

Chapter XIV

Incompatible Images: Asthmatics' Non-Use of an E-Health System for Asthma Self-Management

Michel J. Sassene

Roskilde University, Denmark

Morten Hertzum

Roskilde University, Denmark

ABSTRACT

This chapter investigates asthmatics' reasons for not adopting an e-health system for asthma self-management. An understanding of these reasons is particularly relevant, because clinical evidence indicates that, if used, such systems lead to better asthma management. The investigated asthma system is, however, based on a taken-for-granted image of asthmatics as, per se, striving to be symptom-free. This image is incompatible with interviewed asthmatics' day-to-day performances of their asthma, and renders invisible (a) that their asthma performances emphasize an economy of good passages and of feeling capable, (b) that they achieve the objective of feeling capable in quite different ways, and (c) that feeling capable does not per se equal being symptom-free all the time. To attain long-term use of self-management systems and other patient-centred e-health systems, such systems must acknowledge and link into the manifold performances that comprise users' ways of living with their disease.

INTRODUCTION

Asthma, diabetes, and other chronic diseases cannot be cured. This positions these diseases at the periphery of common conceptions of diseases and their treatment. First, whereas healthcare

professionals can diagnose chronic diseases and make plans for their treatment, the actual treatment, which is thus management, must to a large extent be performed by the patients themselves (Newman, Steed, & Mulligan, 2004). Second, many chronic diseases are in part caused by what

Incompatible Images

can broadly be termed patients' life styles, and the management of these diseases involves as a core element comprehensive changes or restrictions in patients' habits and day-to-day lives (Butler, Rollnick, & Stott, 1996; GINA, 2005). Third, even brief failures to comply with proper management of the diseases may lead to symptoms or an irreversible worsening of the patient's condition. For many chronic diseases, patient-centred e-health systems are therefore seen as a way of supporting patients' self-management of their disease, primarily by providing information not otherwise available and by extending the communication between patients and healthcare professionals beyond infrequent, face-to-face consultations (Ball & Lillis, 2001; Safran, 2003).

This chapter analyses an e-health system for asthmatics. For reasons of anonymity, the system will be referred to as AWeb, and the company developing it as ACorp. Though asthma is a condition asthmatics have to live with, the risks of symptoms can be minimized by taking the right amount of medication. It is, however, no simple task to determine the correct amount of medication, because this depends on various risk factors, which may change dynamically and be hard to foresee. To accommodate the difficulties with dosing medication, asthmatics' self-management of their medication is considered a cornerstone in asthma treatment (Gibson, Powell, Coughlan, Wilson, Abramson, Haywood, Bauman, Hensley, & Walters, 2002; GINA, 2005). AWeb provides tools for asthmatics to manage their asthma themselves. Nevertheless, in spite of the utility of AWeb and considerable marketing by ACorp the system never attained widespread use and was discontinued after five years. To inform other initiatives toward providing e-health support for self-management of chronic diseases, we provide two accounts of the relations between asthmatics and their asthma:

- *The system's image of the user:* How does AWeb set up a way for asthmatics to think about their asthma?
- *The self-image of asthmatics:* How do asthmatics perform their asthma on a day-to-day basis?

The aim of our analysis is to elaborate and contrast these two images. We do not take asthmatics' non-use of AWeb as a rejection of self-management initiatives, but rather seek to inform future initiatives by attempting to explain why AWeb was not taken up by the targeted users.

Previous work on e-health systems for self-management of asthma has suggested several reasons for asthmatics' low uptake of such systems (Anhøj & Nielsen, 2004; Nielsen, 2005). The suggested reasons include inexperience with the Internet and computers, a latency time between starting to use a system and realizing the benefits of using it, and unpredictable interactions between the system and asthmatics' everyday lives. A limitation of this previous work is, however, that reasons for non-use have been derived from studies of asthmatics that—admittedly, to varying extents—are users of e-health systems for self-management of asthma. In the present chapter, we extend previous work by turning to non-users for input to an understanding of what “went wrong” in the AWeb project. Such an understanding is particularly relevant because a clinical test shows that, if used, Web-based asthma monitoring leads to better asthma management (in terms of symptoms suffered, lung function, and so forth) compared to monitoring by asthma specialists or general practitioners (Rasmussen, Phanareth, Nolte, & Backer, 2005).

BACKGROUND

Asthma is a chronic inflammatory disorder of the airways (GINA, 2005). This inflammatory condition causes hypersensitivity to risk factors

such as stress, respiratory infections, animal fur, fungus, and smoke. The symptoms of asthma are mostly suffered as attacks, which typically involve shortness of breath, heavy coughing, troublesome and wheezing respiration, and tightness of chest. To alleviate the symptoms two types of asthma medication are currently available. *Controller medication* prevents the inflammatory condition from worsening and in the long run reduces the likelihood of attacks, but has no immediate effect. *Attack medication* is intended to immediately relieve symptoms during attacks and normally functions by temporarily enlarging the respiratory channels. Since attack medication is hard on the lungs, it is generally recommended to use it as little as possible and instead use an adequate amount of controller medication. However, it is likewise recommended not to use too much controller medication because its side effects are unclear. Hence, it is a real challenge to dose asthma medication appropriately.

In recent years, several asthma-patient education programs have advocated the use of diaries as a means of facilitating asthmatics' awareness of their asthma and commitment to effective self-management. Apart from supporting asthmatics in learning about and managing their condition, diaries are considered useful to healthcare professionals, because diaries provide them with detailed data about asthmatics' physical symptoms and use of medication (Gibson et al., 2002).

The positive experiences with the use of diaries spearheaded the design of AWeb, which was developed by ACorp in collaboration with the national Asthma and Allergy Association and an independent advisory board of asthma specialists. AWeb comprises three parts: a knowledge centre with online resources about asthma and its treatment, a discussion forum where asthmatics can submit questions to a panel of asthma experts and read answers to previously submitted questions, and a diary tool. The diary tool, which is the focus of this chapter, requires that asthmatics register as AWeb users. The intention is that asthmatics log

into the diary tool every day and enter peak-flow measurements, doses of medication taken, and symptoms experienced within the last 24 hours. Based on this information AWeb advises users as to which preventive measures to take with respect to their medication, taking into consideration their asthma history and medication. In this way, the diary tool implements the step model and general self-management guidelines recommended by the Global Initiative for Asthma (GINA, 2005). The diary tool also includes graphics that show trends in peak flow and symptoms coupled with environmental data such as pollen counts; and users can write notes, for example, to elaborate on their symptoms or make notes about special circumstances. Furthermore, the diary tool is directed toward asthmatics as well as their healthcare professionals, who can log in to monitor the well-being of their asthma patients and provide advice when needed. Hence, the diary tool can function both as a tool for self-management and as an extension of the patient-professional relationship.

AWeb was launched in May 2000 and attracted more than 2,000 users within the first three months. During the following year and a half, another 4,000 asthmatics registered as users. After that, new users registered at a rate of approximately 50 new users a month (Anhøj & Nielsen, 2004). However, log files show that of the initial 2,000 registered users only about 100 used the diary tool regularly and they, too, lost interest, resulting in only nine users of the diary by the end of 2000. To attract more users, ACorp initiated a marketing campaign that targeted the opinion leaders closest to asthmatics, namely general practitioners, rather than asthmatics directly. This approach was taken to counter any reluctance from asthmatics toward information and initiatives from a pharmaceutical company with vested interests. As a result, general practitioners promoted AWeb and the number of diary users reached a peak of 307 in January 2002. A year later, February 2003, the number of diary

Incompatible Images

users had, however, declined to 138. Finally, in May 2005, AWeb was discontinued, primarily due to a lack of users (Anhøj & Nielsen, 2004). In explaining the low uptake of AWeb among asthmatics, the project manager we interviewed summed up:

Looking at the whole project in retrospect, the primary reason for the lack of success of [AWeb] can be attributed to the system being too complex and time consuming for the users.

While this does point to an incompatibility between AWeb and the intended users, the following analysis reveals, we will argue, that the incompatibility is more intricate and deeply rooted than a system that is too complex and time consuming for its users.

CONCEPTUAL FRAMEWORK

To analyse non-use, it is essential to avoid the pro-innovation bias, which is common in theories about diffusion of innovations (Rogers, 2003). While factors such as intrinsic motivation and perceived usefulness have been found to predict patients' behavioural intention to use e-health (Wilson & Lankton, 2004), they do not explain why some patients are unmotivated to adopt useful systems. To investigate this we turn to actor-network theory, particularly its performative approach, and to the cyborg metaphor.

Actor-network theory (Callon, 1986, 1991; Law & Singleton, 2000; Mol, 1999; Mol & Law, 2004) dissolves any inherent identity or boundary of actors by asserting that such identities and boundaries are merely ostensive and, in fact, a result of meticulous negotiations. As such, every actor is considered both a network and part of a network, and any stable identity is seen as a fact established through domination. To guide the analysis of actor networks, Callon (1986) proposes three closely coupled methodological principles:

(a) *Impartiality to actors*, which implies that all actors' views are considered as is. No point of view is dismissed as inherent to the identity of the actor. (b) *Symmetry*, which implies that one general vocabulary is used to describe all involved actors, human as well as nonhuman. (c) *Free association*, which implies that the investigator should abandon a priori distinctions between actors and rather let the actors' own explanations define how they are associated with each other. To put these principles into operation, Callon (1986) suggests the use of a vocabulary of translation with four separate moments. The four moments of translation are:

- **Problematization:** How are some actors brought into motion by other actors? The meaning of the term problematization is twofold. It is both about the concrete problem to be resolved and about how some actors are defined by the way in which other actors' present the problem. In the present case study, ACorp presents AWeb as an improvement in asthma treatment.
- **Interessement:** Will the problematization incite the involved actors, such as asthmatics, to accept the identity defined for them? Interessement designates the measures taken by an actor to stabilize the identities of the other actors involved in the problematization. It comprises the means taken to incite actors to share a common goal.
- **Enrolment:** How well does the interessement succeed? Enrolment concerns how the definitions inherent in the problematization are transformed into concrete material form, such as texts and e-health systems. Through this process the problematization is negotiated and its definitions inscribed in artefacts.
- **Mobilization/displacement:** Who becomes empowered to speak on behalf of whom? Mobilization concerns the extent to which actors come to define themselves in accor-

dance with the problematization. If the actors adopt this definition their voice is displaced to the actors presenting the problematization.

By refusing to maintain absolute definitions of actors, be they asthmatics or any kind of technology, actor-network theory enables a renegotiation of their apparent identities and boundaries. As a consequence, reality becomes transitional, situated, and performed. The performative approach (Goffman, 1959; Law & Singleton, 2000; Mol, 1999; Mol & Law, 2004; Star, 1991) entails (a) that reality is not only composed of what is, but also of what is performed, and (b) that these performances could always have been done differently. Hence, to trace how asthma is actually performed, the scope of our study becomes asthmatics' concrete ways of performing their asthma. Using Moser and Law's (1999) concept of passages, the scope of our study becomes the *passages* between different ways of relating to asthma, which are provided by different ways of performing asthma.

Asthma performances are complex, and multiple experiences of asthma are often performed simultaneously and interdependently. In conceptualizing this multiplicity, we draw on the cyborg metaphor (Haraway, 1991). On a general note, the cyborg metaphor presents transgressed boundaries between categories—for example, between organism and machine. For present purposes, we will, however, focus on one characteristic—namely, the cyborg's *split vision* (Haraway, 1991). A cyborg has split vision in that it is capable of accommodating multiple, simultaneous performances that are at the same time irreducible to each other and inextricably intertwined. While a cyborg is by definition both one and many, the different identities may be more or less well-connected and the split vision may, consequently, involve boundaries at various levels of permeability between the identities. We will argue that the cyborg is a useful metaphor in

understanding asthma self-management, because it is ontologically situated between categories.

METHOD

Empirical data have been collected from two target groups. To obtain data about how the AWeb project proceeded and how ACorp perceived the project and the user, two interviews were conducted with the AWeb project manager, supplemented with e-mail correspondence and published reports from the project. The authors are entirely independent of ACorp and were neither commissioned by ACorp to do the study, nor in any other way related to ACorp or AWeb. To obtain data about how asthmatics live with their asthma, four asthmatics were interviewed. All four interviewees were university students. Being young, well-educated, and technology literate, the interviewees did not span the heterogeneity of asthmatics but, on the contrary, represented the segment of asthmatics most likely to use a system like AWeb. Bearing this in mind, it is noteworthy that none of the interviewees had used AWeb. In this sense, the four interviewees are ordinary asthmatics.

All six interviews were semistructured and audio recorded. Whereas the two interviews with the project manager were explorative and clarifying, the four interviews with asthmatics were conducted as life-story interviews (Kvale, 1996). The analysis of the interviews followed a phenomenological approach in which the interviewees' statements were taken at face value and grouped into categories of related statements, each category covering a significant element of interview content. These categories were then applied to group yet more statements and produce abstractions that described patterns in the data. This process of categorization and meaning condensation was guided by our conceptual framework.

AWEB'S TRANSLATION OF ASTHMA

The development and launching of AWeb created a sociotechnical network in which “being an asthmatic” attained a specific meaning. This meaning was brought into being by the AWeb project group as an implicit consequence of the design activities, and it was embedded in AWeb as a taken-for-granted image of the user. By using the vocabulary of translation (Callon, 1986, 1991) this image of the user is revealed as created and, in turn, presented to asthmatics through the four moments of translation.

The *problematization* concerns how some actors are brought into motion by other actors. In this case we will focus on how the AWeb project group brought other actors, especially asthmatics, into motion. As the AWeb project manager remarked: “Of course, we wanted [AWeb] to be as useful as possible to the asthmatics but we are involved in the project for commercial reasons. In the end it was a means to increase sales.” This commercial motivation was a basic premise for ACorp to engage in the project but it should not be taken as an indication of low quality or commitment. Indeed, the project group followed recognized recommendations in their design of AWeb. The commercial motivation was, however, unlikely to incite asthmatics, and was quickly transformed by the AWeb project group into a completely different proposition: Can information technology, and indeed the Internet, support asthmatics in their self-management? This problematization enunciates several actors, including GINA, which had developed the step model that AWeb implements, general practitioners who are expected to support initiatives that are in line with recommended asthma treatment, and the asthmatics, who are seen as highly motivated, comfortable with the Internet, and eager to minimize their asthma symptoms.

In order for AWeb to be successful, the relevant actors had to become interested in the problema-

tization. The AWeb project group applied several strategies of *interessement* to make the other actors partake in the problematization. First and most concretely, AWeb was developed. AWeb included functionality that promised to relieve many of asthmatics' symptoms and ease general practitioners' work. Second, ACorp assumed a withdrawn role and enrolled other actors to speak on behalf of the project, most notably general practitioners but also GINA and the national Asthma and Allergy Association. Third, these other actors were external to the commercial motivation for the project and represented important protectors of asthmatics' well-being. Fourth, the AWeb project group and the actors speaking on its behalf enunciated AWeb as a system that improved asthmatics' self-management and thereby reduced their symptoms.

Through the strategies of *interessement* the AWeb project group presented asthmatics with “a better way” of managing their asthma, available only through the use of AWeb, which at the time was the only initiative of its kind (Anhøj & Nielsen, 2004). Thus, the AWeb project group inscribed the adoption of this better way into asthmatics' decision to adopt AWeb. The number of asthmatics that adopted AWeb was however small, indicating that they approached this *enrolment* process reluctantly. Rather than engaging in regular use of AWeb, asthmatics fluctuated for some time between regular use and non-use and then reverted to non-use. In reverting to non-use the asthmatics not only discontinued their use of AWeb, they also rejected the assumptions defining AWeb as a better way to deal with asthma.

The central assumption in AWeb was that asthmatics are highly interested in their physical well-being and highly motivated toward staying symptom-free. This image of asthmatics remained unquestioned by the AWeb project group, GINA, the national Asthma and Allergy Association, and the general practitioners, but was not adopted by asthmatics to an extent that fostered regular use of AWeb. Hence, the problematization, in-

teressement, and enrolment resulted in a very limited *mobilization* of asthmatics. While the few mobilized asthmatics that used AWeb may be considered early adopters (Rogers, 2003), they provide little basis for understanding the reluctance of most asthmatics to adopt AWeb and its image of asthmatics as, per se, striving to be symptom-free.

ASTHMATICS' PERFORMANCE OF ASTHMA

The image of asthmatics as individuals who per se prioritize being symptom-free is not restricted to the AWeb project. The same line of thinking lies beneath common categorizations of asthmatics according to their commitment to avoid symptoms, for example as either controllers or neglecters (Anhøj & Nielsen, 2004). We will argue that this is an oversimplified and somewhat misconstrued account of how asthmatics relate to their asthma. By looking at how our interviewees actually perform their asthma, we get accounts of complex asthma realities unfolding around the ways in which the interviewees handle the mundanities of their everyday life.

Four Asthma Realities

All four interviewed asthmatics use both controller and attack medication, have tried using peak-flow meters, and suffer more or less frequent asthma attacks. However, their ways of experiencing these aspects of their asthma are highly different.

Kit does not see asthma as a big problem in her day-to-day life: *"I guess many asthmatics suffer more from their asthma than I do, but again, I do have asthma, and if I am not careful I can have an attack."* Kit previously used a peak-flow meter for training her senses by giving her a way of checking that the way her body felt was in accordance with what the peak-flow meter told her. Now, she does not use it anymore. Kit is good at

taking her controller medication. Indeed, she has the controller medication under enough control that in low-risk periods, she reduces her usage of controller medication, and in certain periods, she takes no medication at all, except an occasional dose of attack medication. To Kit, it is important to try to minimize her usage of medication. In Kit's own words: *"Of course money is an issue, but to me it is more important not to feel dependent on any drugs. I would much rather try to change my way of living; do sports, keep my house clean, relax, and just listen to my body."* Thus, Kit does not forget to take her controller medication, but at times, she deliberately omits taking it because she feels she has her asthma under control and likes the sense of being independent of medication. As such, she simply tests herself.

In contrast, John does not care much about his asthma: *"it makes no difference to me."* In fact, John dislikes all aspects associated with asthma. When he first got diagnosed, he tried to use a peak-flow meter and a diary, but for John, these remedies were just reminders of asthma; a "thing" he felt he had quite enough of in his life as it was. He does not want to know his asthma the way a peak-flow meter makes it available to him. In general, John does not care much for understanding the effects and side effects of his medication: *"As long as it makes me breathe, I do not care about what it actually does. In fact, I often forget the brown one [the controller medication] at home. It means nothing to me."* He goes on explaining why he often does not take his controller medication: *"Out of pure laziness, or whatever you want to call it, I sometimes do not take my [controller] medication while feeling bad; just because it feels boring to take it."* In contrast, it is important to John to have his attack medication at hand. He often has attacks, especially at night and in the morning. His way of handling these attacks is to *"take some attack medication and go on with whatever I am doing."* Thus, John deliberately "forgets" to take his medication because he cannot stand to be bothered with the medication, either

Incompatible Images

out of what he himself terms laziness, or because he simply feels like being without it.

In Tina's view, her asthma is more or less under control. Tina has participated in clinical trials and sees this as a way of keeping her own asthma in check while at the same time contributing to the well-being of other asthmatics. And she adds: "*Besides it is only for a short period of time.*" Tina is not very good at taking her controller medication. She tells that it is probably because she cannot feel any immediate effects, which is also why she, for some time, has considered buying a peak-flow meter. She sees a peak-flow meter, which she has used during the clinical trials, as an interesting option, but she just has not gotten around buying one yet. Tina explains that she would like to take her controller medication more regularly, but mundanities repeatedly seem to get in the way:

When you take the medication you need to drink water afterward to avoid the risk of a mouth condition. And I just don't have the time for all that in the morning. But I always bring it with me to work. But when I get to work my colleagues are always late and they always do extracurricular work while on the job. And that pisses me off. So I won't do like they do. So, you see, I cannot take my medication at work.

Tina likes when someone close to her tells her to take her controller medication. Then she feels that she can legitimately spend time to take care of her asthma without seeming too preoccupied with herself. Thus, when Tina omits taking her controller medication, it is out of practical reasons, and because it seems to prevent her from seeing herself the way she wants.

Mike has taken controller medication since he was about 18 years old and says that his asthma does not cause him much trouble. He uses his controller medication on a regular basis. It keeps him virtually free of attacks and works very well for him. He therefore sees no need to test whether

he could do without it. Of course, he sometimes forgets his medication, but in general he is very good at taking it. He stresses that his asthma is under control as long as he takes his controller medication. Thus, Mike practically always takes his controller medication and when he does not, it is out of accident; he never purposefully omits taking it. As the only one of the interviewees, Mike sees his general practitioner about his asthma every six months. He also has his own peak-flow meter and uses it periodically with a diary to check that everything is okay. His use of the peak-flow meter appears to be simple and problem free to Mike: "*All I have to do is blow in a tube and read a small meter. That tells me all I need to know.*" The peak-flow meter gives Mike a sense of control, and he likes the way it lets him know his asthma.

Good and Bad Passages

It is evident from the accounts above that the realities of asthma are different to the four asthmatics. In fact, each asthmatic relates to—and indeed performs—multiple asthmas depending on mood, social context, recency of his or her last attack, and other situational factors. To untangle these interwoven performances, we will draw on the theoretical notion of a passage, which refers to a performance that links other performances together (Moser & Law, 1999). Some ways of performing asthma are rendered smooth and nice to the asthmatic and thus constitute good passages. Conversely, others are rough and unpleasant and constitute bad passages. Good and bad in this connection denote what feels good and bad to the asthmatic and thereby blend physical and psychological aspects.

The four asthmatics occasionally do not take their medication, and they explain these omissions in different ways. In this respect, it is important to note that asthma medication is not only a way in which asthma is relieved, but also a way in which their lungs and their asthma are made known

to asthmatics (Willems, 1998). The medication creates a new sensation of lungs and of breathing. In this sense the medication is constitutive of one performance of asthma. Omission to take medication interrupts the sensation of lungs and asthma provided by the medication and thereby constitutes yet another way of doing asthma. The four asthmatics omit to take their medication when acting upon certain specificities, specifically their present need for medication and for feeling normal and capable. While the specificities differ across asthmatics the notion of good and bad passages reveals strong similarities in the four interviewees' omissions to take controller medication. Given the choice, they all prefer to perform good passages. As such, omitting to take controller medication sometimes provides good passages.

Kit likes not to be dependent on medication all the time and performs her omissions of taking controller medication by dosing down in low-risk periods. This makes her feel capable, and thereby provides a good passage. Like Kit, John does not want to be bothered by his medication all the time. But unlike Kit, he does not plan his omissions, and consequently suffers frequent attacks. Still, being without his controller medication constitutes a good passage to him, because he experiences it as a way of avoiding an image of himself as an asthmatic. Tina cannot find the time to take her controller medication in the morning, and feels that she cannot take it at work. This tension between her self-image and her asthma seems, however, to disappear when someone close to her tells her to take her medication. Thus, she omits her medication when taking it will constitute a bad passage by interfering with the mundanities of her everyday life. Finally, Mike likes to take his medication because he finds it makes him feel well. He tries to take it consistently and feels less capable when he occasionally forgets.

Looking at the omissions of taking controller medication in terms of passages the four asthmatics seem to prefer passages that make them feel capable over being symptom-free per se. The

tensions between perceiving oneself as capable and taking medication change dynamically and in making good passages they will sometimes coincide, and at other times collide. It is, for example, a better passage to take the medication in high-risk periods or when someone else creates a room for taking it without a need for performing a special relation to one's asthma self.

The asthmatics' relation to peak-flow meters provides another example of how good and bad passages are negotiated. Peak-flow meters can measure asthmatics' lung function and thereby provide a means for asthmatics to look inside their body. In the vocabulary of translation, the use of a peak-flow meter becomes a vehicle for displacing the bodily function of respiration from the respiratory system to an external device; that is, a way to excorporate asthma (Mol & Law, 2004). Hence, a peak-flow meter becomes a device for developing a new way of knowing asthma. For example, Kit previously used a peak-flow meter on a regular basis. By relating what she felt to what the peak-flow meter measured, she developed a new sensibility toward her asthma. Indeed, she developed a new asthma self. As such, the peak-flow meter not only provided objective knowledge of her asthma but also contributed to creating the way in which Kit performs her asthma. This way, the peak-flow meter was used to provide good passages. By now, Kit has, however, stopped using the peak-flow meter. It has provided her with the insight she needed to gain control of her asthma, which was her way to avoid that asthma invaded too much of her life. Now Kit has her asthma more or less under control and does not want to engage in further resource-demanding excorporations of her asthma to create a refined asthma self. For Kit, the passages provided by the peak-flow meter have changed from good to bad because the work needed to get an even better grip of her asthma does not seem worth the effort.

Applying the notion of passages to the other interviewees' relations to peak-flow meters reveals further nuances. John prefers not to adopt a

peak-flow meter because it would make him more aware of his asthma by displacing the capacity of his lungs from within his body to an explicit representation outside his body. In subjectifying himself to the peak-flow meter he would have to relate to his asthma in a way that renders some of the work he does in relation to his asthma visible and thereby discords with the way he sees himself—a bad passage. Tina does not mind to use a peak-flow meter for a limited period of time in the context of a clinical trial, but she seems to resist subjectifying herself to a peak-flow meter on a regular basis. The clinical trials detach her from her performance of her own asthma by displacing it to an asthma identity that includes not only herself but also other asthmatics. This generalized asthma identity becomes available to Tina through the clinical trials' aim of benefiting asthmatics in general; and in this context—and apparently only in this context—the peak-flow meter provides good passages. Mike on the other hand has entered a symbiotic relationship with the peak-flow meter on a regular basis. The peak-flow meter provides him with a means to perform his asthma in such a way that he feels liberated from its consequences. To Mike the peak-flow meter provides good passages.

The passages relating to peak-flow meters reveal tensions between developing an experience of asthma by subjectifying to peak-flow meters and the asthmatics' image of themselves as capable. When the self-image is supported, a peak-flow meter creates good passages, which in turn can facilitate use. Conversely, when the self-image is challenged, a peak-flow meter creates bad passages and it is likely rejected.

An Economy of Passages

In relating to their medication and to peak-flow meters, the interviewees seem to perform calculations. They obviously care about how many and how severe attacks they suffer, but they seem to care at least as much about rendering their asthma

smooth. For example, when Tina has an attack she thinks that maybe it is time for her to become more persistent in using controller medication. However, in the midst of all her everyday activities she finds this difficult to do and settles for less persistence: *“I guess it is because I am not that bad. Had my asthma been worse, I am sure I would have worked more with it.”* She makes an effort to tell herself and others that there are pragmatic reasons for her not taking medication and not acquiring a peak-flow meter. Hence, she does work in order not to have to do work. This work provides good passages for Tina, because it renders invisible all the efforts she puts into relating to her asthma and thus enables her to maintain an image of herself as capable.

The preference for good passages over bad passages is a persistent characteristic of the interviewees' asthma performances. Thus, their numerous specific asthma practices appear to be performed according to an overarching economy of passages, which is altogether different from the rationality of medical discourse on asthma treatment. While feeling good and capable is constitutive of the interviewees' economies of passages, they achieve this common objective in individual ways. For example, when Kit has an occasional attack all the work she has done in relation to her asthma since her last attack becomes visible to her and turns from good to bad passages; hence, in her economy of passages, it is worth her while to recap what has happened since her last attack in an effort to avoid a similar incident in the future. Conversely, Mike's economy of passages tells him that it is not worth the effort to challenge his asthma due to an occasional attack; he merely takes his attack medication. Furthermore, the interviewees dynamically adjust their ways of performing their asthma in response to practicalities and other aspects of their day-to-day lives. Sometimes being relieved of symptoms coincides with feeling capable; at other times feeling capable can imply doing things that worsen the physical condition, and as such the economy of symptoms collides

with that of a capable self. Indeed, the interviewees perform not one, but a proliferation of asthmas, all of which are inextricably related through an economy of passages that emphasizes feeling capable over being symptom-free per se.

DISCUSSION

Thus far, we have approached asthma self-management from the perspective of the AWeb project with its focus on striving to be symptom-free per se and from a perspective focusing on specificities, performances, and passages in the lives of four asthmatics. These two perspectives are highly different, and our analysis points to their incompatibility as a key impediment to widespread adoption of AWeb.

A Turn to the User

Patient-centred e-health is generally seen as a potentially powerful tool for disease management because the Web offers a widely available, low cost, and flexible means of communication between patient and healthcare professional and thereby enables treatment programmes tailored to the individual patient and dynamically regulated on the basis of data entered regularly by the patient for purposes of self-management or for monitoring by a healthcare professional (Bulger & Reeves, 2000). These expectations have instigated the development of patient-centred e-health systems for diseases such as asthma, diabetes (Plougmann, Hejlesen, & Cavan, 2001), eating disorders (Carrard, Rouget, Fernández-Aranda, Volkart, Damoiseau, & Lam, 2006), and HIV/AIDS (Caceres, Gomez, Garcia, Gatell, & del Pozo, 2006). However, our analysis of AWeb reveals that even though AWeb is designed to improve asthmatics' self-management, in practice it becomes an extension of healthcare professionals' views on asthma and its treatment. Furthermore, the AWeb case demonstrates that when given the opportunity to

embrace this rational medical behaviour, many asthmatics opt for a different rationale than simply striving to be free from symptoms.

This suggests that the development of self-management systems may benefit from a more thoroughly user-centred approach. While a focus on self-management may itself seem user centred, self-management systems presuppose users' active and sustained involvement and thereby become crucially dependent on being compatible with users' self-image and ways of performing their disease. Otherwise, users simply refrain from adopting such systems or cease to use them. Previous studies of asthmatics' self-management of their medication show that overuse, erratic use, and especially underuse of asthma medication are very common (Bender, Milgrom, & Rand, 1997). Reported reasons for such deviations from recommended practices include forgetfulness, denial that one is an asthmatic, inconvenience, embarrassment, and laziness (Buston & Wood, 2000). Rydström, Hartman, and Segesten (2005) find that young asthmatics' core concern is to avoid that asthma gets the upper hand over their life, and they report three strategies used by asthmatics in relating to their disease: keeping a distance to it, challenging it, and taking it into consideration. While these studies corroborate our analysis, getting to know the user can, however, be difficult because recognizing what knowledge is needed and how to obtain it may constitute major challenges. This is well illustrated in the AWeb case, where it turned out to be insufficient for ACorp to rely on asthma authorities such as GINA and the national Asthma and Allergy Association. Indeed, these authorities must be seen as part of the reason why the AWeb project came to adopt an image of the self-managing asthmatic as always striving to be symptom-free.

The present study shows how the lives of four asthmatics comprise multiple intertwined performances of asthma. Some of these asthmas are performed sequentially and others simultaneously, but all are interdependent. This way

Incompatible Images

asthma can be said to be more than one and less than many in that it is neither possible to reduce the various performances of asthma to one uniform asthma performance, nor to perform the various asthmas in isolation. Rather, the asthmas constitute each other, and the resulting arrangement of irreducible practices constitutes a cyborg (Haraway, 1991). The defining characteristic of a cyborg is its ability to accommodate multiple, simultaneous performances that are at the same time irreducible to each other and inextricably intertwined. As a consequence of this split vision the cyborg is at the same time one and many, and it manages to keep itself together while being situated between categories. A cyborg has no unifying identity but several different identities, which may be more or less well-connected. The cyborg metaphor emphasizes that the individual asthmatic performs a proliferation of visible and invisible works, which are neither reducible to any one kind of work nor observable as individual works. Thus, the asthmatic cannot be adequately characterized by any one of his or her asthma performances, but only by the split vision that accommodates all the different but intrinsically intertwined performances. In this sense, getting to know the user requires attentiveness to the manifold performances that comprise users' ways of living with their disease and to the economy of passages that links the concrete performances to users' self-image.

Implications for E-Health Design

Incompatibilities between a system's image of the user and the self-image of the users constitute a major threat to adoption and use of patient-centred e-health systems. Our analysis of the self-image of asthmatics points toward three implications for the design and evaluation of systems for supporting patients' self-management:

- **Making a business case.** In most systems-development methods the decision to start

a project is made on the basis of a business case that identifies a user need and argues convincingly for the viability of the envisioned solution. An understanding of good and bad passages and of the user as a cyborg will provide for the creation of business cases that more accurately reflect the viability of envisioned solutions and will, thereby, support organizations in making informed decisions about which projects to initiate—and which to avoid.

- **Designing for irreversibility.** Through the process of translation, systems bring users into motion. This is an inherent property of designing systems that aim to introduce changes to current practices, but the mobilization is merely an option presented to users. The more possibilities a system provides for linking into users' practices, the better chances it has of becoming part of some of these practices. And the more practices it becomes part of, the more it becomes ingrained in how users connect and coalesce their multiple performances of their disease. Thus, e-health systems should be designed to link into a variety of users' performances as this is how the mobilization may succeed in reaching a state where it is constitutive of users' self-image and consequently not at risk of being reverted by their day-to-day performances.
- **The performativity of evaluations.** Users are also relating to circumstances and actively performing their disease when they participate in system evaluations and clinical trials. For some users, like Tina, such evaluations provide opportunities for displacing their performance of their disease to a generalized disease identity, and thereby shifting the economy of passages toward one in which the work involved in complying with recommended practices is a good passage. For other users the circumstances of evaluations make them feel more subjected

to their disease, and this constitutes a bad passage by interfering with their image of themselves as capable. In interpreting evaluations, designers should be sensitive to these performances.

AWeb implemented state-of-the-art guidelines for asthma self-management (GINA, 2005), integrated self-management with an extended relationship between asthmatics and general practitioners, and provided personalized treatment advice at any time. Asthmatics' non-use of AWeb should not be seen as a result of dissatisfaction with these facilities, nor can system use be ensured by providing a different set of system facilities. On the contrary, the non-use of AWeb and other similar initiatives is partly explained by their narrow focus on the technology and on a medical rationality, leading to under-recognition of the myriad nontechnological, nonmedical factors involved in adopting and using e-health systems.

CONCLUSION

E-health systems for patient self-management are appearing for a number of chronic diseases including asthma. Whereas clinical trials provide evidence that such systems lead to better asthma management, practical deployment of one such system, AWeb, resulted in non-use by asthmatics. This study investigates asthmatics' reasons for not adopting AWeb by taking a performative approach and thereby keeping the practicalities of how asthmatics perform their asthma in the foreground. The analysis shows that AWeb is based on a taken-for-granted image of asthmatics as, per se, striving to be symptom-free. This image is incompatible with the four interviewed asthmatics' day-to-day performances of their asthma and renders invisible (a) that their asthma performances emphasize an economy of good passages and of feeling capable, (b) that they achieve the objective of feeling capable in quite

different ways, and (c) that feeling capable does not per se equal being symptom-free all the time. The incompatibility of the system's image of the user and the self-image created and maintained by asthmatics through their asthma performances provides a basis for appreciating the manifold asthma performances such a system must incorporate in order to become and remain part of how asthmatics perform their asthma.

REFERENCES

- Anhøj, J., & Nielsen, L. (2004). Quantitative and qualitative usage data of an Internet-based asthma monitoring tool. *Journal of Medical Internet Research*, 6(3), e23. Retrieved May 27, 2008, from <http://www.jmir.org/2004/3/e23>
- Ball, M.J., & Lillis, J. (2001). E-health: Transforming the physician/patient relationship. *International Journal of Medical Informatics*, 61(1), 1-10.
- Bender, B., Milgrom, H., & Rand, C. (1997). Nonadherence in asthmatic patients: Is there a solution to the problem? *Annals of Allergy, Asthma and Immunology*, 79(3), 177-186.
- Bulger, D.W., & Reeves, C. (2000). Interactive Internet Web sites: A potentially powerful tool for disease management. *Disease Management & Health Outcomes*, 7(2), 67-75.
- Buston, K.M., & Wood, S.F. (2000). Non-compliance amongst adolescents with asthma: Listening to what they tell us about self-management. *Family Practice*, 17(2), 134-138.
- Butler, C., Rollnick, S., & Stott, N. (1996). The practitioner, the patient and resistance to change: Recent ideas on compliance. *Canadian Medical Association Journal*, 154(9), 1357-1362.
- Caceres, C., Gomez, E.J., Garcia, F., Gatell, J.M., & del Pozo, F. (2006). An integral care telemedi-

- cine system for HIV/AIDS patients. *International Journal of Medical Informatics*, 75(9), 638-642.
- Callon, M. (1986). Some elements of a sociology of translation: Domestication of the scallops and the fishermen of St. Brieuc Bay. In J. Law (Ed.), *Power, Action and Belief: A New Sociology of Knowledge?* (pp. 196-223). London, England: Routledge.
- Callon, M. (1991). Techno-economic networks and irreversibility. In J. Law (Ed.), *A Sociology of Monsters: Essays on Power, Technology and Domination* (pp. 132-161). London, England: Routledge.
- Carrard, I., Rouget, P., Fernández-Aranda, F., Volkart, A.-C., Damoiseau, M., & Lam, T. (2006). Evaluation and deployment of evidence based patient self-management support program for bulimia nervosa. *International Journal of Medical Informatics*, 75(1), 101-109.
- Gibson, P.G., Powell, H., Coughlan, J., Wilson, A.J., Abramson, M., Haywood, P., Bauman, A., Hensley, M.J., & Walters, E.H. (2002). Self-management education and regular practitioner review for adults with asthma. *Cochrane Database of Systematic Reviews*, Issue 3, Art. No. CD001117. DOI: 10.1002/14651858.CD001117.
- Global Initiative for Asthma (GINA). (2005). *Global strategy for asthma management and prevention*. NIH Publication No. 02-3659. Global Initiative for Asthma (GINA) workshop report. Retrieved May 27, 2008, from <http://www.gin-asthma.org>
- Goffman, E. (1959). *The presentation of self in everyday life*. Garden City, NY: Anchor Books.
- Haraway, D.J. (1991). *Simians, cyborgs, and women: The reinvention of nature*. London, England: Free Association Books.
- Kvale, S. (1996). *InterViews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage.
- Law, J., & Singleton, V. (2000). Performing technology's stories: On social constructivism, performance, and performativity. *Technology and Culture*, 41(4), 765-775.
- Mol, A. (1999). Ontological politics. A word and some questions. In J. Law & J. Hassard (Eds.), *Actor Network Theory and After* (pp. 74-89). Oxford, England: Blackwell.
- Mol, A., & Law, J. (2004). Embodied action, enacted bodies: The example of hypoglycaemia. *Body & Society*, 10(2-3), 43-62.
- Moser, I., & Law, J. (1999). Good passages, bad passages. In J. Law & J. Hassard (Eds.), *Actor Network Theory and After* (pp. 196-219). Oxford, England: Blackwell.
- Newman, S., Steed, L., & Mulligan, K. (2004). Self-management interventions for chronic illness. *Lancet*, 364(9444), 1523-1537.
- Nielsen, H.L. (2005). *Linking healthcare: An inquiry into the changing performances of Web-based technology for asthma monitoring*. Ph.D. thesis, Copenhagen Business School, Copenhagen, DK.
- Plougmann, S., Hejlesen, O.K., & Cavan, D.A. (2001). DiasNet—A diabetes advisory system for communication and education via the Internet. *International Journal of Medical Informatics*, 64(2-3), 319-330.
- Rasmussen, L.M., Phanareth, K., Nolte, H., & Backer, V. (2005). Internet-based monitoring of asthma: A long-term, randomized clinical study of 300 asthmatic subjects. *Journal of Allergy and Clinical Immunology*, 115(6), 1137-1142.
- Rogers, E.M. (2003). *Diffusion of innovations (fifth edition)*. New York: Free Press.
- Rydström, I., Hartman, J., & Segesten, K. (2005). Not letting the disease get the upper hand over life: Strategies of teens with asthma. *Scandinavian Journal of Caring Sciences*, 19(4), 388-395.

Safran, C. (2003). The collaborative edge: Patient empowerment for vulnerable populations. *International Journal of Medical Informatics*, 69(2), 185-190.

Star, S.L. (1991). Power, technologies and the phenomenology of conventions: On being allergic to onions. In J. Law (Ed.), *A Sociology of Monsters: Essays on Power, Technology and Domination* (pp. 26-56). London, England: Routledge.

Willems, D. (1998). Inhaling drugs and making worlds: A proliferation of lungs and asthmas. In M. Berg, & A. Mol (Eds.), *Differences in Medicine: Unravelling Practices, Techniques and Bodies* (pp. 105-118). Durham, NC: Duke University Press.

Wilson, E.V, & Lankton, N.K. (2004). Modeling patients' acceptance of provider-delivered e-health. *Journal of the American Medical Informatics Association*, 11(4), 241-248.

Patient–Centered E–Health

E. Vance Wilson
Arizona State University, USA

Director of Editorial Content: Kristin Klinger
Senior Managing Editor: Jennifer Neidig
Managing Editor: Jamie Snavelly
Assistant Managing Editor: Carole Coulson
Copy Editor: Laura Kochanowski
Typesetter: Carole Coulson
Cover Design: Lisa Tosheff
Printed at: Yurchak Printing Inc.

Published in the United States of America by
Information Science Reference (an imprint of IGI Global)
701 E. Chocolate Avenue, Suite 200
Hershey PA 17033
Tel: 717-533-8845
Fax: 717-533-8661
E-mail: cust@igi-global.com
Web site: <http://www.igi-global.com>

and in the United Kingdom by
Information Science Reference (an imprint of IGI Global)
3 Henrietta Street
Covent Garden
London WC2E 8LU
Tel: 44 20 7240 0856
Fax: 44 20 7379 0609
Web site: <http://www.eurospanbookstore.com>

Copyright © 2009 by IGI Global. All rights reserved. No part of this publication may be reproduced, stored or distributed in any form or by any means, electronic or mechanical, including photocopying, without written permission from the publisher.

Product or company names used in this set are for identification purposes only. Inclusion of the names of the products or companies does not indicate a claim of ownership by IGI Global of the trademark or registered trademark.

Library of Congress Cataloging-in-Publication Data

Patient-centered e-health / E. Vance Wilson, editor.

p. ; cm.

Includes bibliographical references and index.

ISBN 978-1-60566-016-5 (hardcover : alk. paper)

1. Medical informatics. 2. Medical telematics. 3. Medical personnel and patient. I. Wilson, E. Vance (Ellis Vance)

[DNLM: 1. Medical Informatics--trends. 2. Internet. 3. Medical Records Systems, Computerized--trends. 4. Patient-Centered Care--trends. 5. Self Care--trends. W 26.5 P2983 2009]

R858.P384 2009

610.285--dc22

British Cataloguing in Publication Data

A Cataloguing in Publication record for this book is available from the British Library.

All work contributed to this book set is original material. The views expressed in this book are those of the authors, but not necessarily of the publisher.

If a library purchased a print copy of this publication, please go to <http://www.igi-global.com/agreement> for information on activating the library's complimentary electronic access to this publication.