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**The multiplicities of a modest innovation:  
the introduction of a monitoring technology  
for asthma treatment in primary care**

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## **The multiplicities of a modest innovation: the introduction of a monitoring technology for asthma treatment in primary care**

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### **Introduction**

“Since May this year it has been possible for asthmatics to be have a diary concerning their illness on [astma-allergi.net](http://astma-allergi.net). Astma-allergi.net is established in cooperation with the Asthma-Allergy Foundation and the pharmaceutical company AstraZeneca. Using the new dialogue-function, the data of the patient can become accessible to his or her doctor – that is if both parties agree to this. [...]

- AstraZeneca, who are behind this new innovative dialogue-function, has developed the system in cooperation with Danish physicians. This has been done out of a wish to offer doctors and patients a new tool for asthma treatment. The dialogue-function is a possibility for doctors and patients to be able to work with a web-based tool in the monitoring and treatment of a chronic illness like asthma, says Henrik Nistrup, director of sales and marketing in AstraZeneca.
- Fundamentally it is about transferring knowledge between patient and doctor in a way that is as quick and as efficient as possible. The patient can let the doctor follow his condition. On his side, the doctor can get quick and precise knowledge about the state of the patient and give advice and treat in relation to this. [...]

(Press statement from AstraZeneca, 2000)

This text will be concerned with the introduction of a tool for the online monitoring of asthma in primary care in Denmark. As indicated above the tool is presented as an innovation in asthma treatment that unites several interest and promise to help reach a shared goal of better treatment of asthma. The main innovative feature is the possibility to connect patients and doctors – primarily GPs – and make data on asthma accessible via the

Internet, but also to add to the quality of treatment by processing these data using state-of-the-art treatment principles, that have been incorporated into the tool. As such the patients will be able to receive instant messages in relation to the data they enter, telling them how their asthma is doing and how to adjust their medication accordingly – by taking more medication or by consulting a physician. In relation to the GP, he or she has the possibility to use the accessible data to calculate the appropriate level of treatment using a function for calculating the individual patients control-status – that is seeing if the level of treatment is optimal in relation to the current symptoms of the patient. This functionality is based on an algorithm, which uses what specialists often refer to as “the golden standard” of asthma treatment as its model – GINA-Guidelines (Global Initiative for Asthma).

This tool is presented as an innovation that can incorporate many different actors – patients and doctors, pharmaceutical industry, a patient organization, specialists on asthma – and make them come together in relation to a common goal of providing better asthma care. And it did seem to be a promising tool that is in accordance with many of the recent moves toward improving healthcare: It is **patient-centered**, giving the patient a tool to become a better informed and more active/responsible agent in relation to his or her illness; it is based on **state-of-the-art guidelines**, and is in that sense following the initiatives toward EBM and quality improvement, by being a tool for more standardized and scientifically informed medical practice; and it is to help **efficiency in the clinical work** of doctors, by making the appropriate information accessible on demand and by making the necessary calculations automatic.

However, this isn't the story of sweeping success. Though the Internet site and functionalities are still up and running and more GPs as well as other healthcare professionals are still in the process of being enrolled through training courses given by the pharmaceutical company, it has been very difficult to transform these promising visions into new medical practices in primary care.

In this text I will address the rather simple question of why this seemingly self-evident innovation fails becoming the expected huge success in primary care, when it seemed to be able knit together otherwise distant or divergent agent and interest, and in doing so making

the shared goal of better asthma treatment within reach. Different actors in relation to this case do have different answers to this question. My aim is to answer the question by trying to follow the path of introduction and implementation as experienced by a number of GPs, who tried to install the monitoring tool into their practice in 2001 and 2002<sup>1</sup>. The answer offered through this way of analyzing the events, has to do with a seeming mismatch between the practice that was inscribed into the technology and the actual practice in which it was to be inserted. While it seemed possible initially to perform this technology as both an innovative system and a modest one, in that it only optimized and automated what was already agreed upon to be the way of doing things, it seemed to change character when confronted with the everyday life of primary care. In this case, a technology that promised to make issues surrounding asthma easier to handle actually seemed to make them the more difficult: In trying to bind together different locations of the performance of asthma by use of ICT, the multiplicity of the object, rather than a singularity is brought to the fore leaving the GPs with more work of coordination than they started up with. The work of implementation demanded among other things that GPs had to open up otherwise black-boxed routines and entities, such as the diagnosis, the organization of initiative, the appropriate zone of medical intervention and the distribution of medical agency. While the systems protagonists might argue that this overspill of multiplicity and differences where standardization and singularity was sought is just a proof that the work in primary care is flawed with idiosyncrasies and in a state even worse that they would have thought, I would like to make a slightly different argument. Instead I will argue that it is only and specifically by introducing this “modest” technology into primary care that the entities on which it is being founded seem to multiply, become reconfigured and therefore demand even more radical changes in how to work with asthma, than ever imagined by the GPs involved.

Annemarie Mol has made a related point in her argument that the performance of disease as a singular entity often depends on the distribution of differences to different (socio-materially embedded) localities, separated by time and space (Mol, 2003). Conflict between the different ways a disease is being performed in these different local circumstances she argues, is often avoided precisely because of this distribution. Subsequently it might only be

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<sup>1</sup> I have conducted semi-structured interviews with 6 different GPs and have done field observations at the

in trying to coordinate between the different local performances of a disease that such difference come to the fore and therefore become problematic. In the present case, an insistence on one shared reality of asthma in practices of both science, industry, primary care and patients lives, which is stated as an already defined fact, in practice turns out to be a huge task of work of enrollment, translation and alignment of entities to be able to end up with asthma as a well-coordinated, “singular” object (Latour, 1987). However, the singularity is not the result and rather than unifying interests and goals, the GPs – precisely because they are equipped with this technology that bring other locations and agents into being – come to doubt such unity and rather see multiple orders, goals and interests arise. This lack of coherence is not outside of the “object” of asthma, but part of the way it is being performed in these particular instances, with this particular technology. Berg has suggested, a given materialized order, such as a medical protocol or the tool addressed in this case, seem to create or bring along its own disorder when taken into use (Berg, 1998). Disorders that might overflow the way in which the technology was just intended to fulfill a specific, modest function (Latour, 2002). It is in this vocabulary of Actor-Network Theory and related approaches to the study of medicine and technology that I will now turn to the case of asthma monitoring.

## **A win-win-situation**

“Bronchial asthma is a disease with high frequency and considerable morbidity despite of very good options in relation to treatment.”

(From the consensus rapport “Diagnostics and treatment of bronchial asthma in adults” published by the Danish Medical Association, 2002)

“The increase in the number of people being affected by allergies [here seen to cover both asthma, eczema, hay fever and other disease related to hypersensitivity] has to be brought down. The progression of the disease and complications should be prevented among other things through self care-initiatives.”

(From the strategic rapport “Sund hele livet” published by the Danish Government, 2002)

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courses given for GPs at the pharmaceutical company.

Asthma and allergy related illnesses have, together with other chronic diseases, that affect large numbers of people over long periods of time, been given much attention in the last few years from policymakers as well as from the medical profession in Denmark. Asthma in particular is by some said to affect some 5% of the adult Danish population (when drawing on self rapport in health surveys (Mosbech, 1999)), while others refer to a group of 340.000 (= 6.8%) asthmatics, (when including the ones that have not yet been diagnosed and therefore are unaware and untreated (AstraZeneca, internal rapport, 2000)). Every year somewhere between 120 and 250 persons die from asthma (Mosbech, *ibid.*). In 2000 the expenses used in Denmark for purchasing asthma medication for adults amounted to approximately 755 million Danish crowns or 101 million euros (The Danish Government, 2002). Furthermore policymakers point to the costs related to absence from work and school due to illness, as a major source of expenses for businesses and the public sector alike. Lastly, the failure to provide adequate treatment or motivate patients to follow such treatment – which is already seen as being easy accessible in the form of acute and preventive medication – has negative consequences in relation to peoples quality of life, in that the disease might inhibit their daily lives and also prevent them from engaging in otherwise healthy activities (such as being physically active). The attention that has been raised around asthma have primarily focused on ways to improve the treatment that is provided in particular by general practitioners, who see and prescribe treatment for most cases of asthma. Only the more severe cases of asthma are handled by specialists or in outpatient hospital clinics.

The general practitioners have been pictured as both the main obstacle and the main vehicle to reach goals of improving the treatment of asthmatics. The obstacle relates to the generally acknowledged difficulties related to get GPs to follow the standardized and scientifically supported protocols developed and supported by both international and national experts in various fields of treatment, that is also in relation to asthma. However the problem of “non-compliant” GPs is often related to another though highly related problem – that of non-compliant patients. The general notion – as stated in the literature on compliance (*i.e.* Sackett & Haynes, 1976) - is that one should not expect that any more than 50% of the medication prescribed would actually be taken. GPs, being the ones with the most contact over time to the public in health related matters, are being presented in the medical literature and guidelines as being of utmost importance, not just in prescribing the best possible

treatment for people with asthma, but also in educating and motivating these patients to abide to the treatment-plans given, that is complying. In practice compliance in relation to state of the art asthma treatment means that people should not just take their medication when feeling an asthma attack occurring, but also taking preventive medication in periods when they are feeling good, making the necessary changes in lifestyle and regularly seeing their GP for adjustments in their treatment.

For the pharmaceutical companies that are involved in developing and producing asthma medication such issues are of course of outmost importance. The multinational pharmaceutical company AstraZeneca (AZ) has the major marked share on selling asthma medication in Denmark. They are in different ways involved in urging both GPs and patients to become more compliant with “the ratio-pharmaceutical regimen of asthma care” as represented in the guidelines that promises health benefits through the continuous use of both preventive and acute medication for the chronically ill asthma patient.

But also other voices related to asthma care are arguing for more standardized treatment and closer monitoring of compliance and treatment results. As we saw in the quotes above, political as well as professional bodies are trying to intervene through initiatives that promote both standardization of the medical interventions and better compliance of patients through “self-care initiatives”. Also the Danish patient interest group on asthma, the Asthma and Allergy Foundation, argues for better and more standardized treatment plans and better education and information for patients to be able to take the responsibility of their own treatment.

Seen in this light, asthma care isn't an arena for big controversies between interest groups, and positive responses were also abound when AZ in 2001 launched an internet site on asthma and allergy with a central feature that made it possible for asthma patients to monitor their asthma on-line getting immediate responses on the state of their asthma and making it possible for their GP to access their asthma data and use this to optimize their clinical decision-making also by using an on-line professional tool. From the beginning it had been possible to make the Asthma and Allergy Foundation a partner in the development of the site and leading medical specialists in the area supported the development of its

functionalities. In the following I will start by presenting a short description of the functionalities of [astma-allergi.net/linkmedica](http://astma-allergi.net/linkmedica)<sup>2</sup>, and in particular the monitoring tool that was to change asthma treatment in primary care. Following this, I will set the scene of the analysis by introducing the broader lines in the development and distribution of linkmedica. However, to get into the practices of primary care, I will leave the “big” story of innovation rather quickly to engage in the more subtle challenges met by GPs in trying to change their ways of working with asthma.

## The case

In this section I will present Linkmedica and the functionalities of the monitoring tool. The Internet site is defined broadly as concerned with asthma and allergies, and it provides users with a long list of functionalities in relation to these topics. Most are related to information on the illnesses and their treatment, and are made accessible in a knowledge center. Here it is also possible to post questions to a list of (primarily medical) experts within this field. Another area is related to debate - the forum -and it is possible to contribute to a number of different themes on asthma and allergies. The last area, and that which I will primarily be concerned with, is the asthma control area, that is focused on asthma in particular and which holds the possibility of connecting people with asthma with their health care providers. All these functions are 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 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 over physicians. Professional users who are not already registered on this list (specialists, (asthma) nurses, secretaries or newly established GPs), may be so through the AZ, who is managing the site and the control center. The professional user may be provided with a personal password either by participating in one of the courses on “Asthma and the Internet” that AZ provide or on request. The two kinds of users – asthmatics and

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<sup>2</sup> The site changed its name in 2001 to linkmedica following a strategic turn toward internationalization. I will

professionals – can become related through a process, where the asthmatic user chooses his own GP from the list available at the site, and the GP accepts this user to 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 in exacerbation 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>3</sup>, a color related to the state of the asthma (green = in control, yellow = exacerbation, red = danger) and as a curve that is to show the development of the symptoms over time.

The screenshot shows the LinkMedica website interface for an asthma diary. The main heading is "Indtast dine astma værdier" (Enter your asthma values). The user is logged in as "henriette langstrup". The page displays a form for entering peak flow values and other asthma-related data. A calendar on the right shows the month of October 2002, with days colored green, yellow, or red to indicate asthma status. The calendar data is as follows: Oct 6 (white), Oct 7 (green), Oct 8 (green), Oct 9 (green), Oct 10 (green), Oct 11 (green), Oct 12 (green), Oct 13 (green), Oct 14 (green), Oct 15 (green), Oct 16 (green), Oct 17 (green), Oct 18 (green), Oct 19 (green), Oct 20 (green), Oct 21 (green), Oct 22 (green), Oct 23 (green), Oct 24 (green), Oct 25 (green), Oct 26 (green), Oct 27 (green), Oct 28 (green), Oct 29 (green), Oct 30 (green), Oct 31 (green), Nov 1 (white), Nov 2 (white), Nov 3 (white), Nov 4 (white), Nov 5 (white).

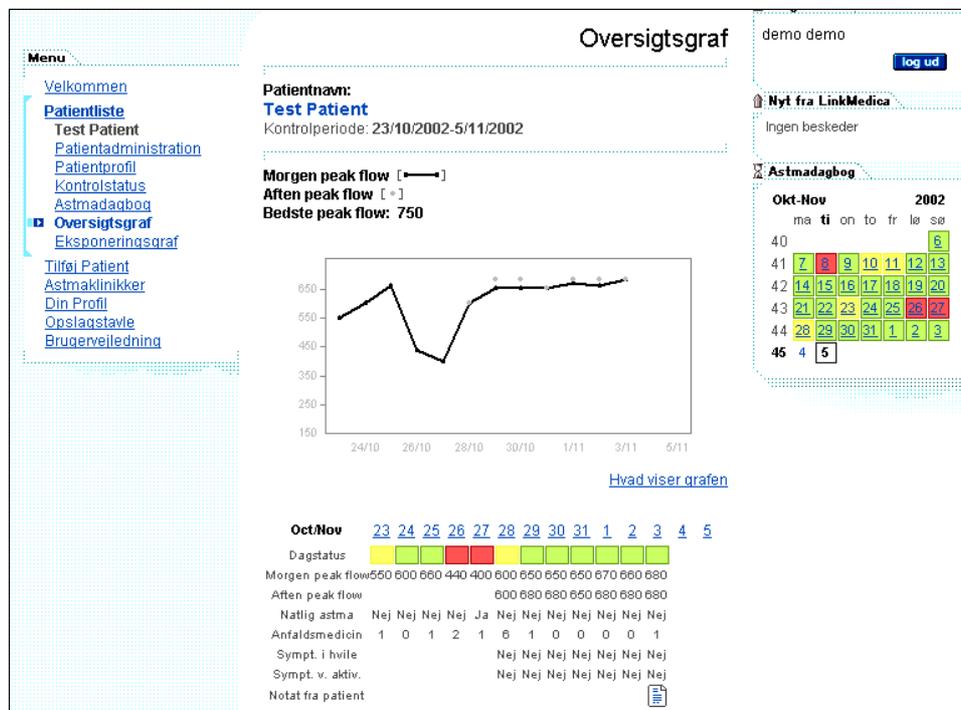
From the patient's asthma diary: "Enter your asthma values". In the lower right corner the colors indicate the asthma status during the last month. White squares indicate that no data has been entered. (Nov. 2002)

use this name for the remaining part of the text.

<sup>3</sup> Peak flow is a value to be read off a small device called a peak flow meter to measure your own lung capacity by blowing hard into a tube. The blow will move an indicator and the value that can be read then is your peak flow.

The professional part of the site has a “patient list” that presents the user with all the asthmatic patients of his that have chosen this particular professional as “primary physician/nurse”. (S)he then has to accept 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. But furthermore, the professional part of the system has a decision-support application that makes it possible not only – as that of the patient – to give advice related to the day-to-day entries, but also to make calculations on the available data over a larger period of time 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 if 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>4</sup>), even though these guidelines only operate four steps of severity of asthma and different treatment related to these four steps.

From the professionals “overview” of one particular patient (Nov. 2002)



<sup>4</sup> Global INitiativ for Asthma

Presently 400 Danish GPs have registered as users of the on-line asthma control center since the possibility was first launched in the fall of 2000. The number of registered patient-users is approximately 7500. However, it is only possible to document 200 unique users (that is both professionals and patients) logging on each week<sup>5</sup>. In relation to this it is important to note, that the system is also used in relation to some ongoing studies that involve somewhere between 100 and 150 research subjects.

## **Performing GPs as data processors with capacity problems (Towards a singularity of asthma treatment)**

“The doctor can use Linkmedica to automatically do the otherwise burdensome and time-consuming calculations, which are necessary as to give the correct treatment following current international guidelines on asthma treatment. In this way routine the asthma patient’s follow-ups are made easier and the time in the consultation is used more efficiently”.

(From the GPs’ user manual, 2002)

In what follows I will show how Linkmedica and in particular the monitoring tool are presented to GPs as modest technology. Technology that can make the work that they are already doing much easier, but apart from this won’t change the content of the work radically. But what this work actually is, how asthma is “done” in practice, might not be a given. Instead the relationship between what is easy and what is troublesome becomes reconstructed locally. Here the monitoring tool participates in performing asthma treatment as a difficult task for which help is needed. The disorder that is being argued – the non-existing compliance with GINA guidelines – seems strangely enough unable to exist without the aimed-at order already being a part of current practice. The goal is thus not only located in some promising future, but also seems to become installed in the present in such a way, that the technology is only a modest means to further an already existing development and aspiration which unfortunately finds itself limited by practical hindrances. The developers of Linkmedica and the monitoring tool seem to acknowledge that it might not be sufficient just

arguing that GINA is the way to “do asthma” and that what the GPs are currently doing, might not only be incorrect but even worse irrational, idiosyncratic and in opposition to authoritarian knowledge. For GINA-guidelines to become the measuring pole by which order and disorder is defined it – or at least the norm of standardized and science based treatment – has to be made an internal part of the existing practice. If this tool is to make it easier to treat asthma, it has to be difficult to start with – that is easy and difficult related to in pursuing the goal of complying with “current international guidelines on asthma treatment”.

In one of the courses being given to GPs in using Linkmedica and the monitoring tool, it seems possible to establish this already existing order of rational GPs, complying with guidelines as far as possible. In this reality disorder – that is limited access to patients’ data, lack of time and capacity – becomes something possible to address effectively using the monitoring tool. GINA and the monitoring tool become in this particular instance active participants in performing the work of the GPs as both defined both by order and disorder – thus making a modest intervention possible.

Using different kinds of advertising, GPs, practice nurses and secretaries have been invited to participate in one of the courses on the subject of “Internet and Asthma” which the pharmaceutical company have been giving since the launch of Linkmedica and the associated monitoring tool. The courses have now been running for a couple of years and in the beginning in particular it was very much framed to be the future users who were to be central as active participants in adjusting and improving the tool. The participants were encouraged to give feedback to the designers and developers and a user group was formed.

The following field note relates to observations made at one such course, where JA introduces a group of PGs and practice nurses to the monitoring tool. He is a medical doctor and has done research on asthma. Currently he is working for the pharmaceutical company and is in charge of the medical part of Linkmedica – that is primarily the monitoring tool.

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<sup>5</sup> Personal message from e-business manager, AZ, May 2003.

JA starts a presentation of the nature of asthma – he asks the participants to bear over with him, as he is quite sure that they know all of it in advance. The reason to tell it anyway is to ensure that they understand how the system is constructed. It is structured around the on-line diary of a patient and JA wants to make it clear that this actually isn't all that different from the paper diary that the patients usually use. There are some parameters in relation to which the patient is supposed to enter data. A part from this the patient has to indicate who her GP is and then the GP is supposed to log on. JA: "This is just an asthma diary on the Internet – it is what we usually do, just made easier!"

In relation to the courses the practices of the GPs are not depicted as being flawed with idiosyncrasies. Rather Linkmedica and in particular the monitoring tool is presented as in concordance with current practices and as possible to adjust further to become fitted for practice. The knowledge and the practice of treating asthma that this tool is representing is said not to be different from what is to be found in the everyday work of the present GPs and nurses. This is the practice of informed and skilled professionals – a group that JA also performs himself as part of by talking of "we" in relation to what is usually done. And as JA is making himself part of their practice, he is also making them - or at least inviting them to become – part of his practice of system development, by asking them to give feedback and join a user group. The tool is said to represent the work and at the same time optimizing it by using the Internet. The Internet is here presupposed to be a ("natural" and unproblematic) part of medical work. Furthermore the asthma diary<sup>6</sup> isn't introduced but is suggested to be something already part of the way the "we"- that is all medical professionals – treat asthma. It is a performance of a shared medical expertise and also rather uniform practice of asthma treatment that is here being done. Furthermore, asthma and its treatment is presented as something primarily concerned with the collection of patient data using standardized parameters and where the access to these data are of crucial importance to the treatment. Also this points to the patient as playing an important role as producers of such

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<sup>6</sup> An asthma diary is a sort of logbook, which is given to a patient together with a peak flow meter (a simple device to measure lung capacity at home). The patient is supposed to measure her peak flow value once or several times a day for a period of time or continuously and enter these values into the often preprinted grid of the diary. Such a diary will often be give to the patient in relation to making a diagnosis (using the diary as a tool to access the variability of the symptoms over time as well as the effect of the medication), as an educational tool to improve the patients understanding of her own illness, to ensure compliance with the ordered treatment regime or/and as a more continuous collection of asthma values to be used at follow-ups to adjust the treatment.

data, though the introduction of this agent and the practice of monitoring at home doesn't seem to introduce less coherency to the object of asthma – quite the opposite.

Asthma – JA tells the participants – is characterized as a variable disease. If it didn't vary – not only among patients but also inside a patient's trajectory – then there would be no need to monitor. But because it varies, it should be monitored. No one permanent treatment can be given. Its intensity has to be adjusted.

Then he shows a matrix with all the parameters and different levels of severity – he tell us that this is “the golden standard” in relation to asthma diagnostics and treatment: GINA-guidelines. At the bottom it says: [www.ginaasthma.com](http://www.ginaasthma.com). “When you make a decision about treatment, it's because this staircase is in your heads – isn't it?” No one really answers. JA goes through the model: Peak flow, symptoms during the day, and symptoms during the night. Then he asks the participants to solve a problem: JA has his own patient that he has been using as a guinea pig – L. The participants are asked to judge the severity of L's asthma and related level of treatment. Everyone is given a paper with fourteen day of diary registrations from L's diary. Furthermore they are given GINA-guidelines on a piece of paper, which also states the algorithm needed to calculate the level of treatment. They have to calculate total use of acute medication, number of days with symptoms (night, rest, activity), lowest peak flow and peak flow variability in the period. JA says that this test is given with the cunning intention of showing to them how difficult it really is using these tools and how much easier it is using the monitoring tool. “It is what they expect us to do – the big wigs” – he points to the algorithm.

GINA guidelines, which the tool is based on and which were previously presented as the provider of order and uniformity when applied though the use of the tool, are here made synonymous to the GPs own cognitive processes. The staircase-model of GINA, which divides asthma cases after severity and prescribes a variable level of treatment in relation hereto, is indicated as already being part of the way the GPs treat their patients, even if only indirectly inside their “heads”. At the same time the practical work of treatment is introduced into the course through the small exercise, where the participants are asked to use these guidelines to categorize and suggest treatment for a patient. JA is very clear in stating the intention behind the exercise – showing to the GPs that they are in need of help, because it is such a difficult task to solve. In this particular situation the limitations of the GPs rationality are not given in advance. The GPs are being performed as data processors with capacity problems, is rather the result of solving the problem of L's treatment. As the GPs (some of the nurses assist, but most of the GPs are doing the calculations alone) engage in the task and start calculating this becomes a difficult and bothersome task to solve without a computer or a calculator assisting in processing the data automatically. To make

something seem easy it first has to be difficult, to be able to create order, there have to be a state of disorder. As stated by the expert, who is also medically responsible for Linkmedica:

“...[it] is very, very difficult to improve something, when you as a GP is of the conviction that everything is fine. Then you have to stir up a lot of prejudices and a lot of preconceptions related to the notion that what you are already doing is really all right and then explain, that it isn't. That in and of itself is a big job.”

(Interview, 2002)

In this local performance of asthma treatment as a difficult medical task, GINA comes forth as being an obvious and unquestioned golden standard. But such an order has to be produced and ensured through much activity. If it weren't possible to depict asthma diaries and (GINA) guidelines as already being part of the current work practice, it would be quite difficult to introduce the monitoring tool as a modest technology, which nevertheless will make the work with asthma easier. All of these rationalizing tools, which are supposed to adding more science, efficiency and effectiveness to the treatment of asthma, bringing together otherwise distant and disconnected actors, are not just producing this envisioned order, but are at the same time, through their very existence, making it possible to identify “the other” – the disorder to be eradicated (Berg, 1998).

The inclination to want to use the tool is thus made felt by the participants on their own bodies struggling with the algorithm, but also strengthen further by referring to “the big wigs” – whether these are medical authorities or policymakers isn't indicated. But their authority and legitimacy to impose standards onto practitioners seems unquestioned.

To sum up, I have just argued that apart from just introducing a new possible way of treating asthma, which includes using some very specific computer-supported tools, JA also performs the current work practice as one having particular work routines, particular tools, a particular division of labor and subscribing to a particular set of moral prescriptions. In this work practice the GP and the patients use a peak flow meter and an asthma diary for home measurements making it possible for the GP to access the necessary data for calculations. The GP will see her or his patients on a regular basis, making it possible to get descriptions on symptoms and also guidelines are supposed to be used to categorize the illness and prescribe a treatment regime in relation hereto. The diagnosis in itself seems unproblematic

in this description that mainly puts the variability to the fore as demanding special attention. Getting access to the correct data and therefore to the patient becomes a central concern. The division of tasks between patients and GP seems thereby given: The GP prescribes the patients to monitor and register their asthma data – the GP assesses the data and adjusts the treatment by using the monitoring tool and its decision-support features<sup>7</sup>. But answering the question of how the patient in the first instance is made accessible for the engagement with such monitoring is far from obvious. The problem of presupposing that patients are already accessible to the GPs through diaries and check-ups is that this might not be the case in practice.

The modesty of the tool, I have argued, is dependent on a particular performance of what already is, performing asthma, the practices and localities of its treatment and the agents related to these practices as all being already aligned though not effectively coordinated and linked. The task that remains seem to be this linking up of entities to conclude the work toward better asthma care and for this linkmedica is an innovative tool. However, in the following I will show that these entities and agents are not already aligned, and that by introducing this tool, this order into their practice, the GPs becomes faced with much work of reconfiguring their practice to suit this particular order. The tool brings new entities, localities and agents into their practice and what might have seemed fairly straightforward – among other things because it was distributed to different localities such as the clinic and the home – now becomes problematic and multiple. Furthermore the experience of most of them is that they cannot make that final link, getting patients to use the monitoring tool and they doubt whether they should really make the effort, as the advantages are no longer that obvious.

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<sup>7</sup> This is particularly interesting in relation to the way the monitoring tool was initially presented to the public. Though with limited success, the Internet site in general and the monitoring device in particular was to begin with targeted to patient-users through commercials on health-portals on the web as well as in other media. In relation to this marketing strategy the monitoring tool was presented as something primarily of interest to people suffering of asthma, who would be able to get automatic advice by using the system. Apart from this they could also ask their GPs to “look in on” the data if they wanted them to and if the GP would agree. Only later a “professional” tool providing decision-support was presented to GPs, encompassing additional features related to the incorporation of the GINA-inspired “stair-model” to assess and adjust treatment over time and only to be done by a professional user. As such the initial marketing strategy targeted at patients indicated a different division of roles and tasks in asthma treatment: One where the person suffering of asthma is the primary person in initiating monitoring assisted by the technology and being the one deciding when and if the GP should also have a look at the data.

The way I have structured the remaining part of the text, is by following the different steps as described to me by the GP in their implementation of the tool in their practice. First I will look at the way the GPs worked to construct their local “asthma-population” finding themselves embedded in a practice already sociomaterially stipulated in a particular way. Second I will attend to the ways in which the introduction of the tool calls on a reconfiguration of diagnostic practices unsettling the very category of asthma opening up to more differentiated definitions of the category. In relation to this I will also address the problem of who has the right to define a medical problem – a question, which also seem to be produced through the introduction of the monitoring tool and which touch upon and problematizes the role of the GP. Third, I will look at the work of turning patients into self-monitoring asthma patients and how this brings the specificities of how asthma is done outside the medical practice into the clinic, raising question of what might be an appropriate zone of medical intervention and the limits of shared interests and common goals.

### ***Performing the population of asthmatics***

To be able to use the monitoring tool the GPs have to have some asthma-patients to treat. In the presentation of the tool it is very much taken to be an unambiguous fact that asthma patients are part of the work of general practice – that they are “out there”. But this self-evident entity – the asthma patient – turns out not to be given after all and the use of different diagnostic tools, work routines and other situated orders seem to be producing asthma patients in different ways. These other tools and practices intended in their own right to acquire and produce knowledge and structure medical work are not just a passive toolbox to be applied onto “the asthma patient”. Rather such tools participate in producing the very phenomenon, that they are to register or order (Mol, 2000). “They intervene in the situations in which they are put to use” in rather specific ways, and what counts as an asthma patient, how one knows such a person and how one locates her depends on the results of such interventions (Ibid. p. 9). Further on we will look into how the monitoring tool intervenes in to the relation between GP and patient, but before such intervention is possible first the patient must be located using tools already at hand.

At the course JA asks the participants to tell a bit about the number of asthmatic patients in their consultations. The first participant to talk is a male GP, who tells us that he has a patient population of 1500 including children. Of these patients

approximately 50-60 are asthmatic and of these  $\frac{3}{4}$  are adults. However after having come up with this number they have been finding more people with asthma since they have started using both new and old diagnostic methods more frequently – that is spirometry and pric test.

One of the other GPs says that he got quite surprised not to find more asthmatics among his patients as he was preparing for the course. They only amounted to 20-30. JA says that it seems as if the asthma patients are taking up too much space in his work since he got so surprised that no more turned up. The GP responds that it depends what is meant by “asthma”. He argues that the “pure asthma patients” are very few and that you only see them rarely. JA asks provokingly if that isn’t just a result of them being to ill and that’s why they seem to take up so much time in the consultation – that it’s a result of bad treatment. Everyone laughs and the GP under accusation denies this to be the case in his practice.

The participants at these courses are often very well prepared when coming to attend. Many have taken their time investigating into the number of asthmatic patients in their patient population while others relies on a more general impression from their daily experience. However the number and the very possibility of “counting heads” seems to be related to diagnostic tools and practices and the very definition of asthma. In the account of the first GP the number of asthma patients have become higher with new practices, while the second GP indicated that he had fewer than he had thought because he put up a criteria of “pure asthma” while looking. In his account there are accordingly different kinds of asthma-patients, some more pure than others.

Whether preparing for the course or actually taking the monitoring tool into use the GP, the nurse or the secretary has to do some work to locate these asthma patients. This work relates to the way in which the GP knows the individual patients and how these are registered and categorized locally. This again relates to existing sociotechnical practices such as diagnostic tools available, recording practices, research file and treatment strategies.

As some of the GPs earlier have participated in clinical research on asthma, they have come to know those of their patients that fit the category of “asthmatic” in a very particular way. They know (maybe not exclusively but still often related to) these persons treatment in relation to the research protocol that has been followed in the study. This means that they have been instructing the patients, often seen them regularly over a period of time to collect data and finally to deliver or process these data to produce research results. One GP tells that he has made himself a file of asthma patients in relation to an earlier study in which he

participated and that this work is now paying off in his search for user to the on-line monitoring tool. His practice is already stipulated materially by the previous research he had done and the way this study had put asthma on the agenda in his work. Now can he – in relation to asthma, while not in relation to other illnesses – look up names in the file and contact the persons that he wants to. Others have had more trouble localizing possible candidates. Even though several at the courses indicates that it is possible for them to do a search on asthma in their electronic patient records it seem more difficult than just pushing the search button. Primarily because the search function only can be used if the entries have been coded in accordance with predefined diagnostic codes and this is often not the case. Even if it is, there are sometimes problems using the search function. In these cases it isn't possible to search the free text of the patient record and this will often be the place in which a reference to asthma can be found. GPs who don't have standardized coding practices have to resort to other ways of finding the asthma patients of their practice, ways that are often somewhat arduous. The following quotes are from interviews with two different GPs.

HLN: How then was the recruitment organized?

A: (Laughs) It was a big problem, because it ended up being based on memory. As it is now we can't make a search on who have asthma and who haven't.

HLN: You don't have any diagnostic codes or...

A: Yes we do, but we are still not able to make a search across the databases. We can search in some statistics, but it isn't something we have really been going into. Just searching across databases, that we couldn't, so we had to use our memory.

HLN: You didn't have a file or anything?

A: No, not in particular.

HLN: Did you then sit down and find them, as they had to come in for check-up any way?

A: No, it was just when they call themselves to get renewed prescriptions to their asthma medication.

(Interview with GP A., 2002)

B: It was kind of uphill work. What we did was the secretary wrote up their names when the patients called in to get a renewed prescription to their medication. Then we contacted them after having checked that they did in fact have asthma – some we contacted over the while others we approached when they came to the consultation.

(Interview with GP. B., 2001)

The medication turns out to be an important marker of asthma patients in primary care and many of the interviewed GPs used this indicator to find possible users. Moreover this relates to the fact that only one of the interviewed GPs had prescheduled check-ups with asthma patients (that is this job was mostly delegated to the practice nurses). The most important recurring contact between the individual asthma patient and his or her primary care clinic, which concerned asthma in particular in most cases, consisted of renewing prescriptions (usually over the phone) and consultations where the patients come on their own initiative. Answering the question of who was asked to use the monitoring tool, GP C says:

C: It was the asthma patient coming to the clinic.

HLN: When they came here anyway? Did you already have prescheduled controls with your asthma patients?

C: With some... no, it is more based on need. I don't have prescheduled controls with asthma patients. I don't do it systematically. Not at all actually. This you will find in relation to diabetes and hypertension and pregnancy and things like that. They'll come in at certain times. Asthma patients don't. Asthma patients come when they fell that they have got a problem, which they can bring to the GP. With things like that, this is the way it is defined.

(Interview with GP C., 2001)

The ways in which the GPs already see their (asthma) patients, whether they have regular check-ups, how they categorize or code them into their filing systems, which possibilities different tools and routines give them to acknowledge someone to be an asthma patient – all these things become important participants in making the GP and his staff able to find users for the monitoring tool. Furthermore specific work has to be done to establish these required asthma identities, that might not have been well defined and separated from other things beforehand. Pen and paper have to be ready by the phone, if someone calls for repeat prescription, records and files much be searched, patients has to be contacted or approached when already at the clinic – work that didn't have to be done previously and work that will often be done by secretaries or nurses.

The many badly treated asthma patients that research on asthma might point, are not sitting in the GPs consultation waiting to be attended to. Rather they have to be produced from the material, technological and other organizational entities and routines, which are already there, making up the work of the individual clinics. In the present case it is clear, that there is

no clear and detached asthma patient, only different local resources that may be mobilized in constructing such a relational quality and work to strengthen it further.

### ***Redefining diagnostic practices and indications for treatment***

And then we have the diagnosis – asthma. In an earlier cited quote a GP said that his population of asthma patients varied in relation to what is being referred to by using the category “asthma”. By saying this he indicated that talking about asthma in general might not be specific enough in pointing to particular patients or in setting up inclusion criteria for the patients who are to use this monitoring tool. As we have seen different entities in the clinic might indicate the existence of asthma in individual patients – diagnostic codes, entries in the record, research files and repeat prescription. But even when such possible asthma identities have been appointed there may be raised doubt as to what the indicator actually is pointing to. If taking the indicator provided by medication, one may run into the problem, that it isn’t just “pure asthma patients” that are given asthma medication such as inhalers for acute relief in cases of airway spasms (Salbutamol ?). This acute relief medication can be prescribed without any significant risk even when there is doubt about the precise diagnosis, since it is seen as relatively harmless, without severe side effects and since the use is initiated by the patients themselves relating to their own experiences of needing and benefiting from the medication. When people come to see their GP with complaints that point to asthma, they can’t always expect to go through a thorough process of diagnosis, that is being diagnosed using different routine techniques such as spirometry<sup>8</sup>, reversibility testing<sup>9</sup> and prick test<sup>10</sup>. Some of the tools necessary to do these tests are not always present in primary care and the involvement

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<sup>8</sup> Spirometry or measurement of the lung function involves testing for FEV1, which refers to the force of the air that the patient can provide in a short (1 second) forceful expiration and FVC, which refers to the total volume of air that the patient can contain. Both measurements are done by letting the patient exhale (either quick and forcefully (FEV1) or slowly and completely (FVC)) into a mouthpiece connected to a reading device either digital or mechanical. The measurements indicate the size of the airways and the elasticity of the surrounding tissue. It is becoming more usual to find a spirometer as a tool within primary care.

<sup>9</sup> Reversibility testing refers to the evaluation of the possible effect of prescribed medication in relation to other measurements (FEV1, FVC and peak flow) and is used to diagnose asthma and assess the level of severity. Airways that are asthmatic are thus expected to react positively to the pharmaceutical treatment given making the improvement visible in the above-mentioned measurements.

<sup>10</sup> Prick test is a way to test allergic reaction to a number of suspected substances that might participate in provoking asthmatic reactions or making already existing asthma worse. It is administered by forcing small amounts of the different allergens into the skin by pricking with a needle. By monitoring possible swelling or rashes in relation to the different allergens allergic reactions are then assessed.

of these in the diagnostic process will in these cases demand a referral to a lung specialist. The indication of asthma might therefore in some cases only be related to the patient's description of symptoms such as breathlessness and coughing, while other GPs might combine different techniques and measurements to produce a diagnosis. Patients may also have been given the diagnosis many years ago and the current GP isn't necessarily the one originally doing the diagnostic work. Most of the GPs interviewed however felt quite confident in their diagnostic routines in relation to asthma and didn't experience a great need to optimize their clinical decision-making process. Though some did use the mentioned tools no one said that they explicitly followed guidelines by doing calculations on the data they produce as to find the level of severity and appropriate level of treatment. Rather they estimate being guided by the data and their previous experience. One GP explains his approach to diagnosing and treating asthma in this way:

B: People come here with asthma or if people come with symptoms, which point to asthma, then we'll do some examinations that will confirm or dismiss the diagnosis. You'd look at the duration of the complaint, whether there is any fever related, if it is just right now they are affected and if it might be a lung infection. If they experience that it is something recurring then we may send them on to an examination of their airways. Using the numbers we get from these test we will then possibly come to the diagnosis of asthma. It also depends on the age group, and looking at how the medication works.

HLN: So you use the pharmaceutical intervention to come to a diagnosis?

B: Yes, if we can register a reasonable improvement in their lung function. What we do is, that we give them a peak flow meter to take home and get them to measure for 14 days to evaluate the variability. Dependent on the magnitude of this variability, we then start up the treatment. We'll chose to prescribe **bronchodilators** ?- long-term and short-term treatment as well. I think that's it. And then they usually come in for a check-up after about a month or so. I guess that it is after this that it stagnates. Because then it might be going all right, and they fell fine and as time goes by they just renew their medication and somewhere along the way they might just quit.

(Interview with GP B., 2001)

In this clinic the diagnostic process (and with this the construction of the asthma patient) takes up to a month and involves different techniques and tools such as lung function measurements (spirometry), home measurements with peak flow meter and reversibility testing. But after the diagnosis is made and pharmaceutical treatment started up there won't necessarily be regular contacts between GP and patient. It is the person experiencing

problems who will initiate the initial contact to the GP and also later in relation to exacerbations it is this person, now having become an asthma patient, who calls the GP to get an appointment. If they feel well (or just don't feel too bad, are busy, or don't want to be a burden on their doctor or for any other reason) they won't go to their GP to have an asthma check up. This is what raises the problem of GPs not being able to prevent exacerbations, as they are not able to attend to the variability of asthma over time if the patients don't come in regularly. But trying to change this order through the monitoring tool some problems are encountered. The first problem is the more practical one of getting in contact with potential users, when work is otherwise organized through patients taking the initiative of making an appointment. Many GPs are simply not used to looking up their patients in this way – as we have already seen – and when they do they may find something quite different, from what they suspected. As such the introduction of the monitoring tool calls upon the work of redoing diagnosis and re-categorizing patients, not necessarily supporting a smooth introduction of the monitoring tool. The second problem is of a more principal nature relating to the question of, who has the right to formulate the problems to be solved in general practice. This question is being raised by some GPs and I want to show how tools and technologies such as the monitoring tool participate in defining the distribution of initiative and responsibility in (asthma) treatment.

### **Redoing relevant diagnoses and identities**

The GPs who have found possible asthma patients to monitor may have to confirm that what they are dealing with is in fact asthma – that is something that is variable and possible to treat more efficiently through continuous monitoring. As I indicated earlier some of the GPs weren't totally convinced that the markers that they used to locate asthma patients actually excluded other and less appropriate identities. It is with the implementation of this monitoring tool that it becomes necessary to validate the existence of asthma in particular patients, something that isn't always necessary to start up treatment. This means that what might be found while validating the initial indicators using more strict diagnostic approaches and terminology might end up being something quite different from asthma excluding rather than including some patients as users. These patients might not have been categorized at all if it wasn't for the implementation of this system that establishes a particular order:

inclusion-criteria, which demand that asthma is differentiated from other diagnoses. However when the GP starts validating these identities and applying more rigid criteria, this may also narrow down the scope of possible users, which he though would benefit from the on-line treatment.

GP B: In a project like this, if you say that there are some asthma patients that you would like to treat and then when they come, you will have to find out whether that have been taking there medication and furthermore, if you haven't been that conscious about their disease, then you'll have to go into it and measure their lung function, their peak flow and things like that. In some cases you will find that what you are dealing isn't asthma at all – rather they have COPD [Chronic Obstructive Pulmonary Disease], which means “**smoker lungs**”, too big lungs. This is a condition, which you cannot treat using this [monitoring tool], and for which you actually can't get any real medication. But it isn't “in” to say: “I have ruined my lungs by smoking to much”. It is more “in” to say: “I have asthma”. And that is why a whole bunch is being excluded, because there isn't any reversibility to be found. You can't give them this medication and see them get better. So these are not asthma patients, and it turned out that I don't have that many asthma patients and that actually surprised me.

(Interview with GP B, 2001)

This GP has to redo the some of the diagnostic work, which went into producing the indicators in his practice that pointed toward certain individual as being asthmatic, as to produce “pure asthma patients” that might benefit from using the monitoring tool. But rather than just confirming these identities, the intervention changes them, differentiating a large number of patients from being asthmatic, identifying them instead as COPD-patients. One obvious consequence is that these patients are not eligible users for the asthma-monitoring tool as control through the adjustment of asthma medication isn't a realistic goal. This GP also suggests that there might be other consequences from producing this more precise diagnosis. Talking about what is “in” among the patients as the diagnosis to name their pulmonary problems, he presents asthma as the category that patients would rather have, because it indicates a condition you are not responsible for having and which might be treated successfully with medicine. The differentiation between asthma and COPD brought on by this work of re-diagnosing, forces both GP and patient to face up with something which haven't got “easy” (on-line) solutions and which suggests that the patient has mistreated his or her own body through smoking, putting it in this irreparable state. This identity might be less than desirable for the patient to hold and the differentiation doesn't

provide the (newly) diagnosed COPD-patient any significant new opportunities, just a more sinister prognosis. As Leigh Star has written “...part of the public stability of a standardized network often involves the private suffering of those who are not standard” (Star, 1991) and the production of such “monstrous” identities are not exogenous to the work of making the standard itself work. Rather they are byproducts that have to live with this new and negatively defined COPD-identity, which does not provide them with new possibilities, but which is necessarily identified and excluded to make the monitoring tool do its’ work of helping asthmatics<sup>11</sup>. As the same GP says in relation to his findings of COPD-patients rather than asthma-patients: “Then you will have to see how you might be able to help them. But in relation to this project, they are not relevant” (Interview with GP B, 2001)<sup>12</sup>. Relating more to the work of the GPs in trying to make the monitoring tool part of their practice, the consequence is also that asthma – in this new and sharper definition – is less pervasive in their patient population than they initially thought. The GPs simply end up having fewer patients that they expect they might help, than they initially thought, making the monitoring tool less potent as a means of handling and improving the treatment of a big group of patients.

## **Promotions, problems and responsibilities**

How to go about promoting new ways of treating an illness to relevant patients? We have already seen that in relation to this on-line monitoring tool, the GPs have had to know where to find the relevant patients using the already existing cues in their practices and furthermore some have had to validate these patients’ appropriateness as users in confirming the existing of asthma. But apart from the work of inclusion and exclusion, the work of promoting new innovative ways of treatment brings on a more general challenge, which

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<sup>11</sup> I am not pretending to know whether this is a great burden to bear for the individual, who has to give up referring to asthma when explaining to others or in their own understanding of their illness. Also it might be possible, that GPs will become more knowledgeable about COPD and more animated to find better ways of treatment for these cases after having had this experience of a higher prevalence of COPD in what they previously thought of as being asthma. But these are mere speculations. The argument presented here only relates to the concrete example of how processes of standardization assist in not only producing the identity of the user, but also – through reordering of previous ways of construing certain identities – producing non-users, at one time defined in relation to and rejected by a particular standard.

<sup>12</sup> In relation to this albeit very contextual “marginalisation” of the COPD-diagnosis it is however relevant to mention that 3.400 Danes die every year from the disease where as the number of deaths associated with asthma is, as mentioned earlier, approximately 120.

relates to defining when something is a medical problem, and something which should be treated by a GP.

As we have seen in the cases presented here, asthma treatment in primary care is often organized around the principle that it is the patients that have to take the initiative to get their treatment adjusted after having been diagnosed. This doesn't just relate to asthma treatment, but relates to a more general principal in primary care preventing GPs from promoting their services to (possible) clients. The Danish legislation on advertisement of health services states that any advertisements addressing patients (being it individuals or the general public) that have not specifically asked for such information can only contain announcement of the professionals name, and other quite formal characteristics of the professional and his practice<sup>13</sup>. As an example it isn't allowed to indicate particular areas of interest that the professional might have such as asthma. However it is legal to advert – objectively, factually and adequately - about available techniques for investigation and treatment. Some of the interviewed GPs felt uneasy with the way the introduction of the monitoring tool first of all meant that they should offer patients this alternative to the usual way of treatment and secondly that the practice of using the tool might mean that they would be the ones asking the patients to come in for a check-up on the basis of data entered into the accessible on-line diary. Relating to the above-presented law, it is difficult to argue that GPs, who are addressing patients to ask them to use the monitoring tool, are breaking any law. However the interviewed GPs do not comment on the content of the law, but more on the principal related to it – that of preventing GPs (and other healthcare providers) from advertising with services to enhance their (primarily publicly funded) sale and in that process producing an unnecessary high demand for certain services – making the public more self-perceived ill and dependent on healthcare than they need to be. One GP comments:

GP D: [...] And I don't really know [how it will work] in relation to the public health insurance and the payment... It might pose a problem if we start calling the patients up if we think they have a bit of fever.

HLN: How is that?

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<sup>13</sup> This law (nr. 463, 1997) is currently being challenged by a proposal for a new law regulating the area (Forslag til Lov om markedsføring af sundhedsydelser, 2002). This proposal suggest a liberalization of the area, providing delivers of health services almost the same possibilities in relation to the marketing of their products as is the case in other areas of commerce. The suggesting is now up for a final vote in the Danish parliament, but is being met with significant critique from both the current opposition (left-wing parties) and from several lobby organizations.

GP D: Well, we are not supposed to call up a patient up if we feel like it. We are not allowed to do uninvited promotion of our services. It has to be the other way around.

The practice of letting the patients have the right to define the existence of a problem that should be attended to by a doctor, means that the GP must regard a started treatment to be working if the patient do not come back with complaints. The prescription of short-term or long-term pharmaceutical treatment or other interventions that are to take place outside the clinic in the privacy of the patient's everyday life makes the supervision of both compliance and effect inaccessible to the doctor. The treatment is carried out in a location that the GP has no access to making it impossible to intervene or to take responsibility as to what is going on in this location. But in introducing the asthma monitoring tool the absence of a patient does not count as an indicator of a well-treated patient, and might also introduce a distinction between being well-treated and optimally treated. In the following quote two GPs are discussing their experiences with the well being of their asthma patients and the reason to introduce the monitoring tool. GP D has not been at the Linkmedica course whereas GP C has. They have just agreed that they actually don't see that many patients that are badly treated or getting bad flare-ups. Their experience is generally that people know how to handle their illness themselves, even if it sometimes means that they don't get the optimal lung function. Also they agree that patients might regulate their behavior to avoid things that provoke their asthma rather than keeping the asthma under pharmaceutical control. But generally "They know what to do".

GP D: I think it is all about self-care - to be fully informed about the illness you have and what action to take in particular situations.

HLN: Is the problem then that you do not know what is going on [at home], who follows the treatment appropriately and who doesn't?

GP D: But we do know! If they weren't well treated then they would come to us – so we know!

GP C: But I guess it is true to say that we don't know whether they are as well as they can be. We don't know whether they could do even better, because we don't see them that often.

(Interview with GP C and GP D, 2001)

In the instance where guidelines are to be followed or the monitoring tool is to be used, it becomes the responsibility of the GP to point out asthma patients and possibly also to address them. The meaning of absent “patients” changes accordingly, making the patient-initiated visits problematic as a central organizing principal for the treatment of asthma. The experience of the patients themselves of feeling “all right”, doesn’t necessarily coincide with optimal “asthma control”. Asthma control is defined by GINA-guidelines as being: “Minimal (ideally no) chronic symptoms, including nocturnal symptoms; Minimal (infrequent) exacerbations; No emergency visits; Minimal (ideally no) use of p.r.n. (as-needed)  $\beta$ 2-agonist; No limitations on activities, including exercise; PEF (peak flow) circadian variation of less than 20 %; (Near) normal PEF; and Minimal (or no) adverse effects from medicine.” (GINA, 2002). In the monitoring tool this ideal of control is translated into two things, in both cases delegating some of the initiative for medical intervention to the technology. There is the indication of control as presented to the patient-users, who after each daily entry of data will receive a color symbol (Green, yellow or red) and a written message telling them whether their asthma is currently well treated and under control or if they should adjust their medication or go see their doctor. This control-status is based on simple parameters using data that relates to the three previous days. The other control-status is calculated in relation to 14 days of entries using 6 instead of 3 parameters and a more complex algorithm based on GINA. It is only the GP or other health professionals that have access to use this tool, which is the decision-support tool of Linkmedica. It is in relation to the use of this control-status that the GP may change the treatment by changing the level of treatment in accordance with GINA. The patient using her part of the system will only be able to regulate numbers of puffs of her already prescribed medication when reacting to the colors and messages she receives through her computer.

In the practice, which does not use an on-line monitoring tool for the continuous surveillance of asthma-data, self-experienced needs, pre-set half-yearly consultations or empty inhalers may prove adequate as ways of bringing people to the clinic, where the GP will assess whether treatment should be changed or whether there is a need for some other medical intervention. With the monitoring tool the rights of the patient and the GP respectively to: 1) formulate a problem, and 2) conclude that it is a problem in need of a medical intervention becomes redrawn and redistributed. The formulation of a problem is

now on the one hand a job to be handled on a day-to-day basis by the messages generated by the algorithm that makes the patients part of the system function – the problem here being defined as exacerbation of the asthma or decline in control. These problems will per se be cast as medical problems and the medical intervention is prescribed by the message that the patient automatically is presented with on her computer screen. On the other hand these data and the daily color-coded scores are equally accessible to the GP on his list of patients using the monitoring tool. He will here be able to see possible exacerbations as they are recorded by the system. Patients getting red alerts telling them to go to the GP or maybe even ER, or just a deterioration – many yellow messages indicating ailing control. Also they may primarily see lacking values, empty diaries indicated by a white color code and telling them that this patient isn't doing her monitoring. And how to relate to this information? When are we dealing with a problem that needs medical intervention? What do the data refer to in the life and body of the asthmatic person?

GP D: “The problem is that if they become red and I am sitting in Australia and recognizes this 10 o'clock at night, that they are really, really red – what then is my responsibility in this? I know something about this person and if this person does react... in situations like that, I don't know what the juridical situation would be. It is comparable to a situation where we receive a really bad lab result [...] I do not want to take the responsibility. [...] They are the ones [the patients] who should take the responsibility and react if they are feeling bad enough. I will not take any consequences of something I see on the Internet.”

(Interview with GP D, 2001)

The developers behind the tool have suggested that the GPs might do daily “ward rounds” on their on-line asthma patient list or have the practice nurses or secretaries do it. However it was stressed at the courses that it should be up to the individual GP how often he or she would look at the patient list. The imagined juridical problems as speculated upon by the GP above, was exorcised by the developers by referring primarily to the statement of informed consent, which patient users have to sign, in which it is emphasized that they themselves have the responsibility to react appropriately to both the messages received and more generally to how they feel and that the use of the system does not substitute traditional consultations with their GP. In one of the earlier designs of the patient list however, it was possible for the professional user to send e-mail directly from the website to the patient (without the patient being able to see the GPs e-mail address when receiving this mail – the

system was presented as the sender<sup>14</sup>). This may be seen as promoting the GPs toward approaching – uninvited - patients on basis of their diary entries and as having a responsibility in keeping an eye on the day-to-day compliance of the patients. This instant e-mail possibility was however not to be found in later editions of the patient list making intervention in relation to day-to-day indicators more bothersome<sup>15</sup> and making the suggested “ward-rounds” less relevant if the data presented isn’t meant to inform any possible medical intervention by the GP. These different possible ways of relating the fact that patient data become accessible to the GP in a different way is however not settled in some more specific instruction of the professional users, but is suggested to be agreed upon by the individual patient and GP in cooperation. What the GP should be oriented toward is rather the long-term control status for which they’ll need the entries of 14 days in order to use the decision-support of the tool to regulate the overall treatment plan in accordance with GINA. And it is in this instance that the GP can judge whether treatment is optimal, that is under control. As the teacher at a course formulates it for GPs in relation to the exercise of looking at on-line patient data: ”L [a patient] isn’t doing alright. The reason we can take the liberty to say that he isn’t doing alright is because we know he can do even better”. In getting access to these data the indication for medical treatment isn’t that people are in a bad condition, but rather that they are not meeting their full potentials. The GP isn’t just there to heal or sooth the illness, but to do “disease-management” and as such she is more given the role of the “life-coach” or consultant, who gives advice on ways to improve the performances of individuals, who themselves are in charge of/responsible for executing these advice.

### ***Redefining the zone of medical intervention***

A central idea in relation to our case of on-line monitoring - and more generally in telemedicine - is that of making the otherwise physically absent patient present through

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<sup>14</sup> This partial anonymity related to the general worry some GPs have in relation to e-mail that they will get spammed with mails from worrying patients if their e-mail address is accessible for the general public. This was especially seen as a problem before the current agreement between the public health insurance and the Organization of General Practitioners in Denmark (P.L.O.), which now makes it possible to get payment for electronic consultations.

<sup>15</sup> That is, having to reveal your e-mail address by using a conventional mail program and yourself filling in the patients e-mail address instead of having it done automatically.

technological mediation. The asthma patients in question are to be mediated more or less in real time qua their data on the Internet without having to leave the privacy of their own homes. This presence is one related to medical intervention more than it is related specifically to the intervention of one particular GP. The GP may still have a privileged position in relation to such intervention (doing initial diagnostic work, prescribing the medicine, initiating treatment regimes and doing the long-term control status calculations), but will by no means be the only one prescribing or executing interventions in such a distributed network. Being present in this way, patients might be able to avoid having to go see their GP face-to-face or call him/her in relation to minor flare-ups in their asthma. They might even be able to avoid such flare-ups altogether – maintaining continuous control - by following on-line messages and seeing their GP only for an occasional check-up in relation to which the control-status can be calculated using the data from the previous period of registration. But reaching such aspirations depends on achieving this more or less continuous presence via data. The (now identified and validated) asthma patient also has to become a user of the on-line monitoring tool. They have to comply with this new delegate of their asthma treatment as well as with the ones already in play – their medication and the various pieces of advice they have been given. The medical technology of asthma and other chronic diseases has already for a long time been percolating into the everyday life of asthma patients, changing not only the distribution of initiative and responsibility but also what counts as medical work and knowledge (Willems, 1995). In relation to devices used for drug inhalation at home, Willems has shown, how these are being inscribed in such a way that they can secure proper inhalation technique leaving as little room for wrong usage as possible to the human user (Ibid. p. 71-72). They are delegated the responsibility and their proper functioning thus becomes of central concern both to the medical professional and the user – making the discussion of devices a central theme in the medical intervention into asthma.

What I would like to address here is the work that the GPs have to do to make patients into users and how this work of making users also (re)introduces areas outside the clinic as medically significant. That is areas related to patients Internet-literacy, Internet-access and more generally the lives they lead, which are to be intervened in when becoming users of the monitoring tool. Enrolling patients as users brings several things into consideration that otherwise might seem irrelevant in terms of the generalized search for standardized and

optimized asthma treatment. Even when having narrowed the initial “asthma population” down to “pure asthma patients”, these may not be easy to translate into users of a on-line monitoring tool, doing self-monitoring and engaging in mediating presence to assist continuous medical intervention. It is not that the GPs as humans have to compensate for that which the tool can’t handle the messiness of individual peoples lives – it is rather that it is by way of this tool that such issues are raised in the first place – trying to purify things seems to – at the same time – hybridize them, making them into a new phenomenon, that was not there to begin with, as Latour have already pointed out (Latour, 1991).

Compliance is most often taken to be the extent to which the patient follows the advice given by the intervening healthcare professional. Another suggestion is presented by Willems (following Law, 1986) as a term referring to the existence of durable, though flexible, links between different entities (between patient and treatment) that permits long-distance control (Willems, 1995). The question of durability is a central one in relation to chronic diseases and intervention into the way people handle their disease outside the spatial and temporal realm of the clinic have now for some time be considered legitimate medical work – that of compliance enhancement (Ibid, p. 125-132). Physicians should be able – using different available tools – to motivate and practically enable patients to follow prescribed treatment (not unlike the aspiration of the people behind Linkmedica to support the GPs in complying with golden standards by enabling them with technology, that is delegated some of the responsibility).

The monitoring tool may tell the GP something about the individual patient’s compliance, it may promote more compliance by educating patients about their illness and learning how to control it, but it is also something additional, which the patient has to comply with. How in practice to connect this tool to patients’ lives concerns the GPs and becomes a task in itself. What are those lives in which it is to be inserted? The ability or practical/material precondition for using a PC and logging onto the Internet becomes relevant for this particular intervention, as does questions related to how busy patients are in their everyday life, their possible benefit or loss in doing the monitoring.

GP E: Trying to make this as easy for myself as possible I chose the ones I thought would be more compliant, that is responsive. Some having executive positions, and some who are well educated, and two young people, who are used to computers.

And then I used some time at an asthma check-up – though I actually think the idea speaks pretty much for itself – but I used some time at an asthma check-up to explain it to them. We had a brochure to give to them and something called a “start-kit” containing a peak flow meter, so we could push-start them. [...] I had some initial great expectation about some of these sailors – we have many sailors in our practice, Svendborg being a seaport – and I thought that it would be really smart if I could be able to manage them while they were at sea.

(Interview with GP E)

The practice nurse A, who primarily handles the asthma patients in this practice, in terms of the use of the monitoring tool and regularly check-ups, has known this patient, S, since she was just a girl. Annette tells that, as an active teenager S wasn't really very interested in keeping her treatment. But after getting husband and child, she suddenly agrees to use the computer and come in for check-ups. Later, after observing the check-up, I ask A and S, how S initially was introduced to the possibility of monitoring:

HLN: Do you remember if you were the one introducing it [Linkmedica] to S?

A: Yes, it was.

S: Was it?

A: Yes, I gave you a brochure to take home – don't you remember that we were talking about you actually being on the Internet on a daily basis? So she got a brochure to take home, and then I said, that you should try to log on, if you felt like it, and create a user-id and choose me as the professional. Visa versa, I would then have to accept being the professional and then it [the system] would inform us, now you are on.

(From observation of Linkmedica-assisted check-up and Interview with nurse A and patient S, 2002)

The ways in which this GP or practice nurse knows their patients becomes relevant to the introduction of the on-line monitoring tool. The specificities of these lives are used as indicators of the relative success of on-line monitoring – for them as well as for the GP/practice nurse. They both point to the necessity of constructing durable links to make this tool work, and that this is contingent upon the strength and durability of other links outside the clinic. Some already existing links may predict whether hooking up to a medical regime and a computer are realistic connections to perform and sustain or not. For example teenagers who's lives are not very organized in terms of routines and home life may have a difficult time following a strict treatment plan and even more in engaging in continuous monitoring, whereas being married and having a child often relates to more routine activities and more time at home. Also the GPs previous experiences with patient's compliance become important, suggesting that these patients are more persistent and trustworthy in their

commitment to treatment. This of course makes patients that are already doing what they have been told by their GP (and therefore maybe are relatively well treated) more likely to be invited to become users (though they may not be the ones with the least control over their asthma). This in a way is comparable to the situation of the introduction course of the GPs: If the order of the tool, which is to be inserted in to a particular site, is already there, then the intervention will be more modest, demand less from the different actors but also become the more successful an implementation.

But the strength of these links to treatment regimes is not only inscribed in people's demographic characteristics or intellectual merits. It is also inscribed in materials – such as the inhalation devices previously mentioned or the mere existence of a computer and Internet link. Here the GP also uses the trick of strengthening the link through materiality. The “start-kit” with a peak flow meter and a brochure is meant to “push-start” the patient to become a user of the monitoring tool. It isn't enough just to talk about the splendor of the tool – the GP has to engage in what Law initially called “heterogeneous engineering” – that is the manufacturing of material, organizational and human entities in the construction of durable connections (Law, 1986). The materialization of the demands of the tool in the context of use is a central intervention to ensure that it in fact will be used (Berg, 1998). All the little things that a tool presupposes to exist already and on which it is dependent, often call on materialization and distribution in their own right. Peak flow meters, written information, computers and Internet connections – all these things have to be in place for the system to work and the GP has to engage in work to insure this. If the PC and the Internet are to become a central delegate in the treatment of asthma, then skills in relation to this become relevant to evaluate or even educate for the GP. Not all GPs find such tasks legitimate or may find it hard to use the time necessary to address them.

GP E: If you where to be really fair to the system, which I haven't had the time to be – and this is something I am only coming to think of as we are sitting here talking now – you should actually buy some time and use it with them [the patients].... [...] maybe talking more concretely about the Internet and things like that. Because even though you might ask them at the consultation, “well, you're familiar with using the Internet” and they say “sure” but in reality this might just mean that they have send an e-mail once and nothing else. So you don't really know. For some people it might be difficult and they could just sit here [in the consultation] and we could fill out the daily status together. That's how the rest of us learned it [the GPs]. I have also been sitting at Astra long ago and gone over it all.

Of the GPs I interviewed none had taken very much time to show the patients how to actually do the monitoring using the computer. Some took the time creating the user-account together with the patient (something which is actually meant to be done by the patient, as it involves pressing some “accept-buttons” that spells out the distribution of responsibility) and browsing through the functionalities of the monitoring tool and the community part of the site. Others relied primarily on patients to go home and learn how to use the system being assisted by the brochure and their own motivation to get their asthma under control.

Furthermore the GPs are not paid for the time used instructing people using this system – When participating in privately funded research that demands instruction or in publicly funded projects such as home measurement of blood pressure, the GPs are used to getting a financial compensation for the time they use. When introducing this tool to patients as a part of general treatment, there is no such compensation.

The GPs seem ambivalent to the task of introducing patients to a tool that also demands some kind of instruction in terms of where to click, how to read messages, and specification as to what this means in relation to the treatment in general. The GPs want the tool to be the tool of the patients, something additional for those who can and will take more responsibility, but without adding to many additional tasks to the GP. They want it to be self-evident for patients that this is something that will help them. They do not want to push patients too hard, on the other hand the GP quoted above sees a parallel in what it took to get him to use the tool.

### ***The immodesty of modest technology***

Most of the GP I interviewed had difficulties doing all the work necessary to ensure durable links between the monitoring tool, their already existing sociomaterial practice, and the asthma patients. The work that I have tried to show here, which was done by individual GPs, secretaries or nurses, who were engaged in taking the on-line monitoring tool into their practice, was experienced by many as being to much hassle. Far from being a modest technology ensuring that what is already done just becomes easier, the introduction of the

monitoring tool called upon reconfigurations of work, responsibility and asthma in ways that exceeded not just their own capacities or those of their patients but which also made them more skeptical towards the consequences of this technology. As such the activities otherwise just seen as (failed) implementation become local occasions in the individual clinic to “reopen” some otherwise implicit routines and (sociomaterially embedded) ways of ordering and see them through the optics suggested by the monitoring tool. It is with the tool GPs start to formulate “asthma patients” as something particular, differentiating it from other identities they might meet, becoming concerned about what they might or might not do when they are not coming to the clinic and whether they are “optimally” treated. But it is also in working to reconfigure their relation to asthma patients, making patients into self-monitoring asthma patients and Internet users that some GPs come to lose their interest in the tool. The work to create and ensure the durability of these relations seems too extensive held against the possible return – both in relation to their practices and the well being of the patients. As one GP comments:

GP E: If you have to push them [patients] all the way and call them up every morning and [say]: “Remember to type in [the data]”, then there is no catch in it. And if you can’t get an educated person to do it, then who can you?”

(Interview with GP E, 2001)

In relation to an evaluation study made for the pharmaceutical company a GP suggests that there might be a problem in relation to getting patients to understand that this primarily is their tool, making it possible for them to get better by avoiding flare-ups and limitations in their everyday activities.

“GP: Well, the first steps are always the hardest. I think it was extremely hard. I used a lot of time in the beginning, but it has become easier.

Interviewer: Do you remember what it was that was hard if you look here?

GP: It was difficult to explain to people in a good way, what it was we wanted, and especially to explain to them that in the end they were the ones benefiting from it. That it wasn’t just something that would make me happy.”

(Nielsen, 2002 – my translation)

With these complaints we return to the problem of promotion that I addressed earlier. Inscribed into the tool in a particular distribution of interest – primarily assuming that

patients and GPs have interests that coincides (which again coincides with the interests of the pharmaceutical company) – all want better treatment of asthma. For GPs this might mean better results in terms of more control with the outcome of ones professional work and for patients more control with ones chronic disease and quality of life. If this were so, there would be no need for promotion beyond the reassurance from the GP that this tool works to do the job. But as we have seen GPs have to more than just offer this way of treatment to patients. They have to interest them, to produce durable relations between the clinic and the lives of these persons or, as one GP suggests, “build a narrative in to the patient”. A common interest isn’t there in advance, but has to be built on location, something that the asthma consultation and the tool don’t seem to afford very easily. This becomes paradoxical for many of the GPs, as they primarily see this tool as something, which can help patients gain control over their disease, their body and greater independence from the intervention of the GP. The GPs feel uncomfortable in promoting it further when patients are not responding positively to their initial presentation. The fact that they will be following standards, getting their practices more orderly, seems to have become less important for most of the GPs at this point. But when patient don’t seem to take up the tool, when they are not responding to the offer by complying, then the GPs takes this to be lack of “maturity” on the part of the patients (as in taking responsibility for ones own health) or the failure of the tool in being able to connect to peoples lives (being too complex, too time-consuming). One GP tells me, that he feels that he has got more knowledge on asthma from trying to put this tool into use. However, this is knowledge, which as made him more skeptical about the order or script of the system, than he had been to begin with. Rather than asthma becoming a difficult and important disease to intervene in and therefore calling on scientifically informed tools and reconstructions of the relationship between GP and patient, the disease has become a more mundane ailment in most cases. By trying to enroll people he has become convinced that the interests of the different participants do not coincide and the downsides of making them do so are too big. Asthma, he now sees as something that people find individual ways to live with, something that isn’t serious or threatening enough to monitor continuously to avoid flare-ups and progressive deterioration of lung tissue. The way the tool focuses on peak-flow is a central issue in relation to way the patients do not continue to use the tool:

GP F: Peak-flow is something, which was invented by the industry and hospital physicians – it doesn't mean anything to patients. Comparing it to diabetes the difference is, that you have something more concrete to threaten people with – they become blind or get their legs chopped of like salami. With asthma you are just not feeling well. It looks too much like something we all have – you would also go to work, even if you had a headache or menstrual pains (cramps?).

Though not trivial for individuals, asthma isn't seen as difficult, but asking patients to take up the tools of "the industry and hospital physicians" participates in making it complicated. It assumes that the means of handling the illness are neutral and of equal importance to patients, GPs, specialists and industry as long as it assist in produce the shared goal: better control of asthma. But for this GP the tool is not neutral and it might make asthma into something more problematic and complicated than it has to be. Even if everyone has equal access to tools and information (though this is hardly the case here) it might not do any good. The monitoring and keying in of peak flow values are necessary for the proper functioning of the algorithms of the monitoring tool. Without these data the GP can't follow guidelines in the form they are given here. Without these data the pharmaceutical company are even further from being able to monitor and secure their market (though they are still not able to "mine" these data in a scientifically relevant way as of yet). These data might promise to be potent in linking these different actors giving them the possibility to act at a distance and producing shared interests, but when standing with the individual patient the GPs become hesitant in putting too much effort into the persuasion to make patients enter data. Asthma can be produced as peak flow readings and messages on a computer screen, but if it doesn't produce other benefits than the avoidance of a potential "headache", which you might already feel that you can get rid of by using medication, then peak flow and self monitoring will not add much value to the life lived with asthma. The patients that are reachable – qua Internet connections, previous compliant behavior, literacy etc. – may also be those that might need medical intervention the least, and will still demand a great deal of involvement from the GP introducing the tool to them in relation to encouraging them to use it.

## Conclusion

The dissemination of medical knowledge and standardized practices through technologically “powered”, materially embedded and distributed tools seems to be a utopia at best. The promised modesty of the linkmedica-tool, which was based on the notion of shared interests, common goals and socialmaterial practices that wasn’t there, was in the end gradually being experienced by the GPs I interviewed as an immodesty actually participating in producing differences in interests of patients, GP and pharmaceutical company. Rather than being the vehicle for producing more sameness, more order by black-boxing the categories of asthma, of the patient, of medical intervention, it actually opened up such categories, while trying to be fitted into already existing practices. Instead of producing more sameness and order, it actually introduced the GPs with more difference in terms of different diagnoses, different kinds of patients, different ways of intervening and (appropriate) zones of medical intervention.

An often-stated lesson of technological innovation is that both practices and tool will have to change to make the tool part of practice. Tools do not change practices on their own from some kind of technological determinism, but have to be picked up and translated while also participating in translating the actors and practices that it becomes engaged in (Timmermanns & Berg, forthcoming). Though designers are often very aware of the many variables that might counter the script of their particular tool, they often see these as stones on the way rather than problems being produced through their particular innovation. A new order doesn’t just replace earlier states of disorder or idiosyncrasies, but participate in reconfigurations of practices and redistribution of sources of contingencies (Berg, 1998). Furthermore a new order that tries to align, tame or make singular too many entities and agents at once, may be confronted with equally big numbers of disorders having to be dealt with in practice.

Asthma treatment and other areas of chronic disease may very well be appropriate areas of technological intervention, and thinking in ways of giving GPs and patients new possibilities of engaging in more cooperative ways of treatment still seems to be of great importance. However, what may be needed is a greater appreciation of the practices in which these changes are to take place, and more open discussions related to the consequences of such reconfigurations and redistribution of disorder and contingencies. For one thing, connecting

the work in to clinic to the everyday lives of people, who continuously or only occasionally are experiencing problems with asthma, in this new and different way inevitably introduces or strengthens otherwise distant complexities as in some way relevant and manageable for medicine. Instead of presuming common interests and singularity one might rather start out asking whether the creation of new complexities (in the work of primary care and in the lives of people with asthma) is a good trade-off for the benefits achieved.

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