construed, is not an invitation to turn everything (including material bodies) into words; on the contrary, performativity is precisely a contestation of the excessive power granted to language to determine what is real. Hence, in ironic contrast to the misconception that would equate performativity with a form of linguistic monism that takes language to be the stuff of reality, performativity is properly understood as a contestation of the unexamined habits of mind

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[36] The concept of discourse constitutes a central concept in Michel Foucault's work and this is related to the concept of the *episteme*, which may be considered as parallel to Thomas Kuhn's understanding of the paradigm and Ludwig Fleck's Denkstile. Discourse emerges in the episteme while also reproducing the episteme. What is spoken is only meaningful in relation to an episteme (Foucault 1972, Smith 2005, Fleck 1977, Deleuze 1986)

> that grant language and other forms of representation more power in determining our ontologies than they deserve." (Barad 2007:133)

Performativity is thus about the formation of materiality. Materiality, although commonly conceived of as somewhat lawful and inert, is in a performative view a process interwoven with discursive, representational practices. Performativity thus also means that the existing is continuously performed and reiterated in order to persist, which means that the existing is also always under construction and transformation. Slight changes in the way things are done lead to novel existences. Performativity thus imply a continuous possibility of transforming the existing (Butler 1993).

As stated by Barad performativity is thus about thinking *differently* about materiality as *neither* simply there, inert, pre-existing and unaffected by our knowledge practices on the one hand (realism), nor as fully produced by these knowledge practices on the other hand (social constructivism, linguistic turn). This complicated notion of materiality and existence constitutes a focal concern in poststructuralism, since a thorough understanding of these processes seems to enable a non-reductionist, anti-essentialist and dynamic understanding of reality (Deleuze 1986).

What is central to performativity, both in the poststructuralist version and in Pickering's version, is thus to address reality without presupposing essentialist assumptions about actors and actions. There are no essences to be recovered but effects that may be substantialized and assembled into a fact. Performativity in the poststructuralist version reiterates this concern with regards to words and things. Words are not just considered as markers more or less adequately corresponding with a reality they are separate from. They intervene with and affect materiality enabling it to be materialized in specific ways and not others. Equally, materiality in return partakes in the production of what can be thought, known and named.

Cosmopolitics: the Parliament of Things

In UCD the concern with the user and use practice is premised by a representationalist understanding of the user either as somebody who should be adequately represented or as an equal participating party in the design process.

With posthumanist STS the idea of the use-practice as pre-existing the information system is challenged; not that the practice in some form does not pre-exist the design process, but that what *becomes* the use-practice is inherently intertwined and co-constructed through the design process. Obviously, this means that to consider the use-practice as having certain properties, strengths and weaknesses, which are not simultaneously a specific enactment of the practice by the designer/researcher, is questionable in a posthumanist ontology. Problems and properties emerge as a relational product (Barad 2007). Consequently, the reference to a problem or a user as genuine or authentic is equally a problem. Rather, such references constitute political actions by attempting to institute an incontestable actor.[37] Posthumanist STS is premised by a skepticism towards references to an authentic fact, user, problem etc., but thoroughly interested in the performative aspects of such references, what they do (Jensen 2004a, 2004b, Jensen & Lauritsen 2005), how they enact reality and what they enable to exist. Considered as such representations are thus not depictions of reality that may constitute an argument for specific actions to be taken, but themselves performative actions produced through intervention. They are also interventionist, since they translate and prolong specific versions of reality. Hence every actor is partaking in construing reality by how they represent reality, but, importantly, every representation constitutes a relation, since it stems from more than one place; it is a product of interaction. Latour's concept of The Parliament of Things explicates this:

> "In its [The Parliament of Things] confines, the continuity of the collective is reconfigured. There are no more naked truths, but there are no more naked citizens, either. The mediators have the whole space to themselves. The Enlightenment has a dwelling-place at last. Natures are present, but with their representatives, scientists who speak in their name. Societies are present, but with the objects that have been serving as their ballast from time immemorial. Let one of the representatives talk, for instance, about the ozone hole, another represent the Monsant chemical industry, a third the

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[37] This happens when a scientist, as the citation above expressed, presents facts as if they were a-historical, objective, disinterested and non-negotiable attributes of reality. This is the highly political aspect of claiming the apolitical, objective nature of science, since it institutes science as an indisputable authority. Feminist and science scholars have in length uncovered science as anything, but apolitical and as endowed with interests, concerns, politics, preferences, economy, gender issues etc. (See Shapin & Schaffer, Haraway 1997, Latour 1993. See also Stengers' argument that challenges a too rigid understanding of science as patriarchal technoscience (Stengers 2000a, chp. 1.)

> workers of the same chemical industry, another the voters of the New Hampshire, a fifth the meteorology of the polar regions; let still another speak in the name of the State; what does it matter, so long as they are all talking about the same thing, about a quasi-object they have all created, the object-discourse-nature-society whose new properties astound us all and whose network extends from my refrigerator to the Antarctic by way of chemistry, law, the State, the economy, and satellites. The imbroglios and networks that had no place now have the whole place to themselves. They are the ones that have to be represented; it is around them that the Parliament of Things gathers henceforth." (Latour 1993: 144)

Latour's Parliament of things designates our posthuman condition, humans and non-humans alike, as networks – authentic, unified, singular persons, objects, things are *gatherings* and thus not merely to be represented, but themselves representatives of multiple others (Latour 2005). Modern democracies and representational science are premised by the belief in an authentic citizen, or a singular object in whose name the politician or the scientist may speak. Without the authority granted to the representative through this constitutive presumption, what are we faced with? A reality where we may be justly skeptical of persons who attempt to speak concisely on behalf of others, as if they have unmediated access to the concerns and reasons of others and simply serve as a vehicle for those they represent. Stengers argues that we should learn to laugh at those politicians, scientists and experts that speak in a manner that obviously reduces those they speak on behalf of (1999). Stengers finds that such representationalist actions, in fact, rather constitute a *poor* interest in those one attempts to speak in the name of. Instead, one's interest is in the power that follows from speaking in crude terms about a problem, a group, an object etc.[38]

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[38] Stengers is utterly critical of science when it becomes an order-word (Mot d'ordre). Science as an order-word nurtures another relation to the object, one where the object plays, not the role as a 'vector of risk', but as what allows the scientist to act as an authority. To act as an authority rests on sustaining and developing an understanding of the object of study as singular as defined by science. It thus hinges on an essentialist understanding of the object, which one can claim to have a full and correct representation of. This impedes the possibility of the scientist to be influenced and 'moved' by other potentially 'un-scientific' claims, since they are pre-disqualified by the self-attribution of authority to science. It is also a problem in relation to the object, since one becomes interested in preserving and reproducing the particular version of the object obtained. Conditioned in this way little incentive exists to provide the object with the opportunity to articulate itself otherwise. Little incentive exists in creating novel understandings and knowledge. Science as order-word is thus in many ways degenerative of the ideal of science, namely to produce knowledge. See Stengers 1997.

In the Parliament of Things, everyone is a spokesperson, and consequently the geometry of representational democracy and science breaks down. The decisive difference between represented and representative dissolves. Society becomes flat in the optics of cosmopolitics; everybody is occupied with the practice of representing and making their accounts matter to others. The difference between serving others as their representative and serving oneself converges. Every representational action is simultaneously to speak for oneself and for others.

Consequently, no representation, no reference to a fact, a citizen, a problem, is incontestable. Arguably, the Parliament of Things is about opening the space for argument and discussion. In the Parliament of Things what matters is that more voices and more concerns become elicited. The immediate objection might be: “Well we cannot include all voices, we must stop at some point, and if the point is simply to include more voices, then we eventually become incapable to take normative action and make decisions.” However, such an objection is premised by the understanding that normative action and descriptive accounts or points of view are separate; *first* we lay out the facts (or decide what constitutes the facts), *and then* we decide what to do and how to act.

But when, as in a posthuman understanding, we acknowledge that our descriptive accounts are themselves specific ways of relating things and enacting reality, then this objection loses its pertinence. The basic contention of the Parliament of Things is that we already construct society as we argue about how to construct it (Latour 2005, Garfinkel 1967). Consider debates on the environment, globalization, immigration etc.; these are all subjects, where, as we discuss them, specific realities are constructed in which specific objects and problems are enacted and made to exist in specific ways on the expense of others. Discussion *is* decision-making and normativity in action.

Hence, we are not short of decisions; we exercise those all the time through our discussion, through what we bring into the discussion. Instead the problem is the idea of facts as a premise for making ‘informed decisions’, since with this modernist understanding a divide between description and normative actions is constituted: “facts first then decision”. In such an understanding the performative and normative aspects of ‘fact’ production are not recognized. On the contrary it has to be consistently ‘bracketed out’ and downplayed. The Parliament of Things is about acknowledging the normativity intrinsic to knowledge production and knowledge production therefore in itself of our concern. Facts and knowledge enact the world in specific ways and not others. It could have been otherwise (Bijker & Law 1992, Law & Singleton 2000, Singleton 1996). Hence, when facts are delegated the role as ‘neutral’, a-political knowledge required in order to make decisions, and one’s interest is with gathering the right and relevant knowledge in order to make informed decisions, one becomes implicitly interested in reducing what constitutes the relevant concerns adhering to a specific problem. Or to put it differently, no incentive exists for complicating the problem, including more factors, more concerns, more voices since thereby the process towards an ‘informed decision’ seems to be slowed down. However, from a democratic as well as a scientific point of view, this constitutes a central problem. In contrast, the Parliament of Things is about the inclusion of complicating factors that contribute to the continuous construction of a society where the complexity, difficulty and uncertainty, immanent to existence, constitute a shared condition. It is about becoming sensitive to the intricacies and normativities of the production of knowledge in order to be able to actively and *explicitly* resist some types of knowledge productions and further and explicitly argue for other types.

With the Parliament of Things our concern is shifted from a concern with accurate representation of singular unified subjects and objects with essential qualities, to how to engage in *affective* relations that enable becoming and transformation to occur. (Stengers 2000b). This may seem abstract, naïve maybe even utopian, but the point is not, as some might argue, to realize an ideal state of complete democratic transparency, where every actor is heard in the exact way they deserve. The point is to have an interest in the experimental practice of bringing diverse concerns, regardless of their seemingly irreconcilable discrepancies, into relation (e.g. medical science and alternative medicine) and allow these concerns the *opportunity* of affecting and mutually transforming each other. Nor is it utopian in the sense as something not presently in the world and thus to be realized in a future to come. Parliaments of Things are already part of our everyday practices, I would argue.[39] One example is clinical practice.

Clinical diabetes practice exemplifies a Parliament of Things, I would argue. In this practice highly heterogeneous data are 'brought together' in order to decide if and how treatment is to be altered. The healthcare practitioner considers various laboratory tests of blood and urine that show data about cholesterol, lipids, blood sugar, ketone etc.; s/he considers data from the nephrologists, the podiatrist, the ophthalmologist; s/he weighs the patient, measures the blood pressure, s/he talks with the patient about how things are going, how s/he feels, her/his problems, practices and habits; s/he considers the trajectory of the disease and the treatment etc. All these aspects do not simply 'add up' and designate a clear path; instead they constitute an inherently complicated, fragmented yet interrelated assemblage where the various pieces of data are related to and juxtaposed to one another. Still decisions are taken, treatment continues in one form or another. Constitutive of this practice is an interest in the complexity of tests, numbers, stories and new tests, or ways of inquiring are continuously introduced, new complexities and complexifying factors are brought in. It would constitute a poor practice if a healthcare practitioner decided only to take a few factors into consideration, or held that novel tests should not be included, or if the practitioner refused to speak with the patient or only exclusively wanted the testimony of the patient and excluded all the lab. tests etc. The clinical practice is premised by a range of different voices that speak in utterly different ways, but about the 'same thing', namely the condition as a network, a multiplicity. Still - despite these incoherent and different voices - action is taken by the end of the visit: "We continue with the treatment as it is" or "we change it slightly in this or that manner."

Isabelle Stengers has designated Latour's Parliament of Things as cosmopolitics, since it is about being inherently uncertain with regards to what may constitute as relevant concerns, relevant actors and significant others and therefore be inherently interested in their articulation.

> "[W]hat would a human be without elephants, plants, lions, cereals, oceans, ozone or plankton? A human alone, much more alone even

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[39] To look for and articulate everyday practices as Parliament of Things constitutes a simultaneous enactment of Latour's abstraction and an intervention in everyday practices by re-conceptualizing them as such parliaments.

> than Robinson Crusoe on his island. Less than a human. Certainly not a human... [W]e do not know what makes the common humanity of human beings and that, yes, maybe, without the elephants of the Amboseli, without the meandering waters of the Drôme, without the bears of the Pyrenees, without the doves of the Lot or without the water table of the Beauce they would not be human." (Latour 1998)

Controversy over ontology?

In the introduction to this chapter I suggested that the difference between STS and design was not that STS is descriptive and design is action-oriented and interventionist. By discussing and presenting central aspects of UCD and posthuman STS I have argued for this difference. UCD is premised by essentialist dichotomies between technology and humans, representation and intervention, laboratories and real-world. But does this mean that in STS there are no such differences and instead these things are conflated into an undifferential mass? No, such arguments simply reproduce a dichotomous understanding between *either* there are a priori, essential differences (those designated by dichotomous understandings) *or* there are no differences. The point is that STS is about abstaining from assuming specific *essentialist* qualities about the world and reality. As the American literature and science studies scholar Barbara Hernnstein Smith puts it:

> "Constructivists…decline to presume either any particular way the world inherently is *or* such an accord. This practitioner ontological agnosticism is not, as realists may see it, a perverse refusal of common sense but *an effort at due methodological modesty and theoretical economy*." (Smith 2005: 6 my italics).

Accordingly, constructivism and posthuman performativity as articulated in STS does not stand in contrast to the dichotomous essentialist presumptions of design as if the ontology implied by design is false while the ontology of STS is true. It does and should not constitute an epistemological dispute over the ontological status of reality. We may, as Smith suggests above, consider constructivism to be, not a perverse refusal of common sense, but an attempt to be rigorously empirical. However, although I agree with this understanding, constructivism is not only an attempt to be rigorous. It is loaded with a particular preference, namely to resist understandings that rely on or seek to represent the world as lawful, orderly and essential. Posthuman STS is just as much about contributing to the becoming of a reality that is relational and anti-essentialist. Hence, by being deliberately uncertain with regards to the qualities of reality and assume that 'essences' are produced through relations, one provides an *opportunity* for the world to become differently, than if loaded with essentialist a priori presumptions. Constructivism and anti-essentialist understandings are about substituting such understandings with the understanding of a continuous emergent and differentiating world, a world of *becoming*. A posthuman disposition constitutes a preference for a lively reality that has surprises in store for us and where the relation, not the related substances, constitutes the starting point of analysis and the source of emergence. Accordingly, such a preference also *contributes* to the production of a lively reality since the constructivist prefers versions of reality that exhibit, or may be researched in a manner, so that emergent behavior is exhibited.

Nobel Prize winner and chemist Ilya Prigogine and Isabelle Stengers' book *Order out of Chaos* (1984) exemplifies such an intervention in contemporary science. In the book they argue for the subversion of the relation between Newtonian dynamics and thermodynamics. With the emergence of thermodynamics in 1824, it was first by Sadi Carnot's work attempted incorporated into Newtonian dynamics. However, when failing to do this thermodynamics was considered the minimal event constituting the limit to Newtonian dynamics that still constituted the (almost) general and universal dynamics. But Prigogine and Stengers show that Newtonian dynamics in contrast constitutes the minimal and highly staged event that relies on very specific and simple objects and set-ups such as pendulums and falling objects. Rather, thermodynamics and the principle of irreversibility intrinsic to thermodynamics actually seem to be the dominant dynamics and Newtonian dynamics the minimal event.[40] Emphasizing temporality and irreversibility, Prigogine and Stengers show how order is an emergent and particular event arising out of chaotic conditions and dissolve again when the system is affected. They offer an understanding of order and chaos in biological and chemical systems as interwoven and where order

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[40] The problem, however, is that Newtonian dynamics has come to constitute an ideal in many scientific disciplines, with its simple universal laws able to describe the future and past of a system provided knowledge of its present state. But to attempt to follow this ideal constitutes a great mistake according to Stengers. She argues that it is a problem when e.g. social sciences adopt the ideal of Newtonian mechanics and attempt to describe and reduce complex phenomena as governed by simple, universal laws. See Stengers 1994.

constitutes the minimal, fragile and staged event. Evidently, such an inversion of the relation between mechanics and thermodynamics furnishes the argument that order needs to be explained and not presumed. Prigogine and Stengers thus contribute to an ontology of becoming through the re-conceptualization of the relation between order and chaos.

Similarly, to be consistently anti-essentialist and constructivist is to contribute to the becoming of an ontology of becoming.[41] In this light, constructivism is not a perverse refusal of common sense, but a contribution to a lively, emergent transformative world of becoming. A constructivist, anti-essentialist ontology is thus a gesture towards opening up rather than foreclosing the qualities of the world. It provides the world an opportunity to become differently realized as more dynamic and transformative than imagined (and preferred) in essentialist understandings. Implicit to such a disposition and its basic principle of relationism (as in contrast to essentialism) is that things and entities relate and impregnate each other in multiple ways without adhering to pre established boundaries. Instead of a lawful, orderly and structured world we have, with constructivism, an *affective* world of relations.

Hence an understanding that constitutes an opening up of the possibilities and potentialities of the world becomes an opening practice itself, since how to affect is not confined to specific types of actions as real interventions. With an affective world there are no innocent positions. There is no position of the merely descriptive, representational scientist as opposed to the action-oriented researcher in the 'real-world' making a difference. There are no sharp distinctions between mere description and concrete intervention, no safe neutral non-political positions. This may be saddening for those who hope and strive for an inherently objective position and for the transcendental good and true. But it is also sad for those who thrive on the distinction between mere description and real intervention, since they cannot insist that their practices are to be preferred over others. How and in what ways descriptions, representations, actions, real-world' interventions come to matter cannot be anticipated nor

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[41] Andrew Pickering's current work on the British cyberneticians is spawned by a similar interest. Pickering argues that the British cyberneticians Grey Walter, Ross Ashby, Stafford Beer and Gordon Pask were driven by an interest not in making specific machinic assemblages perform in predictable and by design intentional ways, but in the emergence of behavior that was a product of their interaction with their surroundings and thus was open-ended and unpredictable.. See Pickering 2002, 2006 and forthcoming.

determined in advance. Arguably, when not subscribing to a sharp distinction between description and intervention, the repertoire of what constitutes intervention and thus potential contributions is considerably broadened. One is provided with an inherently constructive and affirmative position of trying to invent and produce interventions that may be contributive, rather than be confined to think in limited way about certain types of actions as interventions. One becomes able to think more freely about what constitutes a contribution, and one may work to consider and actively argue for what one's contribution does. In relation to design and STS, my argument is thus that following a constructivist, anti-essentialist understanding produces a disposition that is inherently positive and interventionist, since one cannot but intervene, and therefore the real concern is rather how to intervene in a manner that can be argued for as a contribution along as many lines as possible.

My reluctance, as presented in the introduction, to engage in a design process with the intent to design a concept, or a potential technological solution for people with diabetes was premised by a concern with setting up a too generous design setting; a setting that eventually might contribute to the production of a device that might in the end be of little contribution, other than as a trophy of my research. But it would also implicitly contribute to and reproduce the understanding of people with diabetes as in a state of deficiency. I have, instead, through my research attempted to contribute to the understanding of their problem as much more subtle and complicated and therefore in need of sophisticated understandings and conceptualizations.

Chapter 2:

Posthuman Devices for Studying Diabetes Practices

> "[T]he function of scientific thought has less to do with its "truth" than with its *astringent effects,* the way it *stops thought from just turning in self-satisfying circles."* (Lévy-Leblond quoted in Stengers 1997: 5)

Introduction

When science and research is perceived as performative, science is transformed from providing answers to being risky. When science does not per definition deliver objective representations but "elicits properties, rather than essences" (Cussins 2000: 357) then what it means 'to be scientific' is transformed. Science becomes a practice that enacts particular realities, which entails concerns about how these practices are conducted and why thus become pertinent. These considerations are productive, since researchers are urged to consider if and how other types of interactions with the object of study would produce novel types of knowledge. Importantly, this also means that existing representations may be considered as products of sedimented practices of interacting with the object. But for that reason existing, prevalent representations are important, since they constitute a starting point for inventing novel ways of producing representations and knowledge.

In this chapter I will present the devices I employ for studying diabetes practices. Like instruments in a laboratory they are the means that enable the object of study to be elicited in specific ways. Moreover I will present the concrete details of my fieldwork and data analysis. I wish to start by presenting insights from the history of primatology and ethology that has constituted an inspiration for how I have attempted to study the problem of diabetes. Central to these understandings is that science is a performative practice.

Primatology: from simple to complicated

The history of primatology - the study of primates such as baboons, chimpanzees, howlers etc. – is an appropriate starting point for discussing how one can study people and technology. Not because primatology as conceptualized by Sherwood Washburn, the father of North American anthropological primatology, is instrumental in bringing "knowledge of our closest living relatives [that] could help us understand the origins and evolution of human behavior" (Strum & Fedigan 2000: 5), but because the history of primatology exemplifies how a discipline has moved from having a simple conception of its object to a complicated one.

Strum and Fedigan review the history of primatology, and argue that our understanding of primate societies has "moved from a general vision that primate societies revolve around males and are based on aggression, domination, and hierarchy to a more complex array of options based on phylogeny, ecology, demography, social history, and chance events." (Ibid.: 5). Strum and Fedigan state:

> "In the history of studies of the evolution of behavior, explanations have oscillated between the genetic and the environmental… [But] most recently, behavioral ecology has proposed a more holistic model of adaptation that relates environmental and societal processes to those of genetic selection. Behavioral ecology as well emphasizes multicausal analyses." (Ibid. 29).

Primates have thus during the last 50 years 'evolved' from being either strictly behaviorist or sociobiologically determined, to sentient beings with cognitive and strategic abilities capable of exploiting and dominating each other, but also of cooperating and complementing each other. Primates have emerged as *actors* with a history where "age, temperament, tenure in the group, the history of previous interactions and the current social context" (Ibid.:31), are all factors that affect the interactions and lives of primates.

Likewise, the relations between the sexes have turned out to be much more sophisticated than earlier perceived. Instead of being simply dominated by males, females are now understood to be sometimes the dominated party, while at other times exploitative and manipulative of males. These findings are considered by primatologists, such as Strum & Fedigan among others, as intertwined with primate studies conducted by women, because female primatologists were interested in studying female primates not as simply determined by male behavior, a research agenda that was not followed in the early years of primatology.

The history of primatology thus exhibits an interesting movement central to my doctoral research. First, it shows a move towards complication. Contrary to the ideals of traditional philosophy of science the object of study, primates become more complicated as we learn more about them, rather than more simple. Second, the history of primatology shows that how we engage with our object of study has consequences for how it is elicited. Female primatologists were consequential in producing a more complicated and sophisticated knowledge of primates, due to their interest in female primates. An interest that not only affected and sophisticated the understanding of female primates, but affected how primates, female as well as male, are now conceived. Knowledge was produced that transformed apes from determined creatures, whether by environment or genes, to singular actors with specific histories partaking in the performative making of their history.[42] Female researchers interest in female primates thus exemplifies the productiveness of interest.

Bias and interest

In common scientific methodologies interfering with the object of study constitutes bias. Hence the scientist should work to minimize his or her bias in order to access the real, objective world and/or s/he should account reflexively for her biases in order for her peers to evaluate her claim.[43] But the problem of bias becomes significantly re-configured by understandings from primatology and STS. The concern with bias and the wish to minimize it is premised by the understanding that it is ideally possible to obtain an unmediated access to the objective world. But polemically put by Latour, in the last instance it also means that: "[I]f we had no theory, no preconception, no bias, and no standpoint whatsoever, we could benefit from an indisputable, unmediated, pristine access to

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[42] This intertwinedness of the object of study and the view from where it is studied exemplify Donna J. Haraway's call for 'situated knowledge' (Haraway 1991). Haraway argues against both relativism and realism and for 'strong objectivism' as including both the knowledge about an object and accounting for the position from where an object is studied. Tracing and eliciting the view from where knowledge is produced is the tenet of situated knowledge. Knowledge in Haraway's contention is not a universal disembodied view from nowhere, but is embodied and situated. See Smith 2005 for a critique of the rhetorical premises of strong objectivism.

[43] Reflexivity is considered a virtue in much social science research. Reflexivity is premised by a constructivist understanding that science is interventionist and perspectivist. The problem, however, with reflexivity is that it continues the idea of a world that is inaccessible to us and thus exist in a 'real, objective' manner. For critiques and further unfolding of the problem and implicit assumptions of reflexivity see Latour 1988a, Barad 2007, Haraway 1991.

things themselves." (Strum and Fedigan 2000: 366). But with the understanding that science is performative, a concern with bias changes and becomes somewhat irrelevant. It becomes irrelevant, since as Latour ironically remarks above, it presumes that the ideal scientific relation with the world is one without interaction, a practice in complete contrast to what science is and does. As Latour and Vinciane Despret have argued, without techniques, instruments, involvement and interest we do not get a pristine objective description of the world, we get nothing, or in their terminology we get a poorly articulated world.

> "To 'de-passion' knowledge does not give us a more objective world, it just gives us a world 'without us'; and therefore, without 'them' – lines are traced so fast. And as long as this world appears as a world 'we don't care for', it also becomes an impoverished world, a world of minds without bodies, of bodies without minds, bodies without hearts, expectations, interests, a world of enthusiastic automata observing strange and mute creatures; in other words, a poorly articulated (and poorly articulating) world. (Despret 2004a, p.131)

Hence our instruments, theories and representations enable knowledge to be produced. Therefore, a central contention in STS is an appreciation of those instruments, apparatuses, theories and representations, since they are *practices* through which we cultivate and enact relations to the world.

However, in the words of Alfred N. Whitehead: "You cannot think without abstractions; accordingly it is of the utmost importance to be vigilant in critically revising your *modes* of abstraction." (Whitehead 1926: 59). Hence the relation to representations is a complicated one where we, because of the productiveness of abstractions, must be vigilant with respect to how we employ them. Whitehead suggests that we should appreciate representations as enabling us to think, but in addition and because of this quality it is important that we constantly consider how and what they enable us to think. Hence our representations are knowledge producing practices. Representations considered as such can be interacted with and transformed. Related to the concern with bias it is thus not a matter of being careful not to impose one's preconceptions and interests on the object of study. It is rather a matter of using these abstractions actively in the study of things.

Good experiments: studying sheep by means of a bowl of food

> "One of the ways to resist an apparatus is to lead the experimenter to transform his/her questions into new ones that are the appropriate questions to ask that specific individual. In other words, an apparatus that does not have a stake in docility is an apparatus that is designed to give the opportunity to the 'subject' of the experiment to show what are the most interesting questions to address to him; what are the questions that make him/her the most articulate." (Despret 2004a: 124)

Thelma Rowell studies sheep. Sheep are by definition boring, but Rowell, an experienced primatalogist and ethologist, in her research provides sheep with an opportunity to become other than boring. Rowell's research is premised by the understanding that research affects its object of study, but instead of attempting to minimize these affects in order to obtain a pristine representation, she employs *affect* as a research tool.

Food resources and competition over food have been the central focus of classical ethology, mainly, according to Rowell, because they are easy to observe. But what "is much more important to the animals is much rarer, is predation" (Despret 2005: 362). Interestingly enough, the reason why this is easily 'overlooked' by researchers is because the presence of the researcher provides the protection from predators that render what would otherwise be of great concern to the sheep less so, and thus invisible to the observer. The researcher thus provides the sheep with protection from predators, and this turns out to be consequential for the behavior of the sheep; for the sheep the researcher becomes an ally against predators (Ibid. 363). So, the practice of observing the sheep does not only provide access to the behavior of sheep, it also produces conditions that hinder certain kind of sheep behavior (the fear of predators) to be exercised and observed by the scientist. But as Despret argues, the researcher has not just limited his or her access to the 'reality of the sheep', s/he has also enlarged the capabilities of the sheep. Since obviously sheep are able to regard researchers as protection from predators and sheep are thus sentient enough to recognize the difference between researcher and predator and moreover sophisticated enough to change their behavior accordingly.

Through her way of inquiring about the sheep Rowell works towards a more sophisticated understanding of sheep, an understanding that does not accept food resources as providing the principal explanation for sheep behavior. She does so by offering an additional bowl of food to the flock of sheep she studies, so that there are 23 bowls of food for 22 sheep. This simple intervention enables the possibility of new understandings of sheep behavior to be produced, since:

> "The idea is not to prevent them [the sheep] from entering into competition around the supply of food; it is to *leave them the choice* of doing so, to ensure that competition is *not the only possible response* to a constraint, but rather a choice in response to a proposition. If the sheep choose competition, the hypotheses of scarcity of a resource can no longer account for their behavior." (Ibid. 368).

The bowl is thus part of a set-up that makes a difference to how we may understand sheep. The bowl is *interesting* in the sense provided by Isabelle Stengers:

> "I would go so far as to affirm that no scientific proposition describing scientific activity can, in any relevant sense, be called "true" *if it has not attracted "interest"*. To interest someone does not necessarily mean to gratify someone's desire for power, money, or fame. Neither does it mean entering into preexisting interests. To interest someone in something means, first and above all, to act in such a way that this thing - apparatus, argument, or hypothesis in the case of scientists - can concern the person, intervene in his or her life, and eventually transform it." (Stengers 1997: 83-84)

Interest in this sense is thus close to its etymological root: Inter-esse meaning between essences or 'coming between things' or 'connecting entities'. Accordingly, Stengers designates a scientific attitude that obliges the scientist to conduct research that works to bring the hypothesis and the object of study into conversation, so that they may have transformative consequences for one another. In Stengers' view interest and risk are ideally tied together in science practices. She argues that:

> "[T]he singularity of the modern sciences implies the maintenance of the distinction [between subject and object], for it is from this distinction that the risk is born. Once it is a question of science, all human statements *must* cease to be equivalent, and the putting to the test that *must* create a difference between them implies the creation of a reference they designate, which *must* be capable of making the distinction between science and fiction. Thus, the distinction between subject and object, insofar as it expresses this relation of putting to the test, cannot be

> purely and simply eliminated…..It preserves the distinction between subject and object, but modifies it's meaning: it is recognized not as a right, but as a vector of risk, an operator of decentering. It does not attribute to the subject the right to know an object, but to the object the power (to be constructed) to put the subject to the test. (Stengers 2000a, 134)

Stengers argues for an understanding of science that emphasizes the importance of science as a collective practice where the 'vector of risk' constitutes a central aspect. The scientific collective is by definition premised by an interest in the production of novel knowledge. Hence novel understandings proposed by a scientist are of interest to the scientific collective. It is interesting, in the sense provided by Stengers as something that "comes between" scientists, since it forces other scientists to take this novel understanding into account. Consequently, they are interested in putting the novel understanding to the test to see if and to what extent it matters to their research. The point is thus that the collective ideally works to test and/or modify a given novel understanding. Hence, a novel understanding obviously constitutes, not only a risk for the scientist that has proposed the novel understanding, but also for the collective as a whole since the understanding may potentially transform the discipline all together. It is in this manner that the scientist is put to the test by the object through her research, since novel understandings are not simply accepted by the collective but constitute a matter consequential for all.[44] The primary quality of science is thus, according to Stengers, the dynamism involved in the knowledge production of a scientific collective. It is the 'interested' relation amongst scientists that Stengers appreciates and considers inherently constructive. This interested relation (ideally) working in scientific collectives Stengers proposes as an ideal for society in general. She is thus inherently skeptical when it is lacking e.g. in the relation between scientists and laymen, where scientists act as authorities with privileged knowledge to whom the concerns of laymen do not matter to the scientist.

Stengers' cosmopolitical concern is about realizing how the activities, actions and understandings of others matter in the formation of our 'common

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[44] Stengers refuses the idea of science as cumulative. Science is rather a series of events, since from the point that a novel understanding has been generally accepted the discipline is transformed both back in time as well as ahead in time, a new ground is established and from then on everything will have to include the new foundation. Stengers 2000a.

world', there are no innocent or merely 'practical' distributions of work ("scientists 'merely' produce knowledge for society to apply or consume"), only actions that are consequential for our existence.[45] We should thus cultivate relations where others' accounts and activities matters to such a degree that we cannot but engage in a thorough questioning and testing of their accounts and grounds. On this account Stengers formulates a plea "for being done with tolerance", since tolerance equals non-interest to the point where it shifts completely and tolerance is replaced with intolerance (Stengers 2000b). Tolerance is not about the construction of a common world as a collective endeavor, but the epithet of a world of individual entities unrelated to one another until the point where they fight each other. The point is that an interested relation, not a tolerant, entails that others matter profoundly, which is why we need to inquire and interact with them in order to find out how what they do and are is consequential for us. Consequently through this interaction we may transform them as well as being transformed ourselves in return and a novel relation emerges.

Returning to Rowell's research we can say that it is interesting and risky since it is about the (eventual) production of novel knowledge about sheep that probably would matter profoundly for established sheep knowledge. Also it is interesting in the sense that refuses to merely observe the sheep as if mere observation were in fact non-interventionist (which the point on predation challenges), but also as if observation were *enough* in order to learn about sheep. Despret's point based on Rowell is that a representational ideal in favor of a non-interventionist observational approach to sheep only provides us with a very poor understanding of sheep. It is much more interesting what sheep can *become* through research interventions, what they are able to be and how they can become more complicated, sentient beings.[46]

So, according to Stengers and Despret we may define what constitutes a good experiment or a good research set-up as follows: *a good experiment is where the object is provided an opportunity to exhibit novel unexpected behavior that may have transformative consequences for the knowledge we have about it and of the world as*

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[45] Stengers 2005. See also chap. 1.

[46] However, as Despret also points out, for some, for instance meat producers, it constitutes an obvious interest to keep sheep and other animals simple, stupid rather than sentient.

such.[47] When primates become sentient beings with sophisticated communicative and social skills then not only primates' change, so does the world.[48]

Onetouch as a means to provide an opportunity

My experiment was an attempt to study diabetes practices in an *interested* performative manner. I attempted to do that by introducing a device to a group of people with diabetes. I introduced Onetouch to eight persons with diabetes.[49] Besides being a blood sugar measurement device Onetouch enables recording of diabetes relevant factors such as food, health, exercise and medication.[50] Onetouch is promoted as an ideal tool for gaining control over one's diabetic condition.[51]

The problem, I argue, is that chronic disease is obviously something that people with chronic disease would prefer to be without and therefore it seems an obvious and legitimate ambition to aid those people. In return those very people

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[47] Evidently this also means that we cannot define a transcendent criterion for good experiments (or rational science, Poppers ambition. See Popper 1965, Stengers 2000a for a discussion), because we cannot know in advance whether the experiment will result in surprising transformative novel knowledge: "The argument is not simply that surprise is the criterion for good experiments. Instead, we argue that there are no transcendent criteria for good experiments: surprise does not attempt to bypass this uncertainty but instead insists that criteria are inherently *immanent* and cannot be picked a priori to guarantee outcomes. If the setting is conceived as a site of emergence (that is, as a place where rats [baboons, people with diabetes, etc.] acquire entirely new competencies) it is impossible to attempt to define once and for all the universal criteria of good experiments. This does not mean that there is no 'good' but that each experiment proposes a new definition of what good might be.... Attempting to fix the essence of a creature is the opposite of a good experiment where the point is to transform just what this creature is capable of. Nailing down essence (determining who or what one is, once and for all) is a sin we would not dare to commit." (Gomart & Hajer 2002: 10-11)

[48] A year ago I watched a documentary on the Discovery Channel that told the story about a lioness on the Serengeti savannah that had taken in and was fostering a pronghorn calf. The lioness defended the calf against the other lions of the flock and treated it like her cub. Regardless of the fact that this is obviously not normal lion behavior and the example to say the least minimal, it is nonetheless an inherently interesting and fascinating event. Such events, although rare, constitute 'invitations' to transform our understanding of the lion by disturbing and disrupting the general understanding of the lion as a notorious predator. The lioness adds to the categorical notion of the lion a potentiality of the lion as able to engage in a transgenic affectionate relation with its preferred prey. The lion as a whole is thus by the minimal, singular event transformed. All lions and with them the world undergo through this event a *becoming* and a transformation.

[49] The practicalities of the experiment and my fieldwork are described last in this chapter.

[50] Onetouch is described in chap. 3

[51] Consult the product webside at www.lifescan.com and chp. 3 (op.cit)

seem predisposed to be supportive of such an inclination. But this also means that attempts to design devices for chronic disease management not only reproduce and feed into this understanding of the need for aid and people with chronic disease as in a state of lack, but also establish a specific setting. I hypothesize on the basis of my experience from the diet diary evaluation that this is a setting that similar to the setting where the researcher observing the sheep (unwittingly) affected what matters to sheep (researcher = no predators -> different sheep behavior), where people with chronic diseases will confirm the need for such devices and contribute to their design although when left to their own devices other concerns might be more pertinent. Hence, inspired by Rowell's extra-bowl-of-food experiment, my intention with the experiment was to provide the participants *the opportunity* to become *affected* by Onetouch and either realize it as meaningful in one way or another or render it irrelevant. In contrast in e.g. a design process they would be delegated the role of contributing to the design of such technologies, which they would be inherently predisposed to contribute positively to, as argued above. A participatory design process involving people with chronic disease in the design of technologies for their benefit would thus not provide the participants much opportunity to act differently than appreciatively and affirmatively.

It constitutes an important difference to provide participants with an opportunity to discard technologies like Onetouch or to enroll them in the design of such devices. The latter thrive on the obvious inclination people have to be affirmative of such initiatives while the former works to enable them to *practice* their condition in relation to a device intended to aid them. Accordingly, the experiment is inherently anti-essentialist since it does not presume that people are rational, unified subjects with essential qualities, needs and desires. Obviously everybody wants to live long and healthy and will act and respond accordingly when approached in this manner. However in practice the will and wish to live long and healthy is negotiated and translated in multiple ways. The *practiced* subject is thus more adequately a highly relational and multiple subject (Star 1991, Markussen 1996) and the rational subject a product of specific relations and settings. By offering the participants Onetouch I attempted to create a situation that enabled them to be situated in a manner where this relationism would be played out. Where they would be practiced subjects instead of ideal subjects naturally inclined to support initiatives that attempt to make their lives easier and better. The latter being the subject summoned in a design session.

But the experiment was not only anti-essentialist with regards to subjects as relational multiple actors, it was also anti-essentialist when it comes to Onetouch. The experiment was just as much about how would Onetouch be enacted in practice, how it would affect the participants and *become* during the experiment. This interest is one that avoids both the optimistic and pessimistic versions of technological determinism since it does not assume that devices as Onetouch are per se relevant but nor that they are futile or alienating and harmful.

In short the experiment was an attempt to study the performative aspect of how the participants might *become* through the introduction of Onetouch; what Onetouch might *do* to/for the participants that enabled them to elicit behavior that enabled me to reflect on the problem of diabetes.

The materiality of knowledge production

An extra bowl of food, a chronic disease management device, these are material artifacts used as *propositions*, that is, as something intended to make a difference to those they are offered to that enable us in return to produce knowledge.[52] Hence, a change in material set-up has the potential to affect living beings in a manner that enable them to become different and transform how we understand them.[53] As argued above this is an inherently anti-essentialist and performative way of studying a problem. In the words of the English anthropologist Marilyn Strathern in her characterization of the primary tool of anthropology, it is to "use relations to explore relations" (Strathern 2005: 7). Rowell's and my experiment foreground intervention as a means for producing knowledge. Consequently to study in this manner is also to insist on the relational aspect of being, that it matters how one is

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[52] Latour following Whitehead defines propositions as "*offers* made by an entity to relate to another under a certain perspective." (Latour 2000: 372)

[53] The concept of the quasi-object coined by the French philosopher Michel Serres is pertinent for this understanding: "Our relationships, social bonds, would be airy as clouds were there only contracts between subjects. In fact, the object, specific to the Hominidae, stabilizes our relationships; it slows down the time of our revolutions. For the unstable bands of baboons, social changes are flaring up every minute.... The object, for us, makes our history slow." Serres 1995b: 87. The quasi-object thus designates the intimacy and co-constituency of subjects and objects; the thingness of subjects and the sociality of things. See also Brown 2002.

situated, what is offered to you in for how and what you are. In this sense my experiment connects with and prolongs anti-essentialist performative understandings as exemplified with Haraways cyborg figure, Pickerings mangle of practice and actor-network theory. These posthuman understandings all regard the relation as preceding the related entities.

The experiment is thus also a way of relating to and employing those understandings from posthuman STS. With its emphasis on relation and practice the experiment actualizes these central tenets of posthuman STS. These understandings are thereby themselves devices since they stress that actors are relational and performative conglomerates. This meant that the experiment was not simply a matter of an intervention and then an observation of what happens, which would still reiterate a representationalist disposition. No, *the experiment functioned as a relational, performative set-up that instituted and reiterated a relational, performative disposition.* The experiment was thus about consistently trying to see diabetes as a relational practice as a matter of anti-essentialist enactment. In this sense the introduction of Onetouch served as a material practice that invigorated and actualized other performative relational repertoires as devices for my analysis. Just as Rowell's understanding of the sheep as able to be more than boring sheep is an ingredient in her way of studying them, so was my preference for central posthuman understandings an ingredient in my way of analyzing and studying diabetes. I have argued that research in a performative light entails devices, real material entities as in Rowell's case instruments and apparatuses in the laboratory, as well as concepts, understandings, theories in science disciplines in general. They are means by which we can inquire. They are questions asked, and thus responses are inextricably tied to the question. But they are not means of *uncovering*, but of *enacting.*[54]

In the remainder of this chapter I will consider two scholars and their work and concepts, which are specifically central to research in relation to diseases and treatment. They are Annemarie Mol and her concept of *praxiography* and Charis Cussins Thompson and her concept of *ontological choreography.*

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[54] Again the alternative to pre-existence is not 'made up' by science, this is simply an inversion. The intricacy of a posthuman disposition is to avoid thinking in terms of the object as *either* fully fledged before we encounter it, or entirely constructed by our encounter (Latour 1999, Barad 2007, Gomart 2002, Gomart & Hennion 1999).

Praxiography and multiple ontologies

Actions can be detected and accounted for, whereas the laws behind actions can only be presumed as the causes of actions. Annemarie Mol designates praxiography as the study of actions delivered from the assumption of a principle, law or motive behind the action. Instead Mol argue practices should be foregrounded and should not simply be considered as secondary to motives or laws that presumably causes them. Practices are instead inherently productive and performative, they make objects instead of simply manipulate them. Mol designates this disposition empirical philosophy:

> "It is possible to refrain from understanding objects as the central points of focus of different people's perspectives. It is possible to understand them instead as things manipulated in practices. If we do this – if instead of bracketing the practices in which objects are handled we foreground them – this has far-reaching effects. Reality multiplies…Attending to the multiplicity of reality opens up the possibility of studying this remarkable achievement". (Mol 2002: 4-5)

But although reality multiplies, as is evident in Mol's work on the many different ways the object atherosclerosis is enacted in a Dutch hospital, this multiplicity does not lead to the fragmentation of the object and reality. Reality persists; it is not destroyed by multiplicity. In fact it tends to thrive on it. Different actions, doings and practices are manifest everywhere; in turn, the object is multiple.

Mol rejects the common way of thinking that there are different *perspectives* on atherosclerosis, an understanding that preserves the idea that the *object* atherosclerosis essentially is one and singular. Mol wishes to do away with perspectivism, since it is counterproductive in relation to developing normative arguments on treatment and hospital care. Perspectivism allows for the preservation of a well-established dichotomy between the "object as it is" and "how we experience it", a dichotomy expressed in healthcare as residing between medical science and treatment and medical sociology and the patient. Perspectivism thus allows for two registers to be perpetually reproduced and separated. Two registers, a 'natural science' and a 'social science' that both basically subscribe to the same dichotomous understanding between how things objectively *are*, and how they are subjectively *experienced*.

With praxiography a multiple world replaces multiple perspectives on one world. This may not seem to hold any significant difference. However, the crucial difference is that practices, however mundane, of how we engage with things are now 'unbracketed' and have become consequential. They make the object elicit specific properties. If we accept this condition it compels us to consider what practices can be argued for as better than others. On the contrary, we are not equally compelled with an ontology that insists on the singularity of the object and a multiplicity of perspectives. Then we are left in a situation where we may argue infinitely about the best perspective of the thing and hope that at some point the object will speak unequivocally and all perspectives will be silenced.

Mol's praxiography is central to my research because it has enabled me to consider and analyze diabetes practices as performative enactments of diabetes, as ways of doing diabetes that are consequential for diabetes, the treatment and the person with diabetes.

Ontological choreography

Charis Thompson Cussins has proposed the concept *ontological choreography* as epitomizing how objectifying practices and technologies of patients in medicine may, in contrast to humanist critique of those practices as alienating, produce specific situated agencies:

> "[O]bjectification is only sometimes a reductive state in opposition to the presence or goals of a subject. In the various non-reductive manifestations of objectification, patients can manifest agency (and so enact their subjectivity) *through* objectification." (Cussins 1996: 575-6 my italics)

Cussins' work epitomizes a posthuman understanding that explicates "the "dependence of selves on technology" (Ibid. 577). However, not in traditional liberal version of technologies as instruments for and utilized by, the autonomous self. Instead "[t]he components of subject position and the power of technologies in this site are negotiated in a heavily constrained manner, together." (Ibid. 579) The subject is thoroughly entangled with technology. Technology, in Cussins' case those of infertility clinics, enables people to become subjects with agency.

Agency, as Pickering also argues emerges through interactions with medical technologies in infertility clinics. Ontological choreography is premised by the understanding: "of the multiplicity of selves - the different kinds of faces or personae or social roles we routinely switch among as we go about our daily lives – [that] has opened up the possibilities of meaningful conceptions of the self that are not tied to the essential unity of the self." (Ibid. 578).

Ontological choreography thus designates the active formation of objects and subjects in practice. An understanding that is central to my study, since it constitutes a way of thinking about how the subjectivities of people with diabetes are produced through interaction with technologies such as Onetouch and diabetes. And in return how diabetes becomes enacted and realized through these interactions.

In my research my devices have been Onetouch and posthuman ontologies. They are devices generous enough to allow us to consider the mutual formation of diabetes subjectivities and diabetes through interaction. Moreover, they are sensitivity generating since they do not restrain us to think in essentialist categories about the status of either the subject or the object, and therefore the slightest detail, a specific concrete practice, a particular understanding of diabetes, a specific measurement device may, as we shall see, constitute an actor, since it has formative effects for other actors.

I will now present my fieldwork practices that have enabled the writing of the stories to follow in the next part of the dissertation.

The field work and experiment

My empirical fieldwork is comprised of several activities that referred to two interrelated research concerns. The first was with implementation and use of a locally developed Diabetes Electronic Patient Record application, named Diabetes EPR. The second was with the practices of managing diabetes by persons with diabetes. This has turned out to involve four types of fieldwork activities: 1) observation of clinical practice using the Diabetes EPR, 2) participation in the diabetes school, 3) participation in the Diabetes EPR implementation group meetings and 4) the experiment of introducing Onetouch to a group of people with diabetes.

The timeline

When beginning my doctoral research as part of the Healthcare IT (HIT) research program in March 2004, my research interest was already with diabetes practices i.e. treatment and technologies for diabetes care and managing and living with diabetes.[55] So almost immediately I came in contact with JM, head diabetes physician at the Island Outpatient through a contact of my supervisor. In spring 2004 I began to observe the clinical practice at the outpatient clinical focusing on the practice of using the Diabetes EPR application used and developed (partially) at the clinic. I observed the clinical practice for 12 days, approximately 60 hours in the period from spring 2004 until spring 2006. During summer 2004 I participated in three out of five diabetes school sessions, and together with my primary supervisor, associate professor Keld Bødker, I participated in the meetings of a group of healthcare practitioners from the five diabetes outpatient clinics in the Copenhagen region from fall 2004 to spring 2006. Last, I initiated my main empirical work, the experiment introducing Onetouch to eight persons with type 2 diabetes in fall 2005 and followed their use practice closely for 4 months from October 2005 to January 2006.

Observations of clinical practice

I observed the clinical practice by sitting in the examination room approximately two meters from the table where the healthcare practitioner and the patient would sit. Mostly the patient would sit by the end of the table facing the healthcare practitioner who would sit by the long side of the table sometimes keying information in on the computer. This arrangement allowed the patient, the healthcare practitioner and I to look at the screen. The clinical work of the diabetes team at the Island outpatient clinic is sometimes organized, so that the patient is seeing both the physician and the nurse, when this was the case then I would follow the patient form one examining room to another. I recorded these sessions by taking notes. My focus was on the interaction between the patients, the healthcare practitioner and how the Diabetes EPR affected the interaction. Moreover, since I followed the patient I was able to consider the differences and redundancies between the examinations conducted by the physicians and the nurse. In my notes I recorded the clinical data that was elicited during the

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[55] See my motivation in the Introduction

examination and events, comments or phrases that I thought odd. Moreover my focus was on how diabetes was articulated and negotiated in the clinical practice.

Participation in the Diabetes school

The Diabetes school is an educational program offered to people with diabetes by most diabetes outpatient clinics in Denmark. At the diabetes school a group of people with diabetes is gathered. The participants are invited to bring their spouses or close relatives. The teachers are the various healthcare practitioners, nurses, physicians, dieticians etc. working at the clinic. The participants are informed about a whole range of diabetes relevant aspects such as, the physiological aspects of diabetes, the symptoms, the complications potentially following from diabetes, how to live healthier with the condition, how and what to eat, how to prepare oneself when going on vacation, insurance issues etc. Participation in the diabetes school provided knowledge about diabetes. But it also provided an understanding of diabetes as involving multiple concerns and practices. Besides being a site for enacting diabetes, the diabetes school thus also constitutes a site for affecting people with diabetes. When participating in the diabetes school I also took notes. Besides recording what was taught I attempted to capture the interactions between the healthcare practitioners and the participants, which often could be described as negotiations over the responsibilities of the treatment of diabetes.

Participation in the Diabetes EPR implementation group

This group consisted of head physicians, physicians and nurses that worked to further develop and implement the Diabetes EPR system to all of the five clinics in the Copenhagen region. We participated in these meetings mainly as observers interested in following the implementation process of small and locally developed IT systems, but we also attempted to advise and assist the group in ways we felt qualified to.[56] We participated in these approximately monthly meetings for app. 18 months from fall 2004 to spring 2006. In addition to participating in these

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[56] For a description of the Diabetes EPR project and history considered as a process of association and translation and consequently for the diffusion of technology as a matter of interesting others, see Danholt & Bødker 2005

meeting, we also visited four out of the five clinics and interviewed the members of the group working at the particular clinic about their experiences with the system and the implementation process.

The experiment with Onetouch

HN, the diabetes nurse at the Island outpatient clinic that I have collaborated closely with during my research informed me in the summer 2005 about Onetouch, which had just been marketed at that time. I became immediately interested in the device since it resembled the Diet Diary idea as an information and decision support system.[57] I decided to conduct an experiment that introduced Onetouch to a group of people with diabetes in order to see how Onetouch would be received. I formulated a research protocol that was approved of by the ethical committee and a layman's description of the experiment.[58] JM and HN carefully commented and assisted me in this process. I also contacted the Danish branch of Lifescan that manufactures Onetouch and presented my idea of the experiment to the chief of sales, who was willing to sponsor the experiment with apparatuses, lancets and some strips. Lifescan although demanded that the main part of the participants were insulin dependent, since their strips are reimbursed by public health insurance.

The inclusion criteria for the participants were that they had type 2 diabetes since diabetes type 2 is the most widespread type of diabetes and tends to be 'silent' which makes living with and treating the condition for the person with type 2 diabetes an intricate and difficult matter, and that the main part of the participants was insulin-dependent. Moreover, we, HN and I, considered it preferable that there was an equal gender distribution. HN recruited the participants in her clinical practice, which concretely meant that she would ask her visiting patients whether they would participate. Initially, we had hoped for 10-12 participants but we ended up with eight. When the patients recruited by HN had consented to participate I contacted them and we arranged for a first meeting at the clinic.

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[57] See the Introduction, Danholt 2002a, 2002b, 2005a, 2005b.

[58] See appendices A and B

The participants

The eight participants included were 4 females and 4 males between the age of 36 and 78. Time from diagnosis spanned from 6 months to 23 years. I met with and conducted 3-5 informal semi-structured interviews with each of the participants during a four-month period from October 2005 to January 2006. It amounted to 32 interviews that lasted between 30 and 100 minutes and two observations and recordings of two of the participant's visits to the nurse HN. For all but one participant, the first interview was conducted at the Island outpatient clinic and the rest were conducted in the homes of the participants. The last participant preferred to conduct all the interviews at the Island outpatient clinic.

The meetings

The meetings with the participants consisted in semi-structured open-ended qualitative interviews that I prefer to consider simply as conversations. The first meeting was set up at the Island outpatient clinic and was organized so that first the nurse HN would introduce Onetouch to the participants as a blood sugar measurement apparatus in accordance with medical conduct. This would take approximately five minutes. All of the participants were already acquainted with measuring their blood sugar so this constituted a formality. Then HN would leave and then I introduced the further functionality and features of Onetouch. This would take between 30 and 40 minutes. During this walk-through it was my concern that the participants themselves tried out the various operations and features. Last, I conducted the most formal interview of the experiment in which I among other things asked the participants to describe what they did yesterday and how diabetes was part of this day , their diabetes history, their tools and arrangements, problems etc.[59] This part of the meeting took approximately 35-45 minutes.

The following two to four meetings took place in the homes of the participants. I visited each participant once every two to three weeks during the fall and winter. After having small talked for a while I always opened our conversation by asking: "How things were going with Onetouch?" which led to a conversation about the use of Onetouch, but inevitably issues around the participants practices and understandings of diabetes emerged. For each meeting I

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[59] See the interview guide in Appendix C.

had prepared a few questions that either followed up on some of the issues we had touched upon during our last conversation or a general concern I had developed through the various interviews that I then posed to every participant. These questions were for instance: "How does one manage the intricacy between establishing diabetes routines in the face of the ongoing changes that also follow from diabetes?" Or "Describe what it is like to visit the diabetes physician or nurse at the outpatient clinic?" I had also prepared one question for each round of meetings that was about the experiment and research in general. For instance: "Why did you decide to participate in the experiment?" or "What do you consider to be relevant subjects to be researched in relation to diabetes" or "What do you think you have gained from participating in this study, if anything?"

Analysis

The recorded interviews were fully transcribed, partially transcribed or logged. During the transcription process comments and thoughts were added to the transcript document.[60] Provided a posthuman disposition and my interest in accounts that did not simply confirm the general problem of suffering from diabetes, I worked to identify a logic, incidence, action, understanding, practice as a particular way of doing and enacting diabetes, that is as consequential for how diabetes and the person with diabetes became ontologically choreographed. This also implied that I considered these practices without subscribing to a dichotomous understanding between a subjective experience of diabetes and the objective concrete condition, or between a concrete material practice of managing diabetes and a way of talking about or understanding diabetes. The many interviews served, not so much as a vast resource to be analyzed and scrutinized, but were rather a product of an investigation practice that attempted to become attentive and sensitive to the participants practices.

The data recorded with Onetouch by the participants was downloaded to my computer.[61] The interview transcripts and the Onetouch data together constituted the background for writing up "practice reports" about each of the

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[60] See the interview transcriptions in Appendix E

[61] See Appendix H for an example of the data and how it may be visualized by the use of Onetouch and the software provided for the device.

participants. In these reports, I described the participants' use practices of Onetouch and their diabetes practices. These reports constituted a working paper for me, a feedback to the participants and an object for discussion. Each participant received his or her individual report and I then spoke with him or her to receive their comments on their reports.[62] We also held a workshop in the spring 2006 at the Island outpatient clinic in which six of the eight participants participated together with diabetes nurse HN and head physician JM. At the workshop I presented some of my general findings and the notion of diabetes as practice, which was then commented on and discussed. The reports served as background for the stories presented in the dissertation.

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[62] The "Practice reports" (in danish) is presented in Appendix F

Particularizing the Problem of Diabetes

Chapter 3:

An agonistic relation

In this initial chapter of the second part of the dissertation I consider what Onetouch did to the experiment. How it enacted and enabled specific interactions and concerns, and how this relates to some of the points made in the first part. Moreover, I introduce Onetouch and diabetes. Accordingly, this chapter serves as an introduction to the six stories from the fieldwork that follow.

Complaints

> When I met with the participants the first time after our initial meeting and the introduction of Onetouch, I was generally met with complaints about various problems of using Onetouch. These complaints can roughly be rubricated in three ways. Complaints that adhered to: 1) being unable to carry out a task one wished to using Onetouch, 2) considering Onetouch to be inadequate, 3) feeling unable or reluctant to carry out tasks implied by Onetouch. Each of these is exemplified below:"I wanted to delete all the entries we had made at the clinic [at the initial meeting and introduction of Onetouch] since they were not accurate in any way. I found that very, very difficult. When at last after several hours of deleting, then I wanted to start on a Sunday and then (she looks in the handwritten notes she had made): "no ability to make entries" (Bente 70 years) [63]
>
> "I am probably not using all of its features [Onetouch] because I think it has certain limitations. Take for example the feature: "illness" there are only a few options and then "Other". I would like if it was like a cell phone where you have a small keyboard so that you could write specific comments. I think that would be swell." (Doris 55 years)[64]

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[63] Appendix E, Bente: 2, Interview, time: 00.00)

[64] Appendix E, Doris, Interview, time: 2, 00.00

> "There is one thing that is very difficult with this thing and that is the matter of the food. I mean, I don't have the slightest idea how many carbohydrates my meal includes. You have to guess and whether it is correct or not, you do not have the faintest idea. (Bernd 67 years)"[65]

During the meetings I had with each of the participants we spent much time talking about the device. We consulted the manual and went through the various functions of the device. During our meetings Onetouch was the center of attention. We considered problems of using the device: what it could and could not do, and how one was supposed to use the device and the problems that followed from this. The above complaints I consider as resistances through which, not only the use of the device, but also the research set-up, were negotiated.

Negotiating use – negotiating the experiment

So when the participants found it impossible to record food in terms of carbohydrates, fat, protein and calories, as all of them did, they asked me if they were supposed to do this. I replied that they should not if they were unable to, but that they might enter when they knew. Or I suggested that they used the food entry as an indicator when e.g. they had eaten something worth noticing and remembering. Similarly, when they argued that they did not see the purpose in recording their medication or insulin doses every single day, since it was a consistent number of pills or units of insulin they were taking, then we agreed on an opposite strategy of only recording things out of the ordinary. During such negotiations I repeated that my interest was in how they could (or could not) use Onetouch and not that they used it in a specific consistent way. What were at stake in these negotiations were questions of accountability (Garfinkel 1967, Markussen 2007) "What did I expect of them?" "What were they supposed to do?" "How could they explain and excuse what might be understood by me as failure on their part to comply with the experiment?"

These concerns are inextricably entwined with my research set-up. I told the participants that it was not required that they used Onetouch in a specific way designated by me, but that my main interest was in how they could come to use

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[65] Appendix E, Bernd Interview 2. time: 4.22)

the device. So, the task was weakly defined as: "*try* to use Onetouch as you can and see fit." In retrospect whether this is a good set-up can be discussed, since it might be considered as an attempt to deliver little constraints on the participants, overlooking, however, that they inevitably become preoccupied with figuring out what might be the purpose of such a loosely defined task. They may be kept in the 'unknown' with regards to "What is this research project about?", "What is it going to amount to, and what are my contributions going to be used for?"

However, this uncertainty was shared among us, since my hopes were uncertain and unknown as well. I hoped that novelties would emerge unexpected by me. I hoped that the experiment would show me something interesting. Something that enabled me to think about diabetes practices in novel ways. So in that sense both the participants and I were in the "unknown". But, moreover, with this vague set-up that did not e.g. state that the experiment was about mapping the participants actions, or evaluating how they managed their condition or the like, Onetouch was able simply to be 'uninteresting' to the participants instead of being a device through which they provided a testimony. If Onetouch was used as a device for representing their practice, it would have created a situation where the experiment would have predisposed them to use Onetouch. Instead they were offered the opportunity of letting it be, and some of the participants did leave Onetouch mostly untouched.

Agonism

So, these negotiations over the use of Onetouch cannot but tie my initial concerns and intentions together with how the participants came to use the device, and in return how I came to analyze and discuss their practices. From a seemingly trivial aspect of complaints about how to use Onetouch, multiple concerns and consequences are produced. Consequences that can be considered as impeding the experiment with various biases and inadequacies, but which from a performative posthuman ontology are not only inevitable, but also productive.[66] These consequences are productive since they testify about what *matters* for those involved: through the introduction of Onetouch, and consequently the emergence

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[66] Similarly to the argument made by Despret in Chapter 2 concerning Rowell's research on sheep

of these various complaints, a specific relation was achieved - an *agonistic relation*. We came to argue about Onetouch, and Onetouch was thus able to arouse interest, in the sense provided by Stengers.

These various complaints or resistances related to the difficulty of adapting to new technology, the inadequacies of technology, and a matter of transforming technology for one's purposes. They map onto prevalent concerns in design and development of technology and relate to user-friendliness and designing accessible, yet sophisticated technology; they are about the 'clumsiness' and opacity of technology, and they are about configuring technology and use. Now, one way of addressing this would have been to consider the various types of resistances as concrete proposals for re-design of Onetouch. But my posthuman disposition prevents me from treating them as such, since this would entail a modernist humanist stance where technology is attributed the role as inanimate matter that ideally can and should be designed for specific purposes. My concern was exactly not to consider these statements as representational assessments of the technology, but as performative actions, and thus ways of doing and realizing a specific situation and enacting objects and subjects *in situ*. Consequently, I considered these resistances as performative actions of the subjects. I resisted an ontology where the complaints of the participants were solely about the object Onetouch, and in contrast I considered these complaints as configuring a relation and thus as a world-building practice. The participants' complaints were thus following a performative understanding, *ways of acting as a subject assessing a technology*. Their accounts were considered as both referring to and enacting an object and a subject.[67]

The different complaints exhibited various forms of skepticism towards technology that could have been treated as a resource for human centered design. But to treat them like this would have been to conceive of the participants as unaffected of participating in a study where their statements might be interpreted as indicative of how they manage their condition. Their complaints were thus not (merely) treated as referring to an artifact and accounting for their practice and a potential resource for re-design. Their complaints were, in contrast, considered as themselves requiring explanation.

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[67] Since a posthuman disposition is never about looking solely at one pole of the subject-object relation, but about looking at the relation, at quasi-objects and quasi-subjects.

Consequently, I became attentive to their objections and resistances towards Onetouch as focal points of consideration in need of explanation. In practice this resulted in a situation where I attempted to have the participants further explain and ground their complaints, and more importantly I came to speak in favor of Onetouch, defending the technology. I came to defend the technology and to speak in terms, not of how it ought to be, how it could be improved, but instead of how one could make sense of Onetouch and its design, how it might become useful, what it might do if one submitted to its script (Akrich 1992).

So, an inherently different situation emerged than one where the designer/ethnographer/researcher "sides with" the participants and the two parties are allied in a shared concern with realizing a well-functioning technological system. Also, it was a different situation than where the designer is interested in the participants' experience as a resource for design and where consensus and equality is considered central virtues. What was established in my experiment was an agonistic relation rather than one of collaborating towards a (seemingly) shared goal. This is due to my posthuman disposition and its preference for seeing the participants' complaints as performative acts of making both subject and object positions. The following excerpts exemplifies this agonistic relation:

> Bente: But if you want to record something you eat how do you know anything about…. [with regards to amount of carbohydrates, fat, protein and calories]. I mean honestly?
>
> Peter: You are absolutely right because you don't.
>
> Bente: You don't have a clue!
>
> Peter: Only a minority knows, and then you really have to be very dedicated and skilled…
>
> Bente: You have to calculate and make division. Yes you have.
>
> Peter: You are right, but it is also as we talked about [during the introduction of Onetouch]. When it comes down to food then it becomes a huge task.
>
> Bente: It is too much, too much..
>
> Peter: But the idea, I presume, of those that have manufactured this device is: "well if you do this [record food] and become able to figure out how to do it well, then maybe you become able to

see some patterns with regards to how one's blood sugar oscillates.

Bente: Yes, but I can do that without a device. If, for instance, I eat potatoes and carrots and a piece of meat I can see how it affects my blood sugar when I go to bed, in contrast to when I eat pasta. When I have pasta it is high. It isn't when I have potatoes… But the problem is how many carbohydrates do you have… Then you need to have a real pair of food scales and then you have to weigh the quantum and hope that you eat everything and then you have to calculate. It is a bit cumbersome. It is easier to pick up a notebook and write, ”I had pasta for dinner, and therefore my blood sugar is high. However, I sleep much better.”[68]

Peter: “So how is it going?”

Doris: “Well, fine, but I am probably not using all the features of it [Onetouch] because I think it has certain limitations. Take for example the feature ”illness”, there are only a few options and then ”Other”. I would like if it was like a cell phone where you have a small keyboard so that you could write specific comments. I think that would be swell.”

Peter: How have you used it otherwise? What have you gained from using it?

Doris: But I mean, I do not think that I have gotten so much out of using it other than measuring, because when I measure in the morning or at lunch I always have one leg out of the door, so I do not have the time for going into it thoroughly, and it is the same at lunch. So I haven't utilized its facilities… and it is also

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[68] Appendix E, Bente Interview 2, time: 00.25

the same thing in the evening. I have probably only used it as glucometer.

Peter: So you do not look at the diagrams?

Doris: No, not really

Peter: Does that mean not at all?

Doris: Yes (we laugh). I think it has to do with the fact that in order for me to adopt such things I need to have relatively lots of time. I sat down and read the manual and thought now I really ought to, but it doesn't really happen…

Peter: So you have not recorded anything either?[69]

Both of these excerpts offer material for concrete ideas for re-design. One might endeavor to develop a concept, an algorithm, a way of recording food more easily. Or one might supplement Onetouch with a keyboard. This would be of interest if one was preoccupied with design, but this would be predicated by understanding the participants' statements as being articulated by unified, autonomous subjects assessing artifacts, and not as performative acts of doing oneself as an active accountable subject. With a posthuman disposition one is unable to treat these complaints as either to refer solely to the object – Onetouch or to the person posing them. These statements are not univocal but express an uncertainty and refer to a relation.[70] Therefore, they came to function as *attractors* that called for further elaboration. Consequently, they had to be further tested and contested, and as a consequence I came to attribute to myself the role of trying to offer resistance to these complaints. So, through specific resistances, other resistances grew.

This agonistic relation, I argue, is constructive and in accordance with Stengers plea for science as interested and risky. In an agonistic relation one is interested in testing and challenging the others account and consequently in the

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[69] Appendix E , Doris interview 2, time: 00.00 to 04.05

[70] A posthuman disposition is thus sensitive of the multivocality of any statement. A given statement is never solely about what it refers to but as well about the position from where it is stated. Any statement is thus dubious and a source for uncertainty rather than clarity. But this is productive since by refusing to treat any statement as univocal and thus prone to miss out how and why the statement is uttered, one is incited to consider how the statement is related and conditioned. Deleuze 1986, Latour 2005.

last instance, in the other. This is a productive relation since, in principle, it may continue infinitely in questioning and "arguing" with the other. Through a practice of (con)testing the accounts of others, one thus becomes involved with the other, and thereby one is also at risk of being affected and transformed by the other, which is ideally an inherently constructive, affective and transformative process.[71]

We may consider the experiment as agonistic all the way down starting with Onetouch, which proposes a specific way of managing diabetes that is, or may be, resisted in specific ways by the participants whose complaints are then contested by me. My challenge to them becomes an occasion for the participants to further defend (or transform) their position, which again may lead to a further challenge by me, or a transformation of my understanding etc.[72]

Responses to a proposition

Although the agonistic relation seemingly emerged during the experiment as a product of our interactions and my posthuman disposition, the set-up of the experiment is inherently agonistic. The aim of the experiment was exactly to provide the participants the opportunity to articulate how and why they could *not*

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[71] Agonism constitutes a central concern in scholars like Ernesto Laclau and Chantal Mouffe's work (Mouffe 2005a, 2005b). Mouffe considers antagonism and 'the political' to pervade existence due to the relational aspect of identity and the irreducible differences of contemporary societies. Accordingly democracy cannot be captured in the universalist and rationalist terms of contemporary liberalism that seeks and hopes for an harmonious society. Instead democracy must furnish agonistic arenas. Agonism, rather than problematize conflict, considers conflicts as productive and is importantly about acknowledging and respecting those with whom one is opposed instead of considering them to be enemies to be silenced or destroyed. Isabelle Stengers work must be considered as in many ways premised by an appreciation of agonism. In contrast to agonism stands some of the humanist, pluralist strands of critical theory expressed by e.g. Jürgen Habermas that considers consensus to be achieved by surmounting individual differences and attempt to ground arguments on a rational ground free of domination. Humanist design approaches often draw on these latter contentions. See Lyytinen et al. 1988, Hirchheim & Klein 1989, 1994 and Henriksen 2003 for an analysis of Hirchheim & Klein 1989. Importantly a pluralist concern that seeks consensus not necessarily surmounts conflicts as it displaces them. See Markussen 1996, Howcroft & Wilson 2003a, 2003b.

[72] Another related point is that by defending a technological device one is also resisting a somewhat classical humanist critique of technology where technology is continually to be transgressed and renewed due to its many (from a contemporary standpoint) inadequacies. By defending technology we slow down this progressive movement and attempt instead to consider what does a given device do. In the words of Jensen & Lauritsen's (2005) "we read along" with the technology instead of "against it", and thereby give it due process to follow what it does (or may be able to do) rather than to embark on the task of criticizing and transgressing it.

use a device like Onetouch (or symmetrically how and why they could). This constitutes an inherently different starting point than, say, one with an interest in how a device should be designed for the participants to adopt and use it.[73]

The experiment did not position subjects as somebody invited to partake in constructing devices that could aid them, but as somebody whose responses and practice might contribute to the understanding of the problem of diabetes. For instance most of the participants at one point argued that diabetes should not consume and dominate their lives, but this was often uttered as an explanation for their lack of use of Onetouch. In contrast, without Onetouch as the centre of attention the same remark would easily have constituted an argument for devices such as Onetouch, where the device is construed as the answer to the problem. But when uttered within the set-up of my experiment, Onetouch was destabilized as "an answer to a problem", namely the treatment of diabetes and instead configured as "part of a problem" of living with diabetes. This testifies of the complexity of separating treatment and disease in diabetes practices, and is central to the configuration of relations among the interacting bodies in diabetes practices.

The stories that follow and constitute this second part of the dissertation can all be characterized as responses to a proposition, the proposition being Onetouch, or posed by me or by diabetes or treatment or... The stories constitute the participant's arguments for doing as they do. They are all resistances and as such actions. But before turning to the stories I will introduce Onetouch and diabetes in relation.

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[73] In user-centered design approaches such as PD and CSCW the concern is to accomplish a goal through a collaborative effort. However, despite all good intentions of user involvement and participation, the end point is uncertain. Whether and how the device will actually be used when fully developed cannot be predetermined by any methodology or the best intentions. These processes of designing and managing technologies have despite intense efforts in research and methodology *not* led to a situation where the design and implementation of technology is without complications (Henriksen 2003). In design, there is a preference for consensus and constructive participation. Challenge and resistance is easily construed as counterproductive, if not accompanied by constructive proposals; accordingly agonism is something to be overcome in order for consensus to be achieved.

Introducing Onetouch and diabetes

Onetouch® UltraSmart™ is a blood sugar measurement apparatus (or a glucometer) and a digital diabetes logbook produced by the company Lifescan. Lifescan is part of the Johnson & Johnson Corporation, one of the world's largest manufactures of healthcare products. A blood sugar measurement apparatus measures the blood sugar level in the blood. Depending on national treatment standards the blood sugar is measured in mmol/l or mg/dl. In Denmark it is measured in mmol/l. The blood sugar level is generally regarded as affected by three general factors: food, exercise and insulin. Food will generally increase the blood sugar level whereas exercise and insulin decrease it. Insulin is produced in the pancreas and the insulin production is stimulated by digestion. Insulin enables the glucose from the food and released into the blood to enter and be used by the cells.

For people diagnosed with diabetes mellitus the production of insulin or their ability to use insulin constitutes the problem. They are separated into two diagnostic categories. They are either having a dysfunctional pancreas that produces no or only little insulin (type 1 diabetes (T1DM)) or they have become insulin resistant (type 2 diabetes (T2DM)) which means that their cells are resistant to insulin as enabling the glucose to enter the cells or has a decreased sensibility to insulin. However, often the pancreas also becomes dysfunctional after a while for people with T2DM. In either case the diabetes condition results in glucose circulating in the blood and disposed of through urination. The symptoms of diabetes is frequent urination, thirst, weakness and fatigue, weight loss, dry and itchy skin, slow healing of bruises, blurred vision, dizziness, numbness and tingling in fingers, feet and legs, frequent infections.

When diagnosed with T1DM, one has to regulate one's blood sugar level by injecting insulin several times a day. In relation to T2DM, also often referred to as the 'silent condition', one may have only few and subtle symptoms, which means that the condition may be unnoticed for years. Treatment of T2DM often consists in lifestyle changes with regards to dieting and exercise and medication for increasing insulin sensitivity. However, approximately 50% of people with T2DM eventually end up in insulin therapy.

Insulin therapy has during the last decades been developed. Today, there are generally three types of insulin, long-acting, short-acting and mixed ones. The long-acting insulin acts for several hours and is typically injected in the morning or in the evening. The short-acting insulin only lasts for a short while but acts immediately. It is injected together with meals. And the mixed is a combination of both long-acting and short-acting insulin. Generally people with T2DM that becomes insulin dependent will start out with long–acting insulin therapy and then later on more fine-grained therapy may be introduced.

For people who do not suffer from diabetes the blood sugar level is between 3.5 and 7 mmol/l. For people with diabetes their blood sugar level may rise considerable above 7 up to 32 mmol/l (at least this constitutes the upper limit for Onetouch). When the blood sugar level is high it is named hyperglycemia. However, when in insulin therapy there is also the risk that the blood sugar may become critically low, since the insulin released in the blood is no longer regulated by the pancreas but by the person with diabetes. When the blood sugar is low one become hypoglycemic, which is highly unpleasant and dangerous. One becomes nauseous, legs and muscles tingling, one experience lack of control of speech and actions. Eventually one may blackout.

The complications that follow from diabetes are due to a high concentration of sugar in the blood over time. Among other things it leads to calcification and deterioration of the nerves in the extremities and in the eyes as well as damage to the kidneys. This means that people with diabetes are at risk of loosing their sight, sensibility in the extremities due to calcification and atherosclerosis. Consequently, they may be inflicted by gangrene and have resulting amputation. Generally, people with diabetes have an increased risk of cardiovascular diseases.

Treating diabetes correctly entails that one attempts to keep the blood sugar level close to the normal level between 3 and 7 (9) and prevent it from oscillating too much between high and low. In order to do this one should attempt to live healthy by avoiding too much sugar, carbohydrates and fat, exercise and try to regulate the blood sugar level. Self-monitoring of the blood sugar by the person with diabetes constitutes today an important aspect of diabetes treatment.

OneTouch® UltraSmart™

Onetouch was introduced on the Danish market in 2005. Onetouch is promoted as a tool for keeping track, overviewing and controlling one's diabetes condition. Here are some excerpts from Lifescan's websites:

> **"More Than Testing – Information to Help You Manage Your Diabetes**
> The new OneTouch® UltraSmart® Meter is the first combination meter and logbook that gives you an *easier way to understand* your blood glucose results. At the push of a button, you'll see and understand patterns and trends in your blood glucose tests. More than a meter, the OneTouch UltraSmart Meter gives you the option to track exercise, health, medication and food and see how they affect your diabetes. Whether you want to track everything, or just test, the OneTouch UltraSmart Meter gives you an easy way to stay on top of your diabetes."[74]
>
> **"OneTouch UltraSmart glucometer**
> From merely measuring your blood sugar to complete diabetes control. OneTouch UltraSmart glucometer allows you to keep an eye on more than just your blood sugar. You can overview your data in a more organized and comprehendible way than in a logbook, which makes it easier to see tendencies and then make decisions about your diabetes control program."[75]
>
> "In order to be able to control one's diabetes and thereby be successful in the long run, it is important to have knowledge about diabetes and more importantly be able to use this knowledge."[76]

As shown Onetouch is promoted as more than just a blood sugar measurement apparatus, and rather as an information and decision support system. Blood sugar measurement apparatuses have been available for personal usage since the eighties. Accompanying a regular blood sugar measurement apparatus is a logbook in which the person with diabetes can record and comment on their measurements. Typically, the commentaries made might be the blood sugar level, time of day,

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[74] This quote was taken from the lifescan.uk website in june 2006 but is no longer available there but at http://www.patient.co.uk/pharmacyproduct.asp?ID=FMOTUS1. Accessed nov. 2007)

[75] Excerpt from Lifescan's Danish website in June 2006. Unfortunately, no longer available on the internet. My translation.

[76] Equally an excerpt from Lifescan's Danish website in June 2006. Unfortunately, no longer available on the internet. My translation.

whether in immediate relation to a meal or exercise, maybe what one has eaten, bodily sensations etc. Onetouch integrates the blood sugar measurement apparatus and the logbook. Onetouch stores the blood sugar measurements and the memory can contain app. 3300 measurements. Onetouch is about the size of a small cell phone but weighs less.

Onetouch enables the user to attach diabetes relevant data to a blood sugar measurement, data that are stored and may be accessed in various ways. Data is represented through diverse diagrams on the screen of the device as well as through the PC software that can be downloaded without charge from Lifescan's website.[77] Onetouch as most other blood sugar measurement devices is sold cheaply and may often be acquired for free in market campaigns. However, the strips used for measuring the blood sugar cost around 8 dkr. (1€) a piece. One strip is needed for every blood sugar measurement. The strips are unique for the apparatus at least for the manufacturer's apparatus. The manufacturer's income is thus primarily based on the strips and the low price of the apparatus is related to and part of a sales strategy of creating customer dependency. In Denmark people who are in insulin therapy have their strips paid for by the Danish public health insurance.

The functionality and features of Onetouch

In addition to blood sugar measurements Onetouch enable registration of four types of information: exercise, food, health and medication. One makes a recording by pushing the button showing the appropriate symbol. The buttons are shown here:

From left to right they symbolize: exercise, health condition, Fast facts (access information about the data, which we will return to below), medication and food.

The user can make the recordings in the following ways.

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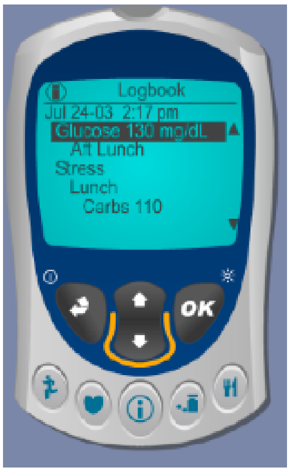
[77] One, although has to purchase a USB-minijack cable in order to connect Onetouch to a PC for app. 80 dkr. Or 10 €.

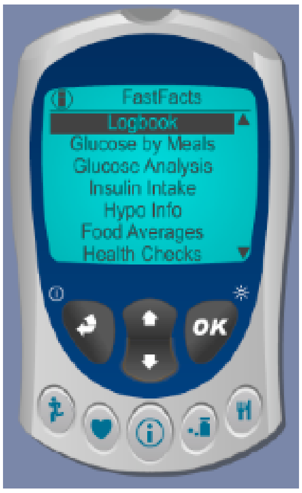
- Exercise is recorded by choosing between three categories: light, medium and hard and the amount of time exercising.
- Health is recorded by choosing between the following categories: stress, hypoglycemia, illness, menses, vacation and other
- Food is recorded in grams of carbohydrates, fat, proteins and calories.
- Medication is recorded by choosing from a list of the most common drugs and insulin types or by simply naming one's medication A, B, C etc.

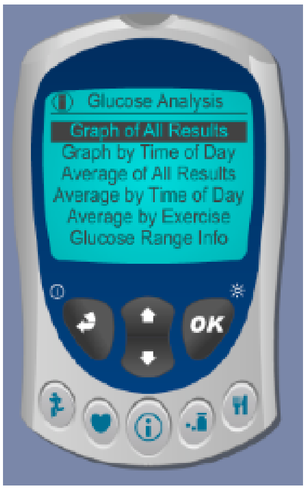
Every recording is provided a time stamp designated by the user so the recording can refer to another time than the present. These recordings stand alone as entries in a diary, but equally one can attach comments to a blood sugar measurement as shown below. The information added to the blood sugar measurement shown here is that the blood sugar is measured after lunch and the user is stressed and that the amount of carbohydrates in the lunch was 110.

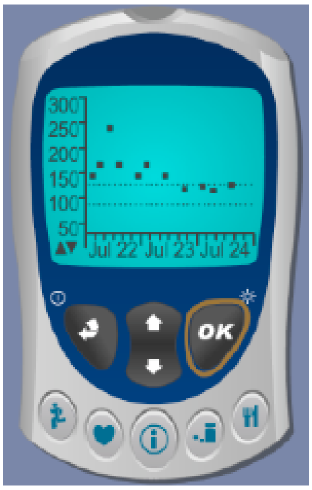


Logbook
Jul 24-03 2:17 pm
Glucose 130 mg/dL
At Lunch
Stress
Lunch
Carbs 110

The button at the center of the five buttons marked with an "I" is the "Fast Facts" button. The Fast Facts button enables the user to review her recordings in various ways. The first figure from the left shown below, shows the screen when we push "Fast Facts". We are thus able to review the logbook, which simply show the user's entries in chronological order with the last first. Or the user may review each diabetes parameter individually: blood sugar, insulin, food, health and exercise. These parameters are then represented in various ways, which will be much too extensive to elaborate fully here. It will suffice to provide one example of how the recordings may be represented. For instance the user might want to review "Glucose Analysis" (the third row). Highlighted and chosen by using the "OK" button would lead to the state illustrated in the figure in the middle below, that also exhibits a number of ways for the user to review her blood sugar. By clicking "OK" to the highlighted first row. All results would be represented in a graph in the manner shown in the third figure







These features exemplify Onetouch as a mobile information- and decision support system, but as mentioned data can be downloaded from Onetouch to a PC. Using software developed by Lifescan the user is able to review the recorded data on the larger screen of a computer and in more ways. [78]

The stories

The remainder of this second part of the dissertation consists in 6 stories. Each story is about one of the eight participants in the experiment. Two of the participants are not represented, not that their stories were not relevant, on the contrary. However, they expressed partially overlapping points to those made in some of the other stories, and, second, the two participants were only scarcely affected by the experiment in the sense that it did not seem to arouse much interest and resistance.[79]

The characteristics of the stories presented are that they illustrate the performative aspects of practicing diabetes. They show how the different participants actively participate in constructing diabetes and their identities. The stories exemplify ways of doing and enacting diabetes. The manner in which the

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[78] Examples of the various ways data can be represented through the use of the software developed for Onetouch is provided in Appendix H.

[79] Arguably this might constitute a good reason for including them; however, I have chosen not to since this seems mainly to contribute to methodological considerations and my aim here is now to consider diabetes practices in a manner that enables me to discuss and develop an understanding of the problem of diabetes.

participants practice diabetes is through their concrete practices, but also through how they refer to and understand diabetes and themselves as persons with diabetes. These practices emerge as responses to Onetouch or to the experiment in general. Practice in this understanding is thus defined posthumanistically, and is thus not adhering solely to a material realm; it is material-conceptual. Moreover, these stories are intertwined with my discussions and include diverse posthuman re-configurations of the problems that emerge. The stories and my posthuman discussions of them enable me to consider 'the problem of diabetes', which will be the subject of the third part of the dissertation. The stories can be read apart from each other and in random order.

Chapter 4:

Mastering his domain

When HN, the diabetes nurse at the Island outpatient clinic, was recruiting the participants for the field experiment she received a phone call from Bernd. Bernd has type 2 diabetes and is a patient in the clinic. Bernd is also head of the local diabetes community in the Island municipality, and an active member of the diabetes community in the Copenhagen region and a member of several diabetes committees and boards. He is also a diabetes instructor tutoring others with diabetes. Bernd had heard about my research at the local centre for the elderly and he would very much like to participate. Since the inclusion criteria for the study mainly consisted in the will to participate, Bernd was immediately included.

I am not an expert in diabetes, but it seemed obvious from the start that Bernd is very knowledgeable with regards to diabetes. He offered many insights to the intricacies and practicalities of diabetes and a life with diabetes. During our talks I sometimes presented him with a problem that one of the other participants had addressed to me. Bernd often offered several possible explanations and potential solutions to the specific problem. The first time I was visiting Bernd we ended up sitting by his computer where he showed me the software for Onetouch, which he had already acquired. He also showed me several other kinds of diabetes software he had purchased over the years.

By the end of our talks, Bernd asked me what I wanted him to do until next time, how I would like him to use Onetouch. I had not prepared ‘homework’ for any of the participants, but had considered it a possibility as a way to have them become more acquainted with and obligated by Onetouch. So, together we assigned ‘homework’ for him that was mainly about using Onetouch in ways that he was reluctant to. Continuously Bernd pushed me to obligate him. And Bernd mainly did his homework.[80] By the end of our second last meeting Bernd proclaimed that for our next meeting he would make an all day profile with Onetouch, which meant that he would measure his blood sugar five-six times in one day.

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[80] Tasks such as meticulous registration of food in terms of carbohydrates, fat, protein etc. were not put forth as homework.

I responded that this was fine and so he did. No task, in principle, seemed to constitute a problem for Bernd. Bernd seemed capable to lift the obligations of diabetes, to follow prescriptions and tasks asked of him and he was keen to show this. However, being able and capable does not necessarily mean that one actually lives in accordance with this expertise. Rather, as it turned out, being able and capable may also come to constitute what is possessed and acquired, but not necessarily what is continually practiced. An acquired skill that as such contributes in forming a confidence in what one potentially is able to do, but, and exactly therefore, not something one continually does. A confidence we may all experience in relation to skills acquired, knowledge formed, well rehearsed practices that ironically enable us to abstain from employing them or further developing or challenging them. Although being an expert in diabetes, Bernd, it seems, does not act in accordance with his expertise. How may we understand this, and what are the ramifications of appreciating the peculiarity of this?

HN, the diabetes nurse at the Island outpatient clinic, said without criticism, but with astonishment and wonder: "Consider Bernd. He knows so much about diabetes and takes part in so many diabetes related activities. And he can sit here and we can talk about how it ought to be and yet his numbers are not at all optimal, *he does not live in accordance with what he knows.*"[81]

Bernd is 67 years old and has had type 2 diabetes for 23 years. He was diagnosed in 1984 and, as most people with diabetes, by chance. He visited his GP due to elusive, trivial symptoms such as thirst, frequent urination and a fungal infection. On the very same day he was admitted to a small hospital in the Copenhagen region and hospitalized for three weeks. His condition was stabilized through medical treatment and diet, and together with the other patients he received diabetes education. Each patient was given a notebook where they would write down questions about diabetes and leave it on the bed table. The nurse on night watch would then pick up the notebooks, answer the questions and return them in the morning. Bernd recalls the stay at the hospital as a pleasant time. The other patients and he had a good time and received nice meals, but the problem, as he describes it, was that they were not experiencing a regular day-to-day life with diabetes. Learning to live with diabetes on a daily basis had to be acquired afterwards. Today Bernd has much experience of living with diabetes. Bernd is

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[81] Personal communication in between visiting patients during fieldwork.

treated with insulin. He injects long-acting insulin in the morning and evening and short-acting insulin with his meals.

An arrangement

Bernd has a box on the bookshelf behind his chair by the dinner table in which he keeps his medication (several products), insulin pens (two kinds), his blood sugar measurement device, the strips for the device, the lancing device for pricking for blood, the needles for the lancing device etc. This arrangement is a tidy one; it associates important objects. Not only is everything Bernd needs to treat his condition in the box, it is also located so that when he sits down by the table he is reminded to attend to his condition and e.g. inject the short-acting insulin that should be taken together with meals, or measure his blood sugar. So whenever he sits down by the table he is reminded to attend to his condition. This is a material arrangement that practically and concretely connects things. It relates food and diabetes and the various devices and medical technologies such as medication, insulin, the blood sugar measurement apparatus etc. This assemblage of chair, table, box, medication enables Bernd to attend to his condition in a specific place and at specific times and in a specific adequate manner. Bernd and this arrangement form a sociotechnical network that enables him to take care of the condition. He says: "I have the box right here, right. Everything is in this box. This and this – the two kinds of insulin and then I take some medicine. What I do is when I sit down by the table then I know that I have to take insulin."[82]

Obviously, Bernd does other things than sitting on his chair by the table. For example, three days a week he is at the local centre for the elderly together with other people with diabetes. The centre is located across the street from where he lives; he can walk there in less than a minute. He tells me that he rarely brings the blood sugar measurement device or his insulin with him, although he is at the centre for 6 hours, he says:

> "Sometimes when I am at the centre it happens I eat there because there is a cafeteria. I rarely eat anything but salad, but strangely enough I always forget to bring my insulin. It ought to just stick to me because then this would not happen, and when I come home I forget to inject it,

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[82] Appendix E, Bernd Interview 5, time: 36.20)

> and I do not measure my blood sugar, and then in the evening [when measuring] I can see: "Wups, there is something wrong here""[83]

As a consequence Bernd attempts to 'repair' his blood sugar, as he puts it, by using the short-acting insulin to bring his blood sugar level down to a normal level. But Bernd's 'repairs' are very likely to disturb the balance of his blood sugar level, which should be avoided in the long run. His 'repairs' disturb the order established through his insulin treatment. The balancing act of keeping the blood sugar level between 4 and 9 is disturbed considerably on these specific days. Obviously, we can consider Bernd's behavior as somewhat inconsistent: the days when he is at the local centre he disregards his diabetic condition. He *should* be measuring his blood sugar and he *should* inject his short-acting insulin while being there in order to prevent his blood sugar from oscillating. Deciding that Bernd's inconsistent behavior is irrational is not difficult; it is based on the obvious discrepancy between a concrete behavior and a correct behavior.

However, further consideration challenges this understanding of Bernd's behavior, since Bernd is quite experienced and knowledgeable - he even tutors others with diabetes. If he were ignorant then matters would be straightforward. But, the puzzling point is that we cannot characterize him as ignorant without ourselves being ignorant to the indicators that contradict this characterization of him. We are thus put in a perplexing situation: what to make of Bernd and his actions? Let us consider how Bernd speaks about his condition.

The active subject and diabetes as manageable

Here are some examples of how Bernd speaks about his condition:

> "I think of it [diabetes] as a friend I am carrying around on my back, a friend that I should stay good friends with all the time. But I am not occupied with thinking about the fact that I have diabetes – not at all"[84]

> "I do not think that the chronic disease I have incurred is difficult to handle because I have influence on it. There are other chronic diseases that you have no influence on. If ultimately one had to choose, it is not

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[83] Appendix E, Bernd Interview 5, time: 28.15).

[84] Appendix E, Bernd, Interview 1, time: 56.45

> the worst disease, although it is not something to cheer about. As Carsten Vagn Sørensen [physician featuring on the radio who also has diabetes] says: “It is the healthiest disease one can have” He has never been this healthy since he has had diabetes. That is probably true, but he is probably also living like this (he whistles and makes a straight line with a hand movement), but not all people with diabetes does that. I have much interaction with other people with diabetes because I am head of the local committee here. There you hear many horrific tales.”[85]

> “It does not bother me that I have to inject insulin. Sometimes people say: “Are you injecting insulin? Are you THAT sick?” Then I answer: “No, I am THAT healthy” because given that one can measure one’s blood sugar…. I only need to, when I am going places, always remember to bring along my insulin – well, I do not bring it here [the outpatient clinic]… But anyway, wouldn’t you like to have such a condition? It doesn’t sound hard, does it? [We are laughing]”[86]

> “So diabetes has brought me a lot of joy – I have experienced a lot”[87]

As these excerpts show Bernd cultivates a quite positive and optimistic understanding of diabetes. Although a chronic disease and therefore not something to “cheer about” he speaks about diabetes as something that has brought him “joy and experience”, something that is not difficult to handle, and as “a healthy disease.” Of course, he also speaks of diabetes as for some and sometimes “horrific”, and as “a friend one should stay good friends with”. Through these understandings Bernd practices diabetes, not primarily as a disease with the negative connotations following this, but as a positive constraint that has added to his life, rather than impoverished it. Diabetes is thus transformed from being distressing and something one suffers from that may cause complications such as blindness, kidney disease, atherosclerosis, gangrene, strokes, cardiac diseases etc., to being an opportunity to lead a healthier life through dieting, exercise and treatment. The conception is that one can lead a healthy life with diabetes, if only you live in accordance with ordinary health prescriptions favorable for most people to live by. This line of thought correlates with the concept of the active, empowered patient that participates actively in the treatment of his or her disease.

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[85] Appendix E, Bernd, Interview 1, time: 59.30

[86] Appendix E, Bernd, Interview 1, time: 1.11.40

[87] Appendix E , Bernd, Interview 1, time: 1.40.30

But from the excerpts above we are also able to recognize that to live as an autonomous, capable person with diabetes is not a *premise*, but an *outcome*. The active autonomous patient in control of his or her disease is conditioned in many ways. S/he has to maintain a healthy lifestyle, measure her/his blood sugar, exercise, take her/his medication, inject insulin (in the right amounts and at the right time) and so on, and *then* s/he may become in control of his or her condition. Autonomy is a result of, to put it in Actor-network theory terms, being enrolled in a network of human and non-human actors, such as technologies, medical science, procedures and practices that makes diabetes do-able. Autonomy is not detachment from things, but attachment to them (Gomart & Hennion 1999). Autonomy considered as such is thus not an individual quality but a well-functioning practice.[88]. To think in this manner about diabetes constitutes an example of ontological choreography, since it is through technologies, medical treatment and diagnosis, insulin, exercise, pens, lancets etc. that the subject with diabetes is realized as autonomous (Cussins 1996, Willems 2000, Struhkamp 2005). However, Bernd is also occupied in ontological choreography through his positive understandings of the condition he has incurred. To consider diabetes in a positive manner, as Bernd does, where the condition obliges him to lead a healthy life that brings him joy and experience is to enact himself as somebody who is not depressed or belittled by the condition, but up to the task. Bernd thus enacts himself as somebody who is anything but determined by the condition, but constitutes a productive challenge. Through this optimist appraisal of diabetes Bernd enacts himself as a confident, capable, resourceful person able to transform

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[88] Posthumanist STS is apt for understanding that living with diabetes relies on a whole range of devices, technologies, techniques and knowledge. Without the diagnosis established through e.g. blood- or urine tests, the person with diabetes would not be a diabetic, but simply ill. S/he would be poorly equipped for improving his or her condition, not knowing what it is, how it is caused etc. and would probably lose sight and limbs and die young. Technologies such as the blood sugar measurement device make diabetes 'doable' by ideally enabling people to contemplate relations between blood sugar levels and influencing factors such as food, exercise, medication etc., and thereby people can act accordingly. Insulin and insulin pens enable the person to inject insulin in the right dosages. Without these technologies the person with diabetes would be in a miserable state far from qualifying as autonomous, but rather simply determined by her/his illness. On this understanding see Mol 2000, 2002, Hennion & Gomart 1999. Considering autonomy as a result of and conditioned by other actors and materialties external to the human subject challenges prevalent traditional humanist understandings, and is therefore referred to as posthumanist. The modernist trick, as Latour phrase it, consists in 'forgetting' or 'diminishing' all these other actors' crucial importance for the human subject (Latour 1993). It will also constitute a central argument in the last chapters of the dissertation.

the potentially diminishing and depressing aspects of diabetes into a productive force. By celebrating diabetes he implicitly celebrates himself and evokes himself as a person who is enhanced by diabetes. However, the confidence that Bernd in this manner articulates may also have a downside to it, because he has become used to consider himself as in control of his condition, at least potentially. The box on the bookshelf epitomizes Bernd's diabetes practice as an arrangement that keeps things in order while also having instituted an order difficult to dismantle.

The box on the bookshelf

Bernds box on the bookshelf; his sociotechnical arrangement constitutes a place and a arrangement where Bernd is person in control of his diabetes.[89] Measuring blood sugar demands some sort of tranquility and composition, which is why a dinner table at home constitutes a good place to do this. You have to insert the needle into the lancing device, take out and insert the strip into the blood sugar measurement device, check that the device has registered the strip. Also, you need to have relatively clean hands when pricking for blood to avoid infections, and you have to have good circulation in your hands for blood to emerge (something that can be problematic for elderly people or if the hands are cold). Then you need to put a drop of blood onto the tiny end of the strip and wait for the result. Not exactly a procedure one would carry out anywhere or anytime.[90] Obviously, sitting by a table at home is a good place for measuring the blood sugar. The medication and the tools in Bernd's box are of great importance to his treatment, and displacing these things may mess up the treatment. Deciding on a specific place for keeping these things and establishing an order is quite sensible and is also recommended by healthcare practitioners when tutoring people with diabetes.[91]

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[89] Three out of four times when I visited Bernd, he sat on that specific chair, 'his chair' and I sat on the opposite side of the table. I have since then come to consider it as his 'command post' from where he controlled his condition. The one time we did not sit by the dinner table we were sitting on his balcony because his wife had a visiting friend and they were occupying the table.

[90] Mol and Law describe how a roadside worker found it difficult to be able to measure his blood sugar during his work day due to dirty hands and lack of places to conduct the procedure (Mol & Law 1999).

[91] When newly diagnosed, people's lives change dramatically and daily life has to be accommodated to the condition. Establishing routines around meals, medication, exercise etc. is of great importance in order to manage the condition in a prudent way.

So Bernd's arrangement is obviously appropriate; it enables him to take adequate care of his diabetic condition. Given that Bernd has accumulated more medication and insulin kinds as well as technologies over the years, having such an arrangement has not become less pertinent. Moreover, according to Bernd he often displaces stuff and, as he puts it, "can run around looking for his glasses for hours".

Of course, as anticipated in the introduction, there is a flipside to this arrangement. However successful the arrangement is in enabling Bernd to take adequate care of his condition when he is at home and sitting on his chair by the table, it also becomes strenuously instituted in Bernd's life and difficult to dismantle. Bernd seems prevented from attending to his condition just as well when going to the local centre for the elderly as when he is at home. Bernd does not bring things along, he tells me; he always seems to forget as he said in the excerpt above. He also stated when I first met him at the Island outpatient clinic: "I only need to, when I am going places, always remember to bring along my insulin – well, I do not bring it with me here [the outpatient clinic]"

But why does he not bring things along? There are two interrelated reasons; the first is that he would risk forgetting and dispersing things in various places, and thereby be in a constant risk of missing something when needing it *wherever* he may be, whether at home, at the centre or other. The second reason is that he feels confident that he does not need to bring it along, since he can 'repair' his condition later. This second reason will occupy us below, but first I will consider the first reason. Bernd's reluctance to dismantle his arrangement constitutes an example of the other produced by a given order. The well-functioning arrangement establishes and co-constitutes the absence of arrangement in other places because bringing things along would risk destroying the order established at home. In Bernd's case the work involved in being able to attend to his condition anywhere in the same manner as he does it at home is not trivial. So, simply to regard that what Bernd ought to do is to carry his insulin and blood sugar measurement device etc. with him across the street would be to overlook the intrinsic risk assessment in Bernd's behavior. It is not only a matter of transporting a specific behavior from one location to more locations as if this diffusion would be of no influence to well-functioning locations. Dismantling his arrangement at home bears the risk that Bernd will not be well regulated *anywhere,* not even at home. So, in this light Bernd's reluctance to dismantle his arrangement is immanently rational. Moreover, although we may at first consider Bernd's box on the shelf as a quite static arrangement, it is performatively reproduced by Bernd's continuous reluctance to dismantle and distribute it. The active care of the arrangement is equally what incites Bernd to establish a practice that does not require his arrangement to be dissolved. Caring for the arrangement co-constitutes his 'irrational' repairing practice.[92] The somewhat counterintuitive answer to why Bernd does not dissolve his arrangement is thus because he *is* experienced and knowledgeable.

Expertise and incompetence

> "I believe I had a fever at one time, had a flu and then you can feel bad, but I know that you should inject 25% more insulin per degree in fever which means that if you are two degrees above normal you should inject 50% more insulin than usual and that is of importance. But of course there are people who would be extremely anxious to do this: "Can it be right? Do I really need that much? Etc."[93]

> "Now, yesterday evening it (the blood sugar) was approximately 10-12 mmol/l and "OK" I say "I want it to drop to 5-6 in the morning" then I inject 3 or 4 units of short-acting insulin, because then the blood sugar will drop 2 mmol/l per unit and it is right on the spot."[94]

These excerpts exemplify Bernd's expertise. These rules of thumbs illustrate how Bernd envisions and practices his condition in a somewhat instrumental and causal-mechanistic way, e.g. when he is sick or when his blood sugar is high.[95] Bernd is not afraid to regulate his blood sugar during a fever with 50% more insulin than needed under normal circumstances contrary, as he says, to many other people

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[92] The understanding of ontological choereography is pertinent and similarly the term quasi-object offered by Michel Serres that express how the object makes the human actor circulate and move around the object, human agency as materially constituted. Obviously, this understanding stands in contrast to a modernist perception of the object as inert and manipulated by the human subject.

[93] Appendix E, Bernd, Interview 1 time: 1.16.12,

[94] Appendix E, Bernd, Interview 2 time: 12.30,

[95] Having a high blood sugar is not of immediate danger, but increases the risk for complications later on. On the other hand low blood sugar may cause seizures and have brain-damaging effects.

with diabetes who would be extremely reluctant to do this. Likewise, his 'repairing' strategy consists in injecting twice as many units of short-acting insulin for every mmol/l he wishes to have his blood sugar drop. The healthcare practitioners warn him against this repairing practice, since when he does this in the evening it may, together with the long-acting insulin that he injects regularly morning and evening, cause his blood sugar to drop critically during the night. Bernd knows that his physician disapproves of his strategy, and he knows and understands the reasons and logics of it. So why does he do it?

Bernd is without comparison the most experienced person in the study. He has had diabetes for the longest time, and he is the one with the most extensive insulin therapy. One of Bernd's friends, Anders, who also participated in the study, told me during one of our talks that if Bernd has eaten too much he simply injects more insulin. Also, Bernd often mentioned during our conversations that many people with diabetes are afraid to inject too much insulin and risk hypoglycemia. What Bernd dares with regard to the usage of insulin less experienced people with diabetes would be very reluctant to do. They would be reluctant due to the potential risks of injecting too much insulin, becoming hypoglycemic and potentially black-out. Bernd, however, has fully adopted insulin into his daily life as instrumental for regulating his condition. Having reached this stage of competence and a perception of diabetes as something he can regulate in a causal-mechanical way, it is not strange that he dares to use insulin in a manner that others, less experienced, would not; rather it seems to be quite understandable. It is similar to being a mountaineer or an extreme skier, who over the years has become skillful to such a degree that s/he dares go places and do things that others less skilled would not. To conceive of such people as mindless daredevils is to exercise little understanding and respect for the acquisition of skills and the passions it produces.[96]

Bernd's actions and his reluctance to dismantle his arrangement at home is thoroughly intertwined with his skills and his confidence in his ability to regulate his blood sugar level post hoc. Through my analysis Bernd's problem has become re-conceptualized from being that Bernd is somewhat irrational or unable to take adequate care of his condition to being that Bernd is skillful, competent and confident in his ability to control his condition that it results in 'incompetent'

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[96] I thank Andy Pickering for urging me to stress this point

actions. Considered as such we are positioned differently as to what may constitute a solution for this problem.

Expertise as heterogeneous practice and 'the ecology of diabetes'

Provided with the above re-conceptualization of Bernd's problem I argue that Bernd's expertise and his practice of trying to regulate his condition post hoc is premised by a reductionist understanding of diabetes. The problem is that Bernd's expertise seems to rely on a thoroughly modernist understanding of diabetes as an object to be manipulated by the person with diabetes. What Bernd seems to 'forget' when continually attempting to repair his blood sugar post hoc is that he interferes with an (ideally) carefully coordinated set of events that are related and positioned in time to follow each other. Injecting insulin in relation to meals and in the morning and night establish an order where meals have to be eaten and insulin injected, not necessarily at specific times a day, but on the other hand not simply skipped. Insulin therapy where one inject both short and long-acting diabetes leads to an orderly diabetes condition, but if the regime instituted by the insulin therapy is not followed and instead insulin is as a momentary instrument to regulate the condition, then the order is disturbed. So what Bernd fails to realize, overlooks or ignores is exactly that the reason he has become able to perceive of diabetes in a causal-mechanical way, is due to the order that he and his healthcare practitioners have established over the years. Diabetes as orderly and an object to be manipulated is thus a *product* of the ordering practices of the treatment, an *outcome* of an interventionist coordinating practice.

Bernd's expertise and ability to consider diabetes as an object to be manipulated that he can simply adjust post hoc is thus not *his* achievement alone, but a sociotechnical imbroglio's achievement. The ironic and interesting point is that Bernd both appreciates his arrangement at home while also failing to acknowledge and appreciate what it does, that it makes diabetes into something that he, hubristically, can treat as an object (ideally, potentially) under his control. He thus partly fails to recognize 'the ecology of diabetes' - as a network of practices and technologies that enables him to be and consider himself as a competent person with diabetes in control of his condition, which leaves room for his ‘incompetent’ or ‘negligent’ actions. The conclusive point is thus that with an increased sensitivity towards ‘the ecology of diabetes’, recognizing the effort of the non-human actors that make diabetes orderly would position him inherently differently with regards to his continuous experiments of adjusting his blood sugar post hoc. It would bring forth the constructed nature of diabetes as orderly and thus as something that requires care rather than something to be presumed. Such an understanding would make it more pressing for Bernd to reconsider his practice and his repairing strategy. Bernd’s practice testifies of the immanent process of ‘othering’ implicit to becoming competent in diabetes and in every other practice. How to become competent immanently produces potential ‘lines of flight’ that escapes competence and produces incompetence. Does it mean that to educate and equip people with tools in order to enable them to become competent is futile? No, it means that the process is never complete and the endpoint never secured.

Chapter 5:

Caring for a medical device

A simple life

Anders lives by himself in a ground floor apartment. The apartment building in which he lives is situated in a street with relative high apartment buildings, so little daylight comes in through the windows. The apartment is a one-bedroom apartment, sparsely furnished. There are a few naturalistic landscape paintings on the walls. The living room floor is fully carpeted with a dark brown carpet, and the colors of the room and the furniture are mainly dark colors of brown and dark green. We sit down by the dining table, which is relatively small and has one end against the wall. The room is dark and we have difficulties seeing the display on Onetouch, so we activate the light in the display. We are not having anything to eat or drink. The situation is one of scarcity; scarcity of light, furniture, space, dining table, food and drink. It conveys a sense of simple living, an ascetic, modest monk-like existence involving only the basic necessities of life. In this setting Onetouch seems excessively high-tech. and misplaced, and as it turns out Anders has used it only as a blood sugar measurement device. However, he has used it consistently three times a day and with a timely exactitude that confirms a life disturbed scarcely by other concerns and activities.

Anders is 78 years old. He used to work as a gardener, but retired several years ago. He has always lived by himself and he has no children. He was diagnosed in 1996 with type 2 diabetes. He began to feel bad from eating pastry and came to suspect that he might have diabetes, because his niece has diabetes. She provided him with sticks for testing his urine, and they showed that he was segregating the protein albumin, which signifies a diabetic condition. He went to his general practitioner and his blood sugar was measured to be 14 mmol/l.

A physician once told Anders that he probably had the condition for up to 10 years before diagnosed. After he had been diagnosed, Anders lost about 15 kg. in relatively short time, and managed to regulate his condition through dieting, weight loss and exercise for several years, but by the end of 2004 his long term blood sugar (HbA1c) was 8.5% app. 1% above the recommended maximum level, and he was admitted to the Island outpatient clinic and put into insulin therapy. According to Anders his GP felt sorry for him that he had to begin insulin therapy, but Anders responded: “If it is necessary then I have to do it. It doesn’t matter if one has to take insulin. It is just a matter of remembering to inject morning and evening. It does not bother me.” Anders receives a mixed insulin therapy, which means that the insulin he injects consists of both long and short-acting insulin. He injects 18 units morning and evening. He is also medicated with tablets for increasing his insulin sensitivity.

A solitary life

Anders attends the local center for the elderly three days a week, but besides this Anders does not do much. Anders seems to lead a solitary and simple life; nothing much happens besides his visits at the center and daily chores such as shopping and going for a walk to exercise his legs. Anders described a regular day for me in this manner:

> “Normally, I mean there may be differences, because I go to the daily centre for the elderly some days and others not. Those days can be a little bit different than the others. But I get up around 7.30, and the first thing I do is to measure my blood sugar. Then I make breakfast, and just before I eat I inject my insulin and then I have my breakfast and coffee. Afterwards, I tidy up a bit. And then a bit later in the morning I measure my blood sugar again. Then yesterday I went into town to Tivoli for the Christmas market. I brought a small packed lunch (two pieces of bread) and bought a cup a coffee. I came home in the evening and measured my blood sugar just before dinner, and just before eating I injected my insulin as I am supposed to. Afterwards I watched TV and had my evening coffee and then I measured my blood sugar just before going to bed.”[97]

It is not odd that Anders focuses on the aspects of measuring blood sugar and injecting insulin, since my research is about ways of managing diabetes. However, it does seem that his life centers very much on diabetes. At the daily center for the elderly he is a member of a group of elders with diabetes. So there is a lot of talk about diabetes during coffee and lunch breaks, and, moreover, there are often various diabetes related activities, such as having invited experts in diabetes.

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[97] Appendix E, Anders Interview 1, time: 37.20

Anders considers his solitary life as both a cause and a remedy for diabetes. When he was diagnosed he was overweight, which he considers as the primary cause for his diabetes condition. The reason he became overweight in the first place was because he was eating out a lot at diners and cafeterias, eating unhealthy. Contrarily, when diagnosed with diabetes he stopped eating out, and began to eat lean healthy food and he swiftly lost weight. This was made possible, he says, because he was by himself and did not have a family to take into consideration. Habits and lifestyle are more easily changed when one needs only to be concerned about oneself.[98] Anders has never had anybody to negotiate his food habits with. Anders describes his modest food habits accordingly:

> "I do not eat sugar or fat, I use rasp oil and a little butter sometimes, but I seldom buy butter either. I eat a lot of vegetables at dinner and potatoes: Two potatoes, vegetables and a piece of chicken or turkey or the like. Mostly rye bread for lunch."[99]

Anders does not despair over the fact that he has diabetes:

> "But I have never been depressed about it. In fact I haven't and nor am I now. Some of those attending the center they are so depressed. But I never have been. I take it as it is, and I live with it and of course it would be nice if one did not have diabetes, but when you have it then it is a disease that…. I mean it would be worse if it was cancer or something like that, or rheumatoid arthritis and one had to be in a wheel chair. You can live with diabetes if only you attend to the condition."[100]

Despite that, much in Anders' life seems to center on diabetes, that he conscientiously measures his blood sugar, takes his medication and injects insulin, he does not consider himself as especially concerned with his condition. Grinning he tells me about the Christmas lunch at the center for the elderly where he ate substantial amounts of sliced pork and fried apples and drank aquavit. Others at the center, however, are pretty wound up about their condition:

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[98] I met the argument posed by some of the other participants that family, friends and relatives should not 'suffer' just because one has diabetes. They should not be submitted to eventual diets due to diabetes. These negotiations and considerations may in practice complicate attempts to change eating habits for the person with diabetes.

[99] Appendix E, Anders Interview 1, time: 1.06.30)

[100] Appendix E, Anders, Interview 1, time: 1.00.00)

> "I mean, I do not think much about it [diabetes]…. There is one over at the center. It is diabetes living with her. She counts carbohydrates and… She is completely… In a way it has ruined her life. There are others, like Bernd who have been living with diabetes for just as long as she has, but his life is not poisoned like hers. When she sees…. "but, I cannot eat this it has too many carbohydrates" ... It is like this all the time and she has to eat at specific times a day and so on. Some people become like this"[101]

In anthropology, cultural studies and STS materiality is considered as constitutive for human action and behavior. Accordingly, liberal understandings of an autonomous subject with a priori right and ability to self-determination is questioned (Haraway 1991, Lutz et al. 1990, Despret 2004b, Struhkamp 2005, Willems 2000). Rather, in the abovementioned approaches autonomy is viewed as an outcome of chains of association of humans and non-humans. The autonomous subject is thus as the universal fact, the well-functioning technology in practice, thoroughly supported and constructed. Autonomy and agency is thus a practice since it is a matter of performing an arrangement. Following this understanding I consider Anders' ascetic life as a practice. He is able to have a focused and keen interest in his diabetes condition since not much seems to interfere with and disrupt this concern. He leads a solitary and modest life. A life in which diabetes constitutes a central aspect since not much else occupies him, and the things that do occupy him, the local center for the elderly, are diabetes related. Diabetes may thus be considered as having required the status as a hobby in the sense that it is through diabetes that much of his social life centers. Interestingly enough regulating diabetes constitutes a central concern and passion for him.

Well-regulated?

As part of his treatment Anders was asked by the diabetes nurse to measure his blood sugar four times a day, which he did for three months with great dedication and precision. This was initiated partly because his insulin therapy was changed from a long-acting insulin to a mixed one and partly since Anders was not satisfied with his long range blood sugar level, the HbA1c test. But Anders' blood sugar does not seem to be affected by the changed treatment in the manner hoped for. The blood sugar does not decline as expected. In fact

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[101] See Appendix E Anders, Interview 2, time 33.00)

according to Anders it was better before. Anders is quite concerned with his numbers and getting below the recommended average of 7.5% (HbA1c):

> Peter: "You say that your blood sugar level is too high?"
> Anders: "Yes, I think it is too high."
> Peter: "Do you sense it?"
> Anders: "No, no I cannot feel it. I do not know maybe it is because I ought to get more insulin, but HN [diabetes nurse] is so afraid of increasing my insulin dosage."
> Peter: "Why do you think that is?"
> Anders: "She says that if one gets to low a blood sugar during the night one might die without noticing."
> Peter: "She is right about that isn't she?"
> Anders: "Yes, she is, but I do not get that low…And with Insulatard (long-acting insulin) my blood sugar level was lower, and it is strange because I was supposed to get lower due to the short-acting insulin in the mixed insulin I use now. That is what the others [persons with diabetes] receive as well. It works now and then goes away. That is what one is supposed to get; a low blood sugar level. But as you can see I do not. But then again they say that when you have my age then it is OK that it is a bit higher. And I must say besides having a bit of trouble with my legs, I do not have any complications. So I am not going to die from diabetes complications."[102]

During our talks Anders expressed concern with his blood sugar level. He was keen to get below the recommended maximum level. However, the diabetes nurse and physician prefer that his blood sugar level is slightly above rather than below the recommended level. This is because of his age and the fact that he has no threatening secondary complications from diabetes. In his case keeping a high average is medically preferable because due to his relative high age and mild symptoms, there is little risk that he, in his lifetime, will suffer from complications due to mal-regulated diabetes. There is a greater risk related to having too low a blood sugar level in the form of blackouts, falling accidents or strokes. The medical opinion is that there is no need to submit Anders stringently to the recommended HbA1c standard. Accordingly, Anders could inject less insulin, be less concerned with dieting, and in general be less concerned with his condition. Anders is aware of this medical rationale. However, he is still keenly interested in getting the numbers right, getting below 7.5%.

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[102] Appendix E, Anders, Interview 2: time 29.30)

Realizing and relativizing diabetes

The HbAc1 test is a measure of the average of the blood sugar level over the previous three months, and it is an important tool in diabetes treatment. The HbAc1 test is the decisive diagnostic tool and arbiter of how well the person with diabetes is regulated. Blood sugar measurements made more or less frequently during the day are momentary. They show the blood sugar level at that specific time. They are helpful in regulating the blood sugar during the day by means of food, exercise, medication and insulin. The HbA1c shows how well one has succeeded in this practice. The daily measurements, dieting, exercise are efforts that are summed up and evaluated by the HbA1c test.

In Anders' case the HbAc1 test plays a significant role. During our talks Anders often mentioned that he was not satisfied with his HbA1c test and that he wished to increase his insulin dose. However, the diabetes nurse and physician were hesitant to follow his request and increase his dosage. They assured him that he was doing fine and that there was no need to strive to get below 7.5% for a man his age. It is an interesting situation; Anders pushing for more insulin while the healthcare practitioners hesitates and tries to mitigate his concern. Anders' concern is to reach 7.5% or below, since the HbA1c constitutes the objective indicator of being well regulated and thus in control of one's condition. However, ironically the HbA1c test is not ascribed the same significance by the healthcare practitioners. For Anders it constitutes an objective standard designating how well he is regulated, but as it turns out in clinical practice the average of 7.5% is not a standard universally applicable to everyone.[103] In Anders' case getting below 7.5% is of slight importance because of Anders' age and his disease trajectory with few symptoms. In other cases, if one is younger, say, mid thirties, being below 7.5% and maybe well below, constitutes an important concern, because when young there is a considerable greater risk of developing complications later on, simply because one has to live longer with diabetes. This clinical reasoning considers the interplay of the various aspects of the condition rather than employing a specific standard universally. The medical rationale is thus not the application of specific golden standards, but a relational practice of taking a heterogeneous ensemble of aspects

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[103] Moreover, as other standards it is continuously negotiated and has been lowered over the years and in the USA the recommended maximum level is now 6.5% - 1% lower than in Europe.

into concern: the age of the patient, his or her general health condition, various tests such as the HbA1c, his or her disease trajectory, his or her current treatment etc. What comes to matter in this relational, deictic practice is inherently dependent on the other aspects.[104]

However, Anders is ambitious and concerned with being well regulated as designated by the HbA1c standard, but in his case medical advice entails that he moderate his ambition. What is asked of him is not to adhere to a diet, or take the right amounts of medication and insulin at the right time, tasks that Anders seems to master and in which he finds a certain satisfaction. No, what is asked of him is to ascribe less importance to the objective standard of well-regulated diabetes - the HbA1c test. Medical advice, although relieving Anders from the tedious task of attending to his condition rather institutes a more difficult one. To follow medical advice entails in Anders' case that he adopts a relational understanding of diabetes, an understanding that does not have a singular standard, as the decisive arbiter, but is relational. The HbA1c test as an objective standard that sets a clear identifiable goal is replaced with a relational assemblage where the HbA1c test derives its importance through its relations with other factors. Consequently, the diabetes condition becomes inherently contextual and emergent because when tied up in relations any aspect, device or factor, may transform the whole.

In this light Anders' somewhat counterintuitive resistance towards medical advice that relieves him from the need to be keenly attentive to his condition can be explained by the fact that Anders is thereby also deprived an objective measurement device. When the HbA1c test is relativized, what will decide if Anders is well regulated? I argue that we may understand Anders as *caring* for the HbA1c test, because for him it constitutes the decisive objective measure of whether he is well-regulated or not, and in the end whether he is in control of his condition or not. The HbA1c is thus inherently intertwined with the formation of his subjectivity and identity as a person with diabetes. The HbA1c and Anders

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[104] Annemarie Mol's recent research focuses on this practical reasoning in clinical practices and appreciates this reasoning which can characterised as inherently complicated, because it compares incomparable disparate aspects (e.g. age and HbA1c) yet can be accounted for and made sense of through the deployment of various different logics. This 'inconsistent', 'partial' reasoning goes against the grain of a widely accepted focus on golden standards, accreditation, securing quality of care etc. Mol works to describe and argue for appreciating this type of reasoning as in fact more sophisticated and exact than application of evidence-based standards. See Lettinga & Mol 1999, Mol forthcoming, Timmermans & Berg 2004, Mesman 2007.

engage in an ontological choreography since the HbA1c constitutes the premise for Anders to become a person in control of his condition, and thus live up to the understanding of the 'autonomous' subject in control of his life.

Moreover, when clinical reasoning relativizes the HbA1c then Anders loses an objective, impartial arbiter. If clinical reasoning from case to case valorises the test then the patient is wholly left to the vices of medicine. Hence, medical reasoning may always have surprises in store for him due to new measuring devices, new scientific knowledge, new understandings of diabetes, novelties that continuously emerge and in effect change established understandings and practices. Who is to tell what significance will be granted to what factors next? This somewhat paranoid reading merely serves to argue that most people, like Anders will probably show scepticism when faced with a reasoning where the value of specific factors may shift and be attributed varying meanings. However, further considered, this constitutes an example of the exact opposite dynamics often attributed to science in critiques of science. These critiques refer to situations where science acts as the indisputable authority preferring one singular version of an object, which, somewhat arrogantly, it presumes society to adopt since it is "proven by science". Clinical practice in Anders' case does not exercise such authoritarian behaviour, on the contrary. In his case 'medical science' includes multiple versions of the object whereas Anders prefers a singular one. So, instead of closing discussion and rejecting uncertainty, medical practice becomes positioned in a manner where it has to explain itself and articulate its rationale. So relativizing the HbA1c leads to the exposure and sharing of medical judgment rather than foreclosure of discussion. Anders is aware of the clinical rationale; it has been explained to him. However, he still wishes to meet the standard and be able to consider himself as being in control.

Cultivating multiplicity

A humanist stance might be that the HbA1c test is an inherently reductionist conflation of the intricacies of diabetes into a singular figure established by rationalist medical science. In this light, when Anders is told not to be too concerned about this figure this would mean that he was liberated from a dehumanizing rationalist medical regime. However, provided Anders's case, we are able to reconsider such a humanist critique. Instead of being subjected to a medical regime, Anders teaches us that the HbA1c test is crucial for his engagement with the condition and the will to become in control of his condition. The HbA1c is thus highly productive in the formation of Anders as becoming well regulated; just as a lap time for a swimmer or a runner constitutes a limit to overcome. Blood sugar measurements, dieting, exercise, insulin therapy all become practices with a direction and a purpose: to become below 7.5%.

But could we not still be concerned that much in Anders' life seems to center around diabetes, and does the fact that he is more concerned about achieving the recommended HbA1c level than his diabetes nurse and physician, bear witness of how he is subject to a medical regime? We could have this concern, but this would also involve that we ignored how the HbA1c test enables Anders to consider himself as in the process of controlling his condition. It furnishes a way for him to consider himself as an autonomous subject, determining his condition rather than being determined by it.

But a humanist critique would also overlook what is already in play in the clinical practice, and between the clinical practice and Anders. There is no need for a critique of the HbA1c test since it is already, as argued, destabilized in the clinical practice. It is not in practice a standard universally applied, but a deictic factor in a heterogeneous assemblage of factors. The HbA1c test achieves its objective status in Anders' practice not in clinical practice; not by the medical regime *in practice*. Of course the test is facilitated and initiated by medicine, but its status as objective is actively performed and reproduced by Anders. The HbA1c test is thus in practice already being re-configured and destabilized. This, however, does not mean that the test may not be subject to critique in other ways, but this only strengthens the point that what the HbA1c test *is*, is really a concern about what it *does* and this is an empirical concern. The HbA1c test is a multiple ambiguous object. It exists as a relational object. It is a deictic factor in clinical medical reasoning and an objective measuring device for Anders, and a means for him in his continuous attempt to realize himself as in control.

This multiplicity might immediately be considered as constituting a problem since it may lead to confusion and misunderstandings. However, I consider it to be productive and constructive. If we consider that the test played the same role for Anders as it did in the clinical practice, we would end up with two equally impoverished settings. If it played the same role in the clinical reasoning as in Anders' life, then the clinical practice would simply apply one standard to fit all without taking into consideration the particularities of each case. Likewise, as argued, if the HbA1c were not considered by Anders to be an objectivist arbiter of being well-regulated, then Anders would be without a motivating force.

So where does this leave us? Well, it underscores that diabetes can be considered as inherently relational, and how this can be viewed as productive and constructive, rather than problematic. We become able to consider diabetes as being realized through various devices such as HbA1c tests, clinical reasoning etc. Consequently, it means that we can appreciate those devices, not for what they *are* (supposedly by referring to and/or deciding their essential qualities), but for how they are *related* and for what they *do*. This means that instead of a critique that is premised by both a singular situated position and a singular object, we may, when considering multiple objects, identify and argue for constructive relations. I consider the argument made here to specify how we can appreciate the HbA1c test as both 'objectivist' and 'relative', but also how the co-existence of the two versions establishes some friction between Anders and the clinical practice that requires their interaction and mutual interest in the others version. The HbA1c test as multiple thus not only makes good sense, but is of outmost importance. If we accept this understanding then we have an interest in cultivating, scrutinizing and evaluating such multiplicities instead of being concerned with eradicating them in order to achieve transparency and unequivocal settings and standards.

Chapter 6:

Resisting the forces of diabetes

Evoking a determinist ontology

Doris is 55 years old, unmarried and has no children. She works as an accountant. She was diagnosed with T2DM in 1994. She is in insulin therapy and injects insulin three times a day. Injecting insulin does not bother Doris much except, perhaps, from the bruises on her thighs. Doris has experienced hypoglycemia, but not very often. Besides hypoglycemia she has few actual bodily symptoms. It is important for Doris that diabetes does not dominate her life. She says:

> "I feel that when one has a condition then it shouldn't take over [ones life], and I prevent it from doing so… It is my life, so if I am going to feel bad after having been out eating a grand dinner and maybe some sweets, well, then it is me who is going to pay, and so be it. This is where I am at: I say I am in charge."[105]

But when this is said, Doris immediately adds:

> "…but of course it [the condition] does come to be in charge because otherwise one would end up in a miserable state. It does determine my actions, but it is not like I am thinking about it all the time. I mean in daily life I do not give it much thought. I don't. I mean it is a condition I have and have to live with, and that is how it is… and of course in the best possible way…."[106]

Doris' statement illustrates the difficulty of deciding what or who is in charge and how, when one has diabetes. Is the condition determining the actions of the person, or is the person determining the condition? Doris' somewhat perplexed account that shifts between determining agencies illustrates this difficulty. It underscores that to regard the practice of treating diabetes as a well-defined matter, and as distinctively separate bodies acting on each other seems reductionist. Rather, it seems like Doris' account could continue infinitely about

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[105] Appendix E, Doris Interview 2, time: 24.35)

[106] Appendix E, Doris Interview 2. time: 25.15

how she takes certain actions, although those actions are affected by her diabetes condition, as well as how she wishes to live her life, which again is related to the condition and so on. Doris' account exemplifies how diabetes and Doris herself are engaged in a 'mangle of practice' where they constitute and affect each other continuously without one fully determining the other (Pickering 1995). Accordingly, we may think of diabetes and the person with diabetes as folded into one another. However, although Doris implicitly acknowledges this co-constituency of diabetes and her personhood, she nonetheless insists on her autonomy and that she *decides* how diabetes should intervene in her life.

> "Well, I have always weighed too much, also as a child, and, therefore, there has always been something determining what I could and could not do. For long periods of time things have been going really well, I've been losing weight and everything and you say: "hey, this is great" and then suddenly it takes over again. So, I have always had something I should be careful of, or adapt to or do, and I think I have reached a point where I say: "Well now I am a grown up person and maybe I would live half a year longer if I did this or that, but if I do like this then I feel better here and now""[107]

All her life Doris has been occupied with keeping her weight, being on a diet, being determined by something other than herself, she holds. Now, she is an adult, and it is up to her to decide how she wants to live her life. For Doris it is a matter of claiming her autonomy. But, moreover, it is not only a matter of resisting being determined by diabetes or overweight, there are also opposite forces, those that cause the overweight, or exacerbate her diabetes condition. It is a tripartite relation. Reconsider the following sentence: "For long periods of time things have been going really well, I've been losing weight and everything and you say: "hey this is great" and *then suddenly it takes over again*." Doris also struggles with an unhealthy lifestyle that she for periods of time manages to keep in check, but which also threatens to take control. She is fighting on two fronts. She struggles to prevent both diabetes and an unhealthy lifestyle from taking over her life. In this field of forces, Doris struggles to claim her autonomy, resisting both the one and the other. But this particular way of thinking about her existence invokes a specific ontology. This is an ontology where these forces are strong and potentially determinist and therefore may 'take over'. In this field of forces she is a subject

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[107] Appendix E, Doris Interview 2, time: 26.30)

who, at particular times is able to resist those forces and at others not. Doris thus enacts an ontology where she is struggling against determinist forces of diabetes and unhealthy ways of living that threaten to dominate her and thus she is legitimized to fight those forces, both of them.

Diabetes as private

Doris will not allow diabetes to dominate her life, and her relation to others should not be influenced by the condition:

> "It is not much fun to have a guest who says "no thanks" to everything and: "I cannot have this" and "I must not do that" and, likewise, to invite people and everything is peas and carrots. It is about finding a way of living where it [diabetes] becomes as anonymous as possible. And I think it is so for many of my friends. They do not think about it. There are no special dishes prepared. I choose if there is something one is not so happy to eat, then you simply let it pass lightly and then you can say no to the sauce or whatever it may be. So I do not think there is anybody giving it much thought in daily life."[108]

Doris' concern is to delimit the condition and prevent it from affecting her social relations. Hence, Doris is preoccupied with demarcating and controlling how diabetes should interfere with her life. She insists that it is a personal, private matter and that her condition should not be a subject for her friends and relatives. We may consider Doris' way of practicing diabetes as a matter of policing and 'bordering in' the condition and preventing it from interfering with her life in ways uncontrolled by her. This constitutes an instance of ontological choreography, since diabetes configured as an objectifying force affects and determines Doris' life and subjectivity specifically. Her agency, in relation to how she polices diabetes, enacts her as an autonomous subject with a personal problem, and thus accordingly also as in control of her condition, since diabetes is not other people's problem.

In the following I will relate Doris' way of managing diabetes to how diabetes is conceived of and taught in training programs for people with diabetes, as I have experienced them by participating in the 'Diabetes school' program at the Island outpatient clinic. Thereby, we may consider Doris' enactment of diabetes in

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[108] Appendix E, Doris Interview 2, time: 32.20

relation to the diabetes school. Through this analysis I am able to suggest a posthuman enactment of diabetes that offers an alternative to Doris' practice. By considering Doris' practice in conjunction with the diabetes school program we can appreciate that it is neither a matter of 'interiorizing' or 'exteriorizing' diabetes, but to engage in an uncertain relation as to what constitute 'insides' and 'outsides', subject and object, person and diabetes.

Going to diabetes school

As argued above, Doris is struggling with different forces relating to diabetes. She is struggling to avoid being determined by diabetes in a manner that impoverishes her life, but equally she is struggling with being determined by an unhealthy lifestyle. We may consider this as an attempt to cultivate a moderate relation with things avoiding either one concern or the other to become dominant.[109] It is a matter of steering clear of Scylla and Charybdis, avoiding one malady (an impoverished life due to diabetes) without coming too close to another (an unhealthy lifestyle and impairment). In the treatment of diabetes and education of people with diabetes, the understanding of a delicate balancing act is articulated. In the diabetes school program at the Island outpatient clinic it is stressed that life does not have to change dramatically when you are diagnosed with diabetes. Diabetes, it is taught, does not require that life have to be dramatically altered and impoverished. On the contrary, it is important that one does not consider diabetes as necessitating dramatic changes. Instead diabetes is articulated 'merely' as a matter of living healthy and sensibly, which means that someone with diabetes can enjoy occasional pleasures such as sweets, ice cream, fast food etc. It is a central message at the diabetes school that diabetes does not entail that life is to be lived in complete austerity. However, life is not to stay unaltered either. So, in that sense living healthy with diabetes does not have to determine one's life by

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[109] It seems to be a central concern to most of us, at least explicitly, to avoid specific concerns and aspects of life to be too dominant. I consider this to be linked with a concern of avoiding what we designate as extremity and fanaticism. The virtue of reflective and critical position is also to be able - or at least to give the expression - to see things from more than one perspective. One may consider the productivity of the ideal of a moderate life in forming subjectivity and identity as a *tuning process* (Pickering 1995), where one is continuously in the process of avoiding diverse extreme positions. However, ironically to avoid what may be considered as extreme positions simply out of principle seems to constitute an extreme principle.

imposing a range of regulations and prohibitions. And moreover, to live healthy and sensibly constitutes a concrete way of avoiding that diabetes *becomes* a determinist, dominant aspect of life in the form of impairing complications.

There are good reasons to approach diabetes in this manner because it de-dramatizes the condition, by articulating diabetes as a condition one can live with and manage without having to transform life dramatically. Diabetes is thus made 'do-able' at the diabetes school in order for the participants to become able to handle their condition as a balancing act of avoiding a life dominated by diabetes in one way (as the inherently healthy living) or the other (as an impairing condition).[110] However, a particular kind of interaction between the participants and the healthcare practitioner teaching the diabetes school struck me as quite interesting in this respect, when I attended the diabetes school as part of my fieldwork at the Island outpatient clinic. I experienced that the participants asked very concrete questions regarding their lifestyle. They asked e.g. " if it was OK to have pineapple in the morning", or "if they should avoid pasta alltogether". The teacher, on most days a diabetes nurse, responded concretely, but also stressed that what is important is not one specific habit, but one's general lifestyle. "Yes, a large ice cream is unhealthy, but you can have one occasionally (and as long as it is not on a daily basis, and accompanied with fast food, sweets and soda etc.)". The point that the healthcare practitioners attempted to put across was that one needs to learn to consider the consequences and become able to counterweigh unhealthy actions with healthy ones. "Have an ice cream, but then take a long walk and eat a salad for dinner (while minding and measuring the blood sugar)."

The important concern at the diabetes school is not to specify how people should live their lives. This would seem to go against the objective of such programs, namely to empower people by enabling them to take active part in their treatment. The aim is to develop the participant's understanding of the intricacies of diabetes so that they may become experts in their own particular diabetes condition. Consequently, the traditional, and much more general, medical treatment plan, which is directed at all people with diabetes is substituted for an understanding of multiple pathways to a healthy life, where individual preferences and desires do not have to become radically subordinated to the treatment. This individualization process can be considered as intimately related to the concern

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[110] For the aspect of making a problem do-able see Fujimura 1987.

coined in sociological critiques of medical practices as objectifying, where the concern is that patients are alienated through standardized treatment procedures.[111]

However, individualizing diabetes in this manner may also be viewed as inherently concerned with optimization epitomized by Michel Foucault's notion of biopower (Foucault 1991). Foucault' concept of biopower holds that the concern of the modern state is to internalize the concern with being healthy, being educated, informed etc., in short, being optimal, in the citizen/patient/user so that what was once the concern of the state becomes the concern of the subject. This reconfigures the relation between the healthcare system and the patient considerably. It is apparent to consider the diabetes school as an instance of biopower because of the obvious concern with making diabetes concretely do-able by de-dramatizing it. The diabetes school aims to affect the participants in a manner that makes the interest of the state (a healthy population) and the desire of the subject converge, namely to realize and sustain a healthy body. Moreover, biopower is about dissolving the oppositional relation between the state and the subject. Without the state as clearly governing subjects, but subjects as governing themselves opposition between state and subjects dissolves. In the optics of biopower it is a risky and possibly counterproductive strategy to subject patients to rigid standardization and objectifying practices, because the medical regime is thereby clearly marked as governing patients, which increases the probability that patients might resist medicine in various ways. Consequently, programs like the diabetes school are concerned with stipulating the importance of attending to the condition for the benefit of the patient, while constructing ways of doing and thinking about this that do not make the condition into an insurmountable task. The overall objective of biopower is an optimally healthy population achieved with minimal effort.

Now, I do not present this Foucaultian reading in order to argue that diabetes schools are about disciplining people with diabetes to serve the interests of a medical regime and the state.[112] Such a reading misses, to my understanding,

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[111] See Leder 1998 for a somewhat classical account of this argument and Cussins 1996 for articulating a posthumanist alternative to this understanding.

[112] When referring to biopower, I am drawing on Foucault's probably most qouted work *Discipline and Punish*, which in isolation may be read as exercising a critique of the modern Western state apparatus, but together with Foucault's late work (1981, 1988) the concern is

not only crucial points in the work of Foucault; it also ridicules diabetes treatment practices. I do not argue ‘against’ current treatment practices of diabetes, as I have encountered them. On the contrary they are preoccupied with making diabetes ‘do-able’. To argue that people with diabetes today are ‘victims’ subjugated to biopower overlook how biopower strategies, such as the diabetes school, are productive. They produce subjects that are sensitive to the intricacies of diabetes and thus sensitive to diabetes. The diabetes school should thus be considered as a way of developing ways of living with diabetes. Hence, the problem is more complicated than being just for or against such treatment strategies. My point is instead that through this process of individualizing diabetes, where the concern is to arrive at an optimal relation to diabetes, a reductionist understanding of what it entails to cultivate such an individual and an exact relation to diabetes is employed. To have an exact individualized relation to diabetes is by no means a trivial task but, as I will argue, quite substantial. It is a matter of becoming hyper attentive to diabetes and allowing diabetes to territorialize life completely.

Territorialized by diabetes

To summarize, the process of individualizing diabetes is done to prevent diabetes from dominating the life of the person with diabetes entirely. Diabetes and daily life must be attuned to one another. The balancing act becomes one of giving diabetes just the right amount of attention; to avoid, on the one hand, that everything is contaminated by a concern with living healthy with diabetes, while, on the other hand, avoiding that the concern with diabetes does not entirely disappear, and result in complications that at some point irreversibly will dominate life. However, practicing this exact and delicate attention is not straightforward.

> “When you are having a good period where you feel good about yourself, then things also seem to work out, and it is not so much of a load as when you are sad or stressed at work, because then you do not have the strength to do the same things when you get home from work. There are definitely good and bad periods. Once I said to the

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not with power, but with the formation of the modern subject. In this light biopower is a productive force that produces subjects and how subjects become requires thus empirical analysis rather than critique of the fact that they are produced. My concern in this dissertation can be read as preoccupied with how subjects are formed in and through diabetes treatment, and how we may develop a normativity around these subject formations.

> diabetes nurse: "If I had been a prominent lady from up north then I would probably have had a minor depression" and she looked at me and said: "but persons with diabetes one often has that". I would not say that I had a depression but it definitely bordered to one. I had enormous difficulties pulling myself together but then it was just for a period of time. There are definitely good periods and bad periods."[113]

Above Doris tells that there are good and bad periods. How she feels has implications for how well she is able to attend to her condition. Things may go well for a while, and then something might happen that turns things around and then she cannot be as concerned with the condition as she ideally ought to be. Unhealthy living may come to dominate things for a while, and then at one point things may change to the better again. Obviously, it is not good practice to live continuously unhealthy for 6 months and then healthy for 6 months. If we contrast that one may have good and bad periods with the understanding of individualizing diabetes, we recognize that to live optimally with diabetes is not compatible with having good and bad periods, not even short ones. The objective is exactly to eradicate the aspect of good and bad periods, and instead have a relation to diabetes where the condition is granted the exact amount of attention continuously.

The optimal moderate relation is thus a minuscule continuous consideration where diabetes is not a burden and a possible source of distress with the consequences of neglect that may follow such sensations. But nor is it to 'disappear' and thus become neglected. Such a relation to the condition is pervasive; diabetes has to invade one's life entirely. The work entailed to cultivate a relation where you are able to enjoy, say, rich meals occasionally, entails that life becomes structured around and for this occasion. Every detail of one's life must be related to the concern with the condition. An occasional ice cream entails that you not only consider what you do after having it, but that you are also aware of what you did before. Moreover, one must develop a complicated sense of accounting for and assessing what different actions are "worth": How do one "pay" for an ice cream or a cheeseburger, how much does it "cost"? Are a 5 km. walk and a salad reimbursement, or will rye bread with lean cheese do? The point is that the strategy implied by individualizing diabetes entails that one's life becomes a terrain

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[113] Appendix E, Doris Interview 1, time: 1.01.00)

territorialized by diabetes.[114] Food, exercise (or lack of), feeling tired or sick, being stressed, medication, insulin therapy, going out, traveling etc.; all these otherwise more or less disparate and unrelated aspects have to be related in order to be able to have an exact, individual relation to diabetes. Consequently, exact attention entails that one becomes *hyper attentive* of the condition, or simply that diabetes becomes life.

I will argue that it is a mistake to considers the concrete changes in the form of changing lifestyles, eating habits etc. as a measure for how radical a transformation the person with diabetes has to undergo. This is a way of thinking that assumes that the fewer actual changes or loss of pleasures, the higher the resemblance with life before diabetes and the better ("you can still have an occasional ice cream, drink red wine, have a juicy steak etc."). However, such an understanding implies a rational subject, self aware and accountable for every aspect of life, as if life was *already* territorialized with the concern of managing one's body. As if eating habits, exercise and daily life were a thoroughly rational activity where every action is the choice of a deliberative, autonomous agent. This understanding presumes all these concerns to be in place whereas they are what needs to be constructed, not presumed. Every nitty-gritty detail of life has to be related to diabetes in order to live a moderate, considered life with diabetes. Accordingly, such an understanding does not recognize the work required to perform an exact relation to diabetes.

In this light, the participants in the diabetes school asking concrete questions on how to live were asking for specific directions in order to *relieve* themselves from the work required to individualize diabetes. They were resisting that diabetes should territorialize their lives because with specific guidelines one becomes relieved from the work, risk and worry it entails to try and live healthy with diabetes. This work is attempted (re-)distributed to the healthcare practitioners.

This is the predicament that surfaces: Diabetes is articulated in the diabetes school program as something to be controlled and should not become a dominant and determining force in one's life. This assumption is in complete concordance with the hopes of people with diabetes. They wish to live as

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[114] The vocabular of territorialization and re-territorialization is developed Deleuze and Guattari (1987) as an attempt to think topographically about psychology, capitalism and the state (among other things).

uncomplicated with their condition as possible. So, interests converge. However, to construe an exact, individual relation to diabetes goes through a cumbersome process of becoming territorialized by diabetes, which stands in contrast to how people like Doris try to realize diabetes, namely as confined. So we may express the difference between the participants at the diabetes school and the teaching healthcare practitioners as consisting, not in the goal, but in how to achieve it. To put it crudely, the participants are interested in acquiring optimal solutions that do not employ them extensively, whereas the healthcare practitioners propose an engagement with diabetes where diabetes is weaved into the fabric of daily life as an *outcome* of a cumbersome process of being territorialized by diabetes. The problem, I will argue, is thus how to articulate that in order for diabetes to become a controlled and a non-dominant factor in life, one has to become hyper attentive and allow diabetes to pervade life entirely. This seems immediately contradictory, and it goes against how we today in the West are accustomed to think about solutions to a given problem. However, such an understanding is central to STS, which is concerned with the work it requires to have something realized as e.g a universal fact or a well functioning technology. The connection to STS is pertinent while it is meaningful to consider realization of diabetes as an intrinsic, integrated part of daily life as a matter of constructing a well functioning technology. It is a matter of constructing a machine, a functional composite of the person with diabetes, the diabetes condition and diverse technologies and procedures. But to address the problem in this manner entails that diabetes is considered as neither exterior nor interior to the subject, but as a posthuman relation.

The production of exteriority

Doris holds that diabetes should not pervade her life. She enacts diabetes as private, confined and controlled. She is preoccupied with controlling how diabetes should affect her life; what consequences it should have on her daily personal life, how it should interfere with her social relations etc. Doris thus enacts herself as a modern human subject who insists on exercising autonomy and control over her life, and diabetes is enacted as an exterior, determining object that she is to resist in various ways. A sharp subject-object dichotomy is thus enacted in Doris' way of practicing diabetes. In the diabetes school program diabetes is in contrast enacted, although not articulated, as something to be accomplished by dissolving a sharp subject-object dichotomy: diabetes must territorialize life in order to become realized as controlled. The point is that when diabetes is forcefully externalized and objectified as it is in Doris' case, it is thus separated from her and her doings. It becomes a determining factor that is somewhat unrelated and detached from her. While in fact diabetes is part of her and her actions are, more or less contingently, consequential for how the condition evolves. The argument unfolded here identifies that even how she thinks about diabetes is consequential for the way diabetes becomes marked and objectified, and thus how it is practiced.

But in contrast to Doris' exteriorization of diabetes it is not a matter of interiorizing diabetes either, so that the condition is conceived of as indistinguishable and inseparable from her. This would mean that diabetes was, ideally, fully controllable by her and would delegate to the person with diabetes the full responsibility for the condition. The posthuman suggestion entails that diabetes is neither completely exterior nor interior to the subject, but materially and discursively intertwined with the personhood and the life of the person with diabetes. This means that one has to handle the difficult relation to the other where the other is not fully realized (as a determining factor) or determined (by the subject). Diabetes is neither a fully realized object exterior to the person with diabetes, because it is realized and formed by the life of the person (as well as in relation to a range of other things), nor is it simply a product of this person's actions. Consequently, in a posthuman perception the object or the subject should not be presumed, but rather their status should be kept in an uneasy high-tension zone of being undecided.[115] If one accepts to be uncertain about what are my qualities and what are the qualities of the other and thus dissolves and destabilizes the self as well as what may qualify as interior and exterior, the concern with 'knowing', 'controlling', 'managing' the other or the self dissolves and is transformed into a concern with *inventing* the self and the other. This entails exploring relations and what might be good ways of relating to the other. One becomes actively preoccupied with *realizing* rather than with *controlling*. It also means that technologies or solutions to manage something are not exterior to the

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[115] The term high-tension zone is suggested by Star (1991) as a position that enables the subject to be sensitive to the self and other in a novel way.

body – the body becomes a technology itself by the ways in which it is able to relate and become available to the other.

In conclusion, ideals of learning or knowing in order to be able to manage conditions like diabetes, which is the ambitions of the diabetes school are questioned and reconceptualized in a posthuman ontology. This is because thinking of diabetes in this manner presupposes and strives for a relation where the object in order to be known by the subject is presumed as separate. In a posthuman ontology it would rather be a matter of 'unlearning' and disrupting ambitions of knowing and instead conceptualize the relation with diabetes as risky, uncertain, difficult, but exactly therefore then a matter of exploring and inventing relations with the condition.

Chapter 7:

Accounting for an unruly condition

When I met with Bente in her home 14 days after our first meeting at the Island outpatient clinic, where I had initially introduced Onetouch to her, she said, "So what are we going to talk about?" "Well, for instance, how are you doing with regards to using Onetouch – are you able to use it?" I replied. She said: "Well yes, yes, but I must admit I cannot see what I shall use it for". Then she told me how she, when returning from our initial meeting at the clinic, had sat down to delete the recordings we had made there, "just for fun", as she put it. However, this turned out to be quite difficult for her, and she had ended up spending hours, but at last she had succeeded. However, when ready to start from scratch, Onetouch now cleansed of 'fictive' recordings, it had occurred to her that in order to record food it would have to be done in grams of carbohydrates, fat, protein and calories. "But you cannot do that!" she exclaimed, "then you have to weigh, calculate, divide and so on, then it is much easier simply to pick up your notebook and write: "I had pasta for dinner and therefore I slept much better.""

Bente had several questions and comments with regards to Onetouch - comments, which she had carefully written down and now launched at me. Some of them, I did not quite understand at the present, others could be explained with reference to her insufficient use and understanding of Onetouch at that point. But this encounter was one that started out with problematization. She proclaimed: "what am I going to do with this device?" "This is too cumbersome" etc. However, obviously Bente put in the effort. She was concerned with the adequacy of the data in Onetouch and wished to delete fictive recordings. She did spend hours doing this, read through the manual, wrote down comments etc. As it turned out, this initial response to Onetouch was similar to her recurring accounts of the complexity of diabetes.

An embodied condition

Bente (70 years old) is a tiny woman. She is active in many ways. She plays Bridge twice a week. She exercises, she does stick walking at the beach several times a week and she goes swimming. She lives alone, and does her shopping and cleaning herself. She smokes. And she has type 2 diabetes. Bente's blood sugar has a tendency to oscillate, which means that her blood sugar go from high to low, and vice versa, in relatively short time spans and due to relative insignificant changes. Therefore, Bente measures a lot in order to, as she puts it, : "…see how she is doing".

Bente injects two different kinds of insulin; a long-acting for the night, and a short -acting, which is injected in immediate relation to her meals. Bente requires very small doses of insulin because of her small body mass. Typically, she will have to inject 2-6 units of insulin together with her meals.

During the study, she conducted in average 4 blood sugar measurements a day, which was by far the most frequent measuring practice among the participants.[116] She makes many entries in her notebook about how she feels, what she has eaten, what her blood sugar is, the amount of insulin she has injected, if she has exercised etc. Moreover, she meticulously writes down situations that are ungraspable to her, situations where diabetes surprises her. These surprising events she presents to her diabetes therapists.

Bente was the participant with most embodied sensation of her condition. She is often hypoglycemic, and her blood sugar tends to oscillate with high latitude. Consequently, Bente has become very observant with regards to her blood sugar. She needs to be if she wants to avoid the very unpleasant and potentially dangerous hypoglycemic seizures. Avoiding hypoglycemia constitutes a point of attention that affects her in many ways since her blood sugar is affected by what she eats, her insulin, her exercise, but also how she feels; if she is stressed or worried. Regulating the blood sugar not only becomes a matter of regulating a self in meticulous detail, it *forms* the self and the body.

Due to her blood sugar oscillation, Bente has developed a sense of her condition in her sleep. She can tell by her dreams if she is hypoglycemic, and she knows that she sleeps well when she has eaten a meal rich on carbohydrates such as pasta. Moreover, when walking out the door, moving away from her home, she cannot help but pause and evaluate how she is doing and feeling – and often she senses that she is in need of carbohydrates. She then walks back into the house to

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[116] The overall average of the participants were 1.7 a day. See the "Practice reports" in appendix F

eat or drink something in order to prepare herself for the trip to the grocery store or a walk on the beach. One concern of hers is how her psyche, as she puts it, affects her condition. She often wonders, when worrying about things like her children, some of who live abroad, how that affects her condition. She has no doubts that it does, and sometimes she wishes that she did not worry so much.

Bente weighs 52 kg., and according to the healthcare practitioners it would be fine if she gained some weight. She needs not worry about keeping a low weight, as it is often the case for people with type 2 diabetes. However, her low weight produces another kind of problem for her; it means that she has to inject very small doses of insulin, namely between 2 and 6 units. However, the relative difference between 2 and 6 is huge. Miscalculation by one unit makes a very perceptible difference to her, whereas a miscalculation by one or two units for somebody injecting 20 units is of little noticeable importance. The standard of insulin units thus concretely affects her practice and her condition, since it is crucial that she injects precisely the amount of insulin she needs. And consequently, even slight differences from day-to-day have to be taken into account.

However, there are also aspects of decreased sensitivity. Once Bente could sense that her blood sugar was low when it was around 3.5 mmol/l, but nowadays it may come close to 1.5 mmol/l without she senses it. It seems that her body has somehow adapted to experiencing low blood sugar and become increasingly numb.[117] Obviously, this disturbs her, and is also why she often experiences the need to measure her blood sugar in order not to be taken by surprise. But in addition, another concern of hers is raised. She wonders that maybe she measures too much and is thereby exposed to measurements which are "unimportant" since they may just be instances on the way to the 'right' (presently) stable blood sugar level. Accordingly, she did not needed to be exposed to these measurements, which may cause her to act in ways she should not, or that causes her to worry, which again may affect her condition. This concern express the intricate concern that may arises when one is measuring a lot, namely: "What are the relations between my actions and the blood sugar level?" "What actions are reflected in the present number?" "What are the temporalities involved?" "Does the present measurement reflect what I did yesterday or two

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[117] Mol and Law also refer to this aspect. See Mol & Law 2004.

hours ago or both, and if so, how?" And the trivial yet crucial point: "Is the blood sugar level presently dropping or increasing?" and if the number is a bit high or low what counter measures should then be taken? Should one try to counter a further increase by e.g. taking a walk (and thereby presume that blood sugar is increasing), or should one do nothing and assume that it is dropping, thereby be in risk that it is in fact increasing, which will mean that other more radical measures should be taken later. These are the kind of considerations one inevitably becomes occupied with when measuring as much as Bente.

One might think that Bente's increased attention necessarily leads to a controlled condition due to the extensive measurements and embodied practices. However, in Bente's case this does not seem to be the case, or at least not in a straightforward manner. It seems instead that complexity and simplicity is folded and each other's prerequisites, exemplified by the measuring practice that provides an unambiguous number on the one hand, while also producing a plethora of concerns on the other. Concerns such as "what actions does this number refer to and is it inclining or declining?" But interestingly enough these concerns, although frustrating, are put to use by Bente, sharing them with others constitute an important aspect of Bente's diabetes practice.

Diabetes as trickster

The third time I visited Bente she had just turned 70 and she had held a birthday party for family and friends. It had been a great party but during the evening Bente's blood sugar had acted strangely. Bente explains:

> "It is completely outrageous. I do not understand it at all". She explained: "The party was Saturday night and as far as I recall it [the blood sugar level] was fine in the afternoon. I inject what I am supposed to… and I do not eat very much, being the hostess and all. I simply did not have any appetite. And I had also brought my insulin for the night, which I remembered to inject, without measuring though. And I dance all night after dinner, and unwrapping the presents, of course. But I dance all night. I was on the dance floor all evening… and at 2.22 am my blood sugar level is 20.4 mmol/l I have taken my insulin and I had not eaten. I don't get it."[118]

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[118] Appendix E, Bente Interview 3, time 01.00

One would expect that Bente's blood sugar level would be low, and in fact very low, since she had taken her insulin as she should, but in addition she had not eaten or drunk much, quite the contrary. Moreover, she claims to have been dancing all night, something that would cause the blood sugar level to decrease. Instead, it increased considerably. Consequently, Bente is completely astonished and says: "And so I do not understand my blood sugar and therefore I cannot use it [Onetouch as well as the blood sugar] in any way. I cannot grasp it."[119]

Consequently, Bente does not experience her condition as controllable, as something she is on top of despite her many measurements and note taking practice, and her embodied relation to her condition. Rather, to her diabetes is complex, and filled with contrasts and incoherencies. So instead of an orderly and controllable condition obtained through meticulous registration aided by a range of technologies – Bente has a messy, complicated and by no means simple condition. This is, as exemplified above, at times frustrating for Bente, but what can she do but continue to measure, take notes and try to manage this unruly condition?

Bente collects her ungraspable experiences. She writes down these experiences on small post-it notes and in her notebook. She puts the post-it notes in the envelope containing her individual patient journal that she brings along when going to her three months visits at the Island outpatient clinic. Her peculiar and perplexing experiences with diabetes are then presented to the healthcare practitioners. This constitutes a matter of accountability. Through her written notes and her blood sugar measurement apparatus, in this case Onetouch, Bente meticulously accounts for situations where diabetes is unruly and complicated. She does this in order to show, not only that she is attentive of these situations, but also that they *happen to her* and is thus not a failure on her part. If Bente did not meticulously account for these occurrences, one might consider her condition to be unruly due to her actions. But when she accounts thoroughly for these occurrences and shows how diabetes is unruly for her, then this understanding is challenged or at least not easily assumed. Bente thereby complicates an understanding of diabetes as ideally controllable if one as a person with diabetes *really* put in the effort. In Bente's practice, diabetes is enacted and realized as an

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[119] Op.cit.

actor or a trickster that surprises and escapes control in various ways.[120] She thereby compels the healthcare practitioners to acknowledge that her condition is difficult and complicated Consequently, they agree that diabetes (in her case) cannot be pinned down or fully controlled, that it surprises and escapes dominance.

When diabetes is construed as a trickster, Bente cannot be held fully responsible for the condition, and accounting for how it surprises and tricks her becomes pertinent. We may articulate her relation in the following circulating manner: *Diabetes as a trickster enables Bente to be an accountable subject through her detailed accounts of the events where diabetes acts as a trickster escaping control.*

So, events such as the party are sources of frustration but also of subject formation. Bente has thus developed an interest in the complexity of diabetes. She is interested in occasions where diabetes is a trickster that surprises and resists control in any complete way. But at the same time, diabetes is not completely exteriorized since in her accounts she is continually occupied with affecting and being affected by the condition through measurements, insulin, eating, exercise etc. So her interest refers to the instances where these actions seem not to work, or where counter intuitive occurrences seem to happen. Consequently, in Bente's case a complicated relation to diabetes, as something which is neither entirely under control, or out of control or, 'outside' or 'inside' her body, is exercised.

Consider the following excerpt from one of Bente's visits; a conversation with the diabetes nurse HN, which illustrates, among other things, Bente's accountability and diabetes as a trickster.

> Bente: "What surprised me very much was the day of my birthday. I had been busy all day, having guests and I must admit that I did not eat much at dinner."
> HN: "Not as much as you expected to eat?"
> B: "No I hadn't… and I had been dancing all evening … and then a blood sugar level at 20. And then I say: "hello". I had injected my insulin for the night."
> H: "Hmmmmm"
> B: "It was high and I had been dancing all night and hadn't eaten very much."
> H: "Well, I would have thought it would have been low."

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[120] The term trickster is by Haraway used to designate the lively, agential nature of science as well as nature as continuously escaping human mastery. See Haraway 1991, 1997, Pickering 1995, 2000, 2003, 2006, Barad 2007

B: “Yes, that is also what I would have expected.”
H: “I was expecting that you would have said that it would have decreased.”
B: “Naah..”
H: “What about alcohol – I suspect that you had a bit of that as well?”
B: “Well, yes I did.”
H: “But that also makes it decrease….. All good sense says that you should have had a low blood sugar….? You danced, you did not eat much, you drank alcohol. All good sense says that you should have had a low blood sugar. This just serves to show how enigmatic it is. And you had injected the same amounts of insulin as you are used to?”
B: “Yes. I had…”
H: “Maybe it was … everything. The whole.. the whole situation as such?”
B: “But I mean the kind of diabetes I have. I mean, when you talk about diabetes… or people should be attentive if the blood sugar level is high then you have to go to the toilet and you get thirsty and so on. If I have a high blood sugar level then I practically do not go to the toilet. I sleep fantastic in contrast to how I was this morning [when it was low], around 5 am I wake up because I have to go to the toilet. I often go to the toilet, it is one of the certain indicators that I am about to have a low blood sugar level.”
H: “You are something else.”
B: “But I find it strange.”
H: “So what you are saying is that you pee more when you have a low blood sugar level?”
B: “I most certainly do.”
H: “(Laughing) This is in exact opposition to what it says in the medical ABC.”
B: “Yes, that is what I am saying. What can one do?”
H: “But dear Bente, I don’t know. And I mean we have been over this before you are just not like most people. That is your charm. You have to make your own experiences, which you have also been very good at, and try to recognize the relations between things. How it works for you.”
B: “Yes, yes I know, but it is just a bit strange.”
H: “It is really strange. And some of it is in complete contrast to what you would expect.”[121]

Being available to the other

Immediately after this conversation between Bente and HN, I asked Bente how she liked HN’s comments about her account of her experience of diabetes at her

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[121] Appendix E Bente Visit (konsultation), time: 27.15

party. And at first she did not know what I was referring to, and then she requested me to repeat HN's response, and then she said that it was OK and what she had expected. She said this without disappointment or resignation. It seems that what was important was telling the story, not HN's response. This confirms that what is at stake is a question of accountability, but it is also a matter of *sharing uncertainty*. Bente shares uncertainty with the healthcare practitioners by imposing on them her puzzling accounts and diabetes as a trickster. HN acknowledges that Bente's account is "strange", and that diabetes is "enigmatic", and that she cannot offer her any specific solution or answer, but encourages her to continue making her own experiences.

But this accountability strategy of sharing uncertainty is obviously quite productive. It results in an analysis and scrutiny of the facts laid out by Bente of the type: "what did you do", "what had you been doing", a matter of negotiating what is to count and what is not - negotiating the accountability of the story, so to say. HN is provided an insight into the daily life and understandings of Bente. It also results in a detailed walk through of the dynamics of diabetes that may be considered as educative for both parties: "Alcohol is supposed to make the blood sugar decrease." "When the blood sugar is high then normally you will have to pee" etc. This elaboration reiterates some of the general dynamics of diabetes while also challenging and complicating them through the empirical details reported by Bente. Consequently, Bente's accounts also challenge textbook understandings of diabetes and present the condition as more complicated and difficult than the textbook version.

I will argue that Bente's diabetes practice as enacting diabetes as a trickster is thoroughly productive since it establishes a relation of interest. Bente has developed a keen interest in occasions where diabetes surprises her, and her condition *does* something contrary to the well established common medical knowledge of diabetes. Bente thus acts as, what Stengers would consider, an interested scientist, one who is interested in a further complication of her object rather than settling with the most immediate general conception. Bente, we might say *adds* to medical knowledge, by providing versions of diabetes that differ from the general understandings. But Bente's interest in these minor, complicated versions of diabetes has risen out of her lived embodied experiences with diabetes. Her body, due to its size, and her way of living has become highly sensitive of diabetes. It has become a fine tuned apparatus for being affected by diabetes. But not only has she become sensitive to diabetes, diabetes has in return become *sensitizised* by her, since she is so immediately affected by the slightest changes in factors such as food, exercise and insulin. One or two units of insulin too many are consequential, pasta meals makes her sleep better etc. Consequently, Bente's oscillating diabetes condition, which is so difficult to control and make sense of, corresponds perfectly with a very direct relation between her practices and the condition. Her body and the condition have, so to speak, *co-evolved* into mutually highly sensitive bodies that cannot but be immediately affected by the slightest move of the other.

Living complexity

Bente does not transgress the complexity of diabetes - she lives it. However, living and sharing this complexity has become a way of practicing diabetes. Diabetes seems to surprise and trick her in various ways, which has, however, furnished a strategy that arguably can be considered as highly productive and constructive. There are three concluding points to be made.

First, Bente's diabetes practice challenges the common sense assumption that frequent measurement of the blood sugar and being highly sensitive of one's condition lead to a situation of being in control of the condition. This is the assumption inscribed in Onetouch. The more you are concerned and aware of your condition the better control you achieve. Bente constitutes an example that challenges the generality of such an understanding. Bente does not master her condition, rather she is continually interacting with it, and in that process she experiences instances of control as well as instances of no control, surprise and frustration. Neither the notion of "being in control" or "not being in control" seem to describe Bente's situation adequately. I prefer to think of her as being in a continuing process of interacting with the condition without achieving a state of equilibrium or rest, a manglish open-ended process, but without an end point of *interactive stabilization* (Pickering 1995). She cannot but be involved in the continuing effort of trying to control diabetes, although control in a crude sense continues to escape her.

Second, diabetes as a trickster seems be highly productive rather than impeding action. It puts a whole lot of things in motion; it sensitizes Bente to the peculiarities of her condition and leads her to take precautions. Accounting for her practice to the healthcare practitioners, includes them in unraveling diabetes and exposes them to a version of diabetes that challenges conventional diabetes. Bente and the healthcare practitioners are thus engaged in an interested relation. All in all, an inherently explorative practice where diabetes becomes something one tries to *unravel* and *follow*.

Last, diabetes as a trickster realizes diabetes as an actor affected by and interwoven with the practices it is part of. Diabetes is thus realized as neither simply 'outside' or 'inside' the person-body. Instead what seems to be at play is a somewhat complicated affective relation that cannot be captured by modernist divisions between object and subject, but might be better conceptualized in terms of quasi-objects or cyborgian. When considered in this manner, it becomes pertinent to consider what relations one is able to engage in with diabetes. How one becomes available to the condition.

Chapter 8:

Diabetes as dubious

White bread with butter and cheese

The three times I visited Edwin he had prepared a plate with pieces of white bread with cheese and butter. We would sit down by the diner table, and I had a glass of water while he drank coffee. During our talks we would eat the white bread with cheese. I was from the outset aware that white bread with cheese and butter is not particularly healthy. It is too rich on fat and carbohydrates. But I also learned that Edwin liked this kind of food very much. He had always eaten white bread in the morning and with his evening coffee. I felt a bit awkward. I could not help thinking that I provided an occasion for Edwin to eat the food he likes so much. On the one hand, being a guest and all, it would seem impolite to refuse the white bread. I was thus somehow inclined to eat it, (and it tasted good, similar to the pieces of bread I was served as a child on vacations at my grand parents'). On the other hand, I thought that I should be modest about what I ate in order to be polite, but also to show that one should not eat too much of this kind of food. And then again, if I ate a lot then Edwin would have less, and that would be better for his condition. Another concern was that eating the bread would also confirm to Edwin that others also like what he likes so much, and therefore it is not so strange that he has difficulties in trying to change this habit. And, moreover, if I did not eat any of the pieces of bread then I might contribute to a sensation that we were from separate worlds. Like a bowl of food for sheep, I was being presented with a plate of white bread, which regardless of how I responded would tell Edwin something that would mediate his responses to me. The plate of white bread was simultaneously a way of remembering and forgetting diabetes. We always ended up with an empty plate.

”You don’t feel it!”

Edwin is 66 years old and retired. He was diagnosed with type 2 diabetes in 1999. He is in insulin therapy and is medicated with approximately seven different kinds of medication. In addition, he also takes herb medication as well. "It cannot hurt", he remarks. Edwin is sometimes bothered by a tingling sensation in his feet. This is the only concrete symptom of diabetes he experiences, and it is not even certain, although it probably is related to the condition somehow, that it is due to diabetes. To him diabetes is primarily enacted through his diagnosis, his visits to the Island outpatient clinic, his blood sugar measurement device, insulin and medication, the fear of secondary complications following from diabetes, and the fact that diabetes obligates him to live and eat differently; all very real and concrete aspects, but still different from a concrete embodied sensation of diabetes. These aspects have to do with treating the condition rather than with experiencing the condition as a disease. Consequently, to him all these aspects seem to lack a concrete cause, or put slightly different, these aspects have become obligations that lack a concrete motivating force. For Edwin diabetes has a dubious quality accompanied with all sorts of dreadful and tedious obligations. His attitude towards Onetouch is in similar ways influenced by this concern: Onetouch seems merely to add to the obligations. It is not considered the remedy, but part of the condition. It is difficult, he says, because you cannot feel the disease:

> Peter: "What about other people and having diabetes? Is it something you tell other people?"
>
> Edwin: "My family knows, friends and a few of my colleagues knew about it. But it is not something I advertise, right? It doesn't matter! You don't feel it! What one is most respectful of is what one sees and hears: "there goes a leg" - it is the secondary complications. But according to them [the healthcare practitioners] nothing seems to be threatening me. But it may come, you never know. One has to be careful. But as I say all the time and have said before: *It is damn hard to take it so serious when you cannot feel it, right? If only it would hurt when you did something wrong. If you do not feel anything then you are not ill, but apparently, even so, you are ill.*"[122]

So when diabetes is not manifest through bodily sensations it is instead manifested by all the things one has to do in order for the condition to continue to be absent. Injecting insulin is one such activity. Edwin tells me that he never will get used to injecting insulin because sometimes it is as if he strikes a nerve, which causes

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[122] Appendix E, Edwin, Interview 1, time: 1.18.45

tremendous pain. Equally, diabetes is present through the many types of medication.

Diabetes is also manifested with regards to food. Food has always played a central role in Edwin's life through cookery and eating. Before the diagnosis Edwin enjoyed white bread in the morning with cheese and jam, and then he could easily miss lunch, but then in the evening he liked a full warm meal; Meat, potatoes and gravy, and then later in the evening, together with a cup of coffee or tee, white bread with cheese. Such eating habits are in sharp contrast to what is recommended as a healthy diet. Instead, he is now supposed to avoid white bread and (fat) cheese, eat more frequent but smaller meals, and enjoy less rich evening meals. Edwin says: "This is how I've always eaten and when you have done so for sixty years then it is difficult to change. It is not something that happens overnight."[123] Diabetes is thus manifested as prohibitive of what Edwin would like to eat. Food has changed from pleasure to sin.

The practice of measuring the blood sugar is also a way that diabetes becomes manifest and present. During the study, Edwin measured in average 1.2 times a day, which is 0.5. below the average of all the participants in the study.[124] Edwin primarily measured in the morning where his blood sugar is relatively stable and low. With regards to blood sugar measurements in relation to consumption he said, "When the blood sugar rises above ten then it is my own fault, and then I do not even need to measure because I know very well that I have sinned too much."[125] This statement is somewhat perplexing because how can Edwin know that his blood sugar is above ten if he does not measure? Edwin as some of the participants thus does not measure himself when he knows the blood sugar is high. Why should he? He knows it is high. This strategy is both facing and avoiding the facts. It is about recognizing that you have done something that in the long run may be bad for your health, and, instantaneously, resist the action of actually measuring to see how 'bad' it is. Edwin thus grants himself the role as a self-aware subject while at the same time sparing himself from the (potentially) concrete saddening details.

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[123] Appendix E, Edwin, Interview 1, time: 59.40)

[124] See Edwin's "Practice report" in appendix F

[125] Appendix E, Edwin, Interview 1, time: 1.10.45)

Edwin also told me during one of our talks that he had used another blood sugar measurement device than Onetouch, one that did not ‘tell’, as he put it. What he meant was that he had used a device that did not store the measurements as Onetouch does, and which, therefore, on a later occasion, e.g. at the diabetes outpatient clinic, could not reveal the measurement.

The folded diagnosis: exact and inexact

Arguably, Edwin does not regret that diabetes ‘does not hurt’, but he questions the reality of a disease - supposedly something bad - that does not hurt. We may consider this peculiar yet quite common sense . Many of the participants reported that at the time when they were diagnosed they were told that they had probably had the condition for several years before being diagnosed. Similarly, it is estimated that up to 100.000-150.000 people with diabetes may be undiagnosed in Denmark today (Sundhedsstyrelsen 2005). Edwin raises the question, when are you ill? When you feel ill, or when you are medically diagnosed as ill? In the case of type 2 diabetes the point is that when you experience illness in the form of continuous pain, then you are probably in a bad shape, which is why it is important, in order to prevent that the condition is realized as painful, that the disease is discovered as early as possible. Accordingly, in order to reduce the risk of a silent and thus in that sense absent condition becoming painful, and thus present in that manner, one has to realize the absent condition as present. One has to realize oneself as ill in order to prevent the concrescence of the condition. Or yet another way of putting it; what is physically absent has to become present in order to stay absent. This is the somewhat counterintuitive folded logic that one is confronted with when diagnosed with diabetes, which obviously opens up to many concerns and doubts.

It is thus not peculiar that Edwin asks: “Can it be?” Or think: “maybe there has been a mistake, I have been wrongly diagnosed.” Or less radically they may think: “How serious is it?” “How will diabetes concretely affect my life, what is my diabetes like?” “How will the disease be actualized in my particular case?” “Maybe it is a mild condition, and I do not have to become all that concerned and thus change my lifestyle considerably?” Consequently, as Edwin expressed it, at one occasion, one becomes concretely concerned about how much difference this particular piece of white bread will do to you, does it really matter? "Do I have to torment myself when I have this? Or rather, how much tormenting is enough? How can I have an exact relation to my condition where I do the exact necessary, no more or no less? These concerns inevitably also include and produce a trajectory.[126] The trajectory emerges with the concern of dying which is implicit to these considerations. How serious is my condition? These are concerns, which inevitably include considerations about age and dying. "How old am I, and how likely is it that I will come to suffer before I die of 'natural causes'?"

We may consider these concerns as defensive, or as escape routes for people to be negligent about their condition, but we may also consider them as being concerned with exactitude mobilized against a highly influential yet inexact diagnosis. What does the diagnosis do? It defines you as chronically ill, which inevitably will change life for the person diagnosed. Life as a whole is instantly transformed (Charmaz 1991, Star & Bowker 1997.), but at the same time, and for obvious reasons, medicine is unable to say anything about how the condition will unfold and affect the life of the diagnosed person, since this depends on a plethora of things, including the person in question. Arguably, the certainty and irreversibility by which the diagnosis is posed is accompanied by a plethora of uncertainties and relative aspects. But what medicine does is to impose a probabilistic regime that states: "if you lead a healthy life, follow the treatment, take your medication etc. then you are continuously reducing the risk of secondary complications of diabetes." Faced with such an understanding, it seems difficult to acquire an experience of doing enough. One seems always to be able to do a little better, and thus one is always in a state of deficiency.

Withholding information

For these reasons - the absence of bodily sensations and the diagnosis as exact and yet inexact - it is not odd that Edwin considers diabetes to be somewhat imposed on him by medicine. This is nicely illustrated by how Edwin described the time when he was diagnosed. At first, as it often is, it was difficult for the physician to unravel what and if there was something the matter with Edwin. But then Edwin's

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[126] The concept of trajectory is central to much medical sociology on experiencing disease. See Charmaz 1991, Star & Bowker 1997.

wife, who accompanied him to the physician, said that Edwin was very thirsty and often went to the toilet, and then suspicion of diabetes was raised, tested for and the diagnosis posed. Now, it is not peculiar that a person close to you, a wife or a husband, is able to describe one's actions better than yourself, and that one's daily practices may be opaque to you. But what is telling in Edwin's case is that when he told me this story he said that he had deliberately withheld this information, since, as he laughingly put it, "They [the healthcare practitioners] have to figure some of these things out for themselves; that is what they are paid and have their fancy education for".

This statement illustrates a thoroughly realist point, namely that if diabetes is there in the body then medicine, being expert in the body, must be able to find the disease without the help of the patient. Hence, Edwin evokes, in this particular instance, a classical relation to medicine where he is the passive object body, and medicine the interrogating active subject able to penetrate and unravel the body. This is a relation often criticized in medical sociology since it is considered to be reductive, alienating and objectifying (Leder 1998). Moreover, it also overlooks the importance of the patient as an active, participating and verbal actor whose testimony is crucial for establishing a diagnosis in clinical practice. In Edwin's case, however, he enacts this classical relation as constitutive of the authority of medical science, namely that it is able to discover an object without being aided by the patient (or his wife). If aided by the patient, Edwin seems to suggest, how can one be sure that the diagnosis is not merely an artificial construct and not a fact? In this manner, Edwin, one might say, turns medical science against itself and destabilizes and questions its authority, that is, its right to decide what is fiction and what is fact. His own experience of not having any significant bodily sensation constitutes a basic empirical fact that challenges the practice of medical science that relies on the assistance of the patients' verbal testimony in order to establish the diagnosis.

Edwin thus in this manner engages in a scientific controversy with medical science, and does so by reference to empiricism, the cornerstone of positivist medical science. Edwin overmatches the realism of medical science, so to speak, with his basic empirical realism constituted by his embodied experience. Moreover, Edwin cares for himself in this manner by refusing to contribute to the realization of a diagnosis; refusing to contribute to making himself ill. Edwin fears that diabetes is imposed on him and resists such an imposition. Viewed like this, Edwin's interest in avoiding illness correlates with medicine, only how differs importantly.

Overmatching the positivism of medical science

Above I have conducted an analysis of Edwin's practice that posits him, not as somebody negligent of his condition, but as somebody occupied with the ontological status of diabetes, and thus how it is manifest in his life. We might also add that his questioning of medicine, which one might find inherently 'irrational', might in other situations be admired as sound skepticism towards authorities. I wish to follow this a bit further. As it is now, the reader may be left wondering whether the point is that Edwin's diabetes condition is inherently relative, and that diabetes is imposed on him by medicine. Through my analysis we have become able to consider Edwin, not as somebody unwilling to face the facts of medicine, but as somebody presenting his own empirically grounded facts. The tables are turned. It is not an 'irrational' patient against 'rational' medical science, but a self constituted empirical scientist against a scientific practice. Edwin as a scientist raises the most fundamental claim against a scientific practice, namely how it is able to constitute its facts. Now, this argument and the above analysis are obviously predicated by understandings in STS, which is strenuously reluctant to attribute rationality a priori to a scientific discipline. Consequently, this means that the a priori assumption of medical science as rational is presumptuous and abandoned. The present problem is thus that as long as we hang on to a classical scientific ideal, Edwin has medical science cornered. The only way out of this, if we hang on to a classical scientific ideal, is to ridicule him and reject his empirical bodily sensation as absurd and the facts posited by medicine as in fact more valid than his embodied experience.

However, from a posthuman STS perspective we are able to make another argument, which goes back to and illustrates science as a constructive practice. Posthuman STS would state that only by engaging in multiple relations with an object, in this case a body with diabetes, we are able to establish a fact, a diagnosis. These relations include a testimony from the patient that addresses various abnormalities, sensations, things out of the ordinary etc., aspects that may or may not qualify as symptoms but also involves and relies on other testimonies produced by various tests and apparatuses. The verbal testimony of the patient is in this understanding important since it provides the clinical practitioner with ideas of the possible diagnosis and thus with what tests to conduct, or which questions to ask the person, just as the other testimonies in return enable the practitioner to formulate questions to the patient. In this light Edwin's challenge of medical science is premised by a traditional understanding of science as having exclusive access to a singular object, constitutes the problem. Edwin evokes an understanding of medical science that it cannot and should not try to live up to. Medical science, clinical practice, scientific practices in general, needs multiple engagements and testimonies with its object in order to be able to identify and constitute diagnosis and facts.

Equally, if we consider Edwin's premise, his embodied experience, we are able to pose a similar argument. Edwin's embodied experience is by him granted significant importance, and, implicitly, he holds that the body is transparent and singular. What he feels is what is there to be felt. If one is in pain then one is ill, if not then one is healthy. And here lies the next objection we may raise to Edwin's account, namely the inherently realist version of the body. Edwin enacts diabetes and himself accordingly through a classic realist ontology, an ontology where objects such as diseases and bodies are supposed to be singular and transparent. The problem, I argue, is thus not that he does not 'face up to reality', or 'face the facts', as some might argue, but that he enacts a realist ontology, which is too reductive and idealist.

Struggling ontologies and becoming sensitive

When we employ a posthuman ontology we are able to address the problem in a whole different manner, since in a posthuman ontology objects such as diseases and bodies are not just simply there, but must be assembled and realized specifically through relations with other entities. In such an understanding, Edwin's condition must be made to exist, and in that process he plays an important role by the ways he engages in diabetes relations.

Similarly, Edwin's body is not simply a fully developed sensitive apparatus, but must be made sensitive to diabetes e.g. through blood sugar measurements, exercise, dieting etc. The peculiar fact that one may become used to subtle symptoms such as fatigue, tingling feet and thirst serves to show the point that the body is not just there before us as an object, but *becomes* in continuous interaction with various forces and entities inside and outside of it.[127] When Edwin, with reference to lack of bodily sensation, argues that it is difficult to "take his condition seriously" he implicitly enacts the body as fully-fledged and a priori equipped to sense if there is something wrong. The body as a singular object is enacted. A specific ontology is enacted, which one might designate classical modernist, where diseases and bodies are presumed as fully–fledged, singular objects preexisting the relations and practices they engage in. Due to this ontology it thus becomes possible, as Edwin does, to question the reality of things and matters that are dubious and do not seem to show steadfast realist qualities. Edwin's problem is not more concrete evidence in the form of e.g. painful experiences, to wish for this would seem brutal, cynical and in many ways pointless. Nor is it that he realizes that he has diabetes despite his lack of bodily sensation, but that he *realizes* that reality does not have the characteristics designated and hoped for by modernist classical science. Reality is of a more dubious, ambiguous quality. Edwin needs to abandon a classical modernist ontology because it is what enables him to continue to be skeptical of his condition.

We may also acknowledge that Edwin in this manner enacts a determinist reality, one where he cannot act without being acted upon by other forces. Without a bodily sensation of pain and suffering following a disease, how are you supposed to become motivated towards leading a healthy lifestyle? If nothing pulls you in a specific direction and determines how you should live, then how are you supposed to know what to do? Diabetes thus enables him to insist on determination as a central aspect of his life. But the crucial point is that reality as deterministic is enacted by him. Hence, Edwin actively engages in enacting a determinist reality in which diabetes becomes difficult to grasp. We may thus in this manner come to realize how a determinist reality and an active subject are interwoven and crucial prerequisites.

So, am I suggesting that it is simply a matter of thinking differently about Edwin's situation? No, I am suggesting that it is not unimportant how Edwin thinks of his situation and the ontology implied, and that the way he conceives of his

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[127] This is an inherently anti-essentialist understanding of the body central to a posthuman ontology.

situation is a practice that enables him to do certain things and not others. In this case, a central point is that to insist on a specific ontology keeps Edwin from exercising other possible ways of living. One might be tempted to think that Edwin has an interest in preserving his insensitivity because as long as he is insensitive he has established a position for himself from where he can contest the reality imposed on him by medicine, and legitimize his failure to follow the advice prescribed by medicine. The normative point I will derive from this is not that Edwin may be conceived as somewhat self destructive by resisting his condition as he does, but that he positions himself in a manner in which he has little or no interest in being transformed and changed. He is not significantly interested in positioning himself in a manner where his insensitivity might be challenged or transformed into sensitivity. He is not interested in exposing himself to the risk of becoming transformed by the condition.

One might consider my reading and analysis of Edwin excessive, but it serves to show how one can become interested in a reductive, determinist understanding of a disease and the body, and how the understanding of medical science as inherently positivist might in fact be challenged by a more positivist one. In Edwin's case such an understanding is not simply a way of *seeing* things, but a way of *doing* things. It enables him to practice himself as a person in a manner where he can stay unaffected by diabetes. My argument is not that Edwin is irrational, (I have argued that he is in fact rather a persistent rationalist and positivist), but that he is active in forging the determinist understanding he submits himself to. My argument has thus to do with punctuating the determinist reality he enacts, since without this the problem posed by Edwin changes. Then the problem is not that diabetes is not felt, but that one must allow diabetes to *become* felt, that one must become sensitive in and through relations with the condition. Hence, Edwin's negligence consists thus not in his failure to live in accordance with medicine, but that he preserves himself in a position where diabetes is only sparsely realized.

Chapter 9:

Transformation through attachment

Tanja lives on the top floor in an apartment building. When I visited Tanja, we sat down by the dinner table in the dining room of her two-room living room. She always asked me if I wanted a cup of tea or coffee. Mostly I drank a glass of water. She had also prepared a small bowl of candy for my sake; she did not have anything. When I got to know Tanja, it made sense to consider the bowl of candy as a means for Tanja to discipline and change herself. She was disciplining herself by having the candy in front of her but not eating it. It was a practice that says "I can offer my guests candy, and I can have candy in my house without eating it". So instead of shunning candy, excluding it from her life, she was submitting herself to the experiment of trying to become somebody who does not desire candy. She was submitting herself to a process of transforming the status of candy and her relation to candy. Tanja was doing something else and more than simply avoiding candy. She was through the bowl of candy working to transform her desire for candy. She was teaching herself to be near candy without desiring it. The intricate and delicate understanding intrinsic to her practice was that desire for candy is not transformed by shunning it, on the contrary, since shunning candy is only a means of avoiding it. Immanent to the shunning of candy is that one needs to do so in order not to eat it. Desire for candy is thus preserved and reproduced through the continuous process of keeping a distance to what one desires. Desire is exactly characterised by distance to the object desired. Desire is longing for what one does not or cannot have. When one possesses what one desires, desire is satisfied and ultimately transformed.

Tanja is ambitiously occupied with her condition. She wants to become somebody who does not desire candy, or at least control her desire for candy, live healthy not because she ought to, but because she wants to. She is preoccupied with a metamorphosis towards becoming somebody with different desires, ambitions and practices, and becoming somebody for whom living with diabetes in a healthy manner is an integral part of her life and person.

Obligating herself

Tanja is 37 years old. She is married and has a son 7 years of age. She works as a pedagogue. Tanja has had diabetes type 2 for about six months. She is medicated, but is not presently in insulin therapy although it is quite likely that she is going to be soon. Tanja is eager to live healthy with diabetes. She says:

> "I feel that I have to get this [diabetes] done. I have to be an old mum. I have a son and a family to take care of. I have to get this done. I have to be an old woman and be able to *see* my grand children not just feel them [with implicit reference to the fact that one of the secondary complications following diabetes may be blindness]. It just needs to be done and that is how it is."[128]

Tanja is eager to do what is necessary in relation to her diabetic condition. Since her diagnosis, she has enrolled herself in various diabetes research programs. When newly diagnosed, her GP knew of a research project about the effects of exercise on diabetes and Tanja was gladly referred to the project. The project obligated her in many ways. She was to do hard physical exercise three times a week for approximately 1.5 hours together with the other participants in the experiment. Physiotherapists and fitness instructors coached the exercise sessions. The research project included weekly blood testing, and the researcher closely monitored the participants. During these visits, the researcher who was very elaborate in explaining about diabetes and her research project tutored Tanja. Thereby Tanja came to learn a lot about diabetes, which also constituted her primary motivation for participating in the experiment. Equally, she participated in my experiment. Tanja and the majority of the participants in my experiment responded, when I asked them why they had volunteered to participate, that they might learn something, and that the experiment might obligate them to be more attentive of their condition. Tanja, who quickly came to consider Onetouch a good tool for her, responded in the following way when I prompted her to express why Onetouch was a good tool:

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[128] Appendix E, Tanja, Interview 2: time: 19.30)

> "What this disease is really about is to change many rhythms and many habits and in order to do that one has to pull oneself together once in a while… The more one obligates oneself the more difficult it becomes to skip the various commitments that should become the good regular habits. It might be that it [Onetouch] is but a small thing and that it is easy to 'cheat' it [by not entering 'unpleasant' data or measuring when one's blood sugar is high (presumably)[129]], but it reminds me of the things I have to do and that is very important to me. So when I sit here and look at these buttons [at Onetouch] I am reminded that I actually have to remember it all, I also need to remember my exercise and so on, and in that manner the more commitments I make with myself and others; it may be this one [Onetouch], it may be my husband, or my colleague, or my dietician, I mean the better I am able to follow the commitments I need to follow to…."
>
> Peter: "I find that very interesting also because diabetes is such a silent condition and then it is about attaching it to some external aspects. One needs to obligate oneself."
>
> Tanja: "Exactly, it is so easy to run around in a specific circle so if you do not all the time enlarge your circle or are able to make leaps out of the circle then it is too easy."
>
> Peter: "What is this circle?"
>
> Tanja: "If one's little daily routine is here (she draws a circle on the table with her index finger) and you don't go to a presentation about diabetes or visit the dietician or go to the fitness center (she draws lines from inside the circle to imaginary points outside of the circle) then things remain as they are."[130]

Although, Tanja also found that Onetouch provided her with overviews of her condition through diagrams that visualized e.g. how her blood sugar was oscillating over periods of time,[131] here she emphasizes a wholly different quality of Onetouch, namely how it obligates her to take care of her condition. Onetouch, although "a small thing", nevertheless reminds her of her condition, and furthermore it reminds her of all the other things she should be attentive of. It *associates* concerns and makes them present. So Onetouch function as a device that makes other concerns emerge when used. By looking at the buttons with their small illustrations of exercise (a running figure), food (knife and fork), medication (a pill glass and some pills) and health condition (a heart), Tanja is

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[129] See chapter 8

[130] Appendix E, Tanja, Interview 3, time:17.20

[131] See the description of Onetouch in chapter 3

reminded of the different concerns she has to attend to. Onetouch embodies the condition by these small symbols, and triggers Tanja's concern with her condition. Onetouch may be a small thing, in more ways, but to Tanja it has a relational and associative quality. It is not a demarcated object, but an actor-network in the sense provided by Latour where size is not granted an absolute but a relational quality; what at one point is large may at another be small, what at one point is a unified, demarcated whole may at another be a heterogeneous multiplicity. The concept of the actor-network does not designate an actor *and* a network as oppositions, or where the former is included or includable in the latter, but an actor (or a network) as both actor *and* network. Onetouch, for Tanja, acquires this quality that may be identified as a demarcated object while simultaneously and immediately rounding up and mobilizing a range of other aspects and concerns.[132]

Obviously, Tanja also ascribes another quality to Onetouch than that of a neutral technology. Onetouch affects her and reminds her of her condition; *it* acts upon her rather than being something she acts upon and uses. Onetouch is something with which she can have commitments, just as with her husband and her dietician. There is no ontological differentiation in her account between what or whom one can be committed to, since, after all, what constitutes Tanja's primary concern, is not what Onetouch can offer as a tool, what it can do *for* her. Her central concern is what it can do *to* her, what it can make her into.

Tanja offers a metaphor for how she considers the problem of diabetes. It is illustrated by thinking of one's life as a circle, an enclosed well-defined space; a habitat or place inside which things are well known, routine and secure. But this secured habitat has to be challenged when one has diabetes, since the problem with the condition is that practices and concerns have become engrained and they need to be transformed. What once was has to change. Therefore, one has to enlarge the circle, move outside, expose oneself to concerns and matters that may affect and change one's circle.

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[132] "ANT is based on no stable theory of the actor; rather it assumes the radical indeterminacy of the actor. For example, the actor's size, its psychological make-up, and the motivations behind its actions – none of these are predetermined." (Callon 1999: 181-2). See also Latour 1996, 1999b, 2005).

To become through others

Tanja commits and obligates herself to others as a strategy for transformation. By committing herself to others she also becomes better at keeping her commitments with herself; others, whether technologies, her husband, healthcare practitioners, external to her are, to Tanja, resources by which she may change herself. Transformation of her habits and lifestyle is thus by her not considered to be an 'internal' private affair, her concern.[133] She does not demarcate herself in this manner; on the contrary, her concern is to obligate herself to others so that she may become different, since by committing oneself to others, a more obligating contract is established than a contract with oneself. No one but oneself is affected if one does not keep a promise to oneself, whereas if one partakes in medical research, sets a meeting with the dietician, agrees with a colleague to meet in the gym., it is no longer oneself who is affected if one does not fulfil one's commitments, but others are as well. We might say that Tanja turns the social contract, by which we as social beings live up to the obligations we make with others, into a resource for herself. The social contract becomes a tool for her to engage in activities that can affect her life. The social contract delivers the necessary pressure, since the consequence of not living up to such contracts is not only that others are abandoned, but ultimately that others may lose their trust in you. The care for oneself and the care for the other become entangled. When we promise others to be there, help out, then we turn the social contract into an instrument that makes us do things that we might not otherwise do, if left to our own devises ("Let's go swimming 1'st of April", "We are going to climb all the way to the top").

Michel Foucault was in the last part of his work explicitly concerned with the production of the self.[134] He considered ancient practices of relating to oneself in Greek, Roman and Hellenistic traditions. It was practices of caring for oneself not merely in terms of taking good care of the body and one's health, but also a caring relation for the self as a soul. To care for oneself entailed that one became

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[133] In contrast to Doris. See chap. 6

[134] Although not as explicitly as in his last works, the central concern of Foucault, throughout his writing, has been the formation of the human subject as an inherently historical product, produced and constructed through knowledge practices and discourses. Foucault 1988.

knowledgeable of oneself, which was considered not an introspective, psychological project as we might conceive of it today assuming a inner corer of the self to be uncovered. To know oneself meant "one had to be concerned with oneself" (Foucault 1988: 20). One way of being concerned with oneself was by accounting for oneself, one's daily practices, chores, ailments etc. e.g. by writing them down in painstaking detail. This constituted a practice of accounting for oneself and appointing a self-auditing role to oneself. Thereby, Foucault argues, the self is produced as something one can have a relation to, not simply something that one is, but something that can and must be continuously inquired and reflected on, and consequently also something that can be scrutinized and changed. By speaking of 'technologies of the self', Foucault emphasized this idea of a relation to oneself as a means to produce the self:

> "Technologies of the self…permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality." (Foucault 1988: 18)

Tanja's relation to herself resonates with Foucault's notion of technologies of the self, since Tanja is cultivating a technological relation to herself. She employs her relation to others, medical research, my experiment, Onetouch, as means to become a person with diabetes that takes adequate and good care of her health. She thereby actively forms a relation to herself as someone or something she can and should transform. She engages in a relation with herself as a self to be made and constructed in a specific way.

To acquire control of diabetes

> "I mean this disease you can live with. I can live and drink coca cola and eat chocolates. I can live like that. It won't have any consequences right now. I won't get ill right now. If I didn't measure my blood sugar I wouldn't know that it was sky high. So in that sense it isn't a disease that makes me ill here and now. But if I don't take care in regulating my diabetes, don't take care in doing my exercise and don't take care in expanding my horizon, well then I damn well will become ill. Then I damn well will only be 50 years old, or I won't have any toes left or I will go blind or something like that. And if I do not make my

> surroundings attentive of my condition then they cannot take my condition into consideration in one way or another. This is what is so strange about this disease. It is me who controls the disease. I have so much influence over this disease. It is I who decide all the time. If you have another disease then it is up to destiny, or the physician or whomever one believes in, the almighty or something else. But in this case it is me and only me who are in control. This is what is so strange about this condition. I cannot think of any other condition that one is able to influence so much."[135]

Above, Tanja emphasizes the devious aspect of diabetes as a 'silent condition', where one may live unhealthy for years without necessarily being affected. However, at one point such a way of life will be irreversibly consequential. This understanding forms a central concern for Tanja. Instead of constituting an argument for the difficulty of taking the condition seriously,[136] it constitutes the reason why it is crucial that she becomes somebody who takes the condition deadly seriously. The silent character of diabetes is the reason why one must be concerned with living healthy, because of its silence the condition must be regulated strenuously. Moreover, Tanja speaks of diabetes as a condition that can be thoroughly controlled. Something she can affect and be in complete control of. But for Tanja this constitutes an ascertainment, an opportunity and a challenge. She knows that her actions are consequential for her health, so she has a decisive influence, but, more importantly, this is why her actions, practices, conducts, desires and habits, in short her being, must be transformed so that they conform with a healthy life with diabetes. Because her actions are so influential, and because diabetes is thoroughly affected by her actions, Tanja must become somebody who acts and thinks in a healthy manner with regards to diabetes. The modesty intrinsic to Tanja's way of thinking is that she does not assume that because one's actions are so influential, then it is simply a matter of exercising control. But when conceptualized as such one does not seize the challenge, instead one can always 'just' take control, but consequentially this may just as well constitute a reason for not doing so and instead postpone one's efforts: "I'll do it tomorrow, after Christmas, when I feel up to it." But implicit to Tanja's argument is that control must be assembled and achieved. It is not simply there to be picked up. Control

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[135] Appendix E, Tanja, Interview 3, time: 17.20

[136] See Chapter 8 in comparison

goes through the active formation of herself as somebody who leads a different life than she used to.

Again, we see how Tanja actively mobilizes her surroundings to help her regulate her condition. She speaks of them as somebody who should be informed so that they can be considerate of her condition. They become resources in her practice of regulating her condition; she does not consider her condition a private matter, on the contrary she includes her surroundings to partake in her practice of managing diabetes.[137] What is of interest here is how we can consider this production of a diabetes subject as a distributed practice, a practice of becoming in control, a process that both includes others and a self. The French sociologists and STS-scholars Emilie Gomart and Antoine Hennion have addressed this as what they name 'sociology of attachment'. Gomart and Hennion propose an understanding that challenges 'dualist oppositions' that 'have long informed sociological debates' between: "holism vs. methodological individualism, agency vs. structure, critical vs. liberal orientations" (Gomart & Hennion 1999: 223). By drawing on (as well as challenging central aspects of) ANT and Foucault's notion of the dispositif "that focuses on objects, conditions and means through which entities in networks emerge"[138], Gomart and Hennion's sociology of attachment does not consider action to come from a specific actor (whether actor or structure), but consider action to constitute an event produced through mediation between subject and the dispositif.[139] Through the study of the practices and articulations of drug users and music amateurs, they show how self-abandonment or self-dispossession constitutes a central aspect of being affected and of cultivating a passion.

"[A]ttachment takes the form of a surprising consensual self-

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[137] See Doris in comparison

[138] The dispositif thus derives from Foucault's central understanding of power as productive rather than as destructive. Through the dispositif, that is, various material, practical conditions, actors emerge. See Gomart & Hennion 1999: 221, Foucault 1991.

[139] "Mediation is a turn towards what emerges, what is shaped and composed, what cannot be reduced to an interaction of causal objects and intentional persons. The network is not a black pool in which to drop, dilute, criticize and lose the subject. It is on the contrary an opening – pried lose with a partly rhetorical liberation of things and an attentiveness to spaces, dispositions, and events – which releases us from the insoluble opposition between natural determination and human will. 'Mediation' allows the course of the world to return to the centre of analysis." (Gomart & Hennion 1999: 226)

> abandonment [that].. have to do with.. accepting that ‘external’ forces take possession of the self; of being ‘under the influence’ of something else; of bracketing away one’s own control and will in order to be expelled or rendered ‘beside oneself’. To talk in this way implies that there are techniques, settings, devices and collective carriers which make this active dis-possession possible.” (Ibid: 221)

Gomart & Hennion thus point to the central aspect of being affected by something, being moved entails that one relieves oneself of aspects of control. But importantly, to do so is also to actively position oneself in a specific way. It is a matter of becoming available to the passions one wishes to be possessed by, which involves that one exercises agency.

> “[T]o ‘abandon yourself to a tune’ is a phrase in which ‘yourself’ denies the possibility of ‘pure’ abandonment. It is not exclusively passive; it involves the participation of both the person and the object. Ignoring the mutual exclusion of ‘passion’ and ‘passivity’ imposed by the theory of action, the human ‘actor’ might pass through a series of peculiar states (being open, patient, receptive, sensitive). These models of being/acting weave together what had seemed polar opposites – passivity and activity, determining and determined, collective and individual, and intention as against causality.” (Ibid.: 227)

Tanja’s practice exemplifies to me a practice of mediation.[140] She exercises agency in the form of obligating herself to being affected by Onetouch, including her surroundings in her condition etc. in order for these things to exercise agency on her, which makes her into somebody who manage her condition. She positions herself and takes actions that make her available to be affected in a manner in the attempt to become somebody that live healthy with diabetes. Tanja’s approach to her diabetic condition is thus inherently de-centered and posthuman. She engages

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[140] Many practices can be thought of in these terms. Skiing for instance. The expert skier is not dominating or controlling her run down the slope in any strong sense, but works to position herself by leaning the body and adjusting the angles of the joints of the lower body, feet, knees and hip in proportion, and thereby enabling an adequate angling of and positioning over the skis in relative exact relation to the terrain. She needs to exercise and relieve pressure at the skis at specific instances of the turn thereby weaving inner and outer forces into a composite that results in a precise run that looks easy and fully controlled, and where the terrain might seem simply to be a surface dominated by the skier. But the terrain, the hardness of the snow, its bumps, its steepness, constitutes for the expert skier a surface that is carefully sensed, read, anticipated and accommodated to in many ways in order for the run to succeed. All in all a practice where the outer forces (gravity and the centripetal forces) the terrain, the equipment must be allowed to execute their agencies together with the movements and forces of the skier. See Danholt 2002.

with her condition in a manner that does not conform to understanding her as either a liberal human subject or a determined actor. She continuously weaves herself into the dispositif, turns it into something that acts upon her in order to become somebody who manages diabetes - in order to become a grand mother.

Implications

Chapter 10:

A performative re-figuring of Onetouch

In Herbert Simon's famous work *The Sciences of the Artificial* (1996), the classical distinction between science and technology constitutes a central premise. This is the distinction where science is considered as (ideally) *representing* the qualities of the world whereas technology *intervene* and change the world. Simon's argument hinges on this premise and he presents how the artificial can be considered a scientific realm on equal footing with science. Much has passed since and with STS. Simon's wish for technology and science being equally recognized has been fulfilled although in complete contrast with his attempt. Instead of technology becoming scientific, as Simon's work constituted an attempt to, and thereby living up to the virtues of science as representational, objective, neutral etc., science has been re-conceptualized in STS as technological in the sense of interventionist, entrepreneurial and constructive. But still the central understanding is that technologies are doing things, intervening in the world. However, when this is said, how we consider their intervention in the world, and not the least how we conceive of change following from technology, constitutes a central concern. In this chapter my concern is with the practices of using Onetouch and evaluating it. I will argue that by appreciating the performative aspects of practice, we are able to develop an argument for technologies such as Onetouch that transforms Onetouch and the practice of living with diabetes importantly. This will constitute a process of multiplying Onetouch, and thereby neither transgresses the technology (through potential re-design) nor preserves it.

One place to start is with the understanding that Onetouch *is* a mobile technology designed for people with diabetes to support them in managing their condition in an efficient, easy and, hopefully, improved manner. However, when this is said, in order to realize this potential it must be used in a specific, circumscribed and consistent manner. It relies on its user to use it as intended by design in order to become such a tool. It constitutes a central understanding in STS that well-functioning technologies and scientific facts are not well functioning or factual before they have been made so. The well-functioning technology and the fact thus have a history, a genealogy. History consists of actions taken and events occurring or happening that in a contingent way leads to a (for the present) stable present, or so at least is a somewhat preferred way of thinking constructively about technology. Things are at first troublesome, but then after a while and with due effort they fall into place and they become functional or factual. However, although constructivist and sensitive to the dynamics of an emergent reality, such an understanding tends to disregard the work that has to be done *continually* for technologies and things to function, as if at first there was work and then it disappeared. Why would it disappear, or rather how does it disappear? In contrast to such an intrinsically asymmetrical understanding that technologies come to work stands the performative understanding that holds that work does not disappear, it is relocated and become invisible (Star & Strauss 1999). From a performative understanding this means that what seems stabilized is in fact actively and continually held in place, and if not, then it ceases to exist, or if slightly affected then potentially completely re-figured. The present is thus no longer simply given but performatively and continuously done and held in place. However, this does not mean that we cannot consider how technologies imply specific assumptions and politics about the user and the world; that we may consider how they are scripted, as Madeleine Akrich designates it. According to Akrich' every technology is designed with an intention for how it is going to be used, it comes with a script (Akrich 1992). Just as a play or a movie, so a technology has a script of how it is intended to be used. But to consider the script of a given technology also tells us something about the purpose of the technology and implicitly what constitutes problems and solutions. The script thus implies and enacts a specific ontology, a reality in which it constitutes an answer to a specific problem. This constitutes a central concern in this chapter in which I will consider the performative aspects of Onetouch and the performative ramifications of doing so. Turning to Onetouch.

Onetouch as information system

The central script of Onetouch is that the user is prescribed to use Onetouch as both a recording and an information system for decision support. Data such as blood sugar levels, food, exercise and health are recorded, and data are processed, related and visualized in various ways (either on the screen), or when downloaded to a PC in many other ways.[141] These data can be assessed with only one (or a few) touch(es). Onetouch is small and is promoted as integrating a blood sugar measurement device and a logbook; it thus prescribes a use practice where it is brought along wherever the user goes.

This script implies a range of things and thus enacts specific problems and concerns in relation to diabetes. Onetouch enacts the problem of diabetes as a matter of "keeping track" of one's condition, as a matter of "having overview" in order to be in "control" of one's condition. On Lifescan's website, a feature illustrates this nicely. The feature, a montage of still pictures supplemented with brief commentaries, is entitled: "Recognize Patterns". It shows a woman returning from a visit at her GP. She is disappointed about her HbA1c level, which she had hoped and expected to be lower than it was. She then sits down with Onetouch and begins investigating the problem. In her data there are no blind spots. According to the amount of data in Onetouch, she measures her blood sugar at least six times a day, which is quite extensive. She then walks through her average measurements for the particular times a day and finds out that her problem is her after-dinner results. She thinks back, and we are shown in flash back how she eats rich meals of pasta and rice (both rich on carbohydrates) and a piece of chocolate cake. Now she realizes why her HbA1c was not as she had hoped for and she lights up, and from then on, no problems. The feature closes with her walking out the door with a man dressed up as if going to a restaurant.[142]

The feature enacts a reality of a simple, rationalist problem-solving model similar to the idealization of medical diagnosis: she has a problem, she investigates the problem, she diagnoses the problem and treats it, end of story. Moreover, the feature is cleansed of practical details of using Onetouch other than as information system. We are not shown any of the many blood sugar measurements that furnish her problem solving procedure. The blood sugar measurements are simply available to her scrutiny as a manager of her body, but, accordingly, she is thus also

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[141] See appendix H

[142] Going out is often where people with diabetes ”leave the condition at home”, so by closing with this scene the feature seems to express that ”not even going out at restaurants is a problem when using Onetouch”. The feature can be watched at Lifescan's website: http://www.lifescan.com/products/meters/ultrasmart/features/ and then choosing the feature ”test drive now” or ”see for yourself” (shifting) at the right side of the page. The link opened then contains four different menus one of which is named ”recognize patterns”. When clicking this menu the flash feature begins. (Website accessed Nov. 2007)

completely cut out from her bodily practice. Her relation to her body is one of supervision, not embodiment. Arguably, it seems very unlikely that she would be unaware of her problem - that her blood sugar tends to get high in the evening, a quite trivial and common problem for people with diabetes since dinner often tends to be the richest meal of the day - if she consistently measures her blood sugar six times a day.

More could be said about this feature. However, the main point is that Onetouch in this feature figures as an information system for decision support that provides data about the condition so that the user can manage the condition by informed decisions. But Onetouch thus also enacts diabetes as something you can control through careful supervision. It reiterates the understanding that if ideally one collects all data about one's condition then one can know it fully and control it.

Last, Onetouch enacts a logic of miniaturization, small size equals mobility, omnipresence and little effort but great gain and constitutes a decisive parameter. In the words of Haraway:

> "[M]iniaturization has changed our experience of mechanism. Miniaturization has turned out to be about power; small is not so much beautiful as pre-eminently dangerous, as in cruise missiles… Our best machines are made of sunshine; they are all light and clean because they are nothing but signals, electromagnetic waves, a section of a spectrum and these machines are eminently portable, mobile." (Haraway 1991: 153)

The logic of miniaturization is concordant with a logic of optimization and capitalization and frames the problem in terms of efficiency and gain. The problem of diabetes is thus enacted as a matter of being informed and knowledgeable and the work entailed in collecting and entering the data is downplayed and invisible. Onetouch as information system enacts diabetes as a phenomenon that can be managed if all relevant data is collected and processed correctly. It makes diabetes complicated and simple in the same movement. Diabetes is made *complicated* by expressing that the problem is to have overview over the relations between exercise, food, medication, and insulin and how they affect each other in multiple ways and Onetouch is an answer to this complexity. Diabetes is made simple by suggesting that if only you have the information and the knowledge provided by Onetouch then managing and living with diabetes becomes easy and straightforward. Onetouch thus enacts a reality where technology is a means for a person with diabetes to manage an object, diabetes. It thus evokes the central modernist understanding of a human actor that employs technological means and gains control over an object.

In contrast to the feature at the Lifescan website, reaching a state where the user is able to make informed decisions on the basis of vast amounts of data was not realized in my experiment. Instead Onetouch was accommodated to a practice in ways that dismantled many of its central features, exactly because the participants considered them to be too laborious. In that sense the practice of recording data was excluded both by how Onetouch is promoted and used.

Onetouch in practice

During the experiment I emphasized that I did not expect the participants to use Onetouch in a specific manner, but that I was interested in how they could use Onetouch; that I was interested in the use practices that might emerge. And it quickly turned out that the participants mostly used the device as a regular blood sugar measurement device.

None of the participants were able to make any substantial registrations of food, because the user has to record the food in carbohydrates, fat, protein and calories in grams, something that was consistently refused by all of the participants, since it seemed too demanding. One has to know every single food item's amount of carbohydrates, fat, protein and calories, weigh every food item and calculate the sum. Consequently, we agreed that people should use the function, as they were able to, which meant that only one participant used it. She used the function whenever she drank 200 ml. of juice, and entered 11 grams of carbohydrates.

With regards to medication, many of the participants argued that what they took was pretty much the same every day. Similarly the insulin dependent participants also injected approximately the same amount of insulin every day. Therefore they argued why record what is the same day in and day out? This seemed redundant and superfluous. Instead, we agreed that they might then record the extraordinary. I became interested in this way of thinking about the extraordinary, and urged the participants to use Onetouch for recording the extraordinary as a way of heightening the sensitivity of diabetes. Using the device as enabling the registration of what is ungraspable, counterintuitive, what they do not understand. Only one participant, Bente, did enter her insulin dosages quite consistently.

In the beginning, some of the participants were keen to record when they had exercised believing that exercise and the blood sugar level might be associated in a diagram. However, exercise is only associated with the blood sugar level if attached to a blood sugar measurement and figures so that the blood sugar measurement is "before exercise" or "after exercise". But still, many of them continued to record when they had exercised, which would then figure as a comment.[143]

Last, the health category was only sparsely used, since most of the participants found it somewhat superfluous and crude.

In general, the use practice that emerged during the experiment was one that rejected the meticulous recording of every piece of diabetes data. Evidently, what was negotiated was the amount and necessity of the work to be done when using Onetouch. Why record what I already know, what is so obvious to me? This seemingly trivial point exemplifies an obvious discrepancy between the script of Onetouch as an information system and a use practice of Onetouch as a recording device. Obviously, in order to be realized as an information system, recordings must be made, which turned out in my experiment to constitute a considerable obstacle. Onetouch did not become an information system, since those that should benefit from it were also those that should supply the system with data. The invisible work crucial for Onetouch as information system becomes visible through how the work needed to be done is neglected. Consequently Onetouch was not realized as an information system in my experiment.

This supports an important and often posed critique of technological systems envisioned as tools supporting a practice without consideration of the invisible work needed for those systems to function and how the practice is employed by the technology in order for the system to be realized as it was envisioned. I will not reiterate such criticism further here, because what I find of greater interest is that Onetouch' failure to become an information system in my experiment was generally premised by the same logic enacted by Onetouch, namely that technologies should be efficient and optimizing.

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[143] See appendix H

The participants rejected Onetouch when it demanded them to do redundant, seemingly irrelevant work (medication) and quite substantial work of weighing and analyzing food products. Onetouch thus *induced* rather than *reduced* work despite how it is promoted and the promises connoted by the name. Arguably, Onetouch paradoxically articulates the paradigmatic understanding of technology as efficient, on the one hand, while, on the other hand, producing work in practice. In this light, the problem is not a discrepancy between one understanding of technology that underlies the practice, and another underpinning the script of the design, but concordance. The use practice and the script *agree* on the paradigmatic understanding that technology is supposed to reduce work; only Onetouch in practice induces it. Onetouch fails as an information system in my experiment, because it first and foremost employs the participants rather than supports them. This will constitute a central concern later in this chapter, but for now we will leave it and consider another performative aspect of the experiment that has to do with being an accountable, active participant.

Performing an active subject

Fourteen days after we first met on 'neutral' ground at the Island hospital, I visited Doris in her home on a freezing winter day around 4 pm. After having small-talked for a while, I asked: "So how is it going?" and Doris replied:

> "Well, it is going well, but I am probably not using all the features of it [Onetouch] because I think it has certain limitations. Take for example the function "Health", there are only a few options and then "Other". I would like if it was like a cell phone where you have a small keyboard so that you could write specific comments. I think that would be swell."

This comment was just one among many proposals I received from the participants on how Onetouch could be re-designed. These comments illustrate the productive process of the interaction between users and technology in the usage of technology. Provided the above statement I began questioning Doris how she had used Onetouch, whether she had used this or that particular feature, and it turns out that she had only scarcely used Onetouch and then she said:

> "I think it is because I am so unaccustomed with technology, me and

> technology that is just not such good a combination. I do not even have a cell phone – well, that is not true, in fact I have two – I just do not use them"[144]

Besides being a wonderful humorous statement, it is interesting in many ways. Arguably, it stands in contrast to her earlier statement. Considered from a representationalist view these contrasting remarks are troubling because they invite considerations about the credibility of her statements. What should one make of them? Which Doris should we trust; the one where she is the expert layperson that expresses the need for making more elaborate comments than Onetouch affords? or Doris as the layperson that informs us that she does not use such technologies? We could of course argue that the two statements are in fact not contradictory and that the keyboard on the cell phone is an omnipresent concept today and can be recognized as a relevant addition to Onetouch by anyone, without being experienced in using cell phones and SMS. But when arguing in this manner then one is interested in maintaining a role for Doris as a lay expert proposing a design suggestion. One is interested in taking her statement seriously as a real obstacle for her to use Onetouch, and if cleared away through re-design (together with eventual other deficiencies of the design), then Onetouch might become a relevant tool for her. One insists on the authenticity of her testimony as referring to Onetouch solely. What is maintained is thus also a relation between an active human subject assessing a neutral tool. A scenario of evaluating a thing in relation to one's needs and desires as preexisting and separate from the artifact assessed. It is an inherently humanist and modernist ontology enacted with this representationalist practice.

In contrast, I prefer to consider Doris' response as performative and thus inextricably intertwined with Onetouch and the experiment (Danholt 2005a, 2005b, 2006). What Doris does is not merely and only to speak about Onetouch and its qualities, she also enacts herself while speaking of Onetouch.[145] In a performative understanding Doris' initial comment is premised by the potential risk that if she is unable to articulate a good reason for not having used Onetouch as extensively as she expects that I expect her to, then she may be considered by

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[144] See Appendix E. Doris, Interview 2, time: 10.10.

[145] This concern goes back to my initial argument for studying diabetes in the manner I have done.

me to be negligent of her condition and thus as potentially irrational, unaware of the seriousness of her condition, stupid etc. Consequently, she addresses an aspect of Onetouch that can be considered limited, and she becomes an accountable subject. She shows her active participation in the experiment both with regards to having used Onetouch (at least enough) to experience this part of its functionality and with regards to returning her lay experience, which may be relevant to me as a researcher/designer. Furthermore, she accounts for lack of use due to, in her view, the inadequacy of the technology, which by definition is qualified by her being delegated the role as a lay expert. Last, Doris also formulates a vision of a technology that takes the condition serious, since she emphasizes the importance of specific, personal comments over categorical, general ones. Onetouch can thus be rejected as simple, reductionist and impersonal and Doris performs a humanist critique of technology. The introduction of Onetouch thus enables Doris to perform herself as somebody interested in making exact, personal recordings and thus as interested in monitoring her condition as well as somebody criticizing crude technologies.

However, with a performative understanding we are put in an uncertain, perplexing position where we cannot consider Doris' statements as referring solely to Onetouch; instead they are a product of an interaction between several bodies (Onetouch, Doris, the experiment). Her statements thus both stem from and refer to multiple actors.[146] But this uncertainty also constitutes an opening since it invites us to reflect on the problem of what she articulates as well as the premises of the articulation. But a design oriented concern is also disrupted, since we cannot consider statements such as Doris' as *only* proposals for design that, if they were followed, would make the participant into a satisfied user of the technology. Such statements are considered performative actions of the persons articulating them that enact them as active subjects interested in their condition. So the uncertainty and opening following Doris' statement constitutes an occasion for me to think of her articulations not strictly as representing her opinion on Onetouch and as a proposal of re-design, but as an *event* that emerges through the experiment that I may pick up and reflect upon and use. I consider her statement as *doing* something, namely as doing herself in a specific way and doing diabetes as

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[146] See chapter 1 and the discussion of cosmopolitics.

something that should be accounted for in personal, precise terms, rather than to consider her utterance as saying something about how she experiences Onetouch.

Doris' suggestion can thus be followed beyond the recognition as design proposal. Although I understand her suggestion to express skepticism towards crude descriptions of one's health condition, her suggestion incites in me the importance of writing as an embodied practice of relating to oneself. The practice of writing or recording data is exactly what is lacking from Onetouch as information system and is also what is resisted in the practice of using Onetouch in the experiment. The practice of recording one's condition seems to be regarded as superfluous and tedious collecting of data. When Onetouch is enacted as information system, data is simply there to be evaluated easily, and in the use practice the participants were keen to object to practices that seemed redundant, extensive or of slight importance. Practice is diminished both in the enactment of Onetouch as information system, and it is diminished in the concrete use practice of the experiment – at least as encountered here.

Emphasizing practice

The various performativities: how Onetouch enacts diabetes and the problem of diabetes, the use practice of Onetouch in the experiment, and how participants such as Doris enact themselves and diabetes in specific ways, all constitute *events* that enable us to reflect upon the ramifications of Onetouch in relation to diabetes. It might constitute an obvious concern of how the potential of Onetouch as an information system was not realized in the experiment, and we might consider how this potential could be realized? This concern would then take us into considering how the practices of recording data could be made easier or more efficient. A range of design suggestions might be generated along these lines: Onetouch could be designed so that it would be easy to make multiple entries on medication. This would make it possible to have daily medication entered once and then repeated for as long as one wishes. We might also suggest that software were developed for translating food into carbohydrates, fat etc. so that users could enter what they had eaten in a less decomposed form (no humor intended), and then Onetouch by data retrieval from various databases, would calculate the amount of carbohydrates, fat, protein and calories in the food. Another suggestion, one that was proposed by Bente, was to measure exercise by integrating or relating Onetouch and a pulse meter in one way or another e.g. by blue tooth technology. We might also follow Doris' suggestion and facilitate entering one's own descriptions, rather than have to suffice with the crude ones offered by Onetouch. Along these lines we could relatively easy generate a range of design suggestions with the intent to optimize the use practice of Onetouch, make it easier and more efficient to use Onetouch.

However, to follow such a concern would also be simply to support the understanding of Onetouch as information system as a relevant way of thinking about the problem of diabetes, where the problem is conceived of as a matter of having overview in order to make informed decisions. Underpinning this understanding is an understanding of the person with diabetes as a rational, motivated human actor who will act rationally and take correct care of his or her condition, if provided the right knowledge and information. Moreover, we continue the logic of miniaturization by considering the problem as a matter of decreasing practicalities. We thereby implicitly diminish the importance of practice and its productivity. We diminish the importance of the embodied practice of collecting data as central for the information system to become an information system, not only because the practice of recording data constitutes a crucial ingredient for the system to have data to process, but also and more importantly that to use and make sense of Onetouch as information system is premised by the situated, embodied knowledges produced through the practice of collecting data. This is why the feature on Lifescan's website is poor, since it illustrates a much too general and superfluous problem that would most likely not constitute a real problem for a person who collects data as extensively as the feature presumes.

The practice of attending to one's condition as a concrete, embodied practice of collecting data; attending to one's condition; reporting on it, as in itself a productive practice through which one becomes sensitive to one's condition, is excluded in the promotion of Onetouch as well as in the use practice in the experiment.

However, a performative, posthuman understanding emphasizes practices as concrete material actions that produce knowledges and bodies. Consequently, we are able with a posthuman disposition to argue that it is *through* the practice of recording one's condition by using Onetouch that one may *become* a person with diabetes sensitive and knowledgeable of one's condition. The practice of recording, following Foucault's notion of the production of subjectivities through panopticism and 'technologies of the self', designates the productivity of being submitted to a regime of concerns and embodied practices that bear on the person with diabetes in transformative ways. Following a performative understanding practice thus constitutes a central part of technology in more than one way. Hence managing diabetes constitutes a practice where diabetes is *done* in specific ways, not simply monitored in order to be managed and controlled. It is *through* bodily practices that one becomes a subject in control of diabetes, practices, which includes technologies, although not mainly as information systems, but more importantly as practices. The enmeshment with technologies such as Onetouch constitutes an opportunity to engage in practices that produce novel bodies and understandings.

A performative understanding thus forms a different concern than one that accepts the diminishment of practicalities as a relevant concern. Instead, the argument that becomes relevant is what could this device do to me if I followed its script meticulously? What might I become? What sensibilities, bodily practices and understandings would emerge? This stands in contrast to a concern with identifying aspects that are articulated as cumbersome by participants and accepting them as potential sources for design. It postpones the inclination for design and produces an alternative argument that takes practices as central to technology rather than something to be diminished. This is an argument that centers not on how this technology could come to fit the user, but holds instead *what the user might become through the practice of using the technology.* It is a posthuman de-centered understanding that considers what one is as a product of the practices and relations one engages in. It forms an argument for engagement with others, human and non-humans, in novel ways, as a process of becoming and transformation.

Multiplying Onetouch

What might happen if one followed the script of Onetouch and began e.g. to record every food item one was eating? Arguably, one would quickly learn about amounts of carbohydrates, fat, protein and calories in various food items, and one would most likely also develop a sense of what constituted a healthy meal in terms of these parameters. One's sensitivity towards how various food items together form a healthy/unhealthy meal would be developed and consequently one's understandings of food would change. Or rather more concisely formulated, food would change; it would no longer be food as it once was. Through the practice of accounting for food, qualities would be added to food, what once tasted good might not be that tasteful anymore and vice versa. When foregrounding practice and a performative understanding of practices as enacting reality, reality multiplies as Annemarie Mol has argued. Reality is enacted through practices, Mol argues, and since practices may differ, multiple realities are produced and may co-exist and interact in various ways (Mol 1999, 2002).

When we consider Onetouch as a practice, we can appreciate how diabetes would become different. Diabetes would then entail a range of recording practices that would relate the person with diabetes to his or her condition in specific and novel ways; food would change, medication would change, exercise would change, blood would change, the body would change, tastes, desires, needs would change. Hence to emphasize Onetouch as a recording practice is also to think of it as doing something to diabetes and thus to the person with diabetes using it. Onetouch as a recording practice is contributing to the construction of a different reality with diabetes. Moreover, by formulating this argument for Onetouch as a recording practice, Onetouch is neither rejected nor defended and preserved. It is re-figured and multiplied. I provide an argument that supports Onetouch as a practice that may potentially produce novel bodies and knowledges. Onetouch is provided an argument that provides it with an opportunity to be different.

Consequently, when I argue for Onetouch as a recording practice that may do something *to* rather than *for* the person with diabetes using it, it constitutes a contribution to the reality of Onetouch. I contribute to the multiplication of Onetouch. By arguing for Onetouch not (primarily) as information system, but as a recording practice that could obligate persons with diabetes in a manner that might transform them, I contribute to the enactment of a reality in which Onetouch as a recording practice is provided an opportunity. When proposing such a re-figuring of Onetouch, I also potentially contribute to the enactment of a reality where people with diabetes may consider the practices of diabetes differently than as tedious obligations for supervision. They might instead come to consider devices such as Onetouch as means to become persons with diabetes who are sensitive to diabetes in various ways.

To consider practices as enacting reality, instead of as manipulating a pre-existing reality, has the important consequence that we may consider the present and problems of the present not as something to be transgressed, but re-figured through novel practices and understandings. My argument for Onetouch as a recording practice does not replace Onetouch as an information system, since it will probably continue to be enacted as such by e.g. Lifescan, but nor do I wish to replace it as an information system, since I do not doubt that processing and presenting data may produce crucial insights for users. On the other hand re-figuring Onetouch is not simply to preserve it as an information system; it produces another way of relating to Onetouch, it constitutes an argument for a supplementary enactment of Onetouch. My contribution is thus to add a novel existence to Onetouch that breaks with the paradigmatic understanding of technology as optimization. This is an understanding that, as we have seen, easily turns against technologies such as Onetouch when they induce rather than reduce work, since then they are simply rejected in the use-practices. I contribute to the *becoming* of Onetouch as more and other than an information system by arguing that the practice of recording constitutes an important quality of Onetouch. Thereby I also dismantle the immediate critique of Onetouch as inciting rather than decreasing work, since this practice is refigured as productive rather than as tedious and cumbersome work to be done in order for Onetouch to be realized as an information system. Due to this re-figuring, it is no longer per se a disqualifying aspect that Onetouch induces rather than reduces work, since this practice is figured as what makes one sensitive and attentive to one's condition. Through this re-figuring we are able to recognize many *potential* processes of becoming. The becoming of Onetouch as other than information system, the becoming of technology as productive in forming rather than supporting subjects, the becoming of attentive subjects by being occupied by technology, and the becoming of diabetes and the many aspects it includes through the practices of recording.

All the participants said they participated in the experiment so that they might learn something. They joined the experiment with the intent to be affected in some way. They positioned themselves in relation to something else (the experiment) so that it might have a transformative effect on them. But Tanja was the one participant who was most articulate and active around this strategy of becoming by being occupied by others. In her practice Onetouch was enacted exactly as a device that acted upon her, made her into something other than she was. She enacted Onetouch as productive in this manner and Onetouch thereby constituted a means to make her into something she is motivated to become, a person living a long and healthy life with diabetes.

Affirming the present

A performative re-figuring as I have attempted here is interventionist since it offers another way of thinking about, arguing for and using Onetouch. It neither transgresses the present nor preserves it, but adds to it. It provides Onetouch with an opportunity to become differently than intended and promoted by Lifescan and thus to become usable by other reasons and means than as an information system. A performative re-figuring differs importantly from design as technology development but not from design considered broadly as transformative intervention in practices, I argue. It differs from design conceived as technology development because it is not about transgressing a present technology by re-designing it to accommodate for its seeming deficiencies; designing a new and better version of Onetouch. Through a performative re-figuring of Onetouch, Onetouch is not replaced by another version, but is multiplied and thereby provided the opportunity to be different without being concretely re-designed.

This also constitutes an important difference between STS and Design. Immanent to STS, I argue, is a care for the present not as conservatism, preserving the present as it is, but a care for the existing, since the existing is not finished, complete or stabilized and thus does not constitute a firm ground to leap from or to criticize (Stengers 2000, 2005, Latour & Serres 1995). The present is continuously made and re-made and can thus be intervened in, in multiple ways. In contrast, immanent to a will to improve and transgress the existing in one way or other, which I consider to be a central concern in design, is the assumption that the present is well-defined, stabilized and finished, so that if we identify deficiencies, then we are legitimized to attempt to transgress the present. However, the will to improve things and transgress the present is thus also immanently premised by a critical assertion of the present. The will to improve the present thrives on recognizing the present as problematic and as in a state of deficiency. Arguably, this constitutes a central problem, since it means that the will to improve things implicitly incites an attitude towards seeing the present as deficient. STS, I argue, is, on the other hand, interested in making sense of the present and thereby immanently contribute to the production of an affirmative, positive understanding of the present.

Chapter 11:

Managing a Relation

> "I pushed my soul in a deep dark hole and followed it in.
> I found myself crawling out as I was crawling in.
> I got up so tight I couldn't unwind.
> I saw so much that I blew my mind
> I just dropped in to see what condition my condition was in.
> Yeah, yeah, yeah - what condition my condition was in."[147]

As we recall my research was premised by an uncertainty with regards to what constitutes the problem of diabetes. So instead of assuming a general definition of an obvious problem with the ambition to provide a solution, I have attempted to concretize and particularize *how* diabetes is a problem. In order to do so I offered my participants an already marketed solution, Onetouch. Onetouch was introduced in order to provide the participants the opportunity to resist or render irrelevant a device like Onetouch, while also providing Onetouch and the participants the opportunity to realize Onetouch as a meaningful and relevant technology. Posthuman STS constituted an anti-essentialist device attentive to how people with diabetes enact their condition. What will occupy us in this last conclusive chapter is the potential consisting in having an ambiguous relation to ourselves, an ambiguous relation, as the citation above expresses, where one is able both to be a body and to take this body into consideration.

Peculiarities and Enactments

The stories I have presented may matter in many ways, probably and hopefully also in ways that I have not reflected upon. I will argue how they illustrate peculiarities and enactments.

Peculiarities. Some of these stories are peculiar; they disrupt and complicate common understandings of the problem of diabetes. The stories about Bernd, Anders, Bente are predominantly such stories. With Bernd we see how

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[147] 2'nd verse and chorus line from the song "Just Dropped in" performed by Kenny Rogers & The First Edition.

competence and incompetence are intertwined. How competence may be considered as a cause of incompetent actions. This story challenges and complicates (but not falsifies) the idea of being competent and skilled and therefore presumably in control of one's condition. It thus complicates the idea of empowering people to an extent where they fully master their condition.

The story about Anders tells how one can become passionate about achieving an identifiable goal, how a medical standard can play a central role in forming the actions and aspirations for a person and in fact overshadow medical advice provided by the healthcare practitioners. Moreover, the story de-stabilizes medical standards as standards and shows how they are subject to negotiation and translation in clinical practice.

Bente's story tell how despite the fact that she has an inherently embodied relation to diabetes that requires that she measures her blood sugar extensively and that she is very sensitive to her condition in many ways, she nonetheless experiences her condition as generally unruly.

These three stories disrupt common understandings such as: "Competence leads to correct living", "Medical standards are crude and objectifying and patients should be relieved from them", "Being highly attentive to one's condition leads to control".

The stories about Doris and Edwin tell how diabetes may be policed or considered dubious. Doris insists that diabetes should not be allowed to control her life, while inevitably it cannot but interfere in her life. Last, Tanja illustrate an approach to diabetes where diabetes is something that should be *made* to matter and where she is to *become* a person for whom diabetes matters.

Enactments. I started out being uncertain about the problem of diabetes and I still am, however it seems that how diabetes constitutes a problem is inherently relative to the person with diabetes. Diabetes is translated in and through their practices. The six stories have in common that all the participants are active in forming how diabetes should matter to them and moreover that diabetes is played out and enacted differently in every story. How diabetes matters and is done differs between the stories. In Bernd's practice diabetes is enacted as an object controlled by Bernd to such a degree that control seems to escape him. In Anders' case it is enacted as a medical standard. In Doris' practice diabetes is enacted as a private matter: she seeks to police how it should be allowed to interfere in her life. In Bente's practice diabetes is embodied and unruly. In Edwin's practice diabetes is enacted as having a dubious existence and in Tanja's practice diabetes is enacted as something that should be realized in a manner so that she becomes able to control it. Arguably, these enactments of diabetes are all thoroughly intertwined with materiality, diabetes is not enacted as the participants wishes rather how they enact diabetes is premised in specific ways. Bernd's incompetence is premised by a long history of living with diabetes, of having acquired experience. Edwin, in contrast is relatively newly diagnosed and has no or few subtle symptoms. Doris has a longer history with diabetes but also has only few weak symptoms. Bente is hypersensitive to insulin and to her condition due to her little body. Anders lives a life of scarcity and few activities and diabetes is at the center of his attention. Tanja, is the youngest and thus has to live a long life and it is thus of crucial importance to her that she seeks to live healthy with the condition.

In accordance with a performative ontology, practices do not manipulate pre-existing unified objects, but objects emerge through practices. Following a performative ontology objects thus multiply. Objects are not 'really' singular, unified objects pre-existing practices, but emerge through practices and conseqeuntly from different practices thus follows different objects. With a performative ontology it thus constitutes an important concern how practices are practiced.[148] How diabetes becomes for the participants is thus intertwined with their practices. This allows us to formulate the problem of diabetes as a matter of managing a relation. The problem of diabetes can thus through a posthuman, performative ontology be formulated as: *how to manage a relation between oneself as a person with diabetes and diabetes.* It is not a matter of: how to manage and control the object diabetes, but how to manage the *relationship* between oneself and diabetes. To manage a relation is thus to attend to (at least) two entities simultaneously and thus to the becoming of diabetes and oneself as an effect of the relation. The person with diabetes and the condition is thus both a product and a producer of one another

To formulate the problem in this manner might seem unspecific and regressive, instead of suggesting concrete ways of relating to diabetes through

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[148] This concern has occupied me throughout the dissertation. For instance my concern with studying diabetes without presuming the problem of diabetes to be evident and given is related to this concern.

specific practices and technologies. But I will argue that to consider the problem of diabetes as a matter of managing a relation can in fact be considered productive.

Enactments of diabetes

So what does it mean to consider the problem of diabetes as a matter of managing a relation? Arguably, when considering the problem of diabetes as a matter of managing a relation it is premised by a performative understanding of diabetes as enacted. Diabetes thus becomes through the practices of managing diabetes. When we consider e.g. Edwin we see how diabetes as a dubious object, difficult to take seriously is reproduced and enacted as dubious by Edwin. Because he cannot immediately sense the condition he is reluctant to follow a diet, measure his blood sugar etc. and consequently diabetes continue to be of a dubious, silent character (until a point were it becomes manifest through physical impairment). In contrast, for Tanja, (thirty years younger) the dubious, silent character of diabetes constitutes a reason why diabetes must be concretized so that it becomes able to matter to her in ways that make her live healthy with the condition.

A performative understanding of diabetes differs importantly from how diabetes is commonly addressed in medical science and medical sociology. The concern in the medical science version is with diabetes as a physiological object. Studies that report on this are typically about how specific clinical practices, medical treatments, self-monitoring of blood glucose etc. affects the physical condition. Such studies includes a range of actors and technologies including the body and person with diabetes in order to be able to determine whether this or that intervention proves to improve the physical condition. What is managed is thus the physical condition. (Bolen et al. 2007, Derosa et al. 2007, Florkowski 2002, McCormick et al. 2002, Mudaliar et al. 1999). This type of literature is found in medical journals and adheres to a positivist, natural science and quantitative research tradition.

Medical sociology focuses on the lived experiences of people with diabetes; how people manage to live their life with diabetes in terms of how it affects the identity and selfhood of the person, her integrity, self-esteem; how people restructure their lives and/or the disease, the personal transformations they undergo etc. (Delmar et al. 2006, Nyhlin 1990, Richardson et al. 2001, Wikblad et al. 1992) Contributions of the medical sociological view often argue that a strict medical science understanding of the condition, not only misses out on the holistic aspects and implication of disease, but may also be counterproductive in its treatment of the condition by objectifying and alienating the person with diabetes (Leder 1998). In these accounts healthcare practitioners (and especially physicians) are often encouraged to become more sensitive to the intricacies of diabetes and the lived experiences of the person with diabetes in order to treat the condition more holistically. This type of literature is found in nursing journals and adheres to the human and social sciences.

Together these two approaches, the natural science and social science, reproduce an understanding of an objective physical condition in the body that involves, cells, the pancreas, the metabolism, blood, insulin, sugar etc. and a subjective experience of the condition that refers to psychosocial aspects. We have thus paradigmatic Kantian relation between an object 'out-there' (or rather in-there, but still an object detached from the subjective experience of it) and a subjective experience of the object that refers to a psychosocial realm. As Mol has argued such ingrained dichotomized divisions consolidate and re-produce a neat bifurcation between the object and the subject. Thereby each tradition can claim their own scientific ground and be in disagreement over what should matter the most, but nevertheless they agree on and re-produce through their opposition the dichotomous ontology that assumes an objective reality of the object and the subjective experience of it (Mol 2002). Both subscribe to the understanding of the object of diabetes as a fully-fledged object that pre-exists the practices through which it is encountered. Medical science addresses the object as such and medical sociology how the person with diabetes experiences life with the object – in both cases the object diabetes is presumed to have a specific objective, ontological status separate from practices and doings.[149]

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[149] So am I suggesting that diabetes does not preexists the diagnose? I would not disagree that something that *comes to be conceived as the cause of diabetes* preexists the diagnosis, but that is not diabetes. The crucial point is that the state prior to the diagnosis is entirely different from the state established with the diagnosis. Prior to what is to become diabetes are e.g. thirst, frequent urination, tiredness etc. but it is only after the employment of a whole range of technologies, procedures, practices and understandings that furnish the diagnosis that it becomes diabetes. After the diagnosis all sorts of practices and technologies (medical treatment, medication, blood samples, blood sugar measurement devices etc.) are employed. To insist that diabetes is inherently the same before and after the diagnosis constitutes in STS not a rigorous perception, but an inherently reductive, imprecise

The problem relating to my experiment and the accounts provided by the participants is that where medical science may be accused of being reductionist and not paying (enough) attention to the person with diabetes, the sociological approach tends to be anthropocentric. Managing or coping with diabetes, as it is often termed in these accounts, is addressed in terms of the human being as sensitive, active, emotional, a subject that experiences frustration, loss, guilt, blame, self-esteem, integrity, dignity, pride etc. We are not considering what the condition *does* to the person since this would seem to adhere to the medical regime, but how the person *experiences* and *interprets* being inflicted by the condition. So what these studies do is in fact to speak about how people with diabetes copes with the sociological aspect of having diabetes. The notion of the human subject as it is defined in mainstream sociology is presumed in these studies.

Moreover, the anthropocentrism of mainstream sociology naturalizes emotions by presuming people's emotions to reside in them: Emotions are 'activated' by external causes. Emotions such as guilt, loss, self-esteem etc. are again presumed to exist as a preinstalled repertoire in the subject. Emotions are then activated when something occurs to the subject. Just as diabetes as a physiological object is assumed by medical science so are emotions delegated an objective essentialist quality in sociology.

And just as the physical object that exists separate from the practices in which it emerges is questioned in a posthuman understanding, so are emotions. Emotions are not natural, universal, a-priori entities, they are not a slumbering repertoire awaiting to be activated, but what we cultivate and produce socially and culturally.[150] Emotions are thus just as much something that *causes* things to be felt and experienced in specific ways as they are *caused* by other factors. Or in Vinciane Despret's terms, elaborating on the American pragmatist William James'

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retrospection that relies on a persistent 'bracketing out' of practice. To hold that there is no difference between diabetes before and after diagnosis is to subscribe to an inherently imprecise and crude understanding of the phenomena. See Fleck 1979, Latours (1999) elaboration of Pasteur's work and the aspect of time, See also Barad 2007 and her notion of intra-action and agential realism that draw philosophically on Niels Bohr's work, feminist studies of science and queer theory.

[150] Despret exemplifies how specific emotions such as e.g. anger, which we in the west considers to be universal cannot be said to exist in the emotional repertoire of the Uktus Despret 2004b. See also Lutz & Abu-lughod 1990.

understanding of emotions: "An emotion is not what is felt but what makes us feel." (2004a: 127).

In a performative understanding medical science does not uncover the object of diabetes and people do not experience having diabetes, instead both of these practices *enact* diabetes. Diabetes is enacted in specific ways both through the practices of medical science and medical sociology. The fact that many people can have undiagnosed diabetes for years illustrates how the condition in order to be realized needs medical apparatuses. Similarly, people's emotional experiences of having diabetes are not merely responses to having diabetes, but also ways of enacting themselves and the condition in particular ways. Through anthropocentric studies focusing on how people cope with diabetes emotions are just as much produced as they are recorded. The emotions that people experience are ways of managing diabetes, feeling depressed is a specific way of managing diabetes, re-gaining self-esteem is a matter of handling diabetes etc. since these experiences are consequential in one way or another for how you relate to diabetes and for the actual practices you exercise

An undetermined relation

When managing diabetes is considered a relation then one is simultaneously a producer and a product of this relation. One is ambiguously positioned. However in accordance to the American pragmatist William James: "Our body itself is the palmary instance of the ambiguous. Sometimes I treat my body purely as a part of outer nature. Sometimes, again, I think of it as "mine", I sort it with the "me", and then certain local changes and determinations in it pass for spiritual happenings" (James 1958:153).[151] James considers at length how emotions have bodily effects, how e.g. anguish and grief result in specific bodily postures and sensations. And equally, he speaks of how specific positions of the body, ways of holding ones head, walking with determination etc. afford specific emotions. James' thus emphasizes the permeability and mutual production of the body and the world:

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[151] Similarly, Annemarie Mol and John Law have pointed to this ambiguity by referring to the different relations we can have to our body as an object – something we have and which can be accessed in specific ways by others e.g. medicine; as an subject something we are and last as something we do through the various practices in and through which it becomes in specific ways (Mol & Law 2004).

> "We see that joyous thoughts dilate our blood-vessels, and that a suitable quantity of wine, because it dilates the vessels, also disposes us to joyous thoughts. If both the jest and the wine work together, they supplement each other in producing the emotional effect, and our demands on the jest are the more modest in proportion as the wine takes upon itself a large part of the task." (James quoted in Despret 2004a: 127)

Vinciane Despret comments on this citation in the following manner:

> "This is an experience of 'making available' that is described here an experience by which both the body and what affects it produce each other. Each of the events (wine, thoughts, vessels, jests) creates an occasion for the others: should we say that the wine made us happy or that we made the wine joyous? Each one authorizes the others and is authorized by the others. The world disposes us to feel, and our body makes the world available. Our feelings dispose our bodies, our bodies dispose our feelings." (Despret 2004a:127)

The ambiguity of our body constitutes an important "undetermined" experience where: "I can no longer know what is the world and what is I, an experience in which the "I" is in the world and the world is in me." (Despret 2004b: 209). By such an undetermined relation James poses our relation to the world as a problem, but an inherently productive and constructive problem. By pointing to the ambiguities of the body and its relation to the world, he, according to Despret, "invite[s] us to a new relationship to ourselves and to the world and he wants to help us construct and invent the access to it." And it is "a question of making the experience less obvious, of offering us the freedom and confidence of being able to construct it differently." (Ibid. 204).

The dichotomy between the world and me is in many ways a practical and inevitable one, but James (in accordance with a posthuman understanding) insists that this dichotomy is exactly a practical arrangement, a way of relating to the world and not how reality is essentially. The dichotomy is a *product* of ways of thinking and relating to the world, not *caused* by a dichotomous reality. Ambiguity with regards to what adheres to what thus constitutes the premise for cultivating other relations to/in the world, other ways of being.

When we can appreciate that the wine makes us joyous just as we in return make the wine joyous, then it is not a paradox to say that we are in the world and the world is in us, but a productive relation. It is a relation of making and experiencing the world as the process of meeting and being met by the world. Our experience of and relation to the world is not given or determined, but constitutes itself a relation to be constructed and invented. Our emotions and experiences are themselves cultivated and may thus be attended to and potentially transformed. This is not to say that we may construct the relation as we desire, but that we may *affect* it and be *affected* by our intervention with it. This constitutes a central premise of an undetermined relation to existence, namely, the aspect of being available to the other. The point is not that I can determine how I will experience the world and thus as one might be tempted to assess this argument, as either solipsism or reality as a blank sheet upon which culture inscribes its meaning (Butler 1993, Barad 2007). The crucial point is that if one appreciatively engages in a relation where I may affect how the world becomes, then I also submit myself to a process of becoming. I partake in a process that may affect me in return where my concerns, understandings, practices, needs and desires may be transformed. To appreciate an "undetermined" relation to existence implies that what is in the world as well as in me is undetermined and may be continuously configured. The self and the world are symmetrically destabilized. Following James we do not simply perceive reality, we do not simply exist, and we do not simply feel. We make perception possible, we come into existence and we make emotions felt.

Hence, what is not felt, what does not exist, continues not to be felt and exist, if one does not cultivate a relation that enables it to be felt and exist and oneself to be sensitive to it. Considered as such what is not felt or experienced by me, whether a chronic condition or the concerns, problems and passions of others, are not simply to be understood as due to the dubious existence of those entities, but refer just as much to my inability to be affected by and be sensitive of those entities and concerns. When we understand it in this manner then what is not felt constitutes a challenge and an invitation to become sensitive and transformed rather than a solid basis for preserving one's position and understanding.[152] With an undetermined relation to existence our concern and

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[152] In the words of Vinciane Despret: "What others are, what they have produced in knowledge and in passion, allows us to think ourselves differently. But this knowledge does not tell us *how* to think ourselves differently, *how* to adopt the heritage that has become the matter of thought" (Despret 2004b:17)

challenge becomes how to ‘become available’ to matters so that I can become sensitive to and implicated by those matters. We may thus consider diabetes to be a matter of how one positions oneself in order to become implicated by diabetes so that living healthy with diabetes becomes not merely an ambition, but an inclination and a desire.

The problem of essentialism

When the object of diabetes is enacted and thus multiple we are positioned differently than when subscribing to an essentialist understanding of diabetes as encountered and re-produced in medical science and mainstream medical sociology. Diabetes is destabilized as object, which might be considered as a potential cause for frustration. On the contrary, following James, it constitutes an invitation to engage in an interested relation to diabetes, that is, one of mutual transformation. The point is that with the notion of reality as multiple, practices and actions matter profoundly, whereas with an essentialist ontology practices are ‘only’ ways of manipulating the object. The object itself stays the same. With an essentialist understanding it is possible to cultivate an inherently ‘uninterested’ relation to diabetes. This is a relation where the disease is an object in me that I ought to treat in a specific manner and where my experience accordingly is one that although in some sense is caused by the appearance of the condition, is still my subjective experience adhering to me. What follows from thinking of reality as multiple and enacted is that ones actions always matter (however not in a determinist sense). Thereby one is incited to act and affect things while simultaneously not expecting that things fall out exactly as one may hope. Arguably, in such an ontology lack of univocal, singular objects do not constitute a source for frustration, since objects are not presumed to be singular in the first place. Objects are not invested with these qualities.

In contrast, an essentialist ontology furnishes experiences of frustration and perplexity when things and objects are not singular and univocal; when reality is perplexing, complex and paradoxical. For instance, Edwin’s relation to diabetes is premised by an essentialist ontology and arguably it constitutes a problem that a disease, supposedly a bad and painful matter, does not express itself as such or at all, and incite him to live in a specific manner that would relieve the pain and thus be healthy. The problem for Edwin is not primarily that type 2 diabetes is silent, but that he (prefers to) subscribe to an essentialist understanding of reality. If Edwin did not expect diabetes to act in the manner he considers a ‘real’ disease to act then the source for his frustration and wonder would be lacking. He would instead be faced with a reality in which things can exist and be harmful and yet not be evident and painful.

Similarly, without an essentialist understanding of diabetes as (essentially) a singular, univocal object the source of frustration when it acts as unruly and complex is emptied out. Accordingly, Bente who continuously experiences diabetes as anything but a singular controllable object is not profoundly frustrated, she has become used to diabetes being a trickster and instead her relation to her ‘frustration’ has become a constructive one of ‘sharing it’ with the healthcare practitioner. She employs her frustration in a manner that makes her into an accountable subject and equally one who is considerably attentive to her condition when it is unruly. Without essentialist foundations one is not by necessity left to perplexity and confusion,[153] but might just as well be inclined to produce relations and interact with the world in order to contribute to the enactment of reality in specific ways. In order to become sensitive to those things that should or can be made to matter. When ‘experience’ and ‘object’ is considered separate, then experience does not *matter* to the object and the object does not *matter* to experience. They do not make a difference to the other and they are thus not decisively implicated. To think in terms of Spinoza it constitutes a sad and impoverished relation when these bodies are by definition unrelated and unaffected by the other. However, when experience and the object are considered as being implicative and affective for the other, then the relation is joyous and productive, since these bodies may then be conjoined in ways to produce a novel and enhanced body:

> “We experience *joy* when a body encounters ours and enters into composition with it, and sadness when, on the contrary, a body or an idea threaten our own coherence.“ (Deleuze 1988:19)

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[153] An argument often posed against relativist, postmodern theory as dissolving foundations and supposedly leaves us with no sense of right and wrong and then ’anything goes’. For a compelling argument and refusal of such slippery slope arguments. See Smith 1988, 2005.

Implications and contribution

To think of diabetes in terms of managing a relation involves the double role of producing and being produced by diabetes, which involves the continuous movement between and assessment of "how I enable the other to become and how I become by implication of the other?" When we appreciate an undetermined relation to the world, then we may also formulate what can be considered a good relation to diabetes in these terms. An undetermined relation to diabetes is one where what diabetes is and may become is not given, but must be explored and invented. The premise is that diabetes has a minimal existence, however in an inherently relative, undefined, partial and yet to realized and concretized form.[154] Equally, this means that what diabetes may become and how the person with diabetes may become is an undecided, open and yet to be realized matter. The diagnosis of diabetes is trustworthy, not despite, but *because* of the various testimonies and procedures required for it to be stated. The diagnosis of diabetes thus constitutes an event that inevitably transforms what follows. But how and in what ways, is undetermined and thoroughly dependent upon and intertwined with the practices through which the condition is enacted.

I consider Tanja's enactment of diabetes as exemplary and good. Not because she seems keen to live healthy with diabetes, but because she engages in a practice of constructing and realizing diabetes in a performative manner. In her practice diabetes is undetermined in many ways. Her rationale is that since diabetes is silent and her actions influential on how diabetes may become, then her transformation into a person who lives in a healthy and correct manner with diabetes is decisive. In Tanja's understanding the dubious existence of diabetes is not puzzling, at least, not to the degree, that she doubts the existence of the condition.

Moreover, Tanja's practice is inherently de-centered and interwoven with diabetes. We might be tempted to think of Tanja as a privileged person who understands the importance of living healthy with diabetes and therefore takes the necessary actions; that she is a autonomous rational subject facing up to reality. However, although Tanja may be considered as privileged in many ways, I will

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[154] See Gomart 2002.

argue that such an understanding is in fact somewhat superfluous and that she should be accounted for differently. In my view it constitutes a better and more fine-grained understanding to consider Tanja as being occupied with 'becoming available' to diabetes, a practice of exposing herself to diverse influences, a process of risking herself and thus of abandoning control. An attempt to decide who or what is in control and determining the other is reductionist. Tanja moves and positions herself in a manner so that she may be influenced and affected by diabetes concerns. Her agency is exercised by how she enrolls herself in diabetes activities that potentially influences her body and identity in consequential ways. She thus submits herself to transformative practices. She engages in a mutual affective relation.

Gomart and Hennion show how the agency of drug users and music lovers and the dispositif that enable their passions to be exercised, is decisive for the drug or music to affect the user (1999). To be affected by something whether a drug, art, other peoples opinions or diabetes, adheres thus neither fully to the one or the other, Gomart and Hennion argue. A beautiful piece of art is not beautiful because of convention or because of its intrinsic qualities. It becomes beautiful and enjoyable through the construction of an affective relation, where the perceiving subject and the perceived object 'become available' to one another, where they become attached. In Gomart and Hennion's account drugs do not simply induce an effect on their users due to their chemical (essential) qualities, drugs acquire their specific effects through the dispositif and a careful organized use practice.

Similarly, Tanja is engaged in the construction of a dispositif and a diabetes practice in which diabetes acquires a quality that makes it an inevitable part of her life. Tanja submits herself to a process of becoming a person that takes adequate care of her condition. I consider it important to articulate her strategy as one that differs from an understanding of the autonomous, capable modern subject, but is about the formation and performance of an actor who is sensitive and available to living healthy with diabetes. Tanja's strategy is more adequately conceived as a matter of relieving herself of control and exposing herself to diverse activities that may affect her in a manner where diabetes becomes her central concern. With Pickering's notion of *dance of agency* we may consider Tanja as engaged in a dance of agency in which she moves or positions herself in a manner where diabetes concerns may affect her and thus transform her (Pickering 1995). Her agency is thus exercised in the service of becoming available to other agencies. She acts so that she may be affected and transformed, an inherently posthuman de-centered process.

But what does this appreciation of Tanja's practice imply and do? We become able to consider the resourcefulness of an undetermined relation to a chronic disease like diabetes when this uncertainty is accompanied with a performative understanding of the object as multiple. This also means that the archetypical figure of the well-regulated person with diabetes is not a repetition of the modern, rational autonomous subject, naturally inclined to live healthy with diabetes and will do so if provided the tools, skills and knowledges. My archetypical figure is one who is modest and uncertain about what is 'in the world' and 'in her'. S/he neither doubts that which does not seem to have a distinct objective quality or considers what seems to have a distinct objective quality as unable to undergo transformation. S/he is thus undetermined with regards to what diabetes and s/he as a person with diabetes may become and is thus occupied with inventing a life with diabetes through diverse practices and activities. This figure is de-centered since s/he exercises her agency in a manner that exposes her to other agencies.

The diabetes nurse HN remarked after the workshop we held as part of my fieldwork that Tanja had a great attitude and was a "dream patient". I wish to emphasize that although Tanja may be considered a dream patient because of her motivation and dedication to live healthy with diabetes, she constitutes the heroine of my experiment because she is *interested* in diabetes. Recalling Isabelle Stengers' definition of science as interesting, Tanja's relation is one of interest in the exact sense that it implies risk. She has an interested relation with diabetes because she submits herself to situations and activities that may transform her, in fact with the purpose of transforming her.

But am I not with Tanja arguing for a relation where one is continuously occupied with diabetes? Is this a good relation to a condition - is it preferable? Or is it not rather enslaving the person with diabetes to a life dominated by diabetes? But what does it mean to be dominated by diabetes? Is life not thoroughly affected and transformed from the moment the diagnosis is posed regardless of how one acts from then on? Is diabetes not present in every activity and part of life as Doris also stated, despite her attempt to police the condition? Most of the participants at one point stated "that everything in life should not be about diabetes". Both Bente and Edwin stated this, which is quite interesting since how diabetes affects and is part of their individual life differs considerably.

The fact that Bente, whose condition is thoroughly embodied and affects her life substantially, can say this is not only amazing but affirmative and up-lifting. One might argue that it is sad because it testifies that she is not able to see how affected she is by diabetes, but I consider it to be affirmative and up-lifting because it shows how you may be thoroughly implicated by diabetes and *still* consider yourself as leading a life where "not everything should be about diabetes". The positive aspect is that Bente by her statement testifies of life thoroughly implicated by diabetes and *still* she does not consider herself to be enslaved by the condition. It testifies of the rich potential and complexity of the body and identity to become in a manner where the person with diabetes does not experience her life as dominated by diabetes, although it seems so to an outsider. It shows how it is possible to live a life that to others seem thoroughly dominated by diabetes but however is not experienced as such for the person in question. Why be concerned about being dominated by diabetes if domination is inherently relative and enacted in practice? If what one might consider to be an enslaved life can be lived unproblematically by another, is this not at least an invitation to consider one's own standards and concerns and thus to risk that they are transformed? Furthermore, and in the last instance, are we not always already dominated in multiple ways and does a concern with not being dominated by a chronic condition not also constitute enslavement?

I consider Tanja's story and the stories and discussions presented in this dissertation to constitute a contribution to diabetes practices since they allow us to consider the problem of diabetes to be multifaceted and thus to have multiple sites for intervention and transformation. An undetermined relation to diabetes is one that enables diabetes to become something other, more, else, different than a disease and thus something to live and exist with in ways where the multiplicity of diabetes and of ones body and identity constitutes a vast resource for novel existences. This constitutes a re-figuring of what it entails to be a person in control of diabetes. Control becomes rather a matter of mutual configuration and entanglement that produces affective bodies sensitive to one another.

Conclusion or tautology?

I started out with relationism as articulated in posthuman STS and I end up with relationism by articulating the problem of diabetes as a matter of managing a relation. Have I not thus produced tautological research? Maybe, however it depends on what we consider the end product of research to be. What has been produced is six accounts of diabetes that in various ways illustrates the enactment of diabetes and the identities, bodies and persons with diabetes. The empirics do not constitute empirics in a traditional sense as informing theory or from which we may derive a deeper understanding of the matter. Neither are the stories, not just or merely evidence for how things 'really' are. No, they constitute themselves a product of a specific concern, a specific set-up and a disposition (a posthuman ontology) that serve to open up and destabilize what it might mean to live with and practice diabetes. To consider diabetes as a matter of managing a relation constitutes an uncertainty that allows diabetes and people with diabetes to engage in affective processes of becoming.

Studying diabetes practices posthumanistically thus produced accounts of the co-constructive and performative aspect of managing diabetes, which in return allowed me to argue for various re-figurings in relation to diabetes treatment. It has enabled me to argue for a multiplication of Onetouch and for a relation to diabetes that emphasizes the potentials in having an undetermined relation to the condition, where a posthuman de-centered relation to diabetes constitutes an 'interested' and productive relation. The stories and discussions constitute a contribution to considering diabetes practices as performative enactments. Furthermore, the experiment enabled us to consider what might constitute good enactments of diabetes. Tanja has been emphasized as engaged in an interested relation with diabetes. I have argued how her relation can be considered as posthuman and de-centered and has in this manner provided an argument in support both of Tanja and a posthuman disposition. The stories overall contribute to support a posthuman disposition and the argument made emphasizes and insists that to produce arguments and understandings that enable us to think differently about a problem, constitutes an important and concrete contribution.

Allow me to conclude with saying that, although Tanja, may be considered the heroine of the experiment and other participants has been given lesser roles, they were all engaged in cultivating affective relations, since they participated in the experiment. And all of them articulated, when I asked them why they participated in the experiment, that they did so because “they might learn something”. All of them were thus exercising their agency in order to become available to the agencies of the experiment; in order for diabetes to matter to them in potentially novel and transformative ways.

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* Not included in this publication for reasons of confidentiality and extent but may be retrieved by request directed to the author.

Appendix A

Type II Diabetes og ny teknologi

Vi vil gerne undersøge hvordan en ny type blodsukker måleapparat, der kan registrere diabetes relevante oplysninger, påvirker og forandrer dagligdagen for type II diabetikere.

Undersøgelsen indbefatter at du bliver introduceret til den nye teknologi og derefter bliver interviewet fem gange i løbet af efteråret og vinteren 2005-2006 ca. hver 14 dag. Interviewene eller samtalerne vil have en varighed på ca. 1/2-1 time pr. gang. Altså i alt ca. 5-6 timer. Desuden vil vi også gerne følge dig når du i den samme periode går til diabetes behandling.

Teknologien der vil blive introduceret er Lifescan's nye blodsukker måleapparat Onetouch UltraSmart. For at deltage i undersøgelsen skal du være vant til at bruge et blodsukker måleapparat. Apparatet vil blive stillet gratis til rådighed.

Interviewene vil blive foretaget af sundheds-IT forsker Peter Danholt. Interviewene vil blive optaget på bånd og blive behandlet anonymt.

Vi håber at du vil deltage i denne undersøgelse, men understreger at det er frivilligt. Hvis du ikke ønsker at deltage vil det selvfølgelig ikke have nogen indflydelse på din behandling.

Undersøgelsen er et led i et større forskningsprojekt der handler om IT i sundhedsvæsnet. Projektet hedder sundhedsit.dk. Projektet har kun forskningsmæssige og ingen erhvervsmæssige interesser i undersøgelsen eller teknologien.

Med venlig hilsen

Peter Danholt	HN	JM
Ph.d. studerende i datalogi	diabetessygeplejerske	overlæge
Roskilde Universitetscenter		

Hvis du vil deltage i undersøgelsen, beder vi dig skrive under nedenfor.

"Jeg bekræfter hermed, at jeg efter at have modtaget ovenstående information såvel mundtligt som skriftligt, indvilliger i at deltage i den her beskrevne undersøgelse. Jeg er informeret om, at det er frivilligt at deltage, og at jeg når som helst kan trække mit tilsgan om deltagelse tilbage, uden at det påvirker min behandling”.

Dato:		Underskrift:...

Navn: ....
Tlf. nr. , gerne mobilnr.: ....

Appendix B

Kvalitativ undersøgelse af introduktion og brug af mobil teknologi i behandlingen af Type II diabetes

Introduktion

Behandling af type II diabetes består i en kombination af farmakologisk og non-farmakologisk intervention. Den non-farmakologiske behandling består i at anspore og uddanne diabetikeren til livsstilsændringer. Der er ingen evidens for effekten af livsstilsændringer, men der hersker en udbredt enighed blandt diabetes behandlere om rationalet i denne intervention. Udfordringen relateret til livsstilsændringer består i at gøre disse vedvarende. Moderne teknologi, såsom mobile computere, udgøre et potentiale i at understøtte og vedligeholde livsstilsændringer. Sådanne teknologier giver mulighed for 1) registrering af diabetes relevant data og dermed 2) patients og behandlers tætte overvågning af lidelsen. En overvågning, der kan danne 3) grundlag for et tættere samarbejde mellem behandler og patient. Det er derfor relevant at undersøge, hvorvidt et sådant potentiale indfries i praksis. Det indebærer at undersøge hvorledes diabetikere og behandlere i *praksis* anvender en sådan teknologi. Ligeledes er det relevant at undersøge hvordan teknologien påvirker og forandrer behandlingen og den praksis, der knytter sig til at leve med og håndtere diabetes. Sådanne indsigter kan bidrage til for at udvikle tilgange til at implementere og designe sådanne teknologier.

Baggrund

Studiet tager afsæt i en konstruktivistisk forståelse af teknologi og sygdom. I relation til teknologi indebærer det en forståelse af at teknologi ikke er et neutralt redskab, men at teknologi forandrer og påvirker den kontekst den indføres i og de aktører, der anvender den på en lang række åbenlyse, såvel som subtile måder. Teknologi og socialitet er i et sådant perspektiv sammenknyttet og står ikke uden for hinanden. En sådan *socioteknisk* forståelse indebærer at en fungerende teknologi altid er et *udkomme* af en proces, hvor mennesker og teknologi er blevet gensidigt tilpasset. (Bijker & Law, 1992; Pickering, 1995)

Type II diabetes er ofte relativ stum og mange diabetikere har ikke tydelige eller smertefulde symptomer. Ligeledes er diabetes som andre kroniske lidelser en tidslig proces, hvor betingelserne og omstændighederne løbende forandres (Star & Bowker, 1997). Disse forandringer kan være, nye behandlingstilbud, nye præparater, nye teknologier, ny information og rådgivning (om kost, insulin, medicin, motion mv.), komplikationer (eller bedring) som følge af sygdommens udvikling eller af kroppens, forandringer i patientens hverdag (arbejdsmæssige, familie relaterede mv.) etc. Derfor kan man forstå behandlingen af diabetes, ikke blot som behandlingen af en bestemt lidelse i kroppen v.hj.a farmakologisk såvel som non-farmakologisk behandling, men ydermere som bestående i at 'virkeliggøre' og *konstruere* lidelsen for patienten i en given nutid med henblik på at minimere fremtidige komplikationer.

Et konkret teknologisk værktøj kan medvirke til at konstruerer lidelsen for patienten. Ligesom at teknologien kan støtte patienten i at håndtere kompleksiteten forbundet med at leve med diabetes. Men følgende en socioteknisk forståelsesramme er det ikke givet at teknologien *reducerer* kompleksitet, den kan lige så vel bidrage til at forøge kompleksiteten. Ligeledes kan teknologiens effekt over tid aftage for nogen i nogen sammenhænge, og tiltage for andre i andre sammenhænge. Et blodsukker måleapparat kan medvirke til at øge nogle diabetikeres egen sensitivitet for blodsukkerniveauet, mens den hos andre kan medvirke til at nedsætte sensitiviteten (Mol, 2000).

Den centrale tese i dette studie er at introduktionen af en ny teknologi bevirker en forandring i den eksisterende praksis forbundet med at håndtere diabetes, og at man ved introduktionen af en teknologi er i stand til *både*, at få indsigt i den eksisterende praksis, såvel som indsigt i potentielle forandringer af denne praksis. Vurderingen af den konkrete teknologi er derfor ikke som sådan en central tematik. Men teknologien spiller en central rolle som konkret materiel genstand, der ansporer deltagerne til at italesætte deres måder at håndterer diabetes på (Danholt, 2005).

Fælles for disse forståelser af teknologi, sygdom og diabetes er at disse ikke er stabile størrelser, men er i et dynamisk forhold med deres omgivelser og hverandre, og at det at behandle og håndterer diabetes er en tidslig aktivitet.

Formål

Den centrale antagelse for studiet er en socioteknisk forståelsesramme. Det vil sige en forståelse af at teknologier og menneskelige aktører påvirker og konstituerer hinanden i en gensidig proces. Formålet med studiet er:

1) at opnå et grundigt indblik i hvordan type II diabetikere i praksis håndterer lidelsen givet de ressourcer, der er tilgængelige for dem (teknologier, medicin, non-farmakologisk behandling, uddannelse, information mv.)
2) at undersøge hvordan en konkret teknologi bidrager til og påvirker behandlingspraksissen og livet med diabetes.

Materialer og metode

Det metodologisk udgangspunkt tager afsæt i videnskabs- og teknologi studier (STS). Disse er empiriske ofte mikro sociologiske studier der fokuserer på *praksis*. De trækker på etnografien, etnometodologi (Garfinkel, 1967) og grounded theory (Glaser & Strauss, 1967) (Strauss & Corbin, 1997). Indenfor STS foreslås en 'teorisvag' tilgang, hvor de begreber der anvendes til at forstå genstanden for forskningen er knyttet til den og dens kontekst. Ligeledes anlægges en dynamisk forståelse om at følge aktørerne i deres praktiske omgang med at påvirke og konstruere deres omgivelser samtidig med at deres omgivelser påvirker og konstruerer dem gensidigt (Latour, 1987). Dette studie vil anlægge et sådant metodisk fokus.

Studiet er interventionistisk, da det vil introducere en bestemt teknologi til en gruppe diabetikere og følge dem for at undersøge hvorledes denne teknologi påvirker behandlingen og deres måde at håndtere diabetes. Ligeledes vil sundhedsIT forskeren spille en central rolle i introduktionen af teknologien og undervejs i feltstudierne. Dette udgør en del af studiets præmis og har dels til formål at opnå en grad af fortrolighed med deltagerne. Men ligeledes forholder studiet sig også til en debat indenfor videnskabsstudier, hvor præmissen er at al forskning til syvende og sidst er interventionistisk. Dette studie tager afsæt i en sådan forståelse og vil inkluderer den som en del af studiet. (Haraway, 1991), (Stengers, 1997).

Konkret vil studiet ske i samarbejde med diabetesteamet på Amager Hospital og type II diabetikere, der er knyttet til diabetesambulatoriet på AH. Studiet vil omhandle introduktion og brug af en mobil teknologi til at registrere og overvåge diabetes relevant data. **Lifescan's Onetouch UltraSmart** blodsukker måleapparat er en konkret teknologi på markedet, der vil søges anvendt til studiet. Lifescan vil stille 10 apparater og 250-300 teststrimler samt lancetter til rådighed for studiet.
Feltstudierne vil konkret indebærer:

- **Observation af konsultationer i klinikken.**
- **Åbne situerede korte interview af behandlere i forbindelse med den konkrete behandling.**
- **Observation af diabetikeres brug af mobil teknologi i dagligdags situationer.**
- **Kontinuerlige åbne semi-strukturerede interviews af diabetikere**.

Forløb
Studiet er berammet til **4-5 måneder** fra primo oktober 2005 til medio februar 2006. I denne periode vil diabetikeren **løbende blive interviewet og observeret** af sundhedsIT forskeren. I alt **5 interviews/observationer**. Ligeledes vil sundhedsIT forskeren også følge diabetikerens kontakt til AH ambulatoriet samt anden diabetesrelevant kontakt med sundhedsvæsnet i det omfang diabetiker og behandler samtykker. (Se også bilag 1, tidsplanen)

<u>Forløbet specificeret</u>:
Primo- medio oktober 2005:
8-10 type II diabetikere søges inkluderet gennem forespørgsel af diabetes behandler HN (Se desuden afsnittet 'Inklusion' nedenfor). I bekræftende fald videregives kontakten til SundhedsIT forskeren, som kontakter deltageren og aftaler et tidspunkt til introduktion af teknologien. Introduktionen til teknologien varetages af SundhedsIT-forskeren og estimeres til at tage omtrent én time pr. deltager. Introduktionen vil finde sted i diabetesambulatoriet på AH.

Medio oktober 2005 – medio februar 2006.
Deltagerne interviewes af SundhedsIT-forskeren ca. hver 14 dag. I alt **fem gange**. Interviewene vil finde sted i diabetikerens hjem eller i ambulatoriet og vil være åbne semistrukturerede interviews. Hvert enkelt interview forventes at vare 1-2 timer. Bortset fra det første interview, vil interviewene blive løbende planlagt ud fra de

tematikker og problemstillinger, der opstår undervejs i relation til den enkelte deltager. Men det centrale fokus vil være på hvorledes praksisser med at håndtere og behandle diabetes påvirkes ved introduktionen af en ny teknologi.

Formålene med det første interview er:

1) At etablere et grundlag for en god kontakt.
2) At beskrive og diskuterer studiet med deltageren herunder at studiet har fokus på at undersøge hverdagspraksisser med diabetes og forandringer af praksisser forbundet med forandrede/nye værktøjer.
3) At interviewe deltageren om vedkommendes 'historie'. Interviewet vil omhandle:
    - Deltagerens oplevede sygdomshistorie. Diagnosticering, sygdomsforløb, behandlinger, forandringer, prognose mv.
    - Deltagerens hverdag. Hvordan ser deltagerens hverdag ud? Familie, arbejde og fritid?
    - Den konkrete praksis. Hvordan lever deltageren med diabetes, hvad gør han/hun, hvilke praksisser, ressourcer, redskaber, teknologier mv. udgør en del af hans/hendes diabetes?
    - Hvordan oplever deltageren kontakten til ambulatoriet og sundhedsvæsnet generelt? Hvordan anvendes disse ressourcer?
    - Hvad er deltagerens forhold til IT og ny teknologi?

Studiet vil blive afsluttet med en halv til hel dags workshop med henblik på erfaringsudveksling mellem studiets tre hoved interessenter: behandlere, diabetikere og sundhedsIT-forskere.

Dataindsamling

Alle interviews og observationer vil blive **lyd optaget og suppleret med notater**. Ligeledes vil **videooptagelser søges anvendt** i det omfang det lader sig gøre og findes relevant og ikke yder nogle væsentlig indvirkning på behandlingen.

Inklusion

8-10 type II diabetikere søges inkluderet i studiet heraf 6-7 insulinkrævende. Studiet vil ikke benytte sig af kontrolgruppe metodik eller lignende medicinske forsknings metoder. Inklusionen vil ske ved at diabetesbehandleren spørger diabetikeren om vedkommende vil deltage i en undersøgelse omhandlende brug af en ny teknologi for at belyse hvordan en sådan teknologi påvirker livet med diabetes. Et afgørende **inklusionskriterium er at deltagerne er vant til at anvende et blodsukker måleapparat**. En **ligelig kønsfordeling** skal søges opnået, mens der gerne må være **spredning i alder og sygdoms komplikation**.

Eksklusion

Der er **ingen eksklusionskriterier** andet end hvis deltagerne ønsker at ophører med at deltage i studiet.

Etik

Videnskabsetisk komité vil blive kontaktet med henblik på afklaring af om studiet kræver komiteens godkendelse.

Publicering

Resultaterne af studiet forventes publiceret i tidsskrifter indenfor medicinsk sociologi, sygeplejen, videnskabs- og teknologistudier, og informations systemer og design. Ligeledes er det ambitionen at søge publicering på den Europæiske Diabetes Kongres, der afholdes i København i september 2006. Det respekteres at der er forskellige forskningstraditioner knyttet til de forskellige fagligheder involveret i studiet. Forfatterskab og kreditering vil afhænge af indenfor hvilken faglighed, der søges publiceret samt på baggrund af en forhandling blandt de involverede forskere om bidrag.

Bidrag og forventede resultater

De forventede resultater består primært i **forståelsesmæssige bidrag**. Det forventes at studiet kan belyse:

- **konkrete problemstillinger forbundet med at etablere og vedligeholde varende livsstilsforandringer i relation til en relativ stum, men kronisk lidelse som diabetes. Herunder problemstillinger i relation til behandler-patient relationen og compliance og non-compliance problematikken.**
- **Potentialet forbundet med anvendelse mobil IT i behandling og indfrielse af dette potentiale i praksis.**
- **Forandringer i lidelsens konkrete levede karakter forbundet med en introduktion og anvendelse af teknologi.**

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Appendix C

Interviewguide – introduktion af Lifescan

Præsentation til de inkluderede:
”Jeg undersøger hvordan folk håndterer det at have diabetes. Det er som et led i et forskningsprojekt, der handler om IT i sundhedsvæsnet og om hvordan IT kan støtte behandling af f.eks diabetes. Jeg vil gerne prøve at forstå hvad det vil sige at have diabetes på et konkret og praktisk plan og en måde til at gøre det er at have noget at snakke om. Derfor har vi denne her nye teknologi (Lifescan apparatet). Et andet formål med undersøgelsen er også at se hvordan måden at leve med diabetes bliver forandret ved at bruge sådan en teknologi her – eller om tingene forandres i det hele taget. Dvs. At jeg i forløbet er meget interesseret hvilke ting du oplever som anderledes eller som forandres undervejs.

I dag havde jeg forestillet mig at vi skulle to ting, snakke om hvordan du lever med diabetes for tiden og introducere til apparatet her. Derfor vil jeg gerne stille dig nogle generelle spørgsmål som vedrører sådan nogle ting som hvordan din dag ser ud, din diabeteshistorie, hvordan det er at gå i ambulatoriet, hvilke redskaber du benytter ifbm. diabetes mm. Alt sådan generelt og overordnet. Spørgsmålene er ikke ment som nogle der skal give nogle bestemte svar, men i stedet nogle beskrivelser og du må gerne give dig tid til at besvare dem. Tanken er at spørgsmålene skal give anledning til samtale om end hvor du nok snakker mest og jeg lytter. Hvordan lyder det? Har du nogen spørgsmål?”

Dagsbeskrivelse.
Jeg ved at du har diabetes og jeg kunne godt tænke mig at bede dig om at beskrive dagen i går fra du stod op til du gik i seng for mig? Du må gerne bruge ti minutter på det.

Hvad lavede du? Hvad fik du at spise, hvordan kom du fra det ene til det andet? Hvordan var diabetes en del af dagen? Hvordan og hvornår var diabetes konkret for dig og hvordan og hvornår var det fraværende?

Diabeteshistorie:
Nu kunne jeg godt tænke mig hvis du vil fortælle mig din diabeteshistorie og lidt om dit liv? Du må gerne bruge 10 min.
alder, familie, relationer, fritid, hobby.
Type?
Medicin?

Oplevelser
Prøv at fortælle mig om nogle oplevelser du har haft med diabetes?
Føling (hypo- eller hyperglykæmi), misforståelser, stigmatisering,

Værktøjer:
Hvilke hjælpemidler anvender du?
Hvilke teknologier? Hvordan er det at bruge: insulinpennen? blodsukkermåleren? vandrejournalen?, pjecer, råd? Hvordan bruger du dem?

Uddannelse:
Har du deltaget i undervisning om Diabetes?
(Diabetesskole? HN?, PL?) Hvornår? Hvordan var det? Kunne du bruge det til noget? Hvad og hvordan?

Forskning
Hvad mener du vil være relevant at undersøge, forske i ifbm. Diabetes?

Appendix D

Aftaler/ deltagere	1. aftale	2. aftale	3. aftale	4. aftale	5. aftale	IC aftaler	Andet
Bernd	Torsdag d. 20/10 kl. 15.00 HN's kontor, IC	Mandag d. 7/11 kl. 11.00 hjemme	Tirsdag d. 29/11 kl.10.00 hjemme	Tirsdag d.13/12 kl.13.00 hjemme	Tirsdag d. 10/1 kl. 10.00 hjemme		
Anders	Mandag d. 14/11 kl. 12.00 HNs kontor, IC	Mandag d.28/11 kl.10.00 hjemme	Mandag d.12/12 kl.10.00 hjemme	Mandag d.9/1 kl.10.00 hjemme		Mandag d. 21/11 kl. 9.30 Konsultation HN	Fredag d. 9/12 kl. ??
Edwin	Onsdag. d. 26/10 kl. 13.00 HN's kontor, IC	Torsdag d. 17/11. kl. 10.00 Hjemme	Onsdag d. 30/11 kl.10.00 hjemme	Torsdag d. 15/12 kl.10.00 hjemme	Onsdag d 11/1 kl. 10.00 hjemme	d. 31/3-06 kl. 9.00 Læge aftale	
NN	Torsdag d. 3/11 kl. 14.00 HN's kontor, IC	Fredag d. 18/11 kl. 10.00 hjemme	Torsdag d. 8/12 kl.10.30 Hjemme	Mandag d. 23/1 kl.15.30 hjemme		d. 24/3 kl. 9.00 Læge aftale	
Doris	Mandag d. 7/11 kl. 15.00 HN's kontor, IC	Mandag d. 5/12 kl.16.15 hjemme	Mandag d. 9/1 kl.16.15 hjemme	Mandag d. 23/1 kl. 14.00 hjemme		Fredag d. 3/2-06 kl. ? Læge aftale, IC.	
NN	Onsdag. d. 26/10 kl. 15.00 HN's kontor, IC	Mandag d. 21/11 kl. 9.00 IC	Torsdag d.1/12 kl. 9.30 IC			Torsdag d. 19/01 kl.10.30 IC	
Tanja	Mandag d. 7/11 kl. 13.15 HN's kontor, IC	Onsdag d. 23/11 kl.16.15 hjemme	Mandag d. 5/12 kl.14.30 hjemme	Mandag d. 9/1 kl.14.30 hjemme		Fredag d. 27/1 kl. 11.00. Læge aftale IC.	
Bente	Onsdag d. 9/11 kl. 10.30	Onsdag d. 23/11 kl. 10.00	Tirsdag d.13/12 kl.10.00 hjemme			Fredag d. 20/1 kl. 9.30 IC konsult.	

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