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*Self-Monitoring: IT and the  
Construction of the Competent Patient*

*Henriette Langstrup Nielsen*

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New Social Science Monographs  
Department of Organization and Industrial Sociology  
Copenhagen Business School  
Solbjerg Plads 3  
DK-2000 Frederiksberg, Denmark  
Phone: +45 3815 2815  
Fax: +45 3815 2828

## ***Papers in Organizations – Editor’s Foreword***

The purpose of the series *Papers in Organizations* is to work as a stepping-stone towards final publication in scientific journals. As such, PiO is a working-paper series, yet with a distinct position in the process towards final publication. The aim of PiO is to be the final stepping-stone in that process:

- For the *author* PiO should add value to the work in progress through the editorial process. A publication in PiO is thus also a measure of the quality of the work – it is no longer simply a draft or an informal contribution to debates, but a work close to final publication.
- For the *reader* PiO should be a good place to be if one wants to keep track of contemporary research within the international field of organization studies. Indeed, many of the papers are manuscripts, which have been submitted to social science journals and as such appear in a rather final stage of completion. Others may contribute with empirical results from ongoing research projects or may in a more theoretical sense contribute to current academic disputes.

In this paper, Henriette Langstrup Nielsen draws upon a performative perspective in order to investigate the work required to perform a body in control, i.e., the self-monitoring competent asthma disease. The author argues that such bodies in control should be seen as produced outcomes. The emerging acting subject associated with the self-monitoring asthma disease is further explained by taking into account medical practices of diverse kinds, notably internet based technologies and tools for the self-monitoring of the disease. The author considers the relationship between the tool and the asthma disease a complex one. In the paper she describes the former as both a technology of representation - performing the body as an object of medical intervention, as well as a technology of patient empowerment. The complexities and tensions of simultaneously becoming a patient object and an empowered patient subject in self control is described and analysed in more detail.

*Kjell Tryggestad/Søren Christensen*

*Editors*

## SELF-MONITORING: IT AND THE CONSTRUCTION OF THE COMPETENT PATIENT

*Henriette Langstrup Nielsen*

### **Abstract**

Initiatives in medical practice that are said to re-insert the subject, thereby overcoming the problems of objectifying practices in earlier times, often operate with a notion of bodies and selves as pre-established entities. In this paper, I will try to show some of the work it takes to produce or perform self-monitoring subjects who participate in keeping their asthmatic bodies in control through the use of an online control center. I argue that the bodies in control and the competent selves related to this technology depend on the establishment of a chronically ill body and on the decentering and incorporation of the clinic in everyday life. Passages into the body are to be kept open in real-time through the involvement of materially heterogeneous arrangements.

The distributed character of this work creates and is dependent on an ambiguity in relation to the question of agency. Who or what acts, decides, looks, knows and so on, is not necessarily defined or otherwise clear in the day-to-day use of the technology. Instead, agency becomes performed in particular instances, where it might become

the property of one part of the network or another. Creating the asthmatic as a free, autonomous agent in this instance depends on blurring other nodes in the network in the day-to-day use of this technology, these being, the physician, the technology, and the scientific set-up. As such, I argue that agency in the form of the self-monitoring competent ill, is best understood as a successful performance of invisible passages and links that hook up bodies, other selves, science and medical practices.

### **Introduction**

Asthma is a variable disease. This is true not only between different people, but also “inside” the individual. Sometimes people feel fine for long stretches of time only to suddenly experience shortness of breath, pressure on the lungs and coughing. They wake up at night, they stay home from work, they skip their physical activities, they get irritable or even frightened. Some have to be assisted to hospital, others go to see their doctor, and still others wait for it to pass – because it is variable, it sometimes will pass. This variability “inside” the individual’s body is a challenge for medicine. There is no cure for

asthma, which will push it aside once and for all. The asthma has to be monitored over time. Pharmaceutical treatment systems that regulate the intensity of the treatment given to the patient on the grounds of then current symptoms, have, in many clinical trials, proved their ability to decrease the variability of the asthma in the individual body, thereby controlling the asthma.

This description of asthma, where it resides, how it manifests itself, who may act on it and how - follows a general discourse on bodies and subjects that resides in medicine and more generally in society at large. People *are* bodies, subject-bodies that act, but they also *have* bodies, object-bodies that may be defined as ill by other subjects with special access to object-bodies, medicine, physicians and other healthcare professionals<sup>1</sup>.

This is a paper on the work it takes to produce specific bodies – bodies in control. And it is a paper on the work it takes to produce specific subjects – subjects that

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<sup>1</sup> To the question of how this dichotomy of body-as-object and body-as-subject has become self-evident in modern medicine, the work of Michel Foucault has provided many answers: among other things the development of medical technologies that made it possible to transgress the boundaries of the skin to gain “direct knowledge” of what dwelled beneath without having to use the accounts of the patient (Foucault, 1973). Hence the body, in modern

control these bodies. Even though the medical profession has been seen as the

primary agent in relation to the task of controlling the body when illness has played a part in putting the body in an uncontrolled state, we would perhaps hesitate to speak about anyone producing bodies much less, producing subjects. The body-object is there as the pivotal object of medicine – the physician as the agent. The subject-body is only an issue to medicine because the illness resides in the person, who has the double blessing or distress of both being and having a body. In arguing that producing bodies in control and subjects that control them is what is done or sought done in relation to my case of distributing and using an online system for the monitoring of asthma, I would like to look at different ways of understanding relations between body, self and technology. The Foucauldian account of the production of a dichotomy between body-as-object and body-as-self within the institution of modern medicine provides some very important tools in relation to my concern. But as some have already pointed out, Foucault situates his research in the early nineteenth century when the technologies of modern medicine were in their genesis (Mol & Law, 1999). How

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medicine, is not known by itself – it is not self-

bodies and selves are produced in today's healthcare practices may not only be accounted for by referring to the clinical gaze of the physician that disciplines and controls the body of the patient. Of equal importance, the focus on the objectification of the body seems to have fostered an unproblematized essentialism when it comes to a description of the body known as the self. This perspective may, for example, be found in branches of feminist medical sociology. This self-knowing, which is said to be kept out of the clinic, seems to become self-evident as non-mediated - an inherent virtue to reintegrate into medicine. The subject and its private ways of knowing should be reinstalled to produce a more "holistic" and egalitarian medicine, re-empowering the patient by adding her point of view to that of existing medical discourse. This "perspectivalism" not only leaves the object/the illness untouched, as Mol has suggested ("..still safe and sound in the body.."), it also black-boxes the subject as a natural, a priori entity (Mol, forthcoming). But how bodies-as-subjects are known might also be highly related to specific situation and technologies within medical practice<sup>2</sup>. I

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aware - but only known by medicine (Ibid).

<sup>2</sup> Nikolas Rose has argued that the autonomous self should be recognized not as an original state of humankind, which can be deprived through, for example, medicalization, but as a product of the contemporary emergence of technologies and expertise of the self (Rose, 1999 [1989]). Rose

find that investigating these issues is highly important, as the autonomously choosing patient has become a prominent actor in current discourses on how we should make our healthcare systems better. Words such as self-managing, self-monitoring, expert patients, and joint decision-making can be found throughout government reports, in medical journals, and in marketing material from the pharmaceutical industry. The patient as a self is required to be installed in medical work. But the models over which this self is conceived, whether that of the customer (the market) or that of the citizen (the state), assume that the self is always already there and that the information necessary to become informed is present and accessible. This leaves only the challenge related to the representational practice of the self (Mol, 1999). But as is the case with body, the performance of subject as an active, choosing self is very much related to the use of particular technologies. A much more potent question to ask then is, how the self and the body *come into being* through specific medical practices, given that the information is never complete, whether a professional or a patient, and given that the

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however produces a highly univocal account that does not allow for many nuances in this "diagnosis" of "the private self" and leaves me wondering how it is - in all its specificity - that these relations between technologies, experts and selves come about.

properties of actors are relational and local<sup>3</sup> (Ibid).

### **Linking the body, linking the clinic**

The greater focus on the patient as an active subject in relation to different kinds of medical treatment is currently having a great impact on the development of various types of medical technologies, which attempt to make patients more active and responsible as participants in their own treatment. One such new medical technology is Linkmedica which explicitly renders the traditional division of roles and responsibilities (active doctors, passive patients) problematic by promoting an Internet application as a central agent in the treatment of asthma. It does this by suggesting to delegate a major part of the work related to the treatment, to the interaction between the asthmatic patient and an Internet application. I would like to look at this particular tool which seeks to both represent the body as an object for medical intervention and monitoring, and also to engage the patients as actively

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<sup>3</sup> By approaching such things as subjects and objects as entities that are performed in particular circumstances, rather than taking them as given ontological categories, I hope to establish myself as working with a symmetrical and performative approach to the study of medical practice. Such a de-ontologica-lizing approach has been promoted in the Actor-Network Theory in studying science and technology in the making, rather than as ready-made objects and facts (Latour, 1987; Law, 1994). In relation to medical practice, many efforts have been made recently to use these strategies in the enquiry into the relationships between bodies, facts and

accountable and competent subjects, thereby rationalizing the treatment of asthma and empowering the patient all at once. In the specific situations of enrollment and use, how does this technology participate in the performance of bodies and selves? How may one be a body and a self with Linkmedica? But first of all, I will introduce you to the system and situate it in the context of my further analysis.

#### **Why should I use Linkmedica?**

Linkmedica is a tool for you, someone with a busy life, in which your asthma is but one thing you have to keep an eye on.

But maybe you experience not being in full control in relation to the medication you are taking on a daily basis.

Or you would like to be better prepared next time you go to see your GP in relation to a control visit for your asthma.

Do you miss out on receiving the latest medical knowledge on asthma and allergies?

Or do you have questions in relation to your asthma that you would like to get some answers to? Then use [www.linkmedica.dk](http://www.linkmedica.dk)!

*Text excerpt from brochure for patients, 2001, my translation*

### **Linkmedica**

Linkmedica is a web-based asthma and allergy site providing information and community features for people with an interest in asthma and allergies. Furthermore, it contains a control center for

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technologies (Hirschauer, 1991; Timmermann,

the continuous monitoring of asthma symptoms, to be operated in cooperation between a person suffering from asthma and his/her General Practitioner (GP) or other healthcare professionals. A pharmaceutical company developed the overall site, originally in cooperation with a Danish patient organization for people with asthma and allergies, while the control center has been developed in cooperation with a group of respiratory specialists. The site and related control center is accessible free of charge for everyone with access to the Internet.

To use the control center you have to submit as an asthmatic user or as a professional user. The asthmatic user can create his/her own user profile on the site alone or be assisted by his/her physician. The professional users may already be registered in advance, as the site uses a publicly accessible database with all the registered GPs in the country to update its list of physicians. Professional users who are not already registered on this list (specialists, (asthma) nurses, secretaries or newly established GPs) may be provided with a valid username through the pharmaceutical company which manages the site and through the control center. The two kinds of users (asthmatics and

professionals) can become related through a process whereby the asthmatic user chooses his own GP from the list available on the site, and the GP accepts this user on his patient list in his part of the system.

The two parts of the system are also different in their functionality. The non-professional part for the asthmatic user provides a diary in which data related to asthma symptoms (I will come back to these in more detail below) are to be entered on a daily basis. The asthmatic user will receive a computer generated message related to these data, accessing whether the asthma is under control or has exacerbated and suggesting how to adjust the current treatment. The data will be represented to the asthmatic user as a diary, every day represented in peak flow values<sup>4</sup>, a color related to the state of the asthma (green = in control, yellow = exacerbation, red = danger) and as a curve that will show the development of the symptoms over time.

The professional part of the site has a patient list that presents the user with all the asthmatic patients that have chosen this particular professional as “primary physician/nurse”. (S)he then has to accept

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1996; Berg & Mol, 1998).

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<sup>4</sup> Peak flow is a value which can be read off a small device called a peak flow meter to measure your own lung capacity by blowing hard into a tube. The air will move an indicator and the value that can be read then is your peak flow.

the person as user to get access to his/her data. In the patient list, it is possible for the professional to see the current color code related to the data of the individual patients, and by clicking on their name, the professional will be represented with a more detailed overview of the person's latest entries, much like what the non-professional user himself is represented with. Furthermore, the professional part of the system has a decision-support application that makes it possible not only to give advice related to the day-to-day entries, but also to make calculations on the available data over a longer period of time, in order to regulate the overall treatment plan. The system will, if asked to, calculate how the patient is doing on a number of parameters related to the data being entered daily, and evaluate whether the patient should be moved up or down in relation to six different steps of treatment. These steps are developed in accordance with international guidelines for the treatment of asthma (GINA<sup>5</sup>), even though these guidelines only operate four steps of severity of asthma and the different treatment related to these four steps.

### **Getting it out there**

The development and distribution of Linkmedica already has a rather scattered

history, which I will attend to elsewhere. For this particular paper, I will just briefly sketch the context for the stories that I will present below. The system was promoted rather early in its development. The pharmaceutical company chose to start to market the Internet site and control center primarily to asthmatics in May 2000, as the professional part of the system was not quite finished at that point. This was primarily done through the public media. In August of the same year, the professional part of the system was added and more intense work was set in motion to enroll primarily GPs and nurses in general practice. The launch was related to another launch of a new combination treatment for asthma developed by the same pharmaceutical company. This treatment was to be tested in a large-scale clinical trial in general practice and the company soon saw the possibility of using the Internet application to collect the necessary data. Usually such data would be gathered by providing the patient-participants with paper diaries to fill out and paper protocols for the GPs to follow. These objects could be substituted by collecting data through the control center on the Internet. This clinical trial was set into motion and patients were enrolled from late 2000 and onwards. There were two different points of entry for asthmatics and professionals at that time, that is, two different Internet

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<sup>5</sup> Global INitiative for Asthma

portals. As this work attracted attention from the mother organization, which wanted to distribute this idea to other countries as well, a common, international design was developed and the two portals were integrated into one common portal, Linkmedica. This was launched in December 2001. A problem recognized early on in promoting the system was the fact that there was no evidence to show that the online treatment system was in fact better than other ways of treating asthma. The medical legitimacy of the system was mainly provided by the use of the GINA guidelines to develop the algorithms that generate messages and calculate suggestions for treatment level, and by the panel of respiratory specialists supervising the site and control center. How the fact that the treatment was monitored using the Internet and especially how a computer generated algorithm would affect the treatment was largely unknown. For this reason, a clinical PhD study was launched in 2001 with the title "Asthma and Internet". It is paid for by the pharmaceutical company, and to be carried out at a respiratory research unit at Bispebjerg Hospital in Copenhagen, Denmark. The research project is to provide evidence as to whether or not Linkmedica, as an asthma treatment system, can provide better treatment than that of more traditional methods, that is at GPs (not

using Linkmedica) or at specialist/respiratory outpatient clinics. It is participants from this study that I have chosen to focus my attention on in this text.

Robert, Bodil and Sara, a young man and two young women, are participating in this clinical study and are using Linkmedica to monitor and control their asthma. They all came into contact with the technology through the research project "Asthma and Internet". When I interviewed them, they had been using Linkmedica for three to eight months, Robert being the most experienced. I interviewed them about participating in the study and their use of Linkmedica. More recently, I have accompanied Robert to control visits at the outpatient clinic. In the next couple of months I am to do the same with Bodil and Sara.

By introducing you to Robert, Sara and Bodil I hope to show, rather specifically, how performances of bodies and selves are shaped through the research project and not least through the use of the Linkmedica system. I would like to illustrate how the self-monitoring asthma patient can become an accomplishment through the making of passages<sup>6</sup> connecting different, specific

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<sup>6</sup> Ingunn Moser and John Law (1999) have used the concept of passages in relation to the investigation of how the specific arrangements in the lives of

situations. This accomplishment is produced through laborious work, “control” becoming almost synonymous with safe and real-time passages between everyday life and the outpatient clinic. But local complexities render some of these passages fragile and may re-appropriate them in other ways than intended.

### **Diagnosis: Becoming an asthmatic**

Robert’s first visit to the outpatient clinic in the respiratory department of Bispebjerg Hospital was because he had been called in to participate in a research project on asthma and self-monitoring on the Internet. On that occasion, proof as to whether he was in fact asthmatic or not had to be established. He had to be diagnosed. Robert did not think he had asthma, but suspected that he might have dust allergy. He was rather surprised to find that he had in fact asthma in a very mild form: “In my family there are no previous cases of asthma. But I was told that it might have been my dust allergy that has developed into asthma. It was kind of tough being told [that I have asthma], but I am also glad to know, because then it’s possible to intervene with targeted treatment.”

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disabled people are linked or not, and how such “good passages” or “bad passages” participate in the performance of subjectivities and bodily competences.

Bodil, on the other hand, knew that asthma was something that ran in her family, but also did not have any particular symptoms that she related to asthma. She nevertheless wanted to take the opportunity to be checked through the study: “It would be practical to have it checked up.”

The first session took about 2-3 hours of answering questionnaires, talking to Liza, the young physician and PhD student in charge of the research, and having their first encounter with some of the technology and practices related to the diagnosis and treatment of asthma. Among the diagnostic tools, was the Vitalograph or Spirometer, a machine that can measure the pulmonary function, and the Nebulizer Controller, another apparatus that can provoke an asthmatic attack through administering the inhalation of the chemical substance Metacolin in increasing doses. The inhalation of Metacolin will make the air passages contract and limit the passage of air when the patient is asked to blow into the Spirometer. If the person reacts on even a very small dose of Metacolin by not being able to blow as predicted for his/her age and height, then there is reasonable indication for diagnosing the person with asthma. If, however, a reaction only can be provoked with high doses of Metacolin, this may only be related to smoking or an existing infection in the air passages. If this

is the case, further examinations have to be carried out to qualify the diagnosis.

Robert reacted to the Metacolin provocation with a decrease in his pulmonary function that qualified him as asthmatic, even if not very severely so. Robert tells me that this test made a big impression on him. He did not really know what to expect and found it very uncomfortable the first time: “[..]I knew what it was. I really felt it was like an iron band that was tight around my chest and how the lungs almost collapsed. This was the experience I had. And coughing... It was liberating afterwards to feel how quickly I profited from the attack medication.” Afterwards, the provocation participants are given attack medication at once to relieve them of their symptoms. For Robert this was the first time he had taken attack medication, or any other asthma medication for that matter.

Having an asthma attack because of this provocation did not provide Robert with an experience he could use to compare with previous experiences of breathing difficulties: ”No, not at all. It really was a totally new experience I have to say. But it was a good thing that I reacted so easily to the medication, so if I have a severe attack, then it is very probable that I can get

through it quickly, because I react quickly to the medication.”

Bodil did not react to the Metacolin provocation with the same convincing result that Robert did. She had to take a peak flow meter and paper diary home with her, and measured her peak flow twice a day for two weeks. She then came back in to be evaluated again to assess whether or not she was in fact asthmatic: “Yes, and then I had to come in again. And in the first period where I had been measuring my respiration, I was precisely this very small decimal point (she [Liza] calculated for me) away from being able to receive the diagnosis asthmatic. So I had to try once again. It would be too bad if it were just some miscalculation, which would prevent me from having it established, and getting it treated. So I did it again for a period of time, I think it was two or three weeks, when I had to measure it [the peak flow, red.] every day. Then I came back in and then I had asthma. That is, I am kind of on the verge. I don’t have too much asthma. It is just.... it is not that I notice it because I can’t catch my breath, but because I become irritable, I get in a bad mood and I become tired. It is very seldom that I feel it because I can’t breathe. It was actually really nice to discover that it isn’t just because I am a sulky cow, but it’s actually because I can’t breathe.”

### **Passages into the body – providing partial connections for the self**

The practice of diagnosis is a piece of work that has to be done to produce bodies which can be recognized by medicine and be monitored in medical terms. There are many different ways of producing a diagnosis of asthma: Spirometry, Metacolin provocation, questionnaires, peak flow variability and reaction to medication. But all of them depend on the making of passages between the specificities of bodies coming into the clinic<sup>7</sup> and the specificities of the clinic. The specificities in this case

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<sup>7</sup> In this paper I refer to "the clinic" as undifferentiated from "the scientific laboratory" even though I am quite aware that a discussion and differentiation of the two concepts might be highly appropriate in this context. The concept of the clinic in this text borrows more from the Foucauldian understanding that places scientific medicine as internal to the workings of the clinic, than from the understandings of the clinical versus the scientific approach to medicine as proposed by Mol (forthcoming). The clinical study, that is the study "by the bed" mimics the ideals of "the experimental way of life" (Haraway, 1997) of the scientific laboratory, but is nevertheless in need of different technologies of witnessing and of restricting witnessing than, for example, the experimental research of the embryological laboratory. The patient – even though mainly seen as an external feature to the illness that resides in the body – however resides in the clinical laboratory, this restricted site for the witnessing of nature. Ways of bypassing this person are created by what Foucault has called the clinical gaze and by the technologies that perform this gaze and grant it permission to speak for that which cannot speak itself, that is the illness (1973[1963]). However, in our case the patient is made active in the gazing into the body though the practice and technology of monitoring, almost becoming a modest witness, knowing herself through bypassing herself (that is, other ways of knowing "herself"). I will get back to this point later in the paper.

are that of the outpatient clinic and the research set-up: questionnaires, intense instruction, the Nebulizer, the Vitalograph, the Metacolin and the attack medication.

Robert did not know himself as asthmatic. When he first got the questionnaires, he found some of the questions were difficult to answer, because they operated with categories which he did not know how to define himself in relation to: "how does your asthma and/allergy affect your daily life?" Not knowing if asthma was part of his daily life or not, he could not quite answer some of the questions. However, the technologies that bypass the obstacles of non-categorized living were present. Getting the Metacolin provocation provided Robert with the identity that gave him access to do a meaningful and competent self-evaluation – a self with asthma inquiring into daily life.

Furthermore, with the Metacolin, Robert is performed as a body less than able, a body that gives in when met by a challenge. The challenge makes him experience his body at its limit. His airway passage is blocked and he cannot breathe. He needs help. Asthma is performed as blocked airway passages, where non-passage may mean death. The medication relieves him quickly of his symptoms. Airway passage is restored. If it did not, there would be a

problem in making the required passage between his lungs and the specificities of the clinic. But the passage works, the network is in place and it makes him able again. As Moser and Law have suggested, ability and disability is about passages between specificities that work or do not (1999). The passages here, of medication and air, are about life and death. Asthma, whether produced here or experienced elsewhere, is non-passage and life threatening. No air, no life. Medication has the power to take the passage and restore it. There is medication that provokes and medication that relieves. Apart from giving Robert a diagnosis, it also gives him a new way of being a body. It creates, at least temporarily, a link between his bodily experience of being acutely ill and the relief that the medication can bring him. The attack medication does not only neutralize the effect brought about from the provoked attack, it also opens up a new route or new pathways into his lungs, making them accessible to himself and to science through the use of medication (Willems, 1998). Willems has argued with Foucault that the inhalation of drugs not only renders the lungs visible, it also “bring[s] new areas inside the lungs into existence” (Ibid p. 114)<sup>8</sup>. The relations made between the

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<sup>8</sup> Willems refers to Foucault’s concept of “The body’s various geographies” that use the cartographic metaphor to point to the fact, that the

chemical substances and Robert’s lungs, brought into existence in particular ways, qualify him to enter the research project. Between the specificities of his lungs and the specificities of the research project, another passage is made, not a passage for air and medication, but a passage for his body (Moser & Law, 1999). The body Robert becomes is a body which is ill from mild asthma (though without other clear experiences apart from those produced in the laboratory) that is relieved by medication, and a body which is accessible and interesting to scientific investigation. His lungs are not able to withstand the intervention, but the body he becomes through this failure gives him access to his lungs and to the research project. That is, it relates him to a different network of heterogeneous

materials that represent him as bodily symptoms, both the ones he might describe in answering questionnaires and the ones that the Metacolin brings about.

For Bodil it took more work to create the necessary passage, the required fit – the work that she had to do to become the asthmatic body, even if only by a decimal point. Here it is the peak flow meter, and her skills in blowing into it twice a day at

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map as much creates the territory as it depicts it

home over an extended period of time, which renders her airways perceptible and accessible for the study. Moreover, this becoming a body ill from asthma actually seems to relieve her of a previous self-perception, that she was a moody, boring and tired person. During the interview she comes back to this point a number of times. Entering into the study, getting the diagnosis, and talks with Liza reframe these characteristics as symptoms that relate directly to the asthma of her body. The knowing and sensing self extends to things and situations we engage in, and the participants learn to bring in other entities in their knowledge of who they are and how they feel.

One of the questionnaires included in the study is a “Quality of Life” questionnaire, which is not developed with special attention to asthma, but is used as a standard questionnaire in other medical studies that have “Quality of Life” as one parameter.

Most of the questions relate explicitly to emotional wellbeing within the last four weeks: “Have you been feeling nervous?” “Have you been feeling full of energy?” “Have you been feeling so low that nothing could cheer you up?” In one of the other

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(Ibid.)

questionnaires related to hay fever, there were a few questions concerning the relation between hay fever symptoms and feelings of frustration or irritability. Interviewing Bodil I asked her how she got the impression that her bad mood was related to her asthma, she answered that it appeared from the questionnaires. She was herself surprised by this connection: “I wouldn’t have thought that these things could be connected, at least not with my breathing. I didn’t think that the symptoms were like that; I thought that they were physical. That it was your lungs and that you would feel it in your chest”. Feeling your body, your lungs, shortness of breath or physical experiences. These are what she expected to be prerequisites for asthma: not depression, or feeling tired or sad. The asthma becomes a container or a label that makes it possible to separate something that before was seen as a feature of the self and therefore also largely uncontrollable. She knows “where to put” her frustration as she says. Bodil is being provided with a new and more specific hierarchy of body and self. Depression or moodiness are symptoms of asthma which reign in the body and therefore it is possible to differentiate from the self and be controlled by the self using the tools of medicine provided by Liza and Linkmedica: “When I take my medication I feel that I get better in a very tangible way, but also

psychologically: I'm not thinking that it might just be me, going around being sulky or that I'm just a hypochondriac.[...] Somehow I actually feel that even though I have got the diagnosis "asthma", I'm actually in better health now than I was before. Because back then I was kind of unhealthy and very easily became unstable and a bit depressed. Now I know that, okay, it is because I have been exposed to too much smoke and maybe I'm also a bit tired". Bodil comes to know herself as an asthmatic through the questionnaires, the diagnosis and use of Linkmedica and this renders her meaningful to herself in a different way. Disentangled from the messiness of embodied being, as a quasi-professional, she becomes partially discontinued from one kind of self.

A diagnosis may be an appreciated possibility, not because it, as a role, frees us from obligations, as Parsons has suggested with his "sick role", but because we get tools to understand and explain ourselves as meaningful: "Our sufferings receive a cause and they are placed in a context" (Rødje, 2002, p.14, my translation). The diagnostic technologies of the research site can help in constructing the self, not necessarily alienating the self, as Cussins has shown in relation to her study of agency for women in relation to infertility treatment (Cussins, 1998). Bodil describes herself as a "new

and improved" subject by engaging in the work of constituting herself as asthmatic, through the constraints that the diagnosis provides her with. In this sense, the diagnostic practice should not only be understood as a professional reduction of Bodil but as something that Bodil also participates in through the work she does and the partial connections she inserts between asthma symptoms, being depressed and the questionnaire.

So here we are with links, passages, ways into the body that perform the body and the self in particular ways in particular settings. In the clinic, Robert and Bodil are performed as ill bodies, bodies in the form of symptoms and bodies that are in need of medical attention. The disability that these performances promote is, however, tightly coupled with the ability that the clinic may also produce: the ability brought about from medication that relieves, or from questionnaires that provide new, partial links between symptoms and self-conception. But if these links are related to the specificities of the hospital and the research project, then how are these passages kept open (Willems, 1998)? How can the way into Robert's (and Bodil's) lungs stay available for Robert and for science? The trouble with asthma treatment in primary care, it is said by respiratory specialists and the pharmaceutical industry,

is, apart from inadequate diagnosis and prescription, that people do not take the medication they are given. This is referred to as non-compliance or non-adherence. People leave the doctor with their prescriptions, but some will not even pick up the medicine at the pharmacist, and if they do they still may not take it as prescribed, if at all. And then they suddenly get worse.

We have drugs and we have the diagnosis: asthma. Getting the diagnosis states that something is wrong and that it should be fixed and that the tools to fix it are around, reliable and available. However, asthma is chronic *and* variable which means that it is always there, but to different degrees. In relation to diagnosis, it is the variability part that represents the problem, sometimes it seems as if the thing to be fixed is not there.. No coughing, no iron band, no nightly awakenings. Drugs that work acutely, and a diagnosis that states chronic, may not be enough to keep the passage into Robert's and Bodil's lungs open. The chronically ill body has to be performed in real-time, but how do we stage this particular body, displaced as it is from the clinic? How do we know the body as ill without the questionnaires, Metacolin provocation, numbers and curves at hand? This is where Linkmedica may come in.

### **Self-monitoring: establishing passages into everyday life**

Many types of devices have been developed to get chronic patients such as diabetics, heart patients, and asthmatics to monitor themselves at home. For asthmatics, the peak flow meter is a device for home measurement and the asthma diary in which the peak flow reading is to be entered has long existed in paper format. Furthermore, some patients have been given small "credit cards" with individualized treatment plans stating at what peak flow level they should increase their medication and which peak flow level should be read as a danger sign and how to react. Green, yellow and red or "the traffic signal". But what happens with these things when the patient has left the consultation room? Sometimes the paper diary is brought back at the next visit, but often it is not. The physician has to engage in the burdensome work of producing the asthmatic body anew every time. He has to ask questions: "Have you had any symptoms? How much medication have you been taking?" He has to do diagnostic work, Spirometry, peak flow, Metacolin provocation.

Paper and peak flow meter seem to be too fragile a pair. The routes they travel are unknown, the peak flow meter is never bought, it is too expensive, difficult to use,

burdensome. The paper gets lost in piles of other papers, brochures and whatever else we bring into our homes. With the Internet, certain passages may already be in place. The body leaving the clinic is only a click away.

### **Becoming a user**

To get on in the research project, the participants had to draw one envelope among three presented to them by the PhD student, Liza. The study randomizes the asthmatics in three groups: some to be treated for their asthma by their GP (not using the Internet), some to be treated at the outpatient clinic, and some to be treated through the Internet, using Linkmedica in cooperation with Liza.

From the beginning, Robert was particularly interested in the use of the Internet as part of the research project: “Yes, I got into the cool group, the fun group. I thought it sounded very interesting when they told me what it was all about. And because I have access to the Internet in my everyday life, that makes it somewhat easier.”

He was told that the fact that he was now diagnosed with asthma did not have to affect his daily life too much, but that he, in relation to the study, would have to measure his peak flow values twice a day

and enter the data in the system: “I had to get into some kind of routine, measuring my peak flow morning and night and then the next day enter them into the system. But that was more or less what it was”. He was also told that he had to come in for control visits approximately every six months, when he would have to do the Metacolin provocation again. In relation to the use of the system, he was told that he was to be aware of the messages he would receive from the system and was supposed to follow them.

The first part of the work of turning the participants into users of Linkmedica is carried out in the clinic. Liza takes them to a computer, logs into the Linkmedica site, and creates a user id for them. She enters name, age, height, sex, and best peak flow into the system and chooses herself as primary healthcare professional. She then shows the participant how to blow and read off the peak flow meter she provides them with, how to enter peak flow and answer the additional questions posed by the system. She shows them how a message looks and tells some (the ones who are not to take preventive drugs, and the ones already in preventive treatment) to follow the advice that the system generates from their data. Participants that are to start using preventive drugs are told to disregard the messages until further notice from her. The

reason for this is that it takes some time (two to three weeks) for the preventive medication to take effect and until then she will monitor them quite closely and offer advice that takes this into account. This she will do by using the professional decision-support in her part of Linkmedica. In every case she will be doing calculations on the data of the participants three times during the first three months of treatment and regulate their treatment in accordance with these computer-generated suggestions. Such changes will be communicated by e-mail and/or telephone. After these three months she will only do control calculations in relation to the control visits that she has with this group every six months during the three years that the study is supposed to run, or if she detects an exacerbation in the asthma of one of her participants. This she might detect when she looks at her patient list in Linkmedica and sees the current color code related to each name on the list. If it has been yellow or red a number of times, she sometimes contacts the participant to ask how he or she is doing. Looking at the list is something she does on a daily basis to find such exacerbation.

Becoming a user is not something you actively choose in relation to this study, you draw an envelope and this specifies your identity. Furthermore, the particular

identity of online monitoring participants is one constructed by Liza when entering your data into the system. Access to your new identity is handed to you on a piece of paper containing your user id and password. On being registered and inscribed into the system, the participants agree to be known as peak flow and nightly awakenings by Liza and themselves, at other points in time than the present here-and-now of the outpatient clinic. They agree to make measurements and use the Internet as part of their daily lives, bringing Liza and other specificities from the clinic into their homes. The home or the office, wherever they choose to measure and enter data, become, at times,, small outpost clinics and they agree to monitor and gather data from the body as assistant medical personnel. But they also get individualized medical treatment. They are being taken care of by Liza.

### **Safety routines**

Robert uses a computer at work on a daily basis. Since first enrolling, Robert has been accessing, more or less every day on weekdays, the Linkmedica site. He logs in, chooses the control center and enters his data: What is his morning and evening peak flow? Did he wake up at night from an asthma attack and how many times has he used his attack medication? When the data is submitted, he receives a standardized

message, generated from these data. The message features a color – green, yellow or red – indicating the current state of his asthma. Beneath is a heading: “everything under control”, “warning” or “danger”, and text telling him how to proceed with his treatment: go on with current treatment, increase dosage for an indicated number of days, or seek immediate help.

Using the system proved to be less of a burden than he had thought: “To begin with I thought it seemed kind of burdensome to do it on a daily basis. But when I tried it in practice and after I knew how I could use it, and when I had gotten used to this daily routine of measuring my peak flow, then I actually thought that it was feasible to do it. And I have to say; maybe it also gives me a sense of security in some way. I know that there is a program that, on a daily basis, 24 hours a day, keeps an eye on things. Of course, it is based on the information and the basis of calculation, but in some way it gives some kind of security, different from if I had had an attack and then had to get hold of a doctor, and this person had to come and have a look at me and then deduce whether my dose was to be raised or diminished. In that sense, I actually feel that the program gives you a sense of security.”

Bodil also talks about feeling more safe not having to go to her doctor to ask for more medication. She likes the fact that the asthma treatment is separated from all the other things she might have to talk to her GP about: “I have so many other things they have to keep an eye on.[...] When I go out there [to Liza, red.] I don’t have to start out by convincing her how I feel [...] It is almost the other way around. They say that you should take lots of medication, that you should get lots of treatment. Whereas I think that I have the impression that if I went to my own doctor, I would have to ask to get more treatment. I don’t think I would like that”.

The system ensures that the way she experiences her asthma and the appropriate treatment (through the system) is in concordance with the way Liza experiences it. Asthma is on the agenda in a shared and particular way through the use of the system. Having to represent herself, as a body with asthma to her own GP is something she would not like to have to do: “It [Linkmedica, red.] seems better guidance to me [...] than if you had to go to the doctor once in a while. Because you often feel like some kind of hypochondriac who is always going to the doctor with all kinds of things. This is what I really think I like about it; that you can do it yourself [...]”.

For Robert, part of the network is in place. He uses the Internet in his daily life. He has made it a routine to measure himself and represent his body as peak flow and nightly awakenings. He watches the curves that track his history of being a self-monitoring asthmatic. And he is happy with the fact that the system keeps an eye on things. Things that he may not even feel before it is too late. Or things he might feel but would not be able to act on without the intervention of a physician. In a way this possible intervention is already present in the system as messages. He has a personalized digital physician in his computer, at his service around the clock. But the thing is that Robert almost exclusively has received green messages: “all is fine”. His peak flow is fairly stable. Nevertheless the system allows him to know his asthma and see that it is under control. By doing his regular safety routines, he knows that he will be told how to act if anything comes up. But of course he gets to know himself in a particular way, as a medical case and at constant risk. It frames the possible scope of relevant action to be taken within a medical repertoire and consequently marginalizes other ways of accounting for and acting on his experiences. This possibility of having other, less potent, ways of accounting for yourself might however be experienced as a

burden, as Bodil’s accounts suggest. The representation that the diagnosis, the self-monitoring, and the participation in the study offers her seems much stronger than having to negotiate with her GP to get more medication. She feels that she can do it herself.

### **Real-time chronicity**

The participants are thus performed as subjects who can act with and on their own bodies in particular ways: blowing into a peak flow meter, using a computer, reading, writing, taking medication, being abled by the technology, which represents them as disabled bodies, chronically ill bodies (Moser, 2000). Being chronic is, in this instance, directly related to these activities, and the fact that they are continuously carried out as safety routines. In using Linkmedica, the participants produce a certain relation between time and body. Time changes from being punctuated by specific events e.g. an asthmatic attack, or a visit to the GP to becoming a linear or at least cyclical time, produced by the continuous monitoring in cycles of days and control visits. So the “real-time monitoring” is about making passages that transport the tools by which the “real” is known into distant places and thereby performing the “real” as something quite particular to be transported back. Asthma becomes something that is always there, not

having to be reestablished either by the GP or by Robert or one of the other participants at particular points in time in particular settings.

### **The ambiguity of distributed agency**

The passages that are enacted through the use of Linkmedica blur distinctions between the different entities involved. The questions of who or what is acting, who is made active and who is made passive are complex. The production of control is delegated to a network of actors. It is embodied in the participants' daily practice of monitoring, done through the computers algorithms, and occasionally centralized in Liza's monitoring and interventions. The question of representation and agency is not an easy one to answer. Who or what is acting, who or what gets represented? What ends up as data in the control center representing Robert's asthma, follows from the highly distributed nature of knowing Robert as asthmatic: technologies as well as other humans (Liza) participate in this process. But since it is a materially heterogeneous network that makes up Robert as asthmatic, we might still want to know, who or what ends up being marked as the one in control? Using the words of Moser we might question whether, "agency is attributed to the machine, and the user is constituted as dependent, and thus incompetent, disabled" or whether

"agency is attributed to the human parts of the actor-network or hybrid collective" thus constituting Robert or Liza as competent (Ibid p. 225)? Not having to enroll other human actors such as a GP, performs Robert as in control of his asthma. It is the data that he generates and enters that give him the instructions which he can choose to follow or not. Being dependent on a GP, on the other hand, might constitute him as dependent, thus disabled. Using Linkmedica, he is managing himself, becoming the acting subject not only of the body he currently has, but also the body he is at risk of getting. He is managing risk and screening himself, so he can know and act without being dependent on his own fragmented, embodied experiences. This way of bypassing the self-report of bodily experiences by way of technology has been criticized in relation to pre-natal diagnostics such as the sonogram (Rapp, 1997). Rapp describes and questions the way the sonogram becomes a window into the mother's womb that disqualifies her embodied experiences or at least leaves them unattended. Medical technology such as the sonogram becomes an obligatory passage point for any knowledge claim to have any significance when, for example, being put in a position of having to make a choice in relation to the pregnancy. In relation to Robert's way of knowing his body through the medical technologies of

peak flow, curves and calculations, it is significant that he is (also) the one doing the monitoring, bypassing himself to know himself.

The representation of an active, autonomous self is enhanced by using Linkmedica to control their bodies, even if they do not experience being ill. This is what I hear in many of the accounts that I get from the participants<sup>9</sup>. But the distributed nature for the use of the system does pose some questions and problems. Sara points to this complexity of control and how agency may be both individualized and shared: "Control may be understood in many ways. It may be understood as someone sitting somewhere and controlling you, but you can also have control over something. In that sense I guess I prefer to think of control in terms of controlling your illness yourself and getting it under control. It is okay by me that in addition to this there is an expert at the other end."

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<sup>9</sup> Of course I should also ask myself what the sociological technology of the interview does in relation to the performance of subjectivities (Callon & Rabeharisoa, 2000). I ask people to speak as subjects thus making this the most available performance. Nevertheless I hope to have been able to provide room for descriptions of practices and situations, that do not necessarily stipulate their possibilities of giving accounts in a too narrow set of subject-object positions. This however is something that I will have to attend to further elsewhere.

Bodil experienced this ambiguity too. In the beginning, Bodil was unclear as to whether she should follow the messages that the system generated or if she should only follow the orders she got from Liza. As a consequence of her not knowing what to do, she did not do anything unless Liza authorized it. That is, she did not follow the messages telling her how to adjust her treatment to her current score: "At one point I didn't know whether I should do what the computer told me, if it told me to double my dose of medication for 14 days or three days or whatever. I didn't know if this was what I should do, or if I should wait for Liza to call me and tell me what to do. So I asked her". Liza then told Bodil that she should do what the computer asked her to do. Becoming more in control by using this technology depends on getting permission or authorization from someone else to act and to know, not just the computer, but first and foremost from Liza, from science. This has also become clear in relation to the question of ownership of the data produced.

### **Ownership of data**

The data in the diary is constructed by a materially heterogeneous collective. In the day-to-day practice of monitoring, agency seems to be appropriated different entities

at different points in time: sometimes the participants are the ones producing the relevant messages to be received and eventually followed by themselves – thus acting as subjects in control. At other points in time, Liza does control calculations that overrule these messages and gives different advice to be followed, different medication to be taken. The question of who owns the data may not be an issue in these relationships, as long as the hierarchy is not questioned. Producing patients that are subjects of their own treatment is a common goal that necessitates a decentering of the clinic, of work, technologies, responsibilities and competencies. But when the hierarchy is questioned, ownership becomes an issue at once. In relation to talking to the participants in this research project, I asked if I could have access to their diaries just to see how they had used them. I hoped this would provide me with insight as to how the design, the representation of data and the messages received, participated in the performances of bodies and selves. I asked to be able to make screen dumps of their diaries at a random point in time, not having any access beyond this one occasion. The participants all agreed to give me access given the anonymity that I promised them, but wanted to be sure that this was okay with Liza. So I asked Liza who was hesitant, but at first only required

that I get written consent and send her copies. After having received written consent and provided Liza with copies, I however encountered further obstacles. One of the participants wanted to be absolutely sure that Liza approved of me having access to his data, as he did not want to provide problems of bias to her research, for which he felt responsible. He called her up to ensure that she was okay with the agreement. Unfortunately, Liza was becoming reluctant and had second thoughts as to how my access might interfere with her research. She told me that she would have to talk to her supervisors with regard to how to handle the affair. I tried to make it clear that I understood that she was reluctant to give me access to her patient list, as I would then see the names and data of the rest of the patients in her study. My wish to have access to the participants' diaries was related to the idea that it would be a way of understanding their accounts from the interviews of how they use the technology in a more concrete manner. Nevertheless, her supervisor agreed with her that it would be problematic if I had access to the diaries, as I would then be using her (Liza's) data in my research. That being the case I would then write this into my research protocol and Liza and her supervisors would also be listed as co-authors of the articles I was to publish using this data.

This small dispute and negotiation of accessibility in relation to my research, however, seems to point to the question of ownership and centers of calculation. In the accounts that the participants give me, they are the ones in control, with the help of Linkmedica and Liza. Occasionally, Liza changes the script a bit and her interventions overrule other ways of producing control. When I asked the participants about having access to their diaries, at the same time, I asked them about their ownership in relation to the data that they generate, and about the subjectivities that are produced in this study. Their immediate positive responses performed them as owners of their data, as the center from which agency and thus choice to allow access must come. But at the same time, the distributed nature of their practice as participants in the study, their close relationship to Liza and her involvement in their day-to-day control, actually made it difficult to be performed as liberal, autonomous subjects if this wasn't first granted by Liza and thus science. Liza, on her part, has other relations that are to perform, than the relations that perform the participants as subjects capable of controlling their own illness, knowing themselves as peak flow and nightly awakenings. These are relations that are not fore grounded in relation to the participants

in the day-to-day interaction, but become strong elements that point to Liza being in control when the distributed character is put to the fore: research-protocol, legal responsibility, her supervisors, medical journals and the pharmaceutical company financing the study. In these contexts, it is of pivotal importance that the physician is produced as the central actor (Berg, 1997). By asking to get access to the personal diaries I entered the network and put the question of agency and ownership to the test. At this point, the individual participants no longer count as individually choosing subjects, something that they may well know and accept, as the participant that needed Liza's permission showed. The data in the individual diaries are at this point, post-hoc, not produced and thus owned by the participants, not by the computer, but by Liza and her supervisors<sup>10</sup>. But the power of Linkmedica still lies in its distributed character, in making control into a collective endeavor

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<sup>10</sup> Patients' right of access to documents has been reformed in the Danish legal context as late as 1998 ("Law on patients' legal status", 1998) permitting patients access to all medical documents related to their treatment. However, this law is not valid in relation to documents that are produced as part of "purely" scientific medical research. The question of whether this law on access to documents, both in relation to treatment and research, is adequate when confronted with a practice that in fact makes patients co-authors of their own medical journal, has not been raised yet. Furthermore, one could question how to define "purely scientific research" when studies like the one presented here often involve some kind of treatment related to a more wide-ranging health-trajectory.

by granting the participants a certain subjectivity and thus agency in relation to the performance of an asthmatic body and a self in control (Ibid).

Above I have tried to show how the use of Linkmedica is producing chronically ill bodies, but at the same time I have pointed to the ambiguity of control, agency and ownership in a distributed practice. The participants, in some situations, experience themselves as abled and competent in relation to their illness by using this technology. But they are not the only ones acting to produce control, both algorithms and Liza participate as well, and when put in situations where authorization is unclear, Liza and science become centers of calculation and action, wherein the participants are little more than silent providers of bodily data.

### **Confessional practice – overflowing the center**

I have tried to show how the diagnosis and the use of Linkmedica establish different passages into the bodies and lives of the participants, changing the landscape and inhabitants along the way. But the map is IN the territory and passages might not be unidirectional (Bowker and Star, 2000). Getting out there in the lives of the participants, performing them as knowledgeable and reliable observers to

their own bodies by providing them with Linkmedica, incorporating the clinic by decentering it, may, however, provide easier accessible routes into the clinic, and into science. I will try to show how, in day-to-day practice, the passages become traveled by other things than peak flow and nightly awakenings, how the multiplicity and situatedness of asthma becomes inscribed into the design of the system and how these consequences, which in a sense overflow the center, do not seem to be a problem. The clinic itself, at times, becomes a legitimate space to perform the subject and the body as a multiple and situated phenomenon.

### **The note**

Earlier I considered how the real-time monitoring bypassed the embodied self-evaluation with its more untamed ways of knowing, producing chronic bodies and daily safety routines in medically legitimate terms. But at the same time, the mere fact that the participants in the clinical study carry these technologies and modes of knowing to other situations, other practices outside the clinic, engaging in other relations actually seems to give self-evaluation and situational accounts a very prominent role to play in how to know asthma. This is exemplified in “the note”. In relation to the daily entries of data, which are necessary for the calculation of

the variability and severity of asthma, another feature and possibility for giving accounts has been added. “The note” is just a non-specified box on the diary page in which it is possible to write a diary note to yourself or to your physician. However, it does not work as a direct message to Liza, because she can only see these notes if she enters the individual control center. Robert specifically asked for this option to be added to the earliest design of the control center, which he started up using: “I mentioned that it would be a good idea if you, as a user, had the opportunity to add some comments. Because sometimes you are very aware of some good reason for getting a low peak flow the day in question. It might also be a good thing for the professionals that it is written down what this is all about”. In the note, Robert writes about the colds he has that make him take more medication, prevent him from blowing a high peak flow and thus make him score yellow. At other times he writes about his sports performances, how he did, and if he was affected by his air passages. He writes about activities that provoke asthmatic attacks such as cleaning his basement. He asks Liza about different things related to the study and his asthma, and day-to-day experiences that he sees as related to his asthma or to the study he reports. What he finds to be outside the standard representation, but still relevant

for understanding the asthma in his body, he adds in “the note”. But by doing this he tinkers with the standard, points to the limitations of the representation, the situated nature of his body and the asthma to be monitored. By doing this, he actively engages in choosing relevant data on how to know asthma, so he is not only providing a window into his body, but also inserting himself in the research project as an active knowledge producer. Moreover, he introduces his life to the clinic. The passages that were to ensure a durable passage into his lungs and back to science also provided the tracks on which stories of going to rock concerts, having a cold, and going for a run travel back into the clinic, and thereby into Liza’s patient list.

Another account comes from Sara: “When it went really, really badly, I wrote in the note that I had an exam in a week, and that was why my peak flow was this low [...]. A few days later I got an e-mail back saying: “Good Luck!” “I say like... What! I thought that was really, really nice. That wasn’t why I had written the note. I wrote it to explain myself. [...] There was a reason; it wasn’t just because I was getting worse and worse, but because I was nervous. When the exam was finished, you could also see it [the peak flow, red.] getting better, and when I had received my results, it got a lot better.”

The self-disclosure that is brought about by the note may be seen as an obligation to make a fair representation of oneself, showing that you are competent even if your data show a declining peak flow, that you are able to see causalities in your everyday life and that you may contribute to the understanding for your individual asthma and thereby to asthma in general. Robert does not see any difference in the interests that he himself and the professional might have in wanting to understand what causes the asthma in particular situations: “It is fairly important for me and presumably also for the healthcare professional. For the user it will be important that it is possible to go back and look into whether there is some kind of pattern in the way you are affected by it [the asthma, red.] and which comments you have written when it has been bad.”

How exactly the notes are taken up as part of the work of the clinic—(this is part of Liza’s work) is not altogether clear. Observing Robert at a control visit, it was obvious to me that he and Liza had a shared knowledge, not only in relation to peak flow values, the “colors” of the resent messages and the rest of the standardized data they share through the diary, but also knowledge of some situation that had triggered an asthma attack in Robert’s

lungs. He had been cleaning his basement and the dust had triggered his asthma. This he had written in a related note. At the control, talk of this attack gets related to Robert’s use of attack medication. Liza tells him that he can take the attack medication as preventive treatment as well if he knows that he is going to do something that might trigger his attacks. This could be before cleaning in very dusty environments or before exercising. Robert tells Liza that he is a bit reluctant to use the medication in this way, because he has some side effects in that his body feels strange afterwards. Liza proposes that he tries another drug that should not have these side effects.

The window that in some sense was to eliminate some of the things that make treatment of asthma into a muddy affair giving direct access to the core, the spatial location of the asthma in the body, seems to also enhance asthma as a multiple phenomenon related to the situatedness of lived, embodied life. This does not seem to be a problem in day-to-day activity. Liza does not, at this point, define these descriptions as outside or irrelevant to her treatment. Actually they seem to be taken in in a very naturalized way and participate in the decisions made, for instance, informing Robert about preventive use of the drugs and changing his medication.

## **Cyborg interlopers or disciplined confessors?**

”So in the practice and culture account, the worlds of science and technology have many more movers and shakers, and what counts as too many or the wrong kind of participants and interlocutors has to be established through multifaceted engagements where the site of action, power, interpretation, and authority are at stake” (Haraway, 1997b, p.221)

Donna Haraway has equipped our analysis of science and technology with the concept of the cyborg, a crossbreed between nature and culture, body and technology, fact and fiction (Haraway, 1991, 1997a). The cyborg is presented as a political figure that calls attention to the intermingling of categories which makes our world possible. Haraway is, in particular, interested in using the cyborg to show that science is practice and culture, not something pure and detached. Science lives through unholy attachments and messy work. The inside or outside of science is not pre-established but takes work to create or uphold. Arguing in such a way she wants to make room for “a motley crew of interlopers to take part in shaping and unshaping what will count as scientific knowledge, for whom and at what cost” (Haraway, 1997b, p.220-221).

The cyborgs are indeed present in this case, and they seem not to have to consider whether they are on the inside or the outside of science or technology. By the very construction of passages that make them into some kind of frontline researchers and clinicians in the field of their own bodies, they become partially connected as insiders and participate in choosing data, interpreting data and looking for causal relations.

Becoming part of the design of the system, the note and its representation of accounting for the self transport other concerns, other stories, other possible ways of knowing the asthma in the body, but, of course, it is difficult to say exactly how they interfere with the practice of the clinic and even more difficult to say how they get represented in the final scientific report of Liza’s study, if at all.

## **Medically empowered subjectivity and autonomy through discontinuity**

In the accounts I have presented here, the decentering of the clinic and delegation of monitoring and control to Robert, Bodil and Sara participate in the performance of the selves that are to act in relation to the illness encountered in their bodies. They take in the tools and concepts of the clinic and thereby come to know and act in relation to their bodies as chronically ill

bodies that they themselves can control. The fact that this control is produced through relations to Liza, to science, to the computer is not of great importance in their accounts. Agency might be heterogeneous and shared and still produce subjectivity. But as the story about ownership of data implied, agency might also depend on the possibility of cutting the network, and claiming discontinuity. Moser and Law have argued that competency and subjectivity are very much about the paradoxical performances of continuity and discontinuity (Moser & Law, 1999). Their stories about Liv, who is disabled, about her wheelchair, her apartment, her care workers try to show us how Liv is performed as both abled and disabled in these particular situations. But most importantly they show how Liv is a cyborg in the sense, that “she is irreducible to a unity, *even though ‘she’ is also a unity*” (Ibid. p. 215).

The claims of discontinuity have been rather few in the material I have presented here. The participants have, more or less, taken up the particular way of performing themselves as ill bodies and competent selves that this system and this study has presented them with. But some accounts of discontinuity are of great importance: as when Bodil tells me that she has to think ahead a lot more than she is used to, but

sometimes she doesn’t “give a damn if something more fun comes up”. Something more fun could be, going on a trip with a band to Germany, not knowing where one will be sleeping, whether there’s a computer, whether your bags will be nearby. Things that are fun overrule Linkmedica, self-monitoring and being in control. Other bodies and selves take over, temporarily cutting the passage between science, the clinic and Bodil’s body - the partial connections.

The question of continuity and discontinuity as part and parcel of the performance of subjectivity and bodily competence is paradoxical. The autonomous, self-managing, competent selves that medicine has become eager to re-install into medical practice, have to be performed through the work of making and maintaining passages into the bodies and into the lives of people. But some people do not want to be performed in this manner. Bodil does not want to buy into this representation all the time, but oscillates between being abled and disabled by the technology, and oscillates between using the passages and cutting them to become who she is. Others never take on the offer of being a subject in their own treatment, being empowered through the use of Linkmedica. A lot of patients actually reject to do this. How may we understand this,

given the descriptions above? Callon and Rabeharisoa have asked much the same question in relation to the participation in the public space (Callon and Rabeharisoa, 2000). How may we understand the refusal to speak one's own voice in the public arena? In our case it has, first of all, been shown that it actually takes a lot of work to produce these subjects that might speak in 'their own voices', representing 'their own bodies'. To be abled by technology, they have to accept being disabled by chronic illness first of all, and on being subjected, they have to participate in a network of distributed agency. But even inside these successful stories of representation, discontinuity becomes part and parcel of the performance of agency, Liza's as well as Bodil's. This means that we might think of other ways of being a subject, than the ones proposed through Linkmedica. Refusing to take the clinic into your home might also relate to refusing to become a permanently ill body. It might not relate to some internal disposition of being uneducated, incompetent and objectified. Other strategies, related to other places and networks than the medical, might be the ones participating in being abled. Other things might be more fun. Discontinuity and refusal to be a certain subject might express subjectivity as well.

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