Technologies of Compliance?

Telecare Technologies
and Self-Management of
Chronic Patients

Ivo Maathuis

TECHNOLOGIES OF COMPLIANCE?

TELECARE TECHNOLOGIES AND SELF-MANAGEMENT OF CHRONIC PATIENTS

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Chapter 1. Telecare technologies and self-management

1.1 Introduction

“Yes, ... I have to take medicine three times a day, and that is what I do.”

(Patient A, interview, January 18, 2013)

“sometimes I start a day earlier, else I will not make it.”

(Patient B, interview, January 16, 2013)

“No, until now I did not start by myself, I always consult my doctor.”

(Patient G, interview, January 22, 2013)

The above quotes show some of the experiences of the chronic lung patients I interviewed to learn more about how they used the medical devices they had received to monitor and treat their illness at a distance. Although all of them used the same devices, these quotes illustrate that each patient reacted in a different way to the advice this technology generated with respect to medication. Some patients accepted this technologically mediated guidance indiscriminately, just because “these devices would know best.” Other patients trusted their own bodily experience with their illness over the advice of some “fancy device.” And others used both their bodily experience and the recommendations generated by the devices but preferred to consult their doctor before taking a decision. These different positions represent in a nutshell what this research is about: the tensions that may emerge between the intended use and behavior inscribed in technological devices and the actual use practices. Although medical technologies are often designed to discipline patients, in this case to follow advice for taking medicines, patients are very creative in finding their own way of living with and treating their illness.

The devices these people used are called telecare technologies.¹ Telecare can be described as “direct patient care, in which the recipient is at home and

¹ Some of the telecare technologies that the patients used are not actual devices but rather applications. However, the patients I interviewed referred to them as devices.

spatially remote from the clinician, nurse or informal carer, and in which communication media are used” (Pols, 2010, p. 375). Policymakers and producers promise that telecare technologies can contribute to solving the problem of the growing demand for care as a result of an aging population, a growing prevalence of chronic illness and a projected scarcity of health-care personnel in the future (Oudshoorn, 2011, p. 14; May et al., 2005, p. 1490; Timmermans & Berg, 2003).

These expectations are based on the assumption that telecare technologies will increase the efficiency of health-care services because they delegate certain tasks and responsibilities of doctors to less expensive nurses, technologies and patients, like monitoring health-related data or applying decision support systems. Moreover, telecare technologies promise to support patients in playing an active role in their own health care (i.e. they are expected to contribute to patient autonomy) (Oudshoorn, 2011).

Reflecting on these promises, I suggest that they reveal different approaches to providing health care. On the one hand, telecare technologies aim to partially replace people and take over care tasks of patients and professionals to make care more efficient. Telecare technologies are, on the other hand, expected to increase the responsibility of patients in taking care of themselves, or “self-managing” their illness, thus, bringing more control and autonomy to their lives.

These potentially conflicting approaches to health care become visible in the ways in which self-management is incorporated in telecare technologies. Maartje Schermer (2009) illustrates that telecare technologies can support different forms of self-management, but contemporary telecare systems predominantly enhance compliant forms of self-management, where patients are supported in following medical guidelines inscribed in these systems, which leaves little room for patient autonomy. Instead of delegating tasks and responsibilities to patients, these technologies take away part of the responsibility from them. However there often is a gap between the foreseen use of a technology and the actual use (see e.g. Latour, 1992). Moreover, users often play an active role in appropriating new technologies and may use them in very different ways than intended by its designers (Oudshoorn & Pinch, 2003, 2008). In other words, while designers develop telecare technologies aimed at incorporating “compliant” forms of self-management, the actual use practice of these technologies might disclose

different forms of patient behavior. Furthermore, the implementation and use of telecare technologies also brings about ethical dilemmas. Do we want health-care technologies that force people to follow medical guidelines, or do we allow patients to live with their diseases according to their own views and wishes?

We, thus, may assume that telecare technologies will become successful and morally acceptable tools to support health care only if patients are enabled to develop adequate self-management practices. Therefore the tension between giving responsibility and autonomy to patients on the one hand and delegating control to technical devices on the other hand needs to be resolved. The central question of this research therefore reads as follows:

**How do telecare technologies participate in enabling and/or
constraining self-management practices of chronic patients?**

This research is part of the Netherlands Organisation for Scientific Research (NWO) program on Responsible Innovation. An important aim of the program is to fund and encourage research that reflects on ethical and social aspects of new technologies from the design phase onwards.² This research therefore reaches further than generating valuable insights on the matters previously described. It also aims to create opportunities to feedback these insights into the design practices of telecare technologies.

1.2 Theoretical framework

In this section I give an overview of the theoretical framework I use in this thesis, starting with the observation that with the shift in health care from acute to chronic diseases, traditional roles of patients and professionals have changed. Patients are expected to become more responsible for their own wellbeing. I distinguish two dominant approaches that are developed to support patients in this new role, namely self-management programs and medical technologies for personal use. These two approaches come together in the development of telecare technologies. One of the important aims of telecare technology is to support self-management

² <http://www.nwo.nl/en/research-and-results/programmes/responsible+innovation> (last accessed 24-04-2014).

strategies of patients. However, the ways in which self-management is articulated in the design and use of these new technologies is largely unaddressed. In order to develop a more in-depth understanding of these design and use practices, theoretical insights need to be explored. I argue that insights from Science and Technology Studies (STS) provide useful heuristic tools to analyze what forms of self-management are inscribed and enacted in design and use practices of contemporary telecare technologies. The section concludes by introducing the approach I use to contribute to a more responsible innovation of telecare technologies.

1.2.1 An increase of patient responsibility in health care

In the past decades, major stakeholders in the health-care sector identified an increase in the prevalence of chronic disease. Therefore the focus in health care changed from the treatment of acute to chronic diseases (Holman & Lorig, 2004). Together with demographic changes, this means an increasing pressure on the health-care system in the future. In order to deal with this situation, traditional divisions of labor change. Health-care tasks usually conducted by health-care professionals are partly delegated to patients (i.e. patients become more responsible for their own wellbeing). Possible tools to support chronically ill patients in their new role are so-called disease- or self-management programs and medical devices operated by patients themselves (Redman, 2004).

Changing role of patients: Support via self-management programs

The concept of self-management originates from the work of Thomas Creer (1976) on the management and rehabilitation of handicapped and chronically ill children (Lorig & Holman, 2003). Although self-management in chronic health care seems to be open for multiple interpretations (Jones et al., 2011), its main characteristic seems to be that patients should become (more) responsible for taking care of their own wellbeing. A conceptualization of “self-management” for patients with a chronic disease frequently used in the medical literature stems from Barbara Redman. In her article about ethical issues related to the concept, she defines self-management as “an individual’s ability to detect symptoms, and manage treatment, physical and psychosocial consequences, and lifestyle changes (such as

exercise and diet) inherent in living with a chronic condition” (Redman, 2007, p. 244).

Two discourses seem to dominate the debate on the need for self-management as a tool to tackle the burden of chronic illness for society. The first discourse reflects a *neoliberal* perspective on the introduction of self-management in health care, while the second discourse suggests a *moral* perspective on this issue.³ The neoliberal perspective of self-management emphasizes the relocation of labor usually conducted by health-care professionals to technologies and patients. This redivision of labor would have several beneficial effects for the treatment of chronic conditions. First, it would lead to significant savings on health-care costs because of a redistribution of health-care tasks from expensive health-care personnel to patients themselves. Second, an increase of effectiveness and efficiency in the care of chronic disease may also be realized by supporting patient empowerment, defined as “perceived self-efficacy” (Holman & Lorig, 2004).

Both arguments for the strengthening of self-management in health care (division of labor and an increase in efficiency) can thus be interpreted as beneficial for the treatment of chronic diseases from an *economic* point of view, based on a neoliberal political perspective.

However, other authors stress the importance of patient empowerment from a moral perspective (Holm, 2005). They emphasize that improving patients’ wellbeing can be considered as positive not only from an economic or medical perspective but also as a virtue of good care because it supports them to live a “good life.” The fact that patients may become more responsible for their wellbeing could enhance their feeling of autonomy, which could encourage patients to make decisions about their treatment according to their own views and wishes (i.e. patients would be enabled to live a more “fulfilling” life according to their own norms and standards).

The ideal of patient autonomy as the greater good in Western health care is questioned by philosopher Annemarie Mol (2008). In her book on contemporary health care she argues that in debates on current care patient choice is often regarded as the leading moral principle in their treatment, while *living* with a

³ See also Oudshoorn (2011) for an analysis of the introduction of telecare related to neoliberal politics.

chronic condition is not only about making choices based on rational considerations, but also about the practice of caring. Mol contrasts the values of the “logic of choice” with the “logic of care” and concludes that the latter values are often overlooked in contemporary (Western) health care.

To summarize, the arguments to improve patient self-management in the treatment of chronic disease take both economic and moral perspectives into account. However, everyday practice of living with a condition might ask for a broader view on health care than a merely economic or moral approach.

Moreover, it is important to include the role of technology to understand the current changes in self-management practices. Most of the literature on self-management merely addresses educational programs as tools to support self-management of chronic patients. The contents and usefulness of these programs are adequately illustrated in a study by Lorig and Holman (2003) on the history of self-management education. Central themes in these self-management education programs are the teaching of self-management tasks and problem solving skills (p. 1). Given the recent introduction of technologies to support self-management, it is important to take them into account as well.

Changing role of patients: Support via technology

As briefly mentioned in the introduction, technologies are becoming increasingly important to support patients to take more responsibility for their health.

Traditionally health-care technologies are located in hospitals and operated by health-care personnel, but in the past decades the use of medical devices by patients outside health-care facilities has increased (Willems, 2000).

However, technologies cannot be regarded as neutral tools that have a pure instrumental effect on existing societal practices like health care. Technologies “do” more, and have often unforeseen consequences. Moreover, the act of “influencing” is mutual. Technologies not only have an impact on society, the reverse process also takes place: Society has an impact on technology and technological development as well. In other words, technology and society are mutually intertwined and influence each other continuously. The interdisciplinary scholarship specialized in analyzing and interpreting the mutual shaping of science, technology and society is called STS. In section 1.2.4 I describe that STS

provides useful conceptual tools to analyze the role of technologies in supporting self-management strategies for chronic patients. But first I introduce two important prior studies on the use of medical devices by patients aimed at increasing responsibility for their wellbeing.⁴

An important STS study on medical devices for a patient's personal use originates from Alan Prout (1996). The author illustrates that the metered dose inhaler (MDI), as a medical device for the self-treatment and management of asthma, can be characterized as a network shaped by both human (social) and nonhuman (technical) elements. By describing the introduction of the device Prout tries to illustrate that technologies, when introduced into real world practices like health care, are not neutral tools "from outside" that can be regarded as independent from the environment where they are employed, but that both human and nonhuman actors (the MDI) are mutually engaged in a process of constituting each other.

Dick Willems (2000) illustrates how the use of (offline) self-monitoring devices combined with self-management plans for the treatment of asthma leads to changing relationships between patients and their body, patients and their physicians and also between patients and medical devices. Patients may incorporate "objective" measurements of their body into the "subjective" experience of felt symptoms, or experience their illness through the data generated by the medical devices. Moreover, with the introduction of self-management plans, patients actively engage in deciding over their own treatment. "They become agents instead of patients" (Willems, 2000, p. 27). The use of these plans in the treatment of chronic illness therefore involves a cooperative, rather than a hierarchical, relationship between the patient and health-care professional.

To conclude, the above articles show that technologies are not neutral tools with only an instrumental impact on the practices they engage in. On the contrary, technologies are inherently social entities that continuously shape and reconfigure their environment by which they are also shaped themselves.

⁴ For an extensive overview of sociological scholarship on medical technologies see Timmermans & Berg (2003).

1.2.2 The introduction of telecare technologies

In the previous section I described two approaches that support chronically ill patients to become more responsible for their wellbeing, namely through self-management programs and medical technologies.⁵ Interestingly, these two different approaches come together in telecare technologies. Telecare can be considered a form of “telemedicine,” in which the treatment and monitoring of diseases is mediated by information and communication technologies (ICTs) (see Figure 1.1 for an example of a contemporary telemedical system).⁶ In this section I present a short summary of recent STS studies on how telecare technologies shape health-care practices.

⁵ In recent years the influence of technology on self-management strategies has increased. As a result, self-management of a chronic disease has become more and more a technology-mediated form of care. This trend is highly visible in the growing market of health-related devices for personal use, like wearable heart rate meters, blood pressure meters, step counters and so on. According to Lupton (2013, p. 394) the terms “self-tracking” and “quantified-self” can be used to characterize this emerging self-monitoring practice. When these mobile devices are used to communicate (via the web) about one’s bodily measurements with others to “enhance disease prevention and management by extending health interventions beyond the reach of traditional care” (Estrin & Sim, 2010, p. 759), these devices are often referred to as mHealth technologies.

⁶ There is no single or uniform definition of the term telemedicine. In general, telemedicine is referred to as the performance of medical health services over a distance (Sood et al., 2007; Wootton, 2001), while in literature the term often is used to denote the exchange of health-related data among professionals. In addition to telemedicine the terms telehealth or e-health are often used.

Figure 1.1: Overview of a contemporary telemedical system with the use of sensors, a smartphone and wired and wireless communication techniques

Source: <http://telemedicine.ewi.utwente.nl/> (last accessed 24-04-2014)

Telecare technologies and the changing role of patients

As described for other offline self-management technologies (Willems, 2000), the introduction of telecare technologies involves changing roles of both health-care professionals and patients in the provision of health care. Initially, sociological literature seemed to pay more attention to the changes telecare would bring about for health-care professionals than for patients (see Cartwright, 2000; Lehoux et al., 2002; Mort et al., 2003; May et al., 2005; Hanlow et al., 2005).⁷ This rather unilateral view on the introduction of telecare changed with studies that elaborated on the adoption and use of these technologies from patient perspectives as well.

In her study on the implications of telecare for the transformation of health care, Nelly Oudshoorn (2011) illustrates that with the introduction of these

⁷ However, recently there is a growing body of sociological literature on the changing role of patients (and other users) of telecare technologies used in elderly care (see <http://www.lancaster.ac.uk/efortt/> last accessed 12-05-2014). However, the focus in this thesis is on telecare technologies for the treatment of chronic conditions.

technologies traditional roles of actors in health care change. Tasks usually conducted by physicians are delegated to (telecare) nurses and electronic devices, but also to patients themselves. Moreover, the location where these tasks traditionally would take place also changes from the hospital to the home environment and, with the introduction of mobile devices, also to places outside the home. With the introduction of telecare, the operation of medical technologies is no longer restricted to medical personnel only; patients are expected to actively contribute to their own care by using medical instruments themselves. This means they become important actors when telecare technologies are introduced to support or (partly) replace traditional forms of care. Some telecare technologies delegate tasks of measuring relevant medical data (like weight and blood pressure) or recording ECGs to patients. By using telecare devices patients then become “diagnostic agents” (Oudshoorn, 2011, p. 149). However, when the inscribed instructions of use are too compelling, this might take away the responsibility from patients to take care of themselves. Patients then might get the feeling that there are medical devices or people in call centers who continuously keep an eye on their health, and they do not have to take care of themselves anymore (besides executing diagnostic tasks).

In her book on the pioneering role of telecare technologies in contemporary health care, Jeannette Pols (2012) concludes that these practices come into existence by the mutual shaping of both medical devices and the environment in which they are “unleashed” (p. 18). Telecare can therefore not be regarded as a simple addition of technologies to existing care practices. On the contrary, by introducing technologies new care practices arise. These technologies may support patients’ self-care but not on their own. Medical devices are nodes in the self-care network together with other artefacts, including people, practices and other things. Pols therefore prefers to use the term “together-management” over “self-care” or “self-management” (2012, p. 75).

The studies of Oudshoorn and Pols also indicate that the initial expectation that telecare would become an easy technological fix for the current and future problems of the health-care system specifically, or the aging society in general, have been (and should be) toned down. Both studies describe how the changing roles of both health-care professionals and patients, when telecare technologies are

introduced, cannot be understood in terms of a linear trajectory in which technologies determine what happens in health care. Instead they suggest that these changes are related to the dynamic interactions between technologies, people and health-care practices. Although these studies thus provide important insights in the ways in which telecare technologies challenge existing health-care practices by introducing new forms of care and other relationships between health-care professionals and patients, they do not address the ways in which self-management is articulated in telecare practices. Equally important, they don't reflect on how insights from its use practices can be applied as feedback for the design of these technologies.⁸ This PhD thesis therefore addresses these themes by trying to understand what forms of self-management emerge in current telecare practices. As a first step I discuss in the next section Schermer's (2009) study on explicit forms of self-management articulated in telecare technologies.

1.2.3 Self-management in telecare technologies: three different forms

Although telecare technologies are expected to contribute to support patients to take more responsibility for their own wellbeing in the treatment of chronic illness, it is not clear which concept(s) of self-management are explicitly inscribed in telecare technologies. Medical ethicist Schermer (2009) distinguishes three forms of self-management that can be promoted by the use of telecare technologies.

The main characteristic of the first form of self-management described by Schermer is that patients become an extension of health-care professionals by taking over practical tasks usually conducted by medical personnel, "especially the taking of measurements" (2009, p. 689). This form of self-management does not involve any decision-making by patients themselves. Moreover, patients are not stimulated to manage their disease according to their own views and wishes (i.e. their *autonomy* is not enhanced). However, through this form of self-management, patients' wellbeing can be improved from a *medical* point of view.

Typical for the second form of self-management is that patients learn to manage their condition in an almost professional manner. They are not only engaged in taking measurements but also stimulated to interpret health-related data and to take proper action, if necessary. Patients become knowledgeable of

⁸ See for a review of both books, Nielsen and Langstrup (2014).

medical guidelines which are usually reserved for medical professionals. Moreover they are “allowed” to make changes to the variables that have a direct impact on their condition (like medication, exercise or diet), but only if this would lead to an improvement of their wellbeing from a medical point of view. Similar to the first form of self-management, patient autonomy is not promoted here. Patients are not encouraged to manage their disease according to their own views and preferences but are prompted to follow guidelines based on medical knowledge only.

A central idea behind the third form of self-management is that patients are encouraged to find their own way to live with their condition based on their own views and preferences, even if this means their choices are not the most optimal from a medical point of view. A crucial element in this form of self-management is that patients’ experience based knowledge is integrated in the prescribed treatment or way of life. Furthermore Schermer describes that in this form of self-management “the relationship between health-care professionals and patients is not (only) based on compliance, but rather on collaboration and concordance” (2009, p. 690). Unlike the first two forms of self-management, this form of self-management supports patient autonomy.

Schermer suggests that the third form of self-management supports patient autonomy as well as their wellbeing.⁹ Her analysis of current telecare practices in the Netherlands shows that these are predominantly aimed at supporting compliance to a medical regime instead of stimulating patient autonomy.

As described above, Schermer distinguishes three forms of self-management that are supported by telecare technologies. However, she did not conduct any detailed empirical research on *how* these forms of self-management are articulated in design and use practices of these technologies. It is therefore important to perform an in-depth analysis of these practices to understand what form(s) of self-management are inscribed in contemporary telecare technologies and whether these support or conflict with self-management practices of both patients and professionals. In the next section I introduce the theoretical approach for this analysis.

⁹ Although she also suggests that in practice this ideal form of self-management might not be suitable for every patient or disease.

1.2.4 STS perspectives on user-technology relations

In this section I present a short overview of the STS theories and approaches that inspired my research and provide the building blocks of my conceptual approach. I discuss these approaches in more detail in the empirical chapters.

As many STS scholars have pointed out, the development of technological artefacts is never a linear process from design table to end-use. The process is widely influenced by all kinds of processes and actors, including users (Oudshoorn & Pinch, 2003, 2008). One of the strands of STS that specifically aims at studying user-technology relations is called user studies. An important insight of user studies is that users play an important role in shaping technologies. Rather than being passive consumers, an image of users that dominated social and cultural studies of technology for a long time, user studies emphasize that both users and technologies are continuously engaged in shaping each other's identities and characteristics. In the remainder of this section I introduce specific concepts developed within the realm of user studies that give me the heuristic tools to formulate and answer the research questions of this thesis.

One of the first approaches in the field of STS that criticized the idea of users as passive consumers of technology is Social Construction of Technology (SCOT) (Pinch & Bijker, 1983; Bijker, 1995; Kline & Pinch, 1996). Central to this approach is that groups of users have interpretative flexibility concerning the technological artefacts they are confronted with. In his study on the social construction of the bicycle in the 19th century, Wiebe Bijker (1995) shows how users influence the development of this technological artefact by giving different meanings to different designs of the bicycle, which in the end leads to a dominant design.¹⁰ In other words, users (in SCOT terminology, relevant social groups) have influence on the eventual shape of a technology.

However, the interpretative flexibility of a technology by users is often partly delimited by choices made during the design process, where users are configured by designers and manufacturers of technologies. To capture this process, Steve Woolgar (1991) introduced the concept of *configuring the user*. To illustrate this conceptual approach Woolgar describes how a new computer is

¹⁰ The process of diminishing interpretative flexibility and the development towards a dominant design is (in SCOT terms) called closure.

tested within a company to see how test-users interpret certain design choices. During this process the developers evaluated whether these interpretations are desirable to include in the eventual design. Phrased differently, interpretations of end-users are delimited by designers who configure how the use of the artefact, according to them, should look. Designers have a particular user and use in mind and they design artefacts accordingly.

Various STS scholars have criticized the configuring-the-user approach by arguing that designers are also configured, for example, by the environment in which they work (Mackay et al., 2000; Oudshoorn & Pinch, 2003, 2008; Stewart & Williams, 2005). This scholarship emphasizes that designers have to deal with constraints on the design by factors like their superiors, financial arrangements, and time constraints. Therefore the configuration process can be said to work both ways (Mackay et al., 2000).

To extend the understanding of the interaction between technology and its socio-technical environment, Madeleine Akrich (1992) introduced the concept of *script*. Developed within Actor Network Theory (ANT),¹¹ the concept has proven to be very useful to analyze how the future use of technologies is prestructured and anticipated in their design. In line with Woolgar's concept of configuring the user, Akrich suggests that innovators of technology have a certain idea about the actors for whom their products are built. Based on these ideas they make decisions about how an artefact should be constructed. These decisions are not without consequences. They can force the end-user to conduct a certain behavior to have the device (in the eyes of the innovator) work correctly. In other words, technologies can prestructure the way in which users behave. When new technologies enter the arena, new practices of use are created with new tasks and responsibilities for the technology itself and its users, described by Akrich as a new geography of responsibilities.

However, not only designers determine whether or how a technology is used, users play a central role in this process as well. Users can adapt the script to their own wishes, or ignore the script by not using a certain artefact. Akrich and Latour (1992) have developed an extensive vocabulary to describe these processes.

¹¹ ANT is a school of thought within STS that uses "semiotics of things" to understand user-technology relations.

The act of writing a script into a technological artefact is called *subscription*. *De-inscription* is used to describe how users react to the script of an artefact. When users do not follow the rules of the script(s) as inscribed by the engineer (*the program of action*) but develop their own interpretation of these rules, this is called an *anti-program*. In this rejection or adaption of technology one can see the “success” or “failure” of a technology and this can deliver valuable insights for the (re)design of technologies.

To conclude, the concepts of *configuring the user*, *configuring designers*, *script* and *program of actions* are helpful instruments to analyze the human-technology relations that are central in this thesis.

Up to this point, I introduced the main concepts I use in my analysis of the design and use practices of telecare technologies. However, the aim of this research reaches one step further than merely a descriptive approach, namely to feedback the insights it generates into the design practice of telecare technologies to realize a better fit between design and use practices. Within STS a specific method is developed to support this aim, which will be described in the next section.

1.2.5 Doing responsible innovation: The method of Constructive Technology Assessment (CTA)

As described in the introduction of this chapter, the research of this PhD thesis is funded by the NWO under the program Responsible Innovation. The central aim of the program is to fund and encourage “research in which the ethical and social aspects of new technology are considered right from the design phase. This prevents expensive adjustments having to be made in retrospect or society rejecting the new technology.”¹² In other words, the aim of the program is to change technological design by anticipating undesirable consequences early in the design process to increase a successful implementation in and acceptance by society.

Within the field of STS an approach has been developed that mirrors the goal of responsible innovation, which is called Constructive Technology Assessment (CTA). The aim of CTA is namely “to broaden technological development by including more aspects and more actors, and at an early stage, so

¹² <http://www.nwo.nl/en/research-and-results/programmes/responsible+innovation> (last accessed 11-03-2014).

as to (hopefully) realize better technology in a better society” (Rip & Te Kulve, 2008, p. 50). The broadening of technological development can take place by feeding insights developed within the field of STS back into the design process. Over the years STS scholars have developed several methodologies for this purpose, like using socio-technical scenarios (Te Kulve, 2011), vignettes (Lucivero, 2012) or design activities (Timan, 2013). Furthermore Schot and Rip (1997) plea for including more actors than just engineers into the development process of technologies at an early stage. A commonly used approach within CTA is to bring together different stakeholders involved in the socio-technical development process of a technology in a workshop setting to have them “probe each other’s worlds” (Rip & Te Kulve, 2008, p. 50), so that reflexive learning can occur. The eventual outcome of such “bridging events” (p. 53) could be that stakeholders reinterpret their initial perception of the technology and change the course of its development over time. In other words, according to the CTA model, by allowing societal feedback in the design process of a technology, the possible outcomes of the introduction of that technology might better serve the wishes and needs of society.

1.3 Conceptual approach and research questions

In the foregoing sections I introduced the theoretical framework for this thesis. This leads me to the following conceptual building blocks about how self-management is constructed and enacted in the design and use of telecare technologies:

- The future use of telecare technologies is prestructured and anticipated in their design by inscription of views and ideas on self-management of patients by developers (configuring users).
- The inscription of views and ideas on self-management during the design process of telecare technologies is not only influenced by their developers but also by external factors (configuring designers).

- Users play an active role in shaping and enacting self-management practices in telecare technologies.
- Feedback of experiences and insights of developers and users of telecare technologies can lead to better design and use practices of these technologies.

Before I formulate the sub-questions of this thesis, I first repeat the main research question:

How do telecare technologies participate in enabling and/or constraining self-management practices of chronic patients?

As described above, prior to or during the design of technologies, developers have (implicit or explicit) views about what role an artefact should play in its future use. These views are inscribed in the script of the technology (Akrich, 1992). Since one of the aims of telecare technologies is to support the self-management strategies of patients, we may assume that the developers of these technologies inscribe specific views about self-management in their design. To answer the central question of this research it is important to first identify *which* views and ideas on self-management are articulated in the design of contemporary telecare technologies. The first sub-question of this research therefore reads as follows:

1. *Which views of patient self-management are inscribed in telecare technologies?*

Developers thus inscribe views on the future use of a technology in the design of an artefact. However, it is unclear where certain scripts come from and why they prevail over others. To understand how scripts emerge it is important to study the design process of a technology. What are the enabling and constraining aspects that influence the design practices of technologies? Are decisions in the design process dominated by technical considerations? Is the design of these technologies predominantly a social process, or could it be that the two are inextricably

intertwined? For this research it is important to find out *why* certain views on self-management inscribed in telecare technologies dominate over others. To clarify these processes I formulate the second sub-question of this research:

2. *How can we understand the design practice of telecare technologies? What are enabling or constraining aspects that shape the design process, and why?*

An important way to prestructure the future use of technologies is to inscribe views regarding the intended use into the technical devices and applications. However, we may assume that the future use will also be shaped by the instructions users receive before they start using an artefact. During the selection of my case study (see sections 1.4.3 and 1.4.4), I learned that patients are taught how to use telecare technologies in so-called self-management courses. Therefore it is important to investigate the views on self-management underlying these courses. To what extent do these courses and the instructions of use that patients receive reflect similar approaches to self-management as inscribed in the telecare technologies? Or do these courses support patients adopting other approaches to learn to cope with their disease? The third sub-question of this research therefore reads as follows:

3. *What understandings of self-management are taught to patients before using telecare technologies?*

In addition to analyzing how developers inscribe views on the future use in a technology and how users are instructed to use technologies, it is important to study the actual use practices of technologies to find out how users perceive and enact the inscribed and instructed views. Do users follow the script of the technology? Do they adjust the script to their own views and wishes or do they even completely reject the script? Based on recent studies in the philosophy of technology, we may assume as well that the telecare technology shapes and

mediates patients' *perceptions* of their disease.¹³ This brings me to formulate the fourth sub-question of this research:

4. *How do telecare technologies shape and mediate patients' perceptions of their disease regarding self-management and actions in dealing with the system?*

These sub-questions enable me to develop insights of how developers prestructure the future use of a technology and how users perceive and enact this. As I explained previously, the aim of this research reaches further, namely to feedback these insights into the development phase of these technologies in order to realize a better fit with their design and use practices. Applied to the topic of this research, the last sub-question of this research therefore reads as follows:

5. *How can we feedback the experiences and insights of developers and users about how telecare technologies should support self-management of patients in the development process?*

1.4 Methodology

To answer the research questions of this thesis I conduct an explorative, qualitative analysis of the design and use practices of contemporary telecare technologies for COPD patients. Thereafter I apply a method developed in the field of STS to feedback the insights I gained from this analysis into the design process of the telecare technologies.

I choose a qualitative, over a quantitative, research approach because it enables me to do an explorative study (Yin, 2003) of a rather new and evolving practice in health care: support of patient self-management via ICTs. This research aims to provide new insights rather than testing a hypothesis or applying statistical analysis to an already well-established fixed practice. Moreover, for reasons of scientific validity, the use of quantitative methods requires the circumstances under which the research will be conducted to be highly comparable and it requires the research population to be large. Individual use practices of innovative telecare

¹³ I explain this mediation perspective on technology in more detail in chapter 5.

technologies are inherently diverse and most of the time the number of participating patients in clinical trials is rather limited. Therefore, they are unfit for large quantitative studies (e.g. randomized controlled trials) on, for instance, efficiency or cost saving effects (Pols, 2012, p. 13), let alone exploring design and use practices of a rather new phenomenon in health care.

1.4.1 Data collection: Case study approach

For this research I perform a case study on the design and use practices of a telecare technology for chronic COPD patients. The telecare technology studied was developed over the course of two consecutive research projects conducted in the Netherlands.¹⁴ According to Yin the choice for a research strategy in social science depends on the type of research question, the amount of influence the researcher has over an event and the position of an event in time (2003, p. 1). He argues that case studies are the preferred strategy in research “when ‘how’ and ‘why’ questions are posed, when the investigator has little control over events, and when the focus is on a contemporary phenomenon within some real life context” (Yin, 2003, p. 1). I argue that for my research, a case study is indeed the most optimal research strategy, for the following reasons: First, this research aims to gain insight in emerging real life events, therefore, the main research question is posed as a how question. Second, as a researcher I have little control over the practices that I investigate. The practices do not take place at organizations I am affiliated with, I am not involved in the design practices of the telecare technology, nor am I involved in testing the use of technology. Indeed, for the provision of my research data, I am highly dependent on practices that are beyond my control. Third, this research aims to gain insight in contemporary and evolving design and use practices of telecare technologies in real life, not to perform an analysis of the introduction of a telecare technology in the past. These three characteristics form the most important reason to prefer the case study as a research approach over other strategies. Moreover Pols (2012) argues that the care practices that make use of telecare are so diverse that it is hard to compare them. To conclude, the feedback activity that is part of this research is indeed rather uncontrollable and part of a contemporary, evolving process of technology in the making.

¹⁴ See sections 1.4.3 and 1.4.4 for a detailed overview of the two research projects.

STS scholar Sampsa Hyysalo (2010) questions the usefulness of studying short term innovation processes in a spatially limited setting for developing insights on the use of new ICTs in health care. However, I argue that the research presented in this thesis is relevant for improving our understanding of current developments in telecare for the following reasons: First, I study both design and use practices in *two* consecutive research projects aimed at the development of the same technology, which represent a longer time span than single case studies. Second, the research projects studied reflect innovation processes exemplifying similar (often EU funded) research and development practices in contemporary health care, and thus, bypass the spatial limitations Hyysalo refers to.

Methods of data collection

As will become clear in this section, the data for this research is collected by using the concept of triangulation (i.e. by applying a mixed methods approach). The research data is assembled by doing a script analysis, semi-structured in-depth interviews, participatory observations and by applying constructive interventions in an evolving design process.

The empirical data concerning the first sub-question is collected by means of script analysis, an approach developed in the field of sociology of technology to analyze how the future use of technologies is prestructured and anticipated during their design (see section 2.4). For the script analysis in this research, I focused on the hardware and software characteristics of the technological devices that together form the telecare system. By reading the devices in terms of what responsibilities and tasks are delegated to users of the technology, I examined how the script of each device will influence their behavior, especially focusing on elements of the script that entail views on patient self-management. Guiding questions indicate how rigid the script of the technology is: whether it “allows” the users to adapt the device to their views and wishes on how to manage their condition, or whether they are “forced” to follow the inscribed rules to have the telecare technology work correctly. More specifically, the analysis focused on how the programs of action inscribed in these devices prestructured the interactions between patients and health-care professionals and the forms of self-management implied in these interactions. In ANT terms this activity is called *de-inscription* (Akrich & Latour,

1992). The script analysis of the telecare technology was performed on the devices that were tested by patients in May and June 2010 in Medisch Spectrum Twente (MST), the local hospital of Enschede.

To answer the second sub-question, I conducted semi-structured in-depth interviews with developers of the telecare technology. The interviewees were developers ($n = 11$) of the multidisciplinary design team of the telecare technology (see section 1.4.2) consisting of the formal project leader, the daily supervisor of the project, a lung specialist, an epidemiologist, a research engineer, a research coordinator, a senior engineer, a software engineer and three junior engineers.¹⁵ The interviews took place during the summer and fall of 2010. The questions of the interviews were aimed at understanding the enabling and constraining aspects of the design process of the telecare technology. Moreover I investigated which views on patient self-management are predominantly inscribed in the telecare technology and examined why certain views prevail over others.

Observations were conducted to answer the third sub-question of this research. I observed a self-management course where patients were informed about the causes, characteristics and symptoms of their chronic condition. Additionally they were instructed how to operate an electronic triage diary that was part of the telecare technology. The self-management course took place in the summer of 2012 at the local hospital (see section 1.4.2). During the observations I focused on how patients were informed about their condition and how they were instructed to “self-manage” their condition while using this part of the telecare technology.

The empirical data used to answer the fourth sub-question was gathered by conducting semi-structured interviews with patients¹⁶ ($n = 8$) who used the telecare technologies between the summer of 2012 and the beginning of 2013 within the context of a pilot randomized controlled trial to investigate the use of and satisfaction with a telehealth program for self-management of COPD exacerbations and promotion of an active lifestyle (Tabak et al., 2014). The interview questions were clustered around specific themes concerning self-

¹⁵ See chapter 3 for a detailed overview of the interviewed members of the design team, their role in the project and their affiliations.

¹⁶ See chapter 5 for a detailed overview of the interviewed patients.

management in telecare technologies. Patients were asked how they experienced the use of the telecare technology, how it influenced their relationships with health-care professionals and how using the telecare technology influenced the perception of their illness. The interviewees were a heterogeneous group of patients and formed a representative sample of the target population. For the analysis I use concepts from postphenomenology and ANT.

To answer the fifth and final sub-question of this research, I organized participatory interventions in the form of so-called CTA workshops. As mentioned in section 1.2.5, the approach of CTA is developed within the field of STS to enhance the development of technologies in order to bridge the gap between foreseen use and actual use of these technologies and to avoid possible negative effects. Within the context of this research I applied the approach of CTA to the design and use practices of telecare technologies with a special focus on potential discrepancies between inscribed views on patient self-management in telecare technologies and enacted practices and perceptions of patients. I organized two CTA workshops to feedback the insights I gained in this research into the design process of the telecare technology. The first CTA workshop took place on January 11, 2011, and the second on June 27, 2013. For the first workshop I invited professional stakeholders involved in the development and use of the telecare technology. The stakeholders that were present ($n = 4$) included members of the multidisciplinary design team, namely an electrical/biomedical engineer and a biomedical technology engineer. They were complemented by the research coordinator of the Department of Pulmonary Medicine of the local hospital, and the nurse practitioner who introduced the technology to the patients. The participants of the second workshop ($n = 9$) were again members of the design team, namely the daily supervisor, an electrical/biomedical engineer, a human media interaction engineer, a biomedical technology engineer, a software engineer, the nurse practitioner, and a physiotherapist, as well as two patients who had experience in using the telecare technology.

1.4.2 Case study: A telecare technology for COPD patients

To answer the research questions of this thesis I conduct a case study on the design and use practices of a telecare technology for COPD patients developed over two consecutive research projects in the Netherlands. COPD is short for Chronic

Obstructive Pulmonary Disease and is defined as “a common preventable and treatable disease, characterized by persistent airflow limitation that is usually progressive and associated with an enhanced chronic inflammatory response in the airways and the lung to noxious particles or gases. Exacerbations and comorbidities contribute to the overall severity in individual patients.”¹⁷ The main risk factor for developing COPD is smoking tobacco. The disease has a progressive course and severely affects the quality of patients’ lives. Current treatment programs are aimed at pharmacological and nonpharmacological interventions, although smoking cessation is the single most effective form of treatment. Additionally, COPD patients benefit from regular physical activity, since it reduces the chances of hospital readmission, increases patients’ life expectancy and slows down the deterioration of lung function and can thus contribute to breaking the vicious circle leading to a reduced quality of life (Tabak, 2014, pp. 10–11).

The two projects that I study form a suitable case for this research for various reasons. First, an important aim of the telecare technology at hand is to support self-management practices of patients (Tabak, 2014, p. 14), which is the central topic of this thesis. Second, the telecare technology is developed to target a chronic condition, namely COPD. Because of the large number of sufferers¹⁸ and its chronic nature, together with heart failure and diabetes, COPD is a prevalent target for telecare developers (Pols, 2012, p. 17). Thus, it enables me to study a technology in the making that will provide relevant insights for similar telecare technologies currently developed for these chronic patients. Third, the aim of this research is to study the design and use practices of an evolving telecare technology, including the possibility to feed my insights back into the design process. These ambitions require the temporal and spatial availability of a suitable case study, hence the choice for research projects conducted at the Telemedicine Group of the University of Twente (UT), a cooperating research and development organization, the local hospital and two local physiotherapy clinics.

¹⁷ *Global Strategy for the Diagnosis, Management and Prevention of COPD*, Global Initiative for Chronic Obstructive Lung Disease (GOLD) 2014. Available from: <http://www.goldcopd.org> (last accessed 24-04-2014).

¹⁸ According to the WHO approximately 64 million people worldwide suffered from COPD in 2004 (<http://www.who.int/mediacentre/factsheets/fs315/en/> (last accessed 24-04-2014)).

The telecare devices and applications I study are developed over the course of two consecutive research projects for the treatment of COPD from 2009 to 2013 that took place in the Netherlands, called “COPDdotCOM” and “CoCo COPD” In the sections below I give an overview of both projects.

1.4.3 COPDdotCOM

The COPDdotCOM project (Figure 1.2) was the result of a combined effort of engineers and health-care professionals involved in the treatment of COPD to design, develop and test a prototype system to support supervised physical training and monitoring from a distance and to improve patient self-management and communication between health-care professionals and with patients (Hermens, 2010).

Figure 1.2: Schematic overview of the COPDdotCOM system.

Source: www.copddotcom.nl (last accessed 24-04-2014).

COPDdotCOM started in October 2008 and lasted until April 2011 and was funded by the Dutch funding agency ZonMW.¹⁹ Partners in the project were the University of Twente (Centre for Telematics and Information Technology (CTIT)), Roessingh Research and Development (RRD) and the local hospital in the city of Enschede MST (Hermens, 2010).

To improve self-management, the project predominantly used two strategies: coaching patients in their daily life to improve their activity behavior and applying self-treatment of exacerbations. For this purpose the following set of technologies were developed:²⁰

- 1) Body Area Network (BAN), consisting of an on-body motion sensor together with a Personal Digital Assistant (PDA) to monitor patients' activity levels and provide feedback to them.
- 2) Communication infrastructure for data gathering and secure transport (RRD database).
- 3) Web portal for patients that contains patients' activity data and the triage diary for self-treatment of exacerbations.
- 4) Web portal for health-care professionals to enable monitoring of patients' health status and coaching of patients.

To improve their activity behavior patients could wear the on-body motion sensor together with the PDA. They measured (via the sensor) and sent (via the PDA) activity data to a database stored at RRD. The activity data was also shown on the PDA in the form of graphs combined by a reference line, representing the patient's desired activity level. Additionally, feedback messages were generated and sent automatically from the database to the PDA in the form of a text message. Through these feedback loops patients could learn to self-manage their activity level over the day. Furthermore, using the web-based portal, patients could access overviews

¹⁹ ZonMW is one of the major organizations in the Netherlands for financing research and development projects in the health-care sector.

²⁰ http://www.copddotcom.nl/html/project_summary.html (last accessed 24-04-2014).

of their activity levels as they were measured over a period of time. Through both applications patients could be coached to improve their daily activity level.²¹

For the self-treatment of exacerbations, patients could use the online triage diary, which was accessible via the web-based portal. Through a decision support system the diary generated medication advice (courses of prednisolone and/or antibiotics) for patients to prevent or treat exacerbations (Effing et al. 2009). In addition to daily medication advice, patients could browse the diary to see the course of their condition and their past use of medication. By using this application patients had the support to self-manage their exacerbations.²²

Health-care professionals could also access the web-based portal of the system to get an overview of patients' health status and use of medication via the electronic triage diary. This information could be used to discuss patients' health status during face-to-face consults. After the COPDdotCOM project finished, the development of the telecare technologies continued within the framework of the CoCo project, which will be introduced in the next section.

1.4.4 CoCo COPD²³

CoCo was a technology-supported care service aimed at the self-management of physical conditions at a distance. CoCo was developed by RRD from 2010 to 2012 together with various partners and focused on integration with (initially) regional care programs.²⁴ Next to chronic pain, oncology and hip/knee problems, CoCo targeted supporting COPD patients. I refer to this part of the care service as "CoCo COPD." The CoCo COPD application consisted of the following components (Tabak et al., 2014):

1) Activity coach to improve daily activity behavior

²¹ See Tabak et al. (2013) for a description how the activity monitoring and feedback application of COPDdotCOM was applied in a randomized controlled pilot trial.

²² See Tabak et al. (2013) for a description how the electronic triage diary of COPDdotCOM was applied in a randomized controlled pilot trial.

²³ CoCo is an acronym for the Dutch words *conditie coach*, meaning *condition coach*.

²⁴ <http://www.zorgvoorinnoveren.nl/netwerk/innovatie/555/conditie-coach-coco> (accessed 25-04-2014).

- 2) Self-treatment of COPD exacerbations via a triage diary on the web portal
- 3) Web-based exercise program
- 4) Teleconsultation through the web portal.

As noted above, the development of the technologies within the framework of the COPDdotCOM project continued in the CoCo COPD project.²⁵ Although the applications aimed at improving daily activity behavior (number 1 in the above list) and the self-treatment of exacerbations (number 2) both evolved, their basic functionality remained the same. Furthermore the web-based portal was further developed and its functionality was extended to include physiotherapeutic exercise programs (number 3) and an application for teleconsultation (number 4).

However, since the latter two components of the telecare system were not fully matured at the time of this research, their design and use practices are not included in this thesis.²⁶

As part of the development trajectory of the described telecare technologies, both research projects included self-management educational programs. When the telecare technologies developed within COPDdotCOM and CoCo COPD projects were tested among patients in randomized controlled trials (Tabak et al., 2013, Tabak et al., 2014), they were asked to attend a self-management course at the local hospital. In two sessions of 90 minutes each, a nurse practitioner from the local hospital in Enschede (MST) educated the participating patients about the causes, characteristics and symptoms of their chronic condition. Additionally, they received instructions on how to use the electronic triage diary that was part of the telecare system. Furthermore, before patients participated in the CoCo COPD trial, physiotherapists of the two participating clinics in Enschede (De Perikhof and FITclinic) explained the workings of the activity coach module of the web-based portal (Tabak et al., 2014). Hence, parallel to technological support, educational

²⁵ Both the sensor and PDA (or smartphone) used in the COPDdotCOM project were replaced by newer versions.

²⁶ In this thesis I refer to the technologies as they were presented in Tabak et al. (2014).

approaches were used to support the self-management strategies of patients using the telecare system.²⁷

1.5 Thesis Outline

This research aims to understand how contemporary telecare technologies participate in enabling and/or constraining self-management practices for chronic patients. To reach this aim the following steps will be taken: In the first empirical chapter (chapter two) I focus on which understandings of self-management are embedded in the telecare technologies for COPD patients analyzed in this PhD research. I present a script analysis of the telecare devices and applications that aim to support self-management practices of patients.

In the third chapter I elaborate on how we can understand the design practice of contemporary telecare technologies. More specifically, this chapter addresses the question of why certain views of self-management are predominantly inscribed in these technologies above others. I present an analysis of interviews with stakeholders that were involved in the development of the telecare technologies and give an interpretation of the collected data by applying conceptual tools developed within the field of STS.

The fourth chapter presents an analysis of my observations of a self-management course for patients who participated in user trials of the telecare technologies. I answer the question asking what understandings of self-management are taught to patients before using the telecare technologies.

The fifth chapter presents my study of use practices of patients of the telecare technologies. The chapter explores how the telecare technology shaped and mediated patients' *perceptions* of their disease regarding self-management and patients' *actions* in dealing with the telecare devices and applications.

The sixth and final empirical chapter presents the results of the CTA workshops I organized to enhance the design of the telecare technologies in order

²⁷ The COPDdotCOM and CoCo projects resulted in various (scientific) publications. See <http://eprints.eemcs.utwente.nl/view/project/COPDdotCOM.html> and [http://eprints.eemcs.utwente.nl/view/project/Conditie Coach.html](http://eprints.eemcs.utwente.nl/view/project/Conditie_Coach.html) (last accessed 24-04-2014).

to bridge the gap between foreseen use and actual use and to avoid possible undesirable consequences of the technology.

In chapter seven I give a summary of the conclusions of each empirical chapter and combine them to answer the main research question. Additionally, I present a guideline that enables designers to anticipate and reflect on which forms of self-management are desirable to incorporate in the design of telecare services for chronic patients. The chapter completes with suggestions for future research.

Chapter 2. Telecare technologies and forms of self-management

2.1 Introduction

As mentioned in chapter 1, this thesis is aimed at understanding the design and use practices of a telecare technology for COPD patients developed over two consecutive research projects in the Netherlands. In this chapter I focus on the telecare technology developed within the framework of the COPDdotCOM research project.²⁸ According to the website, the objective of the COPDdotCOM project is “to design, develop and demonstrate a prototype system that supports disease management program for COPD, which can be tailored to the individual needs of the patient.”²⁹ The project’s website describes the role of patients in the use of the telecare system as follows: “The patient is leading and is supported in managing his disease and realizing his achievements by ICT applications. These applications enable him to be aware of this health condition and teach him adequate strategies to cope with his disease in daily life.”³⁰ Although we may assume that the ICT applications were meant to be used by women as well, the aim of the new technology as articulated on the project’s website is clear. In addition to promoting an active lifestyle and improving communication between users, an important aim of the telecare system was to enhance patient self-management (see also Hermens, 2010). However, it remains unclear what forms of self-management should be supported by the telecare system. Should self-management be aimed at enhancing compliance to medical treatment to make health care for chronic patients more efficient? Should it support patients in taking over tasks usually conducted by health-care professionals to make health care cheaper? Or should self-management be aimed at empowering patients to improve their autonomy? The aim of this chapter is to analyze what views of self-management are incorporated in the design

²⁸ See chapter 1 for an introduction to the COPDdotCOM project.

²⁹ <http://www.copddotcom.nl> (last accessed 24-04-2014).

³⁰ <http://www.copddotcom.nl> (last accessed 24-04-2014).

of the COPDdotCOM system.³¹ The research sub-question of this chapter therefore reads:

Which views of patient self-management are inscribed in telecare technologies?

The outline of this chapter is as follows. After explaining the research methodology in section 2.2, I elaborate on the concept of self-management and its relevance for telecare technologies. Three dominant forms of self-management (Schermer, 2009) will be discerned (2.3). In the next part I introduce the script approach (Akrich, 1992), which will be used in the analysis (2.4). In section 2.4.1 I suggest following Oudshoorn's (2011) extension of Akrich's script approach by presenting the concept of multiple scripts. The chapter continues by introducing the concepts of hardware and software scripts (2.4.3). Next I describe that incorporating instructions for use of a technology is an important aspect of the analysis (2.4.2). In section 2.5 I analyze what forms of self-management are inscribed in the hardware and software, respectively, of both the activity monitoring and feedback application and the electronic triage diary. I end the chapter by formulating an answer to the research question and some concluding remarks (2.6).

2.2 Methods

To answer the chapter's research question I performed a script (Akrich, 1992) analysis to investigate what forms of self-management (Schermer, 2009) are inscribed in the design of the telecare technology that was developed in the framework of the COPDdotCOM project. I analyzed the prototype of the system that was tested in May and June 2010 in the local hospital of Enschede (MST).³² I focus on applications of the system aimed at supporting patient self-management: the activity monitoring and feedback application and the electronic triage diary. For this purpose I analyzed the devices of the system and the web portal I had access to. Furthermore I include the use instructions articulated in a brochure that

³¹ When I refer to the COPDdotCOM system I refer to the telecare technology (consisting of multiple telecare applications) developed within the realm of the COPDdotCOM project.

³² See Koster (2011) for a detailed description of the test and the used technologies.

patients received before participating in the test, since it contains relevant information for the analysis of forms of self-management incorporated in the telecare technology.

2.3 Telecare and self-management

The concept of self-management is widely used in current discourses on the treatment of chronic illness. As described in chapter 1, recent literature on medical ethics discerns three dominant forms of self-management that can be supported by telecare technologies (Schermer, 2009), which can be summarized as follows.

The first form of self-management can be characterized by patients becoming an extension of health-care professionals by taking over practical tasks. This might help improve their health, but it does not promote autonomy, since it does not involve any decision-making by patients. Moreover, patients' own views or wishes regarding the treatment of their condition are not involved. Typical for the second form of self-management is that patients learn to manage their disease in a more or less professional way. Patients become "proto-professionals" (Schermer, 2009, p. 689) by following medical guidelines. As with the first form of self-management, they are not stimulated to integrate their own views on the treatment of their condition. A central idea behind the third form of self-management is that patients are enabled to find their own way of living with their disease. Patients are allowed to make their own choices, regardless of whether these are optimal from a medical point of view. Moreover, patients are stimulated to integrate experience-based knowledge into the treatment of their condition. The relationship between health-care professionals and patients is one of "collaboration or concordance" (Schermer, 2009, p. 690) rather than compliance. Schermer describes the first and second forms of self-management as "compliant"; the third form she describes as "concordant" self-management (2009, p. 690).

2.4 The script approach

As described in chapter 1, the concept of *script* was introduced by French technology sociologist Akrich (1992) to increase the understanding of the interaction between technology and its socio-technical environment. During the design phase developers inscribe specific programs of action into the design based on the expected behavior and skills of the future users, which results in a script: the

design attributes and delegates competences, tasks and responsibilities to the users (Akrich, 1992). In other words, technologies prestructure the behavior of users. When new technologies enter the arena, new practices of use are created with new tasks and responsibilities for the technology itself and its users (Oudshoorn & Pinch, 2003).

2.4.1 Singular technology, multiple scripts

The script approach has proven to be useful to analyze how the future use of technologies is prestructured and anticipated in their design.³³ The telecare system at hand comprises of multiple devices and applications. Thus, it seems to be important to extend the script concept of Akrich (1992), because in her approach the focus is on merely singular technologies. I therefore adopt the modified script approach introduced by Oudshoorn (2011, p. 99), who stressed the relevance of differentiating between scripts of multiple devices of a telecare technology:

To understand how telecare technologies shape the work of telecare professionals it is important to differentiate between the various scripts of the composing technical devices rather than assuming that the telecare technology contains a single unifying script. (Oudshoorn, 2011, p. 99)

Therefore, for an adequate script analysis of the COPDdotCOM system, I incorporate multiple telecare devices and applications into the analysis of the telecare technology.

2.4.2 Hardware and software scripts

I add another element to the script approach as described by Akrich (1992) and Oudshoorn (2011). Telecare technologies are by definition based on ICTs. Consequently, they contain both hardware and software components. Similar to various other contemporary telecare devices (e.g. the Cardiophone³⁴, Vitaphone 1100³⁵, Vitaphone 1300³⁶), the COPDdotCOM system makes use of a mobile phone.

³³ See e.g. Jelsma (2003); Neven (2011); Timan (2013).

³⁴ <http://www.vitaphone.nl> (last accessed 24-04-2014).

³⁵ <http://www.vitaphone.de> (last accessed 24-04-2014).

³⁶ <http://www.vitaphone.de> (last accessed 24-04-2014).

Mobile phones have a clear hardware script. Most of them are small-sized, have a small reading pane, and need to be recharged regularly. However, the usage of these devices also depends on characteristics like the language of the display, the use of text or icons to display information, or what type of information is presented. These characteristics are defined by the software of the device. I therefore suggest refining the concept of script by differentiating between hardware and software scripts of ICT-based technologies. This refinement enables me to provide a considerably more detailed account of the various ways in which the telecare system supports specific forms of the self-management of patients.

2.4.3 Scripts and instructions for use

To understand how the telecare technology shapes use practices of future users I argue it is important to include instructions for use in the analysis as well. Informing patients about how to use the telecare system is important to make sure that they follow the programs of action inscribed in the devices. In the case of the COPDdotCOM system, patients received instructions for use verbally or from a brochure given to them before the trials. Instructions for use can be implicitly or explicitly articulated. Instructions that are explicitly articulated may include tasks of which developers assume that users are not familiar with. For example, an explicit guideline for using the activity meter and PDA may be to keep them close together for proper Bluetooth connection. However, the use of technology may also involve implicit rules that might be considered “obvious” for those who are used to dealing with technical devices, but can be quite obscure for others. An implicit rule of use could be to charge the batteries of the devices regularly. Instructions for use are relevant for my analysis of forms of self-management in COPDdotCOM. For example, instructions about how, when and where patients should wear and use the devices may support or redefine the forms of self-management inscribed in the telecare devices and applications. I therefore include instructions for use in my analysis of the system as well.

2.5 The multiple devices of COPDdotCOM

In this section I introduce the technologies that were used during a four-week testing period of the multiple devices of the telecare system. I focus on analyzing what form(s) of self-management are predominantly inscribed in each individual device.

To improve self-management, the COPDdotCOM project predominantly used two strategies: coaching patients in their daily lives to improve their activity behavior and helping patients apply self-treatment for exacerbations. For this purpose the following set of technologies were developed:³⁷

- a) BAN (consisting of an on-body motion sensor together with a PDA) was developed for the patient, for monitoring activity levels and to provide feedback to the patient for changing activity behavior.
- b) Web portal was developed for the patient, which is able to organize and present the activity data to the patient, and in addition, is used for a triage diary for self-management of exacerbations.

In the next section I focus on each individual device responsible for these elements of the system. I first focus on (a) the hardware and software components of the activity monitoring and feedback application. After that, I follow the same procedure for (b) the electronic triage diary for the self-management of exacerbations. Instructions for use will be discussed with the introduction of the devices.

2.5.1 Activity monitoring and feedback hardware

For monitoring and managing their activity, patients were expected to use the following hardware:

- Activity sensor (white device, see Figure 2.1).³⁸
- Personal Digital Assistant (PDA) (black device, see Figure 2.1).³⁹

³⁷ http://www.copddotcom.nl/html/project_summary.html (last accessed 24-04-2014).

³⁸ MTx-W sensor (Xsens).

³⁹ HTC 3600/3700.

- Personal computer (PC) with Internet connection.

Figure 2.1: Activity sensor and PDA.

Source: Hermens (2010).

I first analyze the script and instructions for use of the two devices depicted in Figure 2.1.

To measure daily activity patterns of patients both the activity sensor and the PDA had to be worn around the waist. Patients were not allowed to wear the device elsewhere on the body because reliable patient data can only be measured at this body height.

The requirements sketched above imply that patients had to behave according to some explicit but also implicit rules. Usage of the two devices means that patients had to wear something to connect the two devices to their waist (e.g. trousers or a belt). This implicit rule reveals a gender script, meaning, this may have been a problem for women who prefer to wear dresses. In a similar vein, it may also have caused problems for men and women who prefer to wear light sports outfits. Although the devices were not bigger than a regular mobile phone, wearing the devices might have caused inconvenience for the skin (when for instance, patients are seated). The instructions for use of the activity sensor and PDA not only specified rules of how to wear the devices but also how frequently they should be used. For example, patients had to wear the activity sensor from the time they got dressed in the morning, until they went to sleep in the evening. This implies that patients were expected to wear the devices all day. They were not supposed to

switch the devices off for any period of the day, because measurement and management of activity levels during the day (which are goals of the devices) would not be useful.

An implicit requirement of the activity sensor and PDA was that both devices have to be charged regularly for proper usage. Patients who were not familiar with this habit might easily forget this or not know how to do this properly. Apparently, this script presupposes a user was familiar with the usage of a mobile phone or other technical devices.

In addition, patients had to be able to use the PDA technology correctly. First, the PDA had based on touch-screen technology. Users had to navigate the device by touching the screen on specified places, marked by words or symbols. Second, the PDA had buttons on top and in the lower front of the device. Consequently, patients had to be able to use the (small) buttons of the device, be able to understand and interpret its display, or know how to use such small mobile devices. This might have been a problem for disabled and/or “computer illiterate” patients. Similar to charging the devices, familiarity with the usage of a mobile phone or other small devices was presupposed in the design of the activity monitoring and feedback devices.

A third device included in the activity monitoring and feedback application was the PC, on which the patients could look at their activity level through a personal web portal. For this, patients had to be able to work with a PC and have an Internet connection at their home or alternative location. When a patient’s PC was used for this purpose, it entered the world of the medicine. Whereas its former use might only have been aimed at playing games or typing letters, the PC now became a medical device. In a similar vein the PDA that was used for the activity monitoring and feedback application partly became a medical device.⁴⁰ This part of the script did not affect what form of self-management was inscribed in the system, but could surely be relevant to anticipate the problems some users may have faced in wearing and using the devices.

⁴⁰ See Oudshoorn (2011) for a similar observation of how the TV set in patients’ homes was turned into a medical device because of the introduction of a telemedical system for heart failure patients.

To summarize, I conclude that specific rules about the proper use of the devices reflect the first form of self-management. Patients had to follow these rules or the devices would not be able to collect and send useful data. One could argue that patients did not have to wear the devices full time (24 hours a day, seven days a week) implying some freedom to use the devices based on patients' own preferences. However, this freedom of use was not aimed at supporting patient autonomy "understood as the positive ability to lead one's own 'chosen or embraced' life" (Schermer, 2009, p. 689). The rules about frequency of use were not solely based on daily routines or own judgment but predominantly followed technical requirements of the devices. Moreover, the script of the activity monitoring and feedback devices presupposed a computer literate user.

2.5.2 Activity monitoring and feedback software

Compared to the scripts of the hardware of the activity monitoring and feedback application, the scripts of the software were more text based. For this analysis I first focus on the software that was used for the activity monitoring and feedback application on the PDA.

2.5.2.1 The PDA

Through the software of the PDA, patients received feedback on their activity behavior via (a) a graph of their activity level, combined with the norm value over time (see left screen of Figure 2.2) and via (b) personalized text messages (see right screen of Figure 2.2). The text messages informed patients about their activity level and instructed them to become more or less active.⁴¹ On the screen of the PDA, as depicted on the left in Figure 2.2, a graph of the patients' activity level was depicted, combined with a graph of a reference line patients should aim for (Tabak et al., 2013, p. 584). The display could be enlarged by touching it on the graph. To use the device's software, patients had to be able to interpret the graphs on the screen. They had to be able to understand that the green line symbolized a "healthy" activity level, and that the blue line symbolized their own activity level. The use of graphs presupposed a certain education level of its users and prioritized

⁴¹ See Tabak et al. (2013) for a detailed explanation on the workings of these devices.

a science-based representation of data as feedback to users. Furthermore, the script of this screen encouraged users to follow the green reference line.

Figure 2.2: Two different PDA screens with different types of feedback.

Source: Tabak (2014, p. 46).

In the bottom left corner of the screen an avatar was depicted. Dependent on the activity level of the patient the avatar was standing, sitting or lying. When the avatar was sitting or lying it was accompanied by an arrow pointing up. It looks like users were encouraged by these symbols on the screen to avoid a sitting or lying avatar and to become active if these are depicted. In the bottom right corner of the screen the word “ADVIES” (Dutch for advice) was depicted. When users touched this part of the screen they would see the latest advice that had been sent to the PDA. The content of the advice was dependent on the activity level of patients and was based on an algorithm.

The advice was sent to the PDA automatically via wireless connection with a computer database based at RRD. The advice screen of the PDA was accompanied by a red exclamation mark and the same avatar as on the default screen. The first sentence of the advice described the deviation between a user's activity level and the desired activity level in terms of percentage. It was accompanied by a text message, which noted that the user had taken some rest or had been more active recently. The text messages were colored black. The third text message on this screen was colored green and contained the actual advice for

the user regarding what to do to come closer to the desired activity level. Possible messages that could have been sent to the patients' PDAs are listed in Table 2.1.

Table 2.1: Feedback messages of the activity monitoring and feedback application for the PDA.

Message #	Message in Dutch	Message in English
Message 1	Probeer wat te ontspannen	Try to relax
Message 2	Gaat u even zitten	Have a seat
Message 3	Blijf zo doorgaan!	Keep going!
Message 4	Goedzo	Bravo
Message 5	Prima	Excellent
Message 6	Het gaat goed!	You are doing fine!
Message 7	Neem even de tijd voor uzelf	Take some time for yourself
Message 8	Pak even een leuk tijdschrift	Read a nice magazine
Message 9	Ga even een blokje om	Go for a walk
Message 10	Zet een lekker kopje koffie	Have a nice cup of coffee
Message 11	Gaat u even een lekker stukje fietsen!	Go for a nice ride on your bike!
Message 12	Maak een lekkere lange wandeling	Go for a nice long walk
Message 13	Heeft u de krant al gelezen?	Have you read the newspaper?
Message 14	Gaat u even 10 minuten zitten	Have a seat for 10 minutes
Message 15	Probeer de trap een paar keer op en neer te	Try to walk up and down the stairs a few
Message 16	Stop even met wat u aan het doen bent	Stop with what you are doing for a while
Message 17	Misschien dat u even kunt gaan zitten?	Maybe you can have a seat?
Message 18	Heeft u de krant van vandaag al gelezen?	Have you seen today's newspaper?
Message 19	Heeft u nog iets uit de stad nodig?	Do you need something from town?
Message 20	Tijd voor een sportieve wandeling!	It's time for a brisk walk!
Message 21	Maak bijvoorbeeld een lekkere lange	Try to take a long nice walk
Message 22	Ga bijvoorbeeld even een lekker stukje	Go for a nice long ride on your bike!
Message 23	Bent u vandaag al buiten geweest?	Have you already been outside today?
Message 24	Ga even een frisse neus halen	Get some fresh air

*Source: Hofs, D. (2010). Architectuur COPDdotCOM. RRD, Enschede. (own translation).*⁴²

⁴² Document received during interview with Dennis Hofs, June 23, 2010.

The content of the text messages presupposed a narrowly defined user. The user was configured as having newspapers and magazines at hand, and being able to walk and ride a bike. Moreover, he or she was configured as living in the city, drinking coffee and being able to walk up and down the stairs a few times. Patients who were not able to read text messages (e.g. visually disabled or illiterate) were excluded from using the devices. Some messages could have been perceived as offensive, for example, by physically disabled patients, like “Go for a walk” or “Go for a ride on your bike.” Moreover, not all patients were equally able to interpret the content of the messages. The text “Have a nice cup of coffee” could be confusing for someone who never drank coffee. Or the text “Do you need something from town?” was inappropriate for someone who lived in the countryside.⁴³ Finally the text messages were often phrased in the imperative mood and might therefore have been interpreted as patronizing towards patients.

I conclude that the use of a graph to display patients’ activity level supports the second form of self-management. Patients were expected to take over interpretative tasks of professionals and could take action accordingly (e.g. by changing their physical activity). Patients knew that following the green line on the graph was best for their condition, from the medical perspective. However, they were not supported to develop behavior that might have enhanced their quality of life, when this meant they behaved in contrast to medical guidelines. The use of the text messages supported the first form of self-management as well. The text messages were not aimed at enhancing patient autonomy (i.e. they do not involve any decision-making by patients) nor was there room for patients’ own views and wishes. The script built in this part of the software presupposed a patient followed advice blindly. I therefore conclude that the script of the software of the PDA contains a mixture of both the first and the second forms of self-management.

2.5.2.2 *The web portal*

For the script analysis of the COPDdotCOM system, the focus in the previous section was on the software used for the activity monitoring and feedback

⁴³ Although clearly stated messages were important to give feedback to patients, more inviting language might have been an option for giving advice to patients.

application on the PDA. In this section I focus on the software for the activity monitoring and feedback application on the web portal.

The webpages that were used for activity monitoring and feedback were part of a specially designed web portal (see Figure 2.3) for the COPDdotCOM system. The brochure asked patients to visit this web portal weekly. The web portal was hosted at RRD. This meant that for using this part of the telecare system, the availability of a computer with Internet connection, and the ability to use the computer and additional Internet browser software was needed.

To visit the web portal patients first had to enter the Internet address of this website in their Internet browser. Thereafter they could enter a personal username and password to see their individual information. In addition to pages for the activity monitoring and feedback application, the web portal contained pages for viewing and filling out the electronic triage diary.⁴⁴ Figure 2.4 shows a screenshot that patients saw when entering the activity monitoring and feedback part of the web portal. Here the activity level of patients was depicted as a blue graph, while the reference line was green.

Figure 2.3: Screenshot of COPDdotCOM web portal.

(English translation: Welkom op het webportaal van COPD dot COM = Welcome to the web portal of COPD dot COM; Activiteit = Activity; Dagboek bekijken = visit diary; dagboek invullen = fill in diary; longinhoud = lung volume).

Source: Hermens (2010).

⁴⁴ Initially, the web portal contained a page for patients to enter their lung capacity. However, the unsupervised use of the spirometers by patients provided unreliable data and was considered unacceptable (Koster, 2011).

The vertical axis represented the average or total activity (measured in cpm).⁴⁵ The horizontal axis represented time. From a pull down menu on the website, patients could choose to look at an overview of the activity level by a day, a week, a month or a year. Depending on the time range, the activity levels were depicted as graphs (overview of a day), or as bar charts where green dots represented the “healthy” activity level (see Figure 2.5). Depending on the chosen time range, the scale of the vertical axis also changed. Sometimes the activity level was depicted as an average within a scale from 1 to 4, or from 1 to 650, or from 0 to 1, without depicting the unit of the scale.

Figure 2.4: Screenshot of COPDdotCOM web portal – Activity monitoring and feedback.

Source: Hermens (2010).

Above the charts there was a caption explaining the colors used in the graphs: orange represents measured values (i.e. *gemeten* in Dutch) and green (lines or dots) represented a reference (i.e. *referentie* in Dutch). It was not explained what these values meant exactly, but the term “reference” suggested something “one should strive for.” It might have worried patients when they were confronted with the fact that their own measured values were not near the reference line or dots. Especially since it was not made clear on the website what these lines meant (e.g. in a help file).

⁴⁵ There was no specification of this unit of activity on the website.

Figure 2.5: Screenshot of COPDdotCOM web portal – Activity monitoring and feedback.

Source: Hermens (2010).

My analysis of the web portal script shows similar findings to the script analysis of the software on the PDA: The use of graphs presupposes a certain level of education of its users and prioritizes a science-based representation of data as feedback to users. This science-based representation of a person's condition is emphasized by using technical terms such as "cpm" or "reference" on the website, which patients might be unfamiliar with. I therefore argue that the website was designed for professional users instead of lay people.

To summarize, I conclude that the use of graphs to display patients' activity level implies the inscription of the second form of self-management. Patients were expected to take over interpretative tasks of professionals and take action accordingly. Patients were supposed to understand that following the green line or dots was best for their condition, from the medical perspective. However, the use of different scales for activity levels, sometimes without clarity in what unit the activity levels are depicted, does not suggest promotion of the second form of self-management by the telecare system, because it is of central importance that patients understood the meaning of the measured data. I therefore argue that promotion of patient autonomy was limited for this part of the system.

Furthermore, the third form of self-management was not promoted by the script of the software at hand. Patients were not supported to find their own way to

live with their condition. Knowledge of their illness was not enhanced by the system. The absence of a help-file and clear definitions of technical terms illustrate this. I therefore conclude that the script of the software for enhancing the activity level of patients was predominantly based on the second form of self-management, although it did not fully conform to the definitions I introduced in this chapter.

2.5.3 Electronic triage diary hardware

As I already mentioned in the beginning of this chapter, next to the activity monitoring and feedback application, the electronic triage diary played a central role in enhancing the self-management of patients using the COPDdotCOM telecare system. For this purpose patients used a computer with Internet connection.⁴⁶ For the script analysis of the hardware of this device, I refer to section 2.5.1.

2.5.4 Electronic triage diary software

The software for filling out the electronic triage diary could be found on the same patient portal as the software for the activity monitoring and feedback application (see Figure 2.3). In the COPDdotCOM brochure patients were asked to fill out the diary on a daily basis. When patients wanted to fill out the electronic triage diary, they saw the latest advice, based on information of the last time the diary was filled out. Patients could continue by clicking an orange square. They would have then saw screens with multiple-choice questions on their health status (see Figure 2.6). The sequence of the questions and their possible answers are depicted in Table 2.2.

⁴⁶ As an alternative to using the PC with Internet connection, a touch screen was developed. When patients did not have a PC with Internet connection, this device would be installed at the patient's home. For unknown reasons these devices were not ready in time to be used for the trial. Patients also received a device to measure their lung capacity: They could be asked to fill out their lung capacity once a week, or when complaints increased, once a day, and enter this volume in the electronic triage diary, but after prior tests the use of the spirometer was cancelled (Koster, 2011). Since their role in the project was limited, I will not perform a script analysis of these devices.

Figure 2.6: Screenshot of COPDdotCOM web portal – Electronic triage diary

woensdag 7 april 2010

Had u klachten over het opgeven van slijm?

Normaal Iets meer dan normaal Duidelijk meer dan normaal

(English translation: Did you have complaints of coughing up mucus? Text in the left box: Normal. Text in the middle box: Slightly more than normal. Text in right box: Clearly more than normal.

Source: Hermens (2010).

Table 2.2: Multiple-choice questions of the electronic triage diary.

1	V	Had u de afgelopen 24 uur meer klachten dan normaal?		
	A	Ja	Nee	
	O	Did you have more complaints than normal the past 24 hours?		
	A	Yes	No	
2	V	Had u klachten over kortademigheid?		
	A	Normaal	Iets meer dan normaal	Duidelijk meer dan normaal
	O	Did you have complaints of shortness of breath?		
	A	Normal	Slightly more than normal	Clearly more than normal
3	V	Had u klachten over het opgeven van slijm?		
	A	Normaal	Iets meer dan normaal	Duidelijk meer dan normaal
	O	Did you have complaints of coughing up mucus?		
	A	Normal	Slightly more than normal	Clearly more than normal
4	V	Wat was de kleur van het opgehoeste slijm?		
	A	Normaal	Anders dan normal	
	O	What was the color of the coughed up mucus?		
	A	Normal	Different than normal	
5	V	Had u klachten over hoesten?		
	A	Normaal	Iets meer dan normaal	Duidelijk meer dan normaal
	O	Did you have complaints of coughing?		
	A	Normal	Slightly more than normal	Clearly more than normal
6	V	Had u klachten over piepen?		
	A	Normaal	Iets meer dan normaal	Duidelijk meer dan normaal
	O	Did you have complaints of wheezing?		
	A	Normal	Slightly more than normal	Clearly more than normal

7	V	Had u klachten over een loopneus?		
	A	Normaal	Iets meer dan normaal	Duidelijk meer dan normaal
	Q	Did you have complaints of a runny nose?		
	A	Normal	Slightly more than normal	Clearly more than normal
8	V	Had u klachten over een pijnlijke keel?		
	A	Normaal	Iets meer dan normaal	Duidelijk meer dan normaal
	Q	Did you have complaints of a sore throat?		
	A	Normal	Slightly more than normal	Clearly more than normal
9	V	Heeft u gebruik gemaakt van kortwerkende luchtwegverwijders?		
	A	Normaal	Iets meer dan normaal	Duidelijk meer dan normaal
	Q	Have you used metered-dose inhalers?		
	A	Normal	Slightly more than normal	Clearly more than normal
10	V	Heeft u de afgelopen 24 uur koorts gehad? (meer dan 38,5 graden)		
	A	Ja	Nee	
	Q	Did you have a fever in the past 24 hours? (more than 38,5 degrees Celsius)		
	A	Yes	No	
11	V	Wat is uw longinhoud?		
	Q	What is your lung capacity?		

Source: Hofs, D. (2010). *Architectuur COPDdotCOM. RRD, Enschede. (own translation).*

Patients received a minimum of one question and a maximum of ten questions, depending on the answer they give to the first question. When the answer to the first question about whether they experienced more complaints than normal is affirmative, they had to fill in the remaining questions as well.

Figure 2.7: Screenshot of COPDdotCOM web portal – Electronic triage diary

(English translation: Do not (yet) start with medication).

Source: Hermens (2010).

The possible answers of the electronic triage diary were depicted in colored boxes, where the answer in the green box was the optimal answer, the answer in the yellow/orange box was medium, and the answer in the red box was the worst

answer, from a health-related perspective. When patients answered the question(s) of the electronic triage diary, the system gave advice for the eventual treatment of the patient. A screenshot of a possible advice response after answering the questions of the electronic triage diary is shown in Figure 2.7

Which advice was applicable to which sequence of answers depended on an algorithm developed in previous studies at MST (Effing et al., 2009). A list of all the possible advice responses is shown in Table 2.3.

Table 2.3: Possible advice of the electronic triage diary.

#	Advies /Advice
1	Start (nog) niet met een kuur. Do not start a treatment (yet).
2	Start met een prednisolonkuur. Start with a prednisolone cure.
3	Ga door met de prednisolonkuur. Continue the prednisolone cure.
4	Start met een antibioticakuur en ga door met de prednisolonkuur. Start a cure of antibiotics and continue the prednisolone cure.
5	Ga door met de prednisolon- en antibioticakuur. Continue the cure of antibiotics and continue the prednisolone cure.
6	Ga door met de antibioticakuur. Continue the cure of antibiotics.
7	Neem contact op met uw arts. Contact your doctor.

Source: Hofs, D. (2010). Architectuur COPDdotCOM. RRD, Enschede. (own translation).

In addition to filling in the electronic triage diary, patients could also view the contents of the electronic triage diary by clicking the corresponding button of the COPDdotCOM web portal (see Figure 2.3).

The COPDdotCOM brochure asked patients to visit the overview of the electronic triage diary weekly. A screenshot of an overview of the data included in the electronic triage diary is depicted in Figure 2.8.

The website contained a table with an overview of the answers that were given to the questions discussed earlier in this section. The tables gave an overview of a week. Patients could scroll through different weeks by clicking orange arrows on the webpage. The answers were depicted by colored squares behind each question, where the colors green, red, orange and transparent, respectively, corresponded to the answers “normal,” “slightly more,” “clearly more” or “not filled

out.” The eventual use of prednisolone or antibiotics that day was depicted by a small syringe behind the type of medication advised for that day. The advice patients received the last time they filled out the electronic triage diary was repeated above the table.

Figure 2.8: Screenshot of an overview of COPDdotCOM electronic triage diary.

Dag	ma 31-5	di 1-6	wo 2-6	do 3-6	vr 4-6	za 5-6	zo 6-6
Klachten	■	■	■	■	■	■	■
Prednisolon							
Antibiotica							
Blok 1							
Meer klachten dan normaal?	■	■	■	■	■	■	■
Blok 2							
Kortademigheid?	■	■	■	■	■	■	■
Opgeven van slijm?	■	■	■	■	■	■	■
Kleur van het opgehoeste slijm?	■	■	■	■	■	■	■
Blok 3							
Hoesten?	■	■	■	■	■	■	■
Piepen?	■	■	■	■	■	■	■
Loopneus?	■	■	■	■	■	■	■
Pijnlijke keel?	■	■	■	■	■	■	■
Luchtwegverwijders?	■	■	■	■	■	■	■
Koorts?	■	■	■	■	■	■	■

Source: Hermens (2010).⁴⁷

Script analysis results

Based on the script analysis of the software components of the electronic triage diary, I conclude the following: First, I conclude that the use of multiple-choice questions by the electronic triage diary prestructured the way patients experienced the diary (i.e. patients could not enter their experience with their disease in their own words, make their own sentences or express their feelings the way they would like). Patients could not answer questions like “Did you have complaints today?” with “no” or “yes” or “I don’t know” or give longer answers to these questions. They had to choose between “normal,” “slightly more than normal” or “clearly more than normal.” It was up to the patients to decide what complaints were normal, what color of mucus was normal or what shortness of breath was normal for their condition. It is unclear what reference was used to define their health status, other

⁴⁷ See appendix I for English translation.

than a form where they filled out what was normal for them (see chapter 4).

Furthermore, the questions that were posed were related to a medical portrayal of their condition instead of a psychological or social approach. Some of the questions might have been experienced as inappropriate, like asking whether the color of one's sputum was normal or not.⁴⁸

Second, depicting possible answers to the questions of the electronic triage diary in colored boxes might have prestructured patient behavior when filling out the diary. When patients were in doubt on what answer to give to a question, they might have unconsciously clicked the green buttons "just to stay out of trouble."

Third, the text messages that were used by the electronic triage diary were often phrased in the imperative mood and, therefore, might have been interpreted as patronizing towards patients. Furthermore the advice of the electronic triage diary was related to the use or nonuse of medication or when to contact a doctor. Other advice to deal with their condition was not taken into account in the electronic triage diary.

Fourth, the use of tables presupposed a certain educational level of its users and prioritized a science-based representation of data as feedback to users. The use of the colors red and green might have raised feelings of something being "right" or "wrong." Patients might have filled out the diary by clicking green buttons only, so that the diary overview of one's condition was positive. When patients were asked how they felt, they might have answered that they felt good, because their electronic triage diary was green. Instead of, because they felt good their electronic triage diary was green. Moreover, patients learned that there was a strong tie between the answers they gave to the questions and the advice the system gave them, which was about the (non) use of medicine or when to contact a doctor. This might have been experienced as a burden, because now patients became explicitly responsible for the treatment of their condition. As I suggested earlier, by using science-based representations of illness, the notion of being ill, or

⁴⁸ In my interview with the lung specialist (see chapter 3) he mentioned how user acceptance of telecare technologies is highly dependent on the nature of the tasks patients are expected to execute. For example, female patients especially dislike the coughing up of sputum (Lung specialist, interview, November 30, 2010).

suffering from a chronic condition shifts from a psychological or sociological concept towards a more scientific representation or “perception” of illness.

Finally, the triage system to support COPD patients in the self-treatment of exacerbations was called a *diary*. One would expect that a diary is a place where people can write down their feelings, emotions, thoughts in their own words, with their own pencil, or in their own color. The electronic triage diary used in COPDdotCOM transformed the meaning of the concept of *diary* into a clinical multiple-choice computer application.

Forms of self-management

In the remainder of this section I elaborate on the different forms of self-management that were inscribed in the software of the electronic triage diary of the COPdotCOM system.

First, I conclude that the part of the electronic triage diary where patients could enter their symptoms reflected the first form of self-management. Patients became an extension of health-care professionals by taking over practical tasks, like estimating the seriousness of predefined symptoms of COPD. A minimum of the second form can be discerned as well, because patients had to interpret their condition in order to fill out the diary and might have developed bodily experience knowledge of their disease when viewing the medical history of their condition. Next to asking anamnesis questions, the computer system advised patients on whether to take medication or not. However, patients were limited to entering information about their health status into the predefined answers of the multiple-choice questions. The questions were about their medical status only. The system might have improved patients’ wellbeing, but did not increase patient autonomy. Moreover, the advice of the electronic triage diary was phrased in a compelling way, with limited freedom for patients to make their own decisions.

Second, I argue that the part of the electronic triage diary where patients could view the electronic triage diary by time span reflected the second form of self-management. The aim of this part of the electronic diary was to allow patients to look back at their disease status earlier in time and maybe become aware of a certain pattern in the course of their condition. This might have enhanced the awareness of experience-based knowledge and improved patients’ wellbeing.

However, patient's autonomy was not supported by this part of the system. Moreover, patients were not supported to take nonmedical experiences into account for managing their condition, nor find their own way to live with their condition. Tabular representations of patients' conditions support this view. I therefore conclude that the third form of self-management was not promoted by the script of this part of the electronic triage diary.

2.6 Conclusion

In this chapter I performed a script analysis to investigate what forms of self-management were inscribed in the design of the COPDdotCOM system, a contemporary telecare technology for patients suffering from a chronic lung condition (COPD).

Before performing the analysis I suggested refining the script approach by noting that technologies that are referred to as singular artefacts can incorporate multiple scripts. I suggested that since the telecare technology consists of a system of multiple devices it should not be regarded as a singular technology containing a singular script. I therefore adopted Oudshoorn's (2011, p. 99) argument that telecare technologies incorporate multiple scripts. I also argued that it is important to differentiate between hardware and software scripts.

Furthermore, I suggested including the instructions for use of the telecare technology in the script analysis to improve the understanding of how the technology shapes use practices. I argued these modifications of the script approach are relevant for understanding what forms of self-management are supported by the telecare technology.

The script analysis resulted in the following findings: The software components of the activity monitoring and feedback application and the electronic triage diary consisted of specific programs available on the PDA and the web portal. The script analysis suggested a preference for a science-based representation of data as feedback to users of the system. The bias towards a science-based approach in the development of telecare technologies was remarkable, taking into account that most COPD patients were on average lower-educated older people who may have not been familiar with this kind of representation of information. Equally important, there seemed little place for making use of the patients' experience-based knowledge in the COPDdotCOM

system. For example, the electronic triage diary used prestructured multiple-choice questions to advise patients whether to use medication or not.

The choice to include multiple-choice questions instead of open questions to encourage and enable patients to articulate their experience-based knowledge of their disease in their own words might indicate that this part of the telecare system was designed for health-care professionals rather than patients. Other ICT systems introduced in health-care for diagnosing diseases or health advice, such as the system used at the medical call center of the National Health Service (NHS) in the UK, show a similar preference for electronic triage systems based on multiple-choice questions (Hanlon et al., 2005), which reflects a reliance on abstract knowledge. However, as Hanlon et al. (2005) and Oudshoorn (2011) have argued, this prioritization of abstract knowledge is problematic because health-care professionals often rely on their own experience and tacit knowledge. In order to provide good care they prefer their practical knowledge and develop “work-arounds” while using the ICT systems because they don’t want to fly blind on the abstract knowledge provided by the system (Oudshoorn, 2011, p. 106–107). If health-care professionals experience problems with using electronic triage systems we may assume that the preference for prestructured multiple-choice questions may also constrain the use of the telecare system by patients (see chapter 5).

Summarizing, I conclude that the devices that together form the COPDdotCOM system incorporated a mixture of the first and second forms of self-management. Remarkably, the third form of self-management was largely absent. In the telecare system there was no place for patients’ own views and wishes on how to live with their condition. This raises the question of why the developers of the COPDdotCOM system did not inscribe the third form of self-management in the system. Why was there no place for patients’ own views and wishes on how to live with their condition? Why were patients not enabled and encouraged to articulate their experience-based knowledge in using the telecare system? Why was there no possibility for patients to discuss treatment of their COPD with health-care personnel? In the next chapter I answer these and other questions in my analysis of the development process of the COPDdotCOM system.

Chapter 3. An analysis of the design process of a telecare technology

3.1 Introduction

In the previous chapter I used Akrich's script approach to illustrate that there were two forms of self-management (Schermer, 2009) predominantly inscribed in the COPDdotCOM system.⁴⁹ These were the compliant form of self-management and the form of self-management where patients became proto-professionals.

Remarkably, the third form of self-management was largely absent. In the technical characteristics of the telecare system there was no place for patients' own views and wishes on how to live with their condition.

In this chapter I analyze the development of the COPDdotCOM system to trace why the telecare technology emerged from the design phase the way it did. Why is it that the third form of self-management was not inscribed in the technical design of the system? Why was the functionality of the electronic triage diary, for example, based on prestructured information exchange, reflecting the first and second form of self-management, rather than designed as a tool for patients to share their experiences about their condition, reflecting the third form of self-management? To answer these questions this chapter focusses on the design process of the telecare technology at hand.

In her inaugural speech as professor "Technology Supported Cognitive Training" at the University of Twente, Miriam Vollenbroek argues that of all telemedical applications that are developed, 75% do not survive the prototype stadium (Vollenbroek, 2009, p. 38). She suggests that the main reason for this low success rate can be found in poor user acceptance of these applications, which she attributes to problems in the design process regarding the capturing of end-user requirements. According to Vollenbroek these constraints consist of the following: first, the occurrence of language barriers between different stakeholders involved

⁴⁹ When I refer to the COPDdotCOM system I refer to the telecare technology (consisting of multiple telecare applications) developed within the realm of the COPDdotCOM project. See chapter 1 for a description of this project.

in the development of a telemedical service,⁵⁰ second, a lack of knowledge about aspects that determine user acceptance of telemedical applications, and third, a lack of good methods to capture end-user requirements (Vollenbroek, 2009, p. 39).

Following Vollenbroek we might be tempted to conclude that better user requirements can eventually solve the problem with user acceptance of telemedical applications. However Stewart and Williams (2005) are less optimistic about this assumption that they describe as the design fallacy, a concept they use to refer to the view that failures in the introduction of new technologies result from inscribing “the wrong values/specification of user requirements in the design” (p. 197). Based on a comparison of actual use practices with user requirements articulated during computer system design, they conclude that design processes are shaped by many other factors than just user requirements. Moreover, they conclude that initially articulated requirements hardly end up in the end products of ICT systems. They argue that “design/development choices are dominated by the ‘taken for granted’ aspects of the innovation – and by a series of design choices that will tend to be justified in technical and pragmatic terms” (Stewart & Williams, 2005, p. 201).

To be sure, I do not suggest that improving user requirements is not important. I argue it is important to keep in mind that design practices are much fuzzier than various design textbooks suggest. Adopting Stewart and Williams’ insights, I suggest it is important to investigate these taken for granted aspects and design choices to explain the absence of the third form of self-management in the script of the COPDdotCOM telecare system. The central research question of this chapter therefore reads as follows:

*How can we understand the design practice of telecare technologies?
What are enabling or constraining aspects that shape the design
process, and why?*

The outline of this chapter is as follows. After explaining the research methodology in section 3.2, I introduce concepts from STS literature relevant for analyzing

⁵⁰ Language barriers, as used here by Vollenbroek, resemble the concept of disciplinary styles. Difference in disciplinary styles results in different approaches and ways of talking about technology styles (Oudshoorn, 1991, p. 28).

technical design processes. I suggest using the concept of configuring the user (Woolgar, 1991) to understand how the multidisciplinary design team conceptualized how the telecare technology could support self-management practices of patients (3.3.1). However, as Stewart and Williams (2005) argued, design processes cannot only be understood in terms of the work involved in configuring users by articulating user requirements. To analyze this process I introduce the concept of configuring designers (Mackay et al., 2000) in section 3.3.2. In sections 3.3.3 and 3.3.4, I introduce two other concepts that enable me to analyze the design process: bricolage (Disco, 1998; Garud & Karnoe, 2003) and path creation (Garud & Karnoe, 2001). In section 3.4 I recapitulate Schermer's (2009) three forms of self-management supported by telecare technologies. In section 3.5 I present my analysis of the design process of the COPDdotCOM system based on these concepts. I end this chapter by formulating an answer to the research question and by some concluding remarks in section 3.6.

3.2 Methods

My analysis is based on a mixed methods research approach (Yin, 2003), namely from semi-structured interviews ($n = 11$)⁵¹ with project members involved in the

⁵¹ The project team consisted of the following: (1) professor in remote monitoring and training at the University of Twente and cluster manager of monitoring and diagnostics at RRD (further referred to as formal project leader), (2) cluster manager of Technology Assisted Pain Rehabilitation at RRD and professor in technology supported cognitive training at UT (further referred to as daily project supervisor), (3) chest physician at MST and research coordinator at MST (further referred to as lung specialist at MST), (4) professor of evaluation and assessment in health-care research at UT, scientific research coordinator at MST and clinical epidemiologist at MST (further referred to as epidemiologist), (5) electrical/biomedical engineer and junior researcher at RRD (further referred to as electrical/biomedical engineer at RRD), (6) senior researcher on acceptance of teletreatment services by end-users at RRD (further referred to as senior researcher at RRD), (7) engineer human media interaction and junior researcher at RRD (further referred to as human media interaction engineer at RRD), (8) engineer biomedical technology and junior researcher at RRD (further referred to as biomedical technology engineer at RRD), (9) software engineer at RRD (further referred to as software engineer at RRD), (10) research coordinator at the Department of Pulmonary Medicine at MST (further referred

development of a telecare technology within the framework of the COPDdotCOM research project.⁵² In addition to the interviews, my analysis is based on documents of the design of the COPDdotCOM system I retrieved during the interviews. I coded my material based on the concepts described above and looked for similar phenomena among it and clustered these. I used Atlas.ti 6.2 software as a supporting tool. All research data were stored on a secure server of the University of Twente, which could only be accessed by me.

3.3 STS views on technological design processes

Over the years, STS studies have illustrated that technological change is largely a social process (Hackett et al., 2008). In this section I give a short introduction of the approaches of sociotechnological change developed in the field of STS that provide useful heuristic tools to analyze and understand the development of the COPDdotCOM system.

3.3.1 Configuring users

The first heuristic tool relevant for the analysis of the design of the COPDdotCOM system is the concept of configuring users (Akrich, 1992; Akrich & Latour, 1992; Woolgar, 1991).⁵³ Central in this notion is the idea that actors involved in designing technologies envision the future use and future users and inscribe these visions in the design at hand. For example, designers envision characteristics of the future users like intelligence, technical competence, age and gender and base their design decisions on these ideas. By configuring the user, designers try to enable and constrain the use of a technology. I use this concept to analyze how the designers of the COPDdotCOM system have tried to configure the behavior and skills of users regarding self-management.

3.3.2 Configuring designers

As described in section 3.1, design processes entail much more than inscribing the future use in the technology at hand (Stewart & Williams, 2005). Other STS

to as research coordinator at MST), (11) research engineer at Novay (further referred to as research engineer at Novay).

⁵² See appendix II for the semi-structured interview question list.

⁵³ See Oudshoorn & Pinch (2003, 2008) for a discussion of the similarities and differences between these two approaches.

scholars have criticized the configuring-the-user approach as well by arguing that designers are also configured, for example, by the environment in which they work (Mackay et al., 2000; Oudshoorn & Pinch, 2003, 2008). This is an important move because potential mismatches between user configurations and actual use practices might result in blaming individual designers who do not do their job as they should. This scholarship emphasizes that designers have to deal with constraints like design parameters set by their superiors, the budget they receive for their projects, and time constraints. Therefore, the configuration process can be said to work both ways (Mackay et al., 2000). STS scholars also emphasized that designers are not the only relevant actors to take into account but that there are more actors involved in the configuration process, such as journalists, policymakers and advocacy groups (Oudshoorn & Pinch, 2003, p. 9). Consequently, the design process is conceptualized as a much more sociocultural process than a merely technical one (Oudshoorn & Pinch, 2008, p. 549). In my analysis I use a similar approach by trying to unravel what actors or dynamics actually constrain the design process of the telecare technology.

3.3.3 Bricolage

The concept of configuring designers enables me to analyze how a technical design process is influenced by “taken for granted” (Stewart & Williams, 2005, p. 6) aspects of innovation like technical, time and money constraints and agendas of funding agencies. I argue that the process of configuring designers during the development of a technology can result in design choices that can be captured by the concept of bricolage⁵⁴ (Disco, 1998; Garud & Karnoe, 2003). Typical for bricolage is that in order to deal with design constraints, engineers use already available artefacts, although not specifically developed for the project at hand, in the design of new technologies. These artefacts are “given by the environment or willy-nilly accumulated in the course of previous projects” (Disco, 1998, p. 137). By focusing on bricolage activities, the importance of improvisation in the design process becomes more visible (Garud & Karnoe, 2003).

⁵⁴ The concept of bricolage originates from anthropologist Claude Lévi-Strauss (1966).

3.3.4 Path Creation

In addition to bricolage, the concept of path creation (Garud & Karnoe, 2001) may be helpful to understand the design choices during the development of the telecare technology. Garud and Karnoe developed this concept as a counterpart of the concept of path dependency, a notion often used to describe how design processes are shaped by previous design choices, such as the layout of the QWERTY keyboard (David, 1985; Arthur, 1989). In contrast they stressed that designers do not always follow the beaten tracks of technological development but sometimes actively modify the design of an artefact, which may be related to improving user acceptance. Trevor Pinch (2001) suggests that the notion of interpretative flexibility is useful to describe the concept of path creation. Interpretative flexibility refers to the phenomenon that different social groups can give different meanings to the same artefact (Pinch & Bijker, 1984). Actors can develop strategies of path creation by adjusting artefacts in such a way that their meaning comes closer to that of a certain relevant social group. Pinch (2001) illustrates this point by arguing that the electronic synthesizer was deliberately developed as a keyboard instrument to gain attention of relevant social groups, particularly musicians. He argues that this strategy of path creation is the reason why modern synthesizers still use keyboards, while initially these instruments used a patch board instead (2001, 384).⁵⁵ The concept of path creation thus provides a useful heuristic tool to analyze whether and how the developers of the telecare system tried to increase the user acceptance of the technology at hand.

3.4 Three forms of self-management

Before I present my analysis of the design process based on the concepts introduced in section 3.3, I briefly recapitulate Schermer's (2009) conceptualization of three possible forms of self-management she discerns in telecare technologies. The first and second forms of self-management are aimed at supporting patients to take over tasks usually conducted by health-care professionals in order to improve compliance to medical treatment. The aim of the

⁵⁵ The concept of path creation should not be mixed up with complying with functional user requirements. Complying with functional user requirements does not necessarily have to do with meanings relevant social groups attach to an artefact.

third form of self-management is to enable and encourage patient autonomy by supporting patients to incorporate their own knowledge, views and wishes in the treatment of their condition.

3.5 Analysis of the COPDdotCOM design process

After introducing the STS concepts that provide useful heuristic tools to analyze the technical design process of the telecare technology, and after recapitulating Schermer's (2009) forms of self-management supported by telecare technologies, this section presents the analysis of the COPDdotCOM system based on my conceptual framework.

3.5.1 Configuring the future use of the telecare system

To analyze how the developers of the COPDdotCOM system tried to configure the future users and use, regarding self-management of patients, I chose an explorative approach by conducting an in-depth analysis of the semi-structured interviews with the team members who were involved in writing the research proposal for the project. These were the formal project leader, the daily project leader, a lung specialist and an epidemiologist. These four people contributed to the project by writing parts of the research proposal. Focusing on the interviews with these actors enabled me to discern views on patient self-management that might not be visible anymore in the technical characteristics of the system because they might have disappeared in the design process for "technical or pragmatic" reasons (Stewart & Williams, 2005, p. 201). During the interviews I learned that the people who participated in writing the project proposal had different views and expectations about what the telecare system should do.

The formal project leader emphasized that the aim of the COPDdotCOM system was to increase the efficiency of current health care for chronic patients by preventing hospitalization and supporting early recovery at home. He argued that monitoring patients for this reason has clear effects on patient compliance:

Yes, it should create a better compliance to the therapy. Really, it should work that way. Compliance with therapy is an important aspect.

(Formal project leader, interview, 2010)

However, he also stressed the importance of communication between patients and caregivers as an important tool to support patient self-management:

We want to improve communication as well ... we actually want patients and caregivers to be able to talk about the same data, so active coaching can take place.

(Formal project leader, interview, 2010)

The daily project supervisor also had a clear view on the future use of the system. She argued that the system should be a tool for health-care professionals to monitor patients' behavior and to intervene when necessary. She mentioned that clinical parameters of patients should form the most important input for the design of the COPDdotCOM system:

The most important input were the clinical parameters, activity measurements, data from the electronic diary and the lung function.

(Daily project supervisor, interview, 2010)

However, she also stressed the importance of educating patients to increase their independence from health-care personnel and argued the COPDdotCOM system should support patients to find their own way in dealing with their condition:

But for the activity patterns an individual goal is set, together with patients as much as possible. ... The physiotherapist does not do that alone. He consults with his patients. Patients have a say in the goal of their treatment.

(Daily project supervisor, interview, 2010)

The daily project supervisor thus valued good communication between patients and their caregivers and urged patients to incorporate their subjective experience with their condition in the electronic triage diary. Furthermore, the daily project supervisor stressed the importance of freedom to use the system when patients felt like it:

If you think: “Well...today I have a party,” or “I do not feel like it,” you should be allowed not to be in the mood. Sometimes patients have some freedom here.

(Daily project supervisor, interview, 2010)

The lung specialist emphasized the importance of behavioral change for the self-management of COPD patients. According to him the COPDdotCOM system could help patients with this goal by educating them about their disease and their treatment. He argued that the telecare technology should support patients to change their behavior but not to replace health-care professionals:

To change patients’ behavior you have to measure regularly, but you should also let go of patients, because otherwise you create a doctor in the form of a device. The device can help to push you in the right direction, but at a certain point it should be redundant.

(Lung specialist at MST, interview, 2010)

Moreover, he regarded the COPDdotCOM system as a tool to empower patients in dealing with their condition:

I think it’s a new ideology..., maturing of patients..., empowering patients.

(Lung specialist at MST, interview, 2010)

The epidemiologist also stressed the importance of the electronic triage diary to monitor patients’ health status and the opportunity for health-care personnel to intervene when necessary. Similar to the daily project supervisor, he also emphasized the educational function of the system by teaching patients to detect symptoms of deteriorating health in an early phase. According to him, patients do not follow medical guidelines automatically:

That doesn’t happen if you don’t explain it. People are not compliant if they do not know why they should take something.

(Epidemiologist, interview, 2010)

He furthermore stressed the importance of experience-based knowledge of patients to develop adequate self-management skills, where he regarded the patient as hands on expert:

I think you should never follow technology completely blindly, if it concerns a disease where the patient is actually the expert. Because you can never fully capture a complex disease in algorithms.

(Epidemiologist, interview, 2010)

To summarize, the analysis of the interviews with the four team members involved in writing the research proposal for the COPDdotCOM project suggests that the future use of the system was configured according to a mixture of the three forms of self-management described by Schermer. Although one team member emphasized that the telecare system should improve patients' compliance as well, all of them predominantly focused on the educational role of the telecare technology to support patient self-management. This reflects the second form of self-management, where patients are supported to become proto-professionals by learning to interpret the measured data and act according to medical guidelines. However, the interviewees also indicated the importance of integrating characteristics of the third form of self-management into the telecare technology. Values like good communication, shared decision-making and the incorporation of patient knowledge were mentioned as valuable assets for patients to develop adequate self-management practices. Given these very rich and thoughtful views on how the telecare system should support patients' self-management, we might expect that the eventual design process would have included a similar broad approach to self-management. As we have seen in chapter 2, many aspects of self-management articulated by the initiators of the telecare system were not inscribed in the design of the telecare technology. In the remainder of this chapter I will try to find a possible explanation for the absence of the third form of self-management.

3.5.2 How designers are configured

How can we understand that user configurations articulated in the beginning of a research and development trajectory are not incorporated in the eventual end

product of the design? As mentioned in section 3.3.2, design processes involve much more than incorporating visions on future users and use. Most importantly, designers may be hindered in completing their initial ideas by specific constraints on their work (i.e. they may be configured by organizational and funding constraints). This is what happened in the COPDdotCOM project as well. During my interviews I learned that the developers of the telecare technology were configured by the specific demands of the funding organization, ZonMW, as exemplified in the next quote:

Yes, this call was specifically aimed at disease management for COPD patients: ICT-supported disease management for COPD patients. It is a very specific call and it necessarily had to be on COPD. Also because PICASSO, which is a national initiative in the field of COPD, co-funded the project. Long Alliantie Nederland was also one of the co-funders so together they joined forces to come up with a nice program. Therefore, something had to be written for this program specifically.

(Daily project supervisor, interview, 2010)

The fragment illustrates that the COPDdotCOM project would only be funded if it was specifically about ICT supported disease management for COPD patients, reflecting how research and development organizations like RRD are configured in their design by calls of funding agencies. In this particular case, this process was augmented by the presence of a national co-funding agency (PICASSO).⁵⁶ Additionally, the developers of the telecare technology were configured by aspects like time, money and technical resources, which constrained the design of the telecare system:

Q: On what criteria are final design decisions made?

⁵⁶ According to the daily project supervisor of the project, the configuration by funding agencies of EU projects is even stronger (Daily project supervisor, interview, 2010).

A: That is a compromise between what people want and what is technically feasible, within the limits of the funding or the duration of the project.

(Daily project supervisor, interview, 2010)

Or, as one of the engineers of the project team articulated:

Q: What are the main inputs for such a project? Patients? Doctors, or technical resources, or...?

A: It is a combination of things. Technologically, a lot is possible. But it is not unlimited, of course. It is also a matter of available knowledge and time. How much time can you devote to such a design? Look, you know how something should look like ideally, but that is not always technically feasible. And yes, everything is connected to one and other.

(Electrical/biomedical engineer at RRD, interview, 2010)

Another project member expressed how efficiency plays a role in the design of technologies, but that in a perfect world they would probably do things differently:

A: Because that's always the case with workshops and the whole design. There is always a tradeoff between ... resources and accuracy. Because you can go on and on, but at a certain point in time you have to say no. So this efficiency, that is an issue.

Q: And where does it depend on?

A: Time, you have four months or half a year and then it should be finished. But in an ideal world, you often need more time.

(Senior researcher at RRD, interview, 2010)

To summarize, the above fragments illustrate how the research team had to deal with multiple design constraints. Developers were configured by demands of funding agencies, the availability of time and money and by technical limitations. In addition to user requirements, these aspects played an important role in the design of the telecare technology at hand.

3.5.3 The role of bricolage in the design process

Although demands of funding agencies, time and technical constraints thus played a significant role in shaping the design process, it is important to understand how these constraints affect design choices. In this section I show how this process of configuring designers sometimes resulted in bricolage as a design approach. The lung specialist involved in the design process of the COPDdotCOM system mentioned how budget constraints of the funding agency primarily urged the design team to use existing technologies:

Because ZonMw had a limited budget, we chose for limited options. We could not develop new devices, only assemble already existing technologies.

(Lung specialist at MST, interview, 2010)

The use of BANs in the design of the COPDdotCOM system illustrates how technologies developed in previous projects were integrated into the telecare system. The development of BAN technology had been a prominent research line within the research and development organization for years.⁵⁷ Moreover, the device to measure patients' activity levels was already developed in a previous research project, before it was integrated in the COPDdotCOM system:

We already had technologies that were developed within RRD, the BAN and the activity meter, which were developed in the Awareness project. ... We already had an application to start with for the project, it only was not aimed at COPD at that time.

(Senior researcher at RRD, interview, 2010)

The PDA used for the COPDdotCOM system was a commercially available HTC 3600 or 3700 (Tabak et al., 2013). The software on the PDA was especially developed for the project, but the device that ran the software was bought "off the shelf":

⁵⁷ <http://www.freeband.nl/project.cfm?id=494> (last accessed 02-03-2012).

From our previous study we are interested in providing local feedback via the PDA. So..., yeah..., not all the decisions you take in a project start from scratch.

(Human media interaction engineer at RRD, interview, 2010)

Moreover, the software used for the transmission of data between the database and the other devices was available “on the market” and used by the Dutch Tax Administration (Human media interaction engineer at RRD, interview, 2010).

After minor adjustments it could be used in the COPDdotCOM system:

No, there was not a lot of development work left for me. Transferring data remotely is something we bought. That is existing software running on the side. That's more about implementation and installation.

(Electrical/biomedical engineer at RRD, interview, 2010)

To summarize, the above fragments illustrate how some devices and technologies developed in previous projects or already available on the market were integrated in the design of the COPDdotCOM system. In other words, the design team of COPDdotCOM sometimes adopted the approach of bricolage in the design of the telecare technology. Consequently, many parts of the telecare system were not originally designed to support self-management of COPD patients.

3.5.4 Path creation to increase user acceptance

In the previous section I described how constraints on the design process narrowed the design choices to using already available artefacts. However, during the interviews I learned that this does not imply that the design process was not attuned to future users. Although most devices were not specifically developed for monitoring COPD, the developers tried to anticipate the future use of the system by COPD patients, particularly by avoiding potential resistance to using the system. The choice of the design team to use a PDA for the activity monitoring and feedback application of the telecare system, for example, can be interpreted as a strategy of the developers of the technology to increase user acceptance of the system by using a “cool” device:

Carrying a PDA does not mean that you are ill, it's even cool.

(Human media interaction engineer at RRD, interview, 2010)

In addition to anticipating the acceptability among patients, the designers also developed strategies to improve acceptance among health-care professionals. The next excerpt illustrates that in order to design a successful technological tool, the engineers of COPDdotCOM were aware of the fact that the web portal containing data about patients' health status should not differ too much from existing systems. The meaning of the *new* information system should connect with the *old* information system:

The requirements of caregivers on how to work with such a system are very clear. They have worked with these data for a long time ... and it should fit in their routine. It should not be totally different all of a sudden.

(Human media interaction engineer at RRD, interview, 2010)

Moreover, the project team deliberately chose not to change existing treatment protocols for COPD patients too abruptly, because it could lead to resistance from medical personnel and lower user acceptance.⁵⁸

And you always use existing treatment protocols. You should adjust them in such a way that you push the technology in it, so to speak.

(Senior researcher at RRD, interview, 2010)

As we can see, the design of the COPDdotCOM system depended on already existing treatment programs for COPD. The developers tried to incorporate the technology into the existing treatment protocols to stay close to practices patients and health-care personnel were familiar with. In other words, they tried not to change the existing care practices of relevant social groups too radically. The

⁵⁸ See also Oudshoorn (2011, 68) on resistance among health-care professionals (boundary work) against the introduction of telecare technologies.

formal project leader phrased his vision on how to be extra careful in designing medical technologies as follows:

Therefore, at a certain point, we started to map the current situation. ... And then you make sure that it is not 180 degrees different. You try to build on that ... That is a wise thing to do, because the more it differs from the existing situation, especially in care processes, the less chance to succeed. That is an important issue.

(Formal project leader, interview, 2010)

Moreover, the lung specialist stresses how important it is to be very precise in what you tell COPD patients about the devices they might use for the treatment of their disease. Using words too “complex” for some devices might trigger negative connotations with technologies in general. The next quote illustrates the importance of creating a path in designing health care technologies that transforms the new technology into a familiar, less threatening device for its future users:

We agreed from the beginning never to use the word computer, but always refer to it as the gadget on top of the TV. We deliberately chose to refer to TV and referred to the device we used as a remote control.

(Lung specialist at MST, interview, 2010)

To summarize, the design process of the telecare system was not merely dominated by bricolage activities. My analysis shows how various design choices can be interpreted in terms of path creation. The designers sometimes deliberately integrated *popular* devices, familiar information systems and treatment protocols in the design of the telecare technology, hereby aiming at higher user acceptance by patients and less resistance by health-care professionals.

3.6 Conclusion

The central aim of this chapter was to contribute to understanding design practices of telecare technologies. I therefore analyzed the design process of a telecare technology developed within the framework of the COPDdotCOM project. I was interested in the enabling and/or constraining aspects that shaped the design

process of the telecare technology, and why, in the technical characteristics of the system, the third form of self-management (Schermer, 2009) was largely absent.

To analyze my research material I used the concept of configuring the user (Woolgar, 1991). The concept helped me to understand how the authors of the research proposal reflected on what forms of self-management should be supported by the telecare technology. I described how their views about how the new technology should support or change patients' behavior and COPD care practices reflected both compliant and autonomous forms of self-management.

To explain the absence of the third form of self-management in the telecare technology I used the concept of configuring designers (Mackay et al., 2000). By applying the concept to the design process of the technology, I learned that the developers of the COPDdotCOM system were highly configured by their environment, particularly by the funding agency of the project. I described how they were predominantly constrained in their design by the availability of resources like time and money. Moreover, the targeted chronic disease (COPD) and the result of the project (an ICT-based disease management system) were predefined in the research call of the funding agency. In this respect, my account of how the designers of this telecare system were configured by the funding agency is not an exception. As with other technologies, the funding of telecare technologies is mainly restricted to financing short-term projects with predictable outcomes (Laudel, 2006; Heinze, 2008; Hyysalo, 2010).

The constraints on the design process had a clear impact on the design strategies of the development team of the COPDdotCOM system. Technologies developed in previous projects, like BANs were integrated in the telecare system. The PDA that was used for the activity monitoring and feedback application of COPDdotCOM was a commercially available device, bought "off the shelf" and the software used for transmitting data was available "on the market" and already used by the Dutch Tax Administration. I captured this design strategy by adopting the concept of bricolage (Disco, 1998; Garud & Karnoe, 2003).

Furthermore, the development of the telecare technology was characterized by design choices that can be described by the concept of path creation (Garud & Karnoe, 2001). I described how the use of specific devices, technologies and

treatment protocols were sometimes deliberately integrated in the design of the system to increase user-acceptance of patients and healthcare professionals.

Summarizing, I conclude that the writers of the research proposal articulated clear views and ideas on the future use of the system, reflecting the third form of self-management. However, the developers of the telecare technology were highly constrained in their design work, which resulted in design choices shaped by processes like bricolage and path creation. In other words, by the constraining aspects of the COPDdotCOM project, developers of the telecare system were urged to include devices that were not specifically designed for the project at hand or to use technologies that had been fitted into already existing treatment protocols. These constraining aspects resulted in the design of a compliant telecare technology, reflecting the first and second forms of self-management, aimed at collecting verifiable and measurable results, instead of creating a new system incorporating data based on experience-based knowledge and patient preferences and priorities, reflecting the third form of self-management.⁵⁹ In this respect the telecare system for the treatment of COPD mirrored the design of many other telemonitoring technologies, which are predominantly aimed at collecting a narrowly defined set of data (Moser, 2008, p. 73; Oudshoorn, 2011, p. 203; Hanlon, 2005, p. 150). As Ingunn Moser (2008) and Oudshoorn (2011) have described for telecare technologies for elderly people and heart patients, respectively, the COPD telecare system favored hard numbers and medical, abstract knowledge. The telecare system thus allowed patients to learn about their disease and take action only within a set of predefined guidelines to encourage compliant behavior. Designing a telecare system that would support the third form of self-management requires another design strategy in which new design approaches should be explored in order to incorporate other ways of knowing and supporting self-management. The constraints on the design team described in this chapter did not allow developers to leave the beaten tracks of developing systems, which explains why the third form of self-management gradually got lost during the design process.

⁵⁹ For example, the electronic triage diary works on a specific algorithm based on the answers of prestructured multiple-choice questions (Effing et al., 2009).

Reflecting on what happened to the views on self-management, articulated as user requirements during the early phase of the design process, the findings of this chapter are in line with Stewart and Williams (2005) who showed that initially articulated user requirements often do not end up in final ICT systems. Akrich (1995) has described a similar dynamic and emphasized that views on future use and users frequently change during the whole design trajectory. My account of the design process of the COPDdotCOM project shows how some user requirements reflecting the third form of self-management disappeared altogether. I therefore conclude that the problem of low user acceptance of telemedical applications described by Vollenbroek (2009) cannot be solved by merely refining and increasing the number of user requirements. It also requires another funding regime in which developers have the time and resources to do reflexive work and adopt creative, explorative design approaches to confirm that the eventual end product meets their views on good care.

Chapter 4. The role of education in self-management supported by telecare technologies

4.1 Introduction

As I argued in chapter 2 of this thesis, there are two forms of self-management (Schermer, 2009) dominantly inscribed in the design of the telecare technology developed within the framework of the COPDdotCOM project. These are the compliant (first and second) forms of self-management. The third form of self-management, where the relationship between patients and professionals is based on collaboration or concordance (p. 689), is largely absent.

However, as STS scholars have illustrated, the future use of a technology is not solely shaped by its design (Oudshoorn & Pinch, 2003, 2008). While Oudshoorn and Pinch predominantly focus on the role of users in co-shaping the design and use of technological objects, I argue that educational programs and instructions for use (see also chapter 2) also play an important role in shaping the eventual use of new technologies. Although there is an extensive literature on the role of educational programs aimed at self-management (Warsi et al., 2004; Lorig & Holman, 2003), the dynamic relationship between technologies and educational programs as two separate but potentially supporting tools for self-management is hardly addressed. In this respect the CoCo COPD project provides an excellent case study to explore these relations.⁶⁰ As briefly described in chapter 1, the testing of the telecare system included an educational program in which patients who participated in the trial learned to complete the electronic triage diary and were educated in early recognition of exacerbations and in starting standardized treatment in case of an exacerbation (Tabak et al., 2014).⁶¹ The educational program was called a self-management course and they were taught by the nurse practitioner. Because the course was presented as a self-management course, rather than user-instruction meeting, we may assume that they were based on specific views of self-management as practiced in the care provided to COPD

⁶⁰ See chapter 1 for an overview of the CoCo research project.

⁶¹ Additionally, patients were instructed by the primary care physiotherapist on how to use the web portal and to perform baseline activity measures (Tabak et al., 2014).

patients at the MST hospital where the testing took place. The central research question for this chapter therefore reads as follows:

What understandings of self-management are taught to patients before using telecare technologies?

To answer this question I investigate how patients are informed about their condition and instructed to use the telecare technology during the self-management course. Are they taught to cooperate with their health-care professionals to learn to live with their disease or urged to follow the guidelines generated by the telecare system? What role does their experience-based knowledge play in using the system and to what extent are they taught to incorporate their own views and wishes about living with their disease while using the system?

The outline of this chapter is as follows. After explaining the research methodology in section 4.2, I give an overview of how the self-management course was conducted, who participated, what the main topics were and what material was used (section 4.3.1). The chapter continues by presenting how patients were supported to articulate their embodied experiences (4.3.2) and how patients were taught to use the telecare system (4.3.3). In section 4.4 I present my analysis of what forms of self-management are discernible in the course. I end this chapter by formulating an answer to the research question and providing some concluding remarks (section 4.5).

4.2 Methods

To analyze the educational program accompanying the introduction of a telecare technology as part of a randomized controlled trial (Tabak et al., 2014), I apply a mixed methods research approach (Yin, 2003). The telecare system tested in the trial was developed within the framework of the CoCo COPD project. The research data were assembled by conducting participatory observations of a self-management course that patients had to attend in order to learn how to complete the electronic triage diary of the telecare system and where they were educated in early recognition of exacerbations and in how to start standardized treatment in

case of an exacerbation. The self-management course was divided over two 90-minutes sessions spread over two successive Wednesday afternoons in the summer of 2012 at the local hospital of Enschede (MST). For the data collection I used an observation scheme.⁶² In addition to the participatory observations, I conducted an in-depth analysis of the course material. I audio recorded each session and transcribed the recordings verbatim. All research data were stored on a secure server of the University of Twente, which could only be accessed by me.

4.3 Self-management course for telecare technologies

The self-management course was taught by a nurse practitioner and took place in a meeting room of the MST hospital. The participants of the first session were two COPD patients (one male, age 63 and one female, age 76), accompanied by their “significant others.”⁶³ In the second session two more patients (two males, age 54 and age 72) were present. The latter two were updated about the first session before the second session took place. The contents of the course can be classified according to three main themes: teaching patients about the medical background of their condition, supporting patients to articulate their embodied experiences with their COPD and teaching patients to use the telecare system. Each theme will be described in the next sections.

4.3.1 Teaching patients about the medical background of their condition

The first session of the self-management course was predominantly aimed at teaching patients about the medical background and treatment of their COPD.

Today, we’re going to talk about what healthy lungs are. How lungs look, how they are made up, what the function of lungs is, what exactly COPD is and its treatment.

(Nurse practitioner, self-management course MST, July 11, 2012)

⁶² See appendix III for the observation scheme.

⁶³ The term “significant other” is commonly used in medical literature to refer to someone who would be called partner, friend or relative in daily language.

As teaching material, a PowerPoint presentation and handouts were used. The PowerPoint presentation consisted of 19 slides (See Figure 4.1 as an example of the PowerPoint slides).

Figure 4.1: Slide used in the self-management course.

(English translation: Luchtweg “gezond” = Airway “healthy”, Luchtweg “COPD” = Airway “COPD”.)

Source: PowerPoint presentation, self-management course, July 11, 2012.

The first couple of slides contained graphs, keywords and short sentences about the human respiratory system and the effects of COPD. Some slides explained the main cause of COPD (smoking) and the key symptoms of the condition (shortness of breath, coughing, coughing up mucus and exacerbations). To prevent the deterioration of patients’ COPD condition, the presentation discussed stopping smoking and having an active lifestyle and healthy diet. Attention was given to the major causes of shortness of breath like changing weather conditions or irritating fragrances. The last slides of the course were about the treatment of COPD and how patients can use medication. In addition to the PowerPoint slides, handouts (or “course book” as the nurse called it) consisting of 15 A4-sized papers were used. The information on the papers mostly corresponded to the information on the slides, although the information in the course book was more detailed and contained an extra section on healthy nutrition for COPD patients.

The teaching material used in the self-management course thus aims to make patients familiar with the causes and treatment of their disease, which is presented to them at a high-school level. Importantly, the content of the teaching material of the course only concerns medical knowledge. It does not include patients' experience-based knowledge, nor does it address emotional or psychosocial aspects of living with COPD.

4.3.2 Supporting patients to articulate their embodied experiences

In addition to the attention paid to the medical background of COPD there was a lot of attention during the course given to patients' embodied experiences with their COPD. The nurse explained that experience-based knowledge – knowing one's body – is at the heart of self-management of chronic illness:

Yes, that's exactly what self-management is about. Knowing what to do in which situation. How can I learn to feel, to know myself.

(Nurse practitioner, self-management course MST, July 11, 2012)

Or, when the significant other of one of the patients asked how to react when the two of them were out of the country and her husband needed medication:

That is part of this self-management course ... that you learn when and how to use your medication, without involvement of your doctor.

(Nurse practitioner, self-management course MST, July 18, 2012)

Moreover, the nurse practitioner emphasized that symptoms of COPD are different for individual patients, including factors that trigger patients' shortness of breath. Some patients mentioned the latter symptom was caused by cigarette smoke or emotional distress. Others mentioned they cannot tolerate foggy weather or perfume:

Here in Hengelo there is this perfume store. I always have to avoid it by taking another route.

(Patient I, self-management course MST, July 18, 2012)

In addition to sharing symptoms of COPD and factors that trigger these symptoms, patients were invited by the nurse practitioner to share their experiences with the medication they used. It became clear that the use of medication varied per patient and that individual patients experienced different side effects. Moreover, during the course the nurse practitioner referred to the importance of “tailor-made” treatment regarding medication for COPD.

Medication for COPD, there is a lot we can give, but it is very much tailor-made, it's very personal. What works for one, may not work for another.

(Nurse practitioner, self-management course MST, July 18, 2012)

One patient mentioned how important it was to him to receive the right instructions on how to use the medication. During the course special attention was given to emotional and psychological aspects of having COPD. Hereby the nurse practitioner not only focused on patients' experiences with the consequences of COPD but also on how it affected the lives and wellbeing of patients' partners. The nurse practitioner involved them in the course by regularly asking them about their experience of living with someone who was diagnosed with COPD:

If I was not around, she could not stay at home. Anyway, we agreed that I would partially take care of her, but I also want some room for myself. I don't want to be totally absorbed in caring for her. I still want some privacy for myself.

(Partner to patient F, self-management course MST, July 11, 2012)

Learning to articulate and rely on experience-based knowledge was also an important part of the course that focused on how patients should use the electronic triage diary. Although the diary's questions were predefined and based on physical symptoms of COPD only (see chapter 2), patients were instructed to use their experience-based knowledge to interpret the physical symptoms they experienced prior to an exacerbation of their COPD. One patient was surprised at how it was possible for the electronic triage to generate advice on medication based on a few questions, without knowing patients' personal circumstances:

But what I lack, are questions like: “Did you do extraordinary things yesterday?” Maybe too much exercise, which caused these symptoms or maybe you experienced some emotional moments, which caused breathlessness, or worsened your symptoms, because that I can trace back. But when I fill it out like this, he [the electronic triage diary] says, “take prednisolone,” while I have my doubts...

(Patient I, self-management course MST, July 18, 2012)

Although the nurse practitioner did not answer this question directly, she emphasized that the electronic diary did not work on the basis of abstract medical data, but on how COPD symptoms were experienced by patients compared to their previous situation. Patients therefore had to determine whether the symptoms they experienced were “normal” or (slightly) “abnormal” compared to living with COPD in their daily life. Furthermore they were taught to determine whether a divergent bodily experience was caused by extraordinary circumstances, like heavy physical exercise, or if they were a precursor to an exacerbation. To support patients with this task they received a form (Figure 4.2) to write down the answers to the question: “What is normal for me?”

Patients were asked to answer questions about shortness of breath, coughing up mucus, the color of the coughed up mucus, and the metered-dose inhalers they use and how many times they use them (measured in number of puffs per day). The nurse practitioner helped each patient extensively to fill out this form. It became clear that individual patients had very different symptoms that were a precursor for an exacerbation. One of the patients explains:

Sweating terribly. Not knowing where to go. Totally breathless. Nevertheless arriving at the physiotherapist, helped by your neighbors though. Still not knowing what is going on, and they bring you home. You simply cannot move anymore.

(Patient I, self-management course MST, July 18, 2012)

Figure 4.2: Form patients receive to write down their “normal” situation.⁶⁴

"Wat is voor mij normaal?"	
Patiëntnaam: <u>Dhr. W.</u> Geboortedatum: Datum uitgifte kaartje: <u>15.05.10</u>	
Kortademigheid: <u>Altijd. Toernemend bij inspanning. Herstel doorgaans snel.</u> <u>Ende dag meer vermoeid, sneller kortademig</u>	
Opgeven van slijm: <u>Iedere dag, niet in grote hoeveelheden</u> <u>Niet eigen bij inspanning, niet afhankelijk v. moment v.d. dag</u>	
Kleur van het opgehoeste slijm: <u>Blank of geel/groen: wisselt</u> <u>geen verschil in moment v.d. dag.</u>	
Ik gebruik als kortwerkende luchtwegverwijder: <u>Berodual</u> Ik gebruik à puffs per dag <u>6x daags 2x 1 puffje /keer.</u>	
<small>Dit kaartje "wat is voor mij normaal" wordt met u bepaald vanwege het (elektronische) dagboek. Want met het dagboek wordt bijgehouden of er geen, kleine of grotere VERANDERINGEN van uw "normale" situa</small>	

Source: Koster (2011, p. 55).

To summarize, during the self-management course patients were taught that knowing oneself is an essential aspect for self-management of their condition. During the course there was room for the emotional and psychosocial aspects of living with COPD, for both patients and their significant others. A large part of the

⁶⁴ English translation:

"What is normal for me?"	
Name patient:	
Date of birth:	
Form issue date:	
Shortness of breath: <u>Always, increasing with physical strain. Usually quick recovery. At the end of the day more exhausted, more rapidly short of breath.</u> Coughing up mucus: <u>Every day, no huge amount. Not worse with physical strain, independent of time of day.</u> Colour of the coughed up mucus: <u>White or yellow/ green: differs, no difference in time of day.</u> I use for metered-dose inhalers: <u>Berodual.</u> I use ...à... puffs per day: <u>6 times per day, 2 puffs per time</u>	
<small>This form "what is normal for me" is discussed with you because of the (electronic) diary. The diary is used to keep up whether there are no, minor, or major CHANGES of your "normal" situation.</small>	

course was aimed at supporting patients to use their experience-based knowledge when filling out the questions of the electronic triage diary of the telecare system, which functioned on the basis of how patients felt compared to their “normal” daily health status. It became clear that the symptoms of COPD, the use of medication⁶⁵ and its side effects varied per patient. This was emphasized by the nurse practitioner who regularly referred to the importance of a “tailor-made” treatment of COPD.

4.3.3 Teaching patients to use the telecare system

In addition to the attention given to the medical background of COPD and helping patients articulate their embodied experiences, patients were taught the practical skills of how to use the telecare system. The nurse practitioner began this part of the course by emphasizing the importance of computer skills:

For this trial you must own a computer and know how to work with it, you must have access to the Internet ... and you need health insurance that covers physiotherapy.

(Nurse practitioner, self-management course MST, July 18, 2012)

Although digital skills were thus important for using the telecare system, they were not addressed during the course. As will be described in chapter 5, patients who did not have a computer or Internet connection at home were excluded from the trial. Instead of teaching general computer skills, the course focused exclusively on the practical skills required to use the electronic triage diary. The nurse practitioner explained the role of the electronic triage diary of the telecare system and how it could support patients in the treatment of their condition:

⁶⁵ During the course the nurse practitioner paid a lot attention to the practical knowledge that was involved in the taking of medication, hereby, emphasizing how important this is for the treatment of COPD. To be able to follow the advice of the electronic triage diary without interference of health-care professionals, the participants of the self-management course received prescriptions for prednisolone and antibiotics so they could pickup these medicines before they started using the electronic triage diary.

Because that is what the computer is going to do, it will indicate when you should start treating yourself with medication.

(Nurse practitioner, self-management course MST, July 11, 2012)

Anticipating potential problems that patients may have experienced in using the electronic triage diary, the nurse practitioner emphasized regularly that patients were allowed to use a paper diary prior to, or instead of, using the online triage diary on the web portal. For instance, when they felt reluctant to use the computer, or were afraid to make a mistake:

If you are going to fill in the diary every day, but still think it is difficult anyway, and you would rather fill it in on paper first, prior to using the computer, I also have a paper version. ... So in case you made a mistake, just keep up the paper diary as well.

(Nurse practitioner, self-management course MST, July 11 and 18, 2012)

Initially, patients were asked to follow the advice of the electronic triage diary:

When it [the electronic triage diary] says: "Start with a course of prednisolone," we do expect you to start with it.

(Nurse practitioner, self-management course MST, July 11, 2012)

The nurse practitioner also explained how health-care professionals, like herself, and the lung specialist used the data patients would enter into the electronic triage diary:

When you come to your doctor's appointment, the lung specialist and I can log in to your data and I can see how often you were advised to start a course [of medication], assuming you indeed took the course. We can precisely monitor this.

(Nurse practitioner, self-management course MST, July 18, 2012)

However, during the course the nurse practitioner emphasized that patients should always rely on their experience-based knowledge instead of the advice of the electronic triage diary:

And when in doubt, and this is the last message of this afternoon, when in doubt, your own feelings are always more important than what the computer says. That transcends everything.

(Nurse practitioner, self-management course MST, July 11, 2012)

She emphasized that when patients had doubt they should always contact health-care professionals (whose telephone number they have from their regular treatment):

But if you have any questions about how you feel, about your illness, or when you are in doubt, you can always call your doctor or call me, okay?

(Nurse practitioner, self-management course MST, July 18, 2012)

Moreover, the nurse practitioner informed patients what phone number to use when they had questions on how to use the system, what happens if they make a mistake and how to deal with technical issues. Remarkably, this functionality to communicate was not incorporated in the telecare system itself.

To summarize, during the course patients were asked to comply with the advice of the electronic triage diary because, according to the nurse practitioner, this information was to be used by health-care professionals to monitor patients' health status and the use of medication. However, the nurse practitioner emphasized that patients should always prefer their experience-based knowledge over the advice of the diary and told patients that when in doubt they should contact health-care personnel, or for technical questions, the researchers in charge of the trial.

4.4 Conclusion

In this chapter I investigated what understandings of self-management were taught to patients before using telecare technologies by analyzing how they were informed

about their condition and instructed to use the electronic triage diary of a telecare technology in a randomized controlled trial (Tabak et al., 2014). I therefore analyzed the educational program, called self-management course, patients had to attend prior to participating in the trial.

Based on my analysis, I conclude that the understandings of self-management taught in the course were mainly based on the third form of self-management as described by Schermer (2009), but also the first and second form can be discerned.

A glimpse of the first form of self-management can be discerned by the fact the nurse practitioner initially asked patients to comply with the advice of the electronic triage diary. However, she emphasized that patients should not be too compliant and should always trust on their experience-based knowledge when in doubt. Moreover, patients were also allowed flexibility in using the electronic triage diary, for instance if they preferred to use the paper version of the diary for some occasions.

The second form of self-management can be discerned in the self-management course since patients were taught to take over interpretative and decisional tasks of health-care professionals. During the course patients were taught to interpret their COPD-related symptoms and determine whether these were normal or deviant from their daily experience. Patients were taught to take over decisional tasks, because they were allowed to adapt medication dosages while using the system, without consulting their health-care professional. This means they were allowed more “executive autonomy” (Schermer, 2009, p. 689). Moreover, patients were taught to manage their disease as a medical professional by enhancing relevant physiological and medical knowledge, including knowledge about the (side) effects of medication and the importance of healthy nutrition. Although the contents of the course material and the verbally transferred knowledge were predominantly based on medical expert knowledge, the nurse practitioner encouraged patients and their significant others to share emotional and psychosocial dimensions of their condition as well.⁶⁶

⁶⁶ The nurse practitioner acknowledged that the attention to patients’ personal experiences was also possible because of the small number of participants of the course (transcript, self-management course MST, July 11, 2012).

In the self-management course patients were taught to self-manage their condition according to the third form in various ways: First, patients were taught to rely on their experience-based knowledge instead of the advice generated by the electronic triage diary. This means that compliance with the telecare system was not promoted here. One could say that at this point patients were stimulated to find their own way of living with their condition. However, they were not enabled or encouraged to manage their condition if this meant making decisions that were not the wisest from a medical point of view. Second, patients were taught to rely on their embodied experience when answering the questions of the electronic triage diary by comparing the symptoms they experienced at that moment with their “normal” health status. Therefore, a lot of attention was given during the course to helping patients become aware of their daily COPD symptoms and writing these, and their regular medication, down on the form titled “What is normal for me?” Third, patients were instructed that when they were in doubt they could always contact their health-care professional or the researchers of the trial. They were taught to collaborate with professionals to discuss the treatment of their condition or when they had questions about the workings of the telecare system. Patients could use the telephone number of their regular health-care professionals or use the telephone number provided to them in the course book or verbally by the nurse practitioner. In other words, the nurse practitioner recognized the importance of communication in the treatment of patients with COPD supported by a telecare system. Remarkably, patients were thus instructed not to follow several important parts of the script of the electronic triage diary. Instead they were taught to develop anti-programs such as using the paper version of the diary, relying on their experience-based knowledge when it came to medication, and communicating with health-care professionals instead of blindly following the advice of the electronic triage diary.

In conclusion, the understandings of self-management taught in the course were predominately based on the third form of self-management. However, I agree with Pols (2012) that given the fact that patients’ significant others were invited to join the patients for the course and the nurse practitioner regularly reminded patients to contact professionals in case of doubt, the term “together-management”

(Pols, 2012, p. 75) might indeed be more suitable to describe how patients were taught to manage their disease.

Despite the small number of patients I observed during the self-management course,⁶⁷ it became clear that the impact and effect of COPD on peoples' lives varies per individual patient. Not only in terms of severity of the condition, but also in the variation of symptoms that patients experience, the factors that trigger these symptoms and the difference in medicines they use. This finding supports the emphasis on the importance of tailor-made treatment of COPD during the course, which is in line with recent literature on telemedicine for patients with COPD (Tabak, 2014, p. 12).

⁶⁷ According to the nurse practitioner, the number of participants of the course was low because many potential participants of the trial did not have proper health insurance to receive additional physiotherapy, which is one of the essential features of the telecare system. During the course the nurse practitioner mentioned she treated approximately 1000 COPD patients per year (transcript, self-management course MST, July 11, 2012).

Chapter 5. How telecare technologies shape patients' actions and perceptions

5.1 Introduction

In chapter 2 of this thesis I argued there are two forms of self-management (Schermer, 2009) dominantly inscribed in the design of the telecare technology developed within the framework of the COPDdotCOM project. These are the compliant (first and second) forms of self-management. The concordant (third) form of self-management (p. 689) is largely absent.

In the previous chapter I argued that for an in-depth analysis of what forms of self-management are inscribed in the telecare technology we have to extend our view beyond merely the technical design of the technology and include how users are taught to manage their condition and use the telecare system.⁶⁸ I therefore analyzed how users were introduced to using the system via a self-management course before the actual use of the system took place. I concluded that the views and ideas on self-management taught in the course were mainly based on the third form, although the contents of the course material and the verbally transferred knowledge were predominantly based on medical expert information only.

In this chapter I will take this argument one step further by suggesting that the only way to learn how telecare technologies shape the self-management practices of patients is to look at how they are used in daily life. To analyze these practices I combine concepts from ANT with concepts from postphenomenology. The differences between these approaches can be summarized as follows: ANT focuses on how technologies shape human *action* by their script (Akrich & Latour, 1992), while postphenomenology focuses on how technologies mediate human *perceptions* of the world (Verbeek, 2005). ANT scholars, most prominently Bruno Latour and Madeleine Akrich conceptualize user-technology relations in terms of dynamic interactions between the programs of action inscribed in the technologies and possible anti-programs of its users (Latour, 1992; Akrich, 1992). This approach

⁶⁸ When I refer to the telecare system, I refer to the telecare technology consisting of multiple telecare applications and devices.

could be a fruitful heuristic to analyze the shaping of patients' actions regarding inscribed forms of self-management of telecare technologies.

This ANT understanding of human-technology relations is criticized by philosopher of technology Peter-Paul Verbeek. He suggests introducing ideas from postphenomenology (Ihde, 1990) to understand how technologies not only prescribe or shape human *action* but also shape human *perceptions* of reality. Following Ihde, Verbeek describes four different ways technologies can mediate human understandings of reality. First, people can embody technologies as if they were an unnoticed extension of their body, like a pair of glasses (embodiment relation). Second, technologies can give a representation of reality that people need to interpret, e.g. thermometers represent how hot or cold it is (hermeneutic relation). Third, people can interact with technologies as if the technologies were other human beings, like automatic ticket dispensers (alterity relation), and fourth, technologies can mediate human perception by being present in the background of peoples experience, like heating systems (background relation) (Verbeek, 2005). The telecare system investigated in this thesis typically reflects a hermeneutic relation. Patients are expected to interpret the data and feedback provided by the telecare devices and applications, which may shape the perceptions of their illness and how they relate to health-care professionals. Equally important, Verbeek and scholars from cultural studies emphasize that human perceptions of technologies may not only be shaped by the programs of action inscribed by designers into the device, but also by interpretive frameworks rooted in daily routines or culture at large (see e.g. Oudshoorn & Pinch, 2008; Lie & Sørensen, 1996). In addition to Verbeek's postphenomenological approach to human-technology relations, this latter approach could also be a fruitful heuristic tool to analyze how telecare technologies shape patients' perceptions of their disease and their autonomy.

For the analysis conducted in this chapter it is important to take into account that the telecare technology studied is not (yet) part of the daily care routines of patients suffering from COPD. The use practices that are explored are part of a pilot randomized controlled trial conducted at the MST hospital in Enschede. It is relevant to be aware of the fact that the test-users are configured in

the clinical trial.⁶⁹ They are not so much configured in their actions regarding the telecare technology but more in their identity as a COPD patient by the setting up of inclusion and exclusion criteria for the trial. Since these recruitment strategies of the research team influence the understanding of self-management use practices of the telecare technology, I argue it is important to include them in the analysis.

The central aim of this chapter is thus to analyze how the telecare technology shapes patients' actions regarding inscribed forms of self-management of telecare technologies and their perceptions of their disease.

The research question of this chapter therefore reads as follows:

How do telecare technologies shape and mediate patients' perceptions of their disease regarding self-management and actions in dealing with the system?

Did they experience an increase of autonomy in dealing with their condition? What were their reactions to the instructions the telecare system generated? Did patients have the feeling their experience-based knowledge was recognized by the system? These and other experiences with the telecare system are analyzed in this chapter.

The outline of this chapter is as follows. After explaining the research methodology in section 5.2, I give an introduction to the activity monitoring and feedback application and the electronic triage diary patients used in the trial of the telecare technology in section 5.3. In section 5.4 I analyze the selection criteria of the trial and describe how this affects what patients were included or excluded in the trial. Next, I present an analysis of patients' experiences with the system, what role the system played in their lives and how they configured themselves in interaction with the system (5.5). Thereafter I analyze what the experiences of patients mean for the various forms of self-management incorporated in the telecare technology (5.6). I end this chapter by formulating an answer to the research question and providing some concluding remarks (section 5.7).

⁶⁹ For an explanation of the concept of user configuration, I refer to chapter 1 and chapter 3 of this thesis.

5.2 Methods

My analysis is based on semi-structured interviews ($n = 8$) with COPD patients who used the telecare technology in a pilot randomized controlled trial (Tabak et al., 2014) within the framework of the CoCo COPD study.⁷⁰ The activity monitoring and feedback application and the electronic triage diary that were part of the telehealth program studied in the trial originate from the COPDdotCOM project (Research Protocol CoCo COPD, 2011, p. 12). Although there were some differences between the two telecare systems for the treatment of COPD developed in the COPDdotCOM project and the CoCo project (see section 5.3), there were important similarities between the systems, which warrants further studying the latter applications in this chapter. The trial took place in the local hospital, MST, in the city of Enschede, the Netherlands, from April 2012 to June 2013. The interviews were conducted in January 2013. The interviewees consisted of a heterogeneous group of COPD patients.⁷¹ Their ages ranged from approximately fifty to eighty years. Three of them were female and five of them were male. Some of them were still working, some of them were retired. The majority (five) of the interviews took place at patients' homes; three were conducted elsewhere.⁷²

The educational background of the patients ranged from primary school to university level. All of them lived in the city of Enschede, in the East of the Netherlands. Some of the interviewees were joined by their significant other during the conversation, but the majority of the interviews consisted of a one-on-one exchange between the researcher and the patient. The nationality of the patients was Dutch. All the interviews were conducted in their native language. The patients were all diagnosed with COPD and took part in the clinical trial for at least a few months. The interviews were recorded and transcribed verbatim. For the

⁷⁰ See appendix IV for the semi-structured interview question list.

⁷¹ I will not reveal individual personal characteristics like age or sex because of privacy regulations. Permission to contact patients has been achieved via the patients' informed consent procedure of the CoCo researchers and with approval of the Medical Ethical Committee of the MST hospital.

⁷² One patient preferred being interviewed in the researcher's office, one of the interviews took place in the cantina of the local hospital, and one interview took place at the patient's work place.

analysis of my research I use the so-called bottom-up approach, meaning I code fragments of text of the transcription to associate common themes, after which they are clustered into theoretical notions relevant for this case study. I used Atlas.ti 6.2 software as a supporting tool. All research data were stored on a secure server of the University of Twente that could only be accessed by me.

5.3 The CoCo COPD application

As already outlined in section 5.2 of this chapter, the activity monitoring and feedback application and the electronic triage diary that were part of the telecare system studied in the trial originated from the COPDdotCOM project (Research Protocol CoCo COPD, 2011, p. 12). However, to indicate how both applications evolved, I will briefly introduce these devices and how they worked.⁷³

5.3.1 The activity monitoring and feedback application

The activity monitoring and feedback application used in the CoCo COPD study worked as follows: Patients wore an activity measurement device that was connected via Bluetooth to a smartphone (Figure 5.1).

Figure 5.1: Activity sensor (Inertia Technology) and smartphone (HTC Desire S).

Source: Research Protocol CoCo COPD (2011, p. 17).⁷⁴

⁷³ For an extensive overview of the workings of the applications, I refer to Tabak et al. (2014).

⁷⁴ Document received during interview with Monique Tabak, July 14, 2010.

The smartphone sent the measured data via wireless Internet to a database and received automatically generated feedback messages back from this database, which then appeared to the user on the screen of the smartphone. Additionally, the measured data appeared on the web portal, which could be looked at by professionals and eventually by patients via the Internet (Figure 5.2).

Figure 5.2: Overview of activities on web portal.

Source: Research Protocol CoCo COPD (2011, p. 19).

The most important differences between the activity monitoring and feedback application studied in chapter 2 (the COPDdotCOM system) and the one that was used in the CoCo COPD trial were that more individual activity goal settings were used and that the motivational cues were more tailored to individual users. In the COPDdotCOM system the reference line was partly based on the mean activity line of healthy controls. In the CoCo COPD trial the reference line was set by the physiotherapist based on preferences of individual patients regarding their goal and physical capacities. Additionally, in the COPDdotCOM system users received feedback text messages automatically, based on the difference between the measured activity and the reference line. The text messages of the activity monitoring and feedback application used in the CoCo COPD trial were based on the activity of the last two hours and of the day so far. At the end of the day the

patients received a summary of their activity behavior (Tabak, 2014).⁷⁵ The differences between the two systems reflect a development in designing a more tailor-made telecare system.

5.3.2 The electronic triage diary

The electronic triage diary was based on an automated triage system, which generated advice about medication. The advice was based on answers given by patients to one or more questions about the patient's condition (Figure 5.3).

Figure 5.3: Electronic Triage Diary

(English translation: Did you have complaints of coughing? Text in the green box: Normal. Text in the yellow box: Slightly more than normal. Text in the red box: Clearly more than normal).

Source: Research Protocol CoCo COPD (2011, p. 18).

It could advise to (not) start a course of a specific medicine, prednisolone, start a course of prednisolone combined with antibiotics, or to contact a health professional. Again, the answers to the questions and the generated advice,

⁷⁵ In addition to the software of the activity monitoring and feedback application of COPDdotCOM, newer versions of the hardware were also used: The activity sensor used in COPDdotCOM produced by Xsens Technologies, Enschede, the Netherlands, was replaced by an activity sensor of Inertia Technology, Enschede, the Netherlands. The PDA used in COPDdotCOM (HTC 3600/3700) was replaced by a smartphone (HTC Desire S) (Tabak, 2014).

together with the medication for that day were listed on the web portal, which could be viewed by both patients and health-care professionals.

The electronic triage diary used in the CoCo COPD trial did not undergo significant changes compared to the electronic triage diary studied in chapter 2. Both consisted of the digital version of the diary described by Effing et al. (2009) (Tabak, 2014, p. 65, 124).

5.4 Inclusion and exclusion criteria of the trial

As briefly described above, the researchers used specific inclusion and exclusion criteria to decide which patients were allowed to participate in the clinical trial (see Box 5.1 and Box 5.2).⁷⁶ These selection criteria illustrate one of the major challenges researchers face in creating test situations. According to STS researchers, tests are fundamentally problematic because of tensions that exist between creating a test that is sufficiently like the real world in which the technology will be used and, simultaneously, sufficiently like other tests in order to produce reproducible test results (Mackenzie, 1989, p. 415).

Box 5.1: Inclusion criteria for the CoCo COPD trial.

1. Clinical diagnosis of COPD defined by GOLD criteria
2. No exacerbation in the month prior to participation in the study
3. ≥ 3 exacerbations or 1 hospitalization for COPD in the two years prior to inclusion
4. Post-bronchodilator FEV₁ 25%–80% of predicted
5. (Ex) smoker
6. Age > 40 years
7. Ability to read and write the Dutch language
8. Internet access at home
9. Be able to follow treatment protocol
10. Signed informed consent of the patient to participate

Source: Research Protocol CoCo COPD (2011, p. 15).

⁷⁶ Translated from Dutch.

Box 5.2: Exclusion criteria for the CoCo COPD trial.

1. Other disease with low survival rate
2. Other diseases that may affect bronchial symptoms and/or pulmonary function (e.g. heart failure, sarcoidosis)
3. Severe psychiatric illness
4. Uncontrolled diabetes mellitus during COPD exacerbation in the past or hospitalization for diabetes mellitus in the two years prior to participation
5. Regular use of oxygen therapy (> 16 hours per day or PO₂ < 7.2 kPa)
6. Maintenance therapy with antibiotics
7. α 1-antitrypsin deficiency
8. Pathological conditions that can seriously affect activities in daily life (e.g. amputation, paresis, progressive muscle disease)
9. Impaired hand function causing inability to control application

Source: Research Protocol CoCo COPD (2011, p. 15).

Downer has described these tensions as a conflict between “representativeness” and “reproducibility” (2007). The test practices of the CoCo COPD trial are an example of these tensions. On the one hand, the trial aimed to “evaluate the use and satisfaction with a telehealth programme,” which was considered as “essential for creating a standard for future telemedicine interventions” (Tabak, 2014, p. 120, 122). As a consequence the trial required a selection of patients that was representative of the larger COPD patient population. On the other hand, the inclusion and exclusion criteria indicate that researchers in practice favored a test situation that would contribute to producing valid, reproducible test results that would meet the requirements of randomized controlled trials (RCTs).⁷⁷ Consequently, the representativeness of the selected trial participants was partly lost.

The exclusion criteria illustrate that the researchers only selected relatively healthy patients, both in terms of physical and psychological conditions. They decided to exclude patients who suffered from multiple diseases and/or a severe

⁷⁷ See also chapter 6, where the cluster manager reflected on her experiences during this controlled trial. She described how randomized controlled trials constrain the flexibility of researchers.

(COPD) condition that required the use of oxygen therapy. Since COPD is known for its co-morbidity (Schnell et al., 2012), excluding COPD patients who were diagnosed with another disease as well does not contribute to gaining insights in how the telecare system will be used in the real world, at least not by patients with multiple diseases. A closer look at the inclusion criteria exposes how the selection was not only based on disease-related criteria. The researchers also selected patients on their ability to read and write the Dutch language. Again, representativeness may be a problem here given the demographic distribution of COPD, where people with less education and lower socioeconomic background are overrepresented in the overall group of COPD patients (Prescott & Vestbo, 1999).⁷⁸ Selecting patients based on their Dutch language skills might have resulted in excluding patients who might have had problems with reading and writing this language. This criterion thus excluded analphabetic people and newcomers in the Netherlands who might have been more fluent in their native language than in Dutch.

Another selection criterion that was not related to the health condition of patients was that people who did not have Internet access or a computer at home were not included in the trial. Although dominant policy discourses seem to suggest that almost all Dutch citizens older than fifty years use computers and Internet (Duimel, 2007), COPD patients invited for this trial show another reality. Of the 101 patients that fulfilled the inclusion criteria, only twenty-nine patients agreed to participate in the trial. In the scientific publication on the trial, researchers mentioned the lack of access to computers and Internet at home as an important reason why patients did not participate in the trial (Tabak et al., 2014). This inclusion criterion not only reduced the number of trial participants but also hampered the representativeness of the trial. It is apparent that many COPD patients did not use the technologies required for using the telecare devices and applications and might not have had the required digital skills. The patients included in the trial were therefore not representative of the larger COPD population.

⁷⁸ In my interview with the lung specialist, he told me that COPD was a "typical condition for poor people – rich people have heart diseases." (Lung specialist, interview, 2010).

To be sure, my aim is not to criticize the researchers who organized this trial. Instead, my analysis shows the complexities involved in the testing of telecare devices and applications in randomized controlled trials. Creating a test situation that is representative for the target group would imply adding more complexity. However, as STS researchers have shown, there is a strong need to reduce complexity in testing to create doable test situations (Suchman, 2007; Neven, 2011, p. 135; Oudshoorn, 2003). In this respect, the use of strict inclusion and exclusion criteria can be considered as an important tool to reduce complexities. The disadvantage however is that the results of the test can only be applied to a select group of patients.

5.5 Patients' experiences with the telecare technology

"There is no such thing as the 'Dutchman'," were the words of former Princess, currently Queen, Maxima of the Netherlands, spoken in a personal speech at the presentation of a report by the Scientific Council for Government Policy (WRR) on national identity.⁷⁹ I could also use these words to describe the variety of identities of COPD patients. THE COPD patient does not exist which is vividly demonstrated by the difference in demographic backgrounds and health conditions described above. Given these different identities, we may expect that the ways in which patients respond to using a telecare technology may vary. I therefore analyze the diversity in patients' actions and perceptions. In my analysis I focus on *actions* patients performed when they become users, or maybe even non-users, of the telecare system. In addition to patients' actions I focus on how the telecare system changed patients' perceptions of their condition and their relationship with health-care professionals. Finally, I reflect on what forms of self-management can be discerned in the actions and perceptions of patients.

⁷⁹ Speech of Prinses Máxima, September 24, 2007, at the presentation of the WRR report *Identificatie met Nederland*, Den Haag (<http://www.koninklijkhuis.nl/nieuws/toespraken/2007/september/toespraak-van-prinses-maxima-24-september-2007> last accessed 19-06-2013).

5.5.1 Patients' actions regarding the telecare technology

To understand how the telecare system shaped the actions of patients, I first explore how patients reacted to the inscribed patterns of use. I analyze the extent that patients followed the programs of action (Latour, 1992). Because I focus my analysis on two different applications of the telecare system, I present my analysis for each of them: the activity monitoring and feedback application and the electronic triage diary.

The activity monitoring and feedback application

The activity monitoring and feedback application showed a varied picture in use that stretched from following the script of the equipment as best as possible on the one hand, to nonuse of the equipment on the other. This difference in use seems to be related to how much trust patients had in the correct functioning of the devices. Once patients noticed that the activity monitoring and feedback application worked in accordance with their own experience-based knowledge, they seemed to be willing to follow to the script. The activity monitoring and feedback application worked sufficiently according to four patients, while the other four mentioned they had some problems with the devices. These patients did not consider it a useful tool that could seriously help them manage their COPD. They developed different strategies like partially following the script of the application or not using it at all.

Let me first take a closer look at the patients who were content with the activity monitoring and feedback devices. The experiences as articulated during the interviews illustrate how the patients integrated the newcomer in their daily life. Most patients emphasized they used the feedback text messages as motivational cues over the representation of their activity level via graphs.⁸⁰ They only followed the advice of the text message included in the feedback message when they could fit it into their daily activities, when the circumstances allowed them to, or when they felt the time was appropriate. For instance, when patients received a message while at work, they waited for a good moment to adhere to the advice. Patient G answered the following when I asked her whether she followed the advice of the feedback text messages:

⁸⁰ Some patients mentioned they looked at an overview of their activity level on their computer at the end of the day.

If it is possible, I will do it. However, when I am at work, I cannot follow the advice. If it indicates that I have done too much and should take some rest during work, I cannot follow that advice.

(Patient G, interview, January 22, 2013)

Another patient told me that he also tried to follow the advice of the text messages of the activity monitoring and feedback application but only when it suited him:

Yes, except for one day. The weather was bad, just like this week, it was snowing and raining so I stayed at home to watch TV. Then I got a notification two times that my activity was low, but I decided to ignore it, because I did not want to walk in that weather. Otherwise, if I could, I would follow the advice.

(Patient E, interview, January 18, 2013)

Another patient again told me she and her colleague had laughs about the system giving her the advice to become more active while the weather was very warm that day:

But that thing does not know it is 35 degrees Celsius!

(Patient H, interview, January 17, 2013)

Patients who accepted the system thus tried to integrate its use into their daily routine. They followed the advice of the system as best as possible, although they still had some complaints about attaching the activity devices to their waist so that they would work correctly. One patient mentioned the activity sensor would easily drop from the case attached to his belt, for instance, when he leaned over. Another patient mentioned that when she noticed the devices did not work the way they were supposed to, she would “tinker” with them until the devices worked correctly and she could follow the script.

There are also activities that are not measured. We bike a lot, but those activities are absolutely not measured. At a certain point you notice this, you shuffle a bit with the devices and then it works.

(Patient G, interview, January 22, 2013)

As mentioned above, there were four patients who had quite some difficulties using the activity monitoring and feedback devices. Different problems seemed to have caused the selective or nonuse of the activity monitoring and feedback equipment for this group. For two patients the devices did not generate feedback at all, or at least, it was not visible to them. One patient believed the physiotherapist apparently only wanted to *monitor* the activity level of the patient, and did not want to confront her (the patient) with the automatically generated feedback. She did not understand what the devices were for, nor could she look up her activity level on the web portal. The fact that the other patient did not receive feedback at all seemed to be the result of a technical flaw of the equipment because even his physiotherapist was surprised the patient did not get feedback messages.

Yes, that is what my physiotherapist said the other day: “Have you never received a message that your activity level was too low?” I said: “Not that I know of.”

(Patient C, interview, January 31, 2013)

What these two selective users have in common is that their lung condition was quite severe. One of them had to carry oxygen to stay “active” at all during the day. The other patient could hardly walk to the front door without feeling exhausted. In other words, these patients would have a hard time following up the feedback messages, even if they did receive them.

Two other patients who had trouble with the activity monitoring and feedback application *did* receive feedback messages but had other problems. For one patient the devices generated feedback that was totally not in accordance with his own experience-based knowledge of his activity. Or as he phrased it:

I have the measuring device [the activity monitoring and feedback devices] right here, and it should measure movement, but to be honest, I do not have much faith in it. Well, I have been busy the whole day, but it still says...So I wonder whether the people that install this thing understand it themselves. The first time I got it my activity level was at 350/400 percent, now it continuously says I am too low.

(Patient A, interview, January 27, 2013)

Moreover, the script of the devices did not match with his daily life pattern. When he would walk his dog at six in the morning the devices did not register this activity because according to settings of the application, it only started measuring at eight in the morning.

What I also dislike about the device ... I start working at half past seven, and at six o'clock I walk my dog, but the thing does not start measuring until eight o'clock in the morning. I've been walking for half an hour already, but the thing doesn't register any of that.

(Patient A, interview, January 27, 2013)

To summarize, this patient experienced a discrepancy between the measured and represented data of the equipment and his own experience-based knowledge of his activity level as well as conflicting norms between the script of the devices and the patient's daily life pattern. These negative experiences made this patient lose trust in the devices, which ultimately lead to nonuse of this application of the telecare technology. The other patient who became a skeptical user of the activity monitoring and feedback application did not trust the correct workings of the devices either:

It does not work. I now have a new one, and the previous one was also new. You see that it works, but you do not see what it does, and actually it should say: "You have been active today," but you only see that message once or twice and the rest of the week you do not see it anymore. So then I call these people and they tell me they see that it works, but it does not

work for me. It does not indicate whether I am too active or not. This happened three or four times now so it does not really work well.

(Patient B, interview, , January 16, 2013)

So, this patient only got feedback once or twice. This patient also had no access to the web portal to view the measured activity level:

I do not have access to that. I don't know if I can. I do not have that. I only have that thing [the activity monitoring and feedback devices], which I return in a week.

(Patient B, interview, January 16, 2013)

Remarkably, the times that the devices *did* work correctly for this patient, it would certainly discipline his behavior. He admitted that the devices actually motivated him to alter his activity pattern:

Yes, it certainly has an effect. When you use that thing you know it will count, so if you planned to go for a walk the next day, you change your mind and go for a walk a day earlier. That is ... we all have something with measurements and numbers, that is how it is, I think. So it does stimulate.

(Patient B, interview, January 16, 2013)

In conclusion, the users of the activity monitoring and feedback application can be divided into three categories. Four patients were enthusiastic about its workings and tried to follow the script of the equipment as well as possible, although they still experienced some imperfect elements of the devices. Two patients seemed not to be able to follow the script of the devices because of their health condition. Their physiotherapist only seemed to use the equipment to monitor their activity, and maybe change it via the physiotherapy program. The equipment was thus not used to change their daily activity pattern through feedback messages. If enhancing self-management strategies of patients is one of the goals of this part of the telecare system, these patients are difficult to include in the target group of the system.

Lastly, two patients experienced too many human or technical failures with the devices and therefore did not trust the devices at all. For one of them these even lead to the strongest anti-program response: nonuse of the equipment.

The electronic triage diary

The use practices of the electronic triage diary show how most patients tried to follow the inscribed programs of action when it came to filling in the multiple-choice questions about their COPD symptoms on a daily basis. Reasons for deviating from this “daily basis” rule of the script of the application can be divided into two categories: because of practical reasons, or of reasons that indicate a mismatch between the script of the electronic triage diary and people's daily lives. Among the practical reasons, patients mentioned hospitalization because of their condition, being away from home without the possibility to fill in the electronic triage diary (because of the absence of an Internet connection) or simply sometimes forgetting to fill in the electronic triage diary on some days. The other reason why patients sometimes did not fill in the electronic triage diary was because the electronic triage diary contained a very specific script on *when* to fill it in during the day. One patient mentioned he had to fill it in before twelve o'clock in the afternoon every day or else the system would automatically switch to the next day (Patient B, interview, January 16, 2013), and some patients mentioned they could not fill in the electronic triage diary after twelve o'clock at night that day, because, according to the calendar of the electronic triage diary, a new day had started. Or to quote one of these patients:

No, I think it works until 12 o'clock at night, but I am a night owl so ... sometimes I end up late before my computer, and then I'm too late to fill it in on time.

(Patient G, interview, January 22, 2013)

This quote illustrates a clear mismatch between the script of the electronic triage diary and the patient's daily life pattern. Based on the information patients entered, the electronic triage diary generated advice on whether patients should take medication that day or not, or whether they should contact their doctor. This

advice was based on an automatically generated algorithm. Some patients mentioned that this algorithm did not apply to their condition, because the number of days the system advised them to take specific medication was simply too short (Patient A, interview, January 27, 2013), reflecting another mismatch between the script of the electronic triage diary and a patient's individual situation. The compliance to the medication advice varied per patient. Some patients mentioned they do not take medication without the advice of the electronic triage diary, even if, according to their experience-based knowledge, they should have started with a course of medication.

Q: Does it occur that you want to start taking medication, but that the system does not yet advise you to, but that you start anyway?

A: No, most certainly not. Otherwise, you should not participate in this test, I think.

(Patient D, interview, January 22, 2013)

This patient prioritized the advice of the electronic triage diary because she did not want to disrupt the clinical trial, but other patients mentioned they listened to their body and took the advice of the electronic triage diary as complimentary to their own experiences:

Sometimes I start a day earlier, or else I will not make it. Even today, the system said: "Do not continue with the prednisolone," but I did start, otherwise I would not be here.

(Patient B, interview, January 16, 2013)

Although there are differences between patients in how they reacted to the program of action inscribed in the electronic triage diary, most patients acknowledged the validity of the questions. They trusted the advice the electronic triage diary generated when it was in accordance with their own embodied experience. However, patients did mention they felt reluctant to follow the medication advice it generated, without contacting their health-care professional first.

A: "Start a course," or "Do not start a course."

Q: And do you follow that advice?

A: Yes, this week I got advice and indeed, I felt really sick and when I got the advice to start with the treatment, I called the lung specialist and he prescribed me a course [of medication].

Q: But you do not start a course yourself when you do not feel well?

A: No, not yet, so far.

(Patient E, interview, January 18, 2013)

Apparently, human contact is still essential for patients before they take a decision on how to treat their condition. However, in the electronic triage diary, or any other application of the CoCo application, there was no option to contact health-care personnel. There was no option to send an e-mail within the program, start a chat session or ask for advice on a forum. Moreover, no information about any form of contact with health-care personnel was given in the program. Some patients mentioned they had the e-mail address or cell phone number of a health-care professional "accidentally" at their disposal and would use this to work around the script of the electronic triage diary.⁸¹ Others mentioned they used the telephone number of the CoCo researchers that was distributed at the self-management course (see chapter 4), which was organized prior to using the system. Remarkably, this information was communicated verbally and on paper and was not exchanged via technical means in the application. When I asked patients whether health-care personnel ever contacted them based on the information they recorded in the electronic triage diary, the answer was unanimously negative. That is, the information flow was one-way, from patients to databases, and via databases to health-care professionals. Patients did not receive feedback via the system from their health-care professionals, only via the algorithms of the programs in the electronic triage diary.⁸² Oudshoorn uses the notion of "a-symmetrical tele-co-presence" to describe this phenomenon (2011, p. 176).

⁸¹ See Oudshoorn (2011, p. 105) on how telecare workers use the regular phone to work around the script of a telecare device.

⁸² Patients did receive feedback via the regular consults.

Adjacent to the absence of any form of communication via the CoCo application the majority of the patients mentioned they missed the ability to add information to the standardized answers they were expected to enter into the electronic triage diary. Often they thought that the overall nature of their condition or their experience with their COPD could not be sufficiently described by answering the prestructured questions in combination with the limited number of multiple-choice answers of the electronic triage diary. Patient B on his experience with the diary:

I find it very unfortunate you can't add a small remark. There are a few options for a few questions: "Do you have more or less complaints of coughing?" I sneeze quite often, but I cannot make note of that anywhere.

(Patient B, interview, January 16, 2013)

This patient mentioned he sneezes a lot when his condition gets worse, but he could not indicate this symptom in the electronic triage diary. Next to not being able to add specific details about one's COPD symptoms, in general, another patient mentioned she lacked the option to add information that might affect her condition, but does not need immediate COPD-related treatment at the moment she fills in the electronic triage diary:

The only thing I find very unfortunate is that you can't make your own remarks. It is just answering the standardized questions. You cannot ask questions via the diary itself or emphasize you think something might be a cold, which does not need immediate attention. I regret that this form of consultation is not possible.

(Patient G, interview, January 22, 2013)

Moreover, this patient also desired the ability to consult her health-care professionals *via the system* about her condition. What patients mentioned as a positive characteristic of the use of the electronic triage diary was the ability to start taking medication the minute they wanted to (either because of their own decision, or supported by the advice of the electronic triage diary). Before, when

patients felt they needed medication, they could only get this on doctor's advice. They first had to contact their health-care professional to get a prescription for their medicine. After this they had to go to the pharmacy to collect their medication. However, this only took place when patients felt an exacerbation coming on and could get access to medication on time. But it could also happen that patients were too late for this procedure and needed emergency help to get to the hospital and recover there from an exacerbation. Now, with the use of the CoCo application, patients could get prednisolone and antibiotics at their homes before they started to feel ill, and start with a course, without going through the time-consuming procedure of getting their medication. Patients felt this had a positive effect on the treatment of their condition. They would start earlier with the use of medication.

You realize that when you already have medication, and the diary says you should start, you indeed start taking them earlier, which helps to reduce complaints earlier.

(Patient G, interview, January 22, 2013)

This was not only due to the fact that they already had the medication at home, but the advice of the electronic triage diary would also give them more self-confidence in the contacts with health-care personnel, as if the advice of the electronic triage diary to start with medication was sort of a backup to their experience-based knowledge. For some patients this made the step to contact health-care personnel easier (Patient G, interview, January 22, 2013; Patient D, interview, January 22, 2013).

5.5.2 Patients' perceptions regarding the telecare technology

In the introduction of this chapter I described how technologies may not only participate in changing the actions of patients but also mediate the perceptions of their illness. As philosopher of technology Asle Kiran (2012) has suggested, technologies mediate the perceptions of the world and ourselves in two different ways. On the one hand, they reveal possibilities of how we can perceive ourselves in relation to others and the world. On the other hand, technologies may also conceal

possibilities of how we can perceive these relationships. Based on the script analysis of the telecare devices and applications (chapter 2) and the analysis of the design process (chapter 3), we may assume that the telecare technology at hand also involves this revealing-concealing dynamic.

Because the design of the system as reflected in chapter 3 favors medical knowledge and predefined physical symptoms, the telecare technology mediates a perception of illness and the self in which taking care of one's lung illness is transformed into measuring activity levels and filling out an electronic triage diary that largely excludes patients' practical embodied knowledge. Patients were disciplined to take action within a set of predefined medical guidelines. The script of the telecare system thus conceals different ways of learning to live with COPD, which would take into account a more contextualized approach to illness and self-management, including psychosocial and emotional consequences of COPD and patients' experience-based knowledge. In the analysis presented in this section, I use this revealing-concealing perspective as a background to analyze how the telecare system changed patients' perceptions of their illness, themselves and their relationship with health-care professionals.

Patients' experiences with using the activity monitoring and feedback devices clearly illustrate that these telecare devices have opened up new possibilities to cope with their disease. For some, these devices made them more aware of what they could do themselves to improve their condition. Or to quote one of the patients:

You become more aware because of CoCo: sometimes it urges you to become more active, but not too much, I don't know, there is some kind of reference now.

(Patient B, interview, January 16, 2013)

For one of the patients the use of the activity monitoring and feedback devices changed her perception of her disease and herself because it made her realize she could be more active than she thought she could be:

What has increased is that you take a little more effort now. That you don't stop once you get out of breath, but that you realize you can take a bit more. I think that's an advantage, that you know you do not have to stop because you are out of breath, you can go quite a bit further. Kind of weird to say, but you are not yet at the top.

(Patient G, interview, January 22, 2013)

She also explained she was aware of the fact that her activity was registered without clearly explaining to me what this meant to her, besides that the devices served as a big stick to stay active:

I think it's intuitive. You're not like: "I don't feel like it today." It is more that you are like: "Let's just do it, because it is better for me." It works like a big stick.

(Patient G, interview, February 22, 2013)

These quotes illustrate how the telecare system not only changed patients' perceptions of their illness but also their sense of self. The use of the activity monitoring and feedback devices enabled them to perceive themselves as active individuals who could make a difference in terms of how their condition constrained their daily life. Instead of being passive, the technology opened up the possibility of an active self that aims to find another balance between deteriorated lung capacities and an active life style.

The use practices of the electronic triage diary show equally important changes in how patients perceived themselves in relation to their disease. During the interviews almost all patients emphasized that the biggest change of using the telecare system was that they had direct access to medication and that they themselves could decide when to take them. As I described in section 5.5.1, patients sometimes started earlier with using medication than before they used the telecare system, which they experienced as positive for their health condition. The telecare system thus opened up the possibility of becoming more autonomous with respect to taking medicine.

The experiences discussed illustrate how the telecare system at hand plays an important role in revealing new ways, or supporting already existing routines, of how patients perceive their illness and their sense of self. However, the telecare system also conceals specific ways of living with COPD. During the interviews I learned that almost all patients experienced their condition much broader than can be passed on via the electronic triage diary. As I already mentioned in the section about patients' actions regarding the use of the electronic triage diary, patients missed the opportunity to add some of their own individual experiences with their condition that they thought relevant for the medication advice of the electronic triage diary. They perceived and experienced their condition as including much more than the aspects scripted in the application and they missed the opportunity to express these experiences.

That's the routine it has and the rigid questions. When I'm talking to you, I can tell more than I can express in that diary. Sometimes the nuance is often as important as the observation itself.

(Patient C, interview, January 31, 2013)

Unlike the electronic triage diary, patients did not perceive that the activity monitoring and feedback application reduced their condition into measuring their physical activity only, although one patient questioned the usability of the devices:

I regularly got a message on the "iPhone" saying I was too active. But I think you can never be too active. ... When you are, your body will tell you.

(Patient D, interview, January 22, 2013)

In addition to changing perceptions of illness and self, the telecare system also affected patients' perceptions of their relationship with health-care professionals. First, the use of the electronic triage diary supported patients to become more assertive in contacting health-care professionals. Most patients mentioned that they experienced the advice of the electronic triage diary as a sort of backup to their

own experience-based knowledge, which helped them contact health-care professionals earlier than they used to do:

Yes, yes, but that's also partly due to the diary because that also indicates that you should contact your doctor, so you are pushed to take action from that side as well.

(Patient G, interview, January 22, 2013)

However, as already described in section 5.5.1, some patients still felt reluctant to call their health-care professional, despite the advice of the electronic triage diary; they still felt shy about “bothering” their health-care professionals:

So it was not over yet, the last day or two, and it [the electronic triage diary] indicated: “Please contact your doctor” ... and then I thought, well, tomorrow it is over ... In hindsight, that might have been stupid.

(Patient D, interview, January 22, 2013)

The use of the electronic triage diary not only changed the physical contacts between patients and health-care professionals. For some patients the electronic triage diary also made it possible to experience the virtual presence of health-care professionals:

It is also a matter that you are aware that they think with you and sympathize with you, and that you are supported.

(Patient F, interview, January 24, 2013)

Although the virtual presence of health-care professionals thus opened up new possibilities for fostering the relationship between patients and health-care professionals, for one patient the telecare system made his relationship with health-care professionals less transparent. This patient, who received an activity monitoring and feedback application that did not work correctly, had the feeling that health-care professionals kept information secret for him:

No, no, you don't see that on the website, only on that thing [the smartphone]. Let me put it this way: You cannot look back. It's just what I do today, tomorrow it's gone. Then it's over and out. It's like it is kept secret. That is the feeling I have a bit.

(Patient A, interview, January 27, 2013)

Summarizing, I conclude that the telecare system mediated patients' perceptions of their illness, themselves and their relationship with health-care professionals. Although most patients were explicit in articulating how the use of the telecare devices and applications affected them, some patients also emphasized that the telecare system was not applicable to their situation. They mentioned they felt too young, too healthy or too good to use the system and that the telecare technology would probably be suitable for other patients, in other places or in other times, but not for them.⁸³ Importantly, the virtual presence of the health-care professionals as mediated by the telecare system was perceived as positive. Although patients were aware of the fact that health-care professionals could "watch over their shoulder" when they used the different devices of the telecare system, they did not perceive this as negative. They did not consider this as an invasion of their privacy or as a limitation to their freedom to deal with their condition the way they preferred.

5.6 Conclusions

In this chapter I have shown how the telecare system shapes patients' actions and mediates patients' perceptions of their disease by analyzing their use practices during a randomized controlled trial of the telecare system.

⁸³ In his thesis on representations of the elderly and aging in the design of ambient intelligent technology, Louis Neven (2011) showed that test-users often do not see themselves as a potential target group of the new technology, whilst designers think the test-users are a good representation of the potential end-user. I also observed this phenomenon in my research. Some test-users configured themselves as different from the targeted end-users and thought of themselves as being younger, fitter and less dependent on technological support for their condition.

First, the chapter delivered important insights on the constraints of organizing trials. I described how the selection criteria the researchers used for the trial reflected a conflict between “representativeness” and “reproducibility” of technological tests (Downer, 2007). Because there is strong need to reduce complexity in testing to create doable test situations (Suchman, 2007; Neven, 2011, p. 135; Oudshoorn, 2003), the patients included in the trial were not representative of the larger COPD population. Therefore the results of the test can only be applied to a selective group of patients.

Second, I described how patients' actions were shaped in dealing with the telecare system. I therefore analyzed how patients enacted the inscribed patterns of use to explore the extent to which they followed the programs of action (Latour, 1992). Although the variety of test-users was largely narrowed down by the inclusion and exclusion criteria of the trial and the number of interviewees was limited ($n = 8$), the chapter shows the many different ways in which the patients acted with and experienced the telecare system. Users made their own interpretation of the script of the technology at hand. The analysis showed that the urge to follow the script of the telecare program varied per application and per patient. Patients who received well-working activity monitoring and feedback devices interpreted the script as rather flexible instead of compulsory. Usually they followed the generated advice of the feedback messages only when it suited them. In other words, patients domesticated the devices to fit in their daily lives (Lie & Sørensen, 1996; Silverstone & Haddon, 1996). They seemed to be aware of the fact that immediate adherence to the script was not mandatory for this part of the system. However, although the script of this application was interpreted as flexible, patients did change their activity pattern. The analysis of the use practices of the electronic triage diary shows a similar interpretative flexibility of the script of this part of the telecare system. The majority of the patients followed the program of action of the application. They complied with the advice of the electronic triage diary for various reasons: It was in accordance with their experience-based knowledge, they trusted their doctor who advised it or they wanted to comply with the validity of the trial. However, other patients did not strictly follow the script of the electronic triage diary. Instead they relied more on their experience-based knowledge or preferred to deal with their disease according to their own views and

wishes. Importantly, both groups of patients were rather critical about the restricted script of the electronic triage system. Almost all of them emphasized they missed the option in the electronic triage diary to add experience-based knowledge and to communicate with health-care professionals. The fact that patients were allowed to have medication at their disposal before official approval for an eventual treatment was regarded as a positive change compared to usual care.

Third, my analysis of how the telecare system mediated patients' perceptions shows how the telecare system has changed patients' perceptions of their illness, themselves and their relationship with health-care professionals. The activity monitoring and feedback devices changed patients' perception of their physical capacities, which they often underestimated. This also enabled patients to perceive themselves as active individuals capable of changing the constraining consequences of their condition. The use practices of the electronic triage diary also changed patients' perceptions of themselves in relation to their illness. On the one hand, the telecare system enabled patients to become more autonomous regarding the taking of medication, because they were allowed to have medication at their disposal before eventual treatment was approved by their caregivers. On the other hand, patients experienced that the electronic triage diary reduced their illness to a few multiple-choice questions, while they perceived their condition to be much broader. They emphasized they missed the opportunity to express these experiences. Additionally, the telecare system also affected patients' perceptions of their relationship with health-care professionals. The use of the electronic triage diary supported some patients to become more assertive in their contacts with health-care professionals. They experienced the advice of the electronic triage diary as a sort of backup to their own experience-based knowledge, which helped them to contact health-care professionals earlier. However, other patients still felt shy about contacting their health-care professionals. In addition to changing actual contact with health-care professionals, some patients emphasized they experienced the telecare system as a virtual presence of health-care professionals.

Based on my analysis of how patients' actions were shaped by the script of the telecare system and how the telecare system mediated patients' perceptions of their illness, themselves and their relationship with health-care professionals, I conclude that there is no dominant form of self-management enacted in patients'

use practices of the telecare system. The different use practices reflect a mixture of all three forms of self-management described by Schermer (2009). The first form of self-management can be discerned when patients emphasized they followed the advice of the electronic triage diary blindly, without taking their own views and wishes on how to live with their condition into account. The second form of self-management is observed in the use practices where patients took over interpretative tasks of their health-care professionals by filling in the questions of the electronic triage diary and by using the graphs of the activity monitoring and feedback devices as motivational cues. Although the scripts of the telecare devices and applications were not designed to support the third form of self-management, the use practices of both the activity monitoring and feedback devices and the electronic triage diary reflect this form of self-management as well. Patients incorporated the use of the activity monitoring and feedback devices in their daily lives and ignored or postponed feedback advice if they were not convenient. Moreover, the activity monitoring and feedback devices enabled patients to change their perception of their physical capacities. In that sense the telecare system mediated and strengthened patients' experience-based knowledge. The third form of self-management can also be discerned in patients' usage of the electronic triage diary, particularly when they decided to deviate from the advice of the application and act according to their own preferences. Additionally, the telecare system enabled patients to gain more "executive autonomy" (Schermer, 2009, p. 689) with respect to taking medicine or contacting health-care professionals, although for the latter they needed to develop "work-arounds."

To summarize, the central aim of this chapter was to analyze how the telecare technology shaped patients' actions regarding inscribed forms of self-management of telecare technologies and their perceptions of their disease and how they related to health-care professionals. In line with ANT, I conclude that the use practices of the technology are mutually shaped by both patients and the telecare system. Most importantly, the chapter shows a broad variety in use practices in which the creativity and personal preferences of the users, their health conditions, daily life routines and the flexible interpretation of the scripts of the devices and applications resulted in different self-management practices. Remarkably, these use practices also illustrate how patients tried to deviate from

the scripts of the devices and applications, because they preferred to rely on their experience-based knowledge. This explains why telecare technologies that were not explicitly designed to support the third form of self-management nevertheless resulted in use practices that reflected this form of self-management as well. In this respect, the self-management course that patients participated in before using the devices and applications seems to have played an important role in supporting them to trust their own experience-based knowledge (see chapter 4). I therefore conclude that self-management should not be considered as an intrinsic quality of a telecare system. Which form of self-management eventually emerges is the result of a continuous interaction between each individual patient and the telecare technologies, and the ways in which patients are taught to use them.

Chapter 6. Broadening the design of telecare technologies: The CTA workshops

6.1 Introduction

In the previous chapters we have learned that there is often a gap between what designers inscribe into a technology and how users react to and/or perceive these inscriptions. Based on my script analyses⁸⁴ of the telecare technology at hand and the analysis of the design process,⁸⁵ I showed that the third form of self-management is largely absent. However, before patients started to use the system they were enrolled in an educational program in the form of a self-management course⁸⁶ where they were instructed to prioritize advice from their experience-based knowledge over the instructions of the telecare system.⁸⁷ Additionally, patients were told to contact their health-care professional if they needed advice. These are typical characteristics of the third form of self-management, self-management where the relationship between patient and health-care professional is one of concordance and cooperation (Schermer, 2009, p. 690). In the previous chapter, which was based on analysis of the actual use of the system, we also saw that patients sometimes ignored the instructions or advice of the system and acted according to their own insights on how to deal with their disease.⁸⁸ Again, this is behavior that can best be described by characteristics of the third form of self-management.

This gap I described between foreseen or inscribed use, and actual use of technologies, is not exceptional. The history of technology shows us numerous examples of a mismatch between intended use of a technology and its' actual use (Oudshoorn & Pinch, 2003). A recent example is the use the Google search engine, which initially was developed to enhance the output of relevant search results on the Internet, but nowadays, is largely used by the United States Government for

⁸⁴ See chapter 2.

⁸⁵ See chapter 3.

⁸⁶ See chapter 4.

⁸⁷ When I refer to the telecare system, I refer to the telecare technology consisting of multiple telecare applications and devices.

⁸⁸ See chapter 5.

national security reasons as well.⁸⁹ What we see is that technologies (often) don't (only) do what they are expected to do but may entail unintended consequences.

As described in chapter 1, this thesis, as part of the Telecare at Home research project is funded by the NWO research program, Responsible Innovation. The Responsible Innovation program aims "to consider the ethical and social aspects of new technology from the design phase onwards."⁹⁰ The next step would then be to feed these insights back into the design of new technologies in order to prevent "expensive adjustments having to be made in retrospect or having society rejecting the new technology."⁹¹ It is called responsible innovation because it focusses on creating awareness among stakeholders involved in the technological development trajectory about what possible impacts their design choices might have for the future. Within the field of STS, methodologies (or approaches) have been developed that address the aim of the Responsible Innovation program. One of these approaches is Constructive Technology Assessment (CTA). In this chapter I analyze whether and how the approach of CTA can be a helpful tool to bridge the gap between the inscribed forms of self-management by developers in the design of telecare technologies and the actual forms of self-management enacted in use practices of these technologies. The research question of this chapter therefore reads as follows:

How can we feedback the experiences and insights of developers and users about how telecare technologies should support self-management of patients in the development process?

The outline of this chapter is as follows. In section 6.2 I give an introduction to CTA as an approach to enhance the development and co-shaping of technology and society. I elaborate on the history of the approach and explore the use of different CTA tools for preparing and organizing the workshops developed by different STS

⁸⁹ Tiekstra, Jurgen. (10-10-2013). 3Doc: Terms and conditions may apply. Television. VPRO.

⁹⁰ <http://www.nwo.nl/en/research-and-results/research-projects/02/2300153802.html> (last accessed 13-10-2013).

⁹¹ <http://www.nwo.nl/en/research-and-results/research-projects/02/2300153802.html> (last accessed 13-10-2013).

scholars over the years. In the methods section (6.3) I give an overview of how, when and where the CTA workshops I organized took place. The chapter continues by describing the Telecare at Home workshops (6.4) by introducing the research questions (6.4.1), the setup and the used methodologies (6.4.2). Thereafter I give a detailed description of the proceedings of the actual workshops I organized (6.5) and formulate an answer to the research questions of the workshop based on analyses of the different sessions (6.6). I end by formulating an answer to the central research question of this chapter and some concluding remarks in section 6.7.

6.2 Theoretical framework: CTA as an approach for responsible innovation

As mentioned above, within the field of STS the method of CTA is developed to reflect on possible undesirable outcomes of technological developments, with the aim of feeding these insights back into the design process of technologies. In this section I give an introduction to the method of CTA, elaborate on the history of the approach and explore the use of CTA tools for preparing and organizing workshops developed by different STS scholars over the years.

6.2.1 Introduction to CTA

CTA originates from a rich tradition of technology assessment (TA) approaches that stem from the early 1960s (Smits & Leyten, 1991). Initially TA was used as a tool for governments to develop policy on how to deal with potential future negative side effects of technological development in order to control them. From the 1980s this first-generation TA evolved into a form where the emphasis shifted from *policy* interventions to *design* interventions. The central aim of this second-generation TA was “anticipating potential impacts and feeding these insights back into decision-making, and into actors’ strategies” (Schot & Rip, 1997, p. 251). This form of TA is known as Constructive Technology Assessment (CTA). Importantly, CTA also focusses on the design aspect of technology: “CTA shifts the focus away from assessing impacts of new technologies to broadening design, development, and implementation processes” (Schot & Rip, 1997, p. 251). This shift in focus on broadening design, development and implementation is what makes CTA suitable

as a tool for an approach like responsible innovation because ethical and social aspects of the new technology can be taken into account and integrated (via the feedback loops) from the beginning of the innovation process.

One of the challenges of CTA is that it is difficult to decide when to intervene in the technological development process, if possible at all. If the intervention is too early in the technological development process, one risks disturbing the potential innovative capacity of the new technology and never see it flourish. Alternatively, if the intervention is too late, the technology be too developed, where it is very hard to steer it in another direction. In STS literature this problem is known as the Collingridge dilemma (Collingridge, 1980). However, over the years, consensus has been established that an early assessment is preferable (Lucivero et al., 2011).

6.2.2 CTA Workshops

Characteristic for CTA is the inclusion of different stakeholders in the early phases of the development of new technologies. By organizing “bridging events” (Garud & Ahlstrom, 1997, p. 44) between these stakeholders, mutual learning strategies are supported in order to create a “better technology in a better society” (Schot & Rip, 1997, p. 266). These bridging events are usually created by organizing workshops to facilitate “reflexive learning” among these stakeholders.

Bottom-up vs top-down approach

Until now, CTA workshops focused on enhancing the integration of emerging science and technology in society at a macro or meso level (see e.g. Te Kulve, 2011; Parandian, 2012; Lucivero, 2012; Bitsch, 2013) by involving stakeholders such as scientists and engineers, representatives of industry, or policymakers, therefore applying a top-down approach to assessing technologies. However, studies from the field of STS have shown how important users are for technological development (Oudshoorn & Pinch, 2003; Lie and Sørensen, 1996). I therefore suggest organizing CTA workshops at the micro level by involving end-users (the so-called bottom-up approach) in the event. By end-users I not only mean medical professionals who have to work with the system, but people (or in STS terms, actors) who have experienced the use of a technology in daily life. I agree that for

some emerging technologies there are no real end-users yet, since they are in a very premature phase of development (e.g. nanotechnology). However, telecare technologies are not entirely new for society since some patients and health-care professionals already make use of them. Yet they are still in the beginning of their development process, and therefore a suitable topic for CTA workshops at the micro level. However, the preparation and execution of these workshops involves specific work of the involved CTA agent(s), as I will illustrate in the next section.

Workshop preparation

As argued above, proper preparation work by the organizing CTA agent(s) is needed for the workshops to become a success. In his thesis on CTA interventions in the world of nanotechnology, Te Kulve (2010, p. 141) articulates four specific *pre-engagement* activities that are required in order to make the intervention workshops (the actual engagement activity) a success. These are:

1. Understanding of the new technology, especially focusing on different expectations among stakeholders and potential emerging path dependencies.
2. Awareness of actors' tendency to anticipate future social embedding of new technologies.
3. Selection of relevant stakeholders for the workshops based on various characteristics of the participants related to the new technology.
4. Taking broader socio-technical developments into account by considering the role of actors that are potentially relevant for future development or implementation of the new technology.

Since these pre-engagement activities are an important prerequisite for successful CTA workshops, I also included them in the preparation of the workshops I organized for this research. I elaborate on this further in section 6.4.2, but first I

introduce various tools that have been developed to make the actual engagement activity a success.

Workshop tools

In addition to these pre-engagement activities, the *actual engagement activity* is also of crucial importance for the success of CTA. Over the years several scholars have introduced different tools to achieve reflexive learning among stakeholders in the CTA workshops.

A classical approach is to trigger discussion among stakeholders by asking *questions* about the emerging technology and then have participants react to each other's arguments. In this approach it is important for the CTA agent(s) to ask the right questions and to lead the debate by distilling differences in stakeholders' arguments in order to use these differences to (re-)activate the debate.

Another CTA tool is the use of so-called socio-technical *scenarios*, where in the form of a storyline, possible futures of the new science and technology in society are sketched (Rip & Te Kulve, 2008). In these futures various ethical and social norms that play a role in the development and implementation process of the technology are taken up in order to trigger stakeholders' ideas of these norms. All of this occurs to achieve the bigger aim of enhancing stakeholders' reflexivity.

Next to the use of questions and scenarios, I suggest that using *propositions* can also be a prolific way to trigger stakeholders to share their visions about a new technology and its potential social consequences. Like with scenarios, propositions are useful because one can use rhetoric to invite stakeholders to react, which may involve slightly provoking them by using sharply formulated propositions. This might open discussions or reveal stakeholders' opinions or views that one using "traditional" interviewing or debate techniques might not uncover. The eventual aim is to stimulate mutual learning between stakeholders.

In his research on emerging surveillance technologies in Dutch nightscapes, Timan (2013) enriched the CTA toolbox with a challenging approach. He introduced methods from design studies to achieve reflexive learning among stakeholders. Through the use of visible and tangible objects (although in the form of pictures of objects), stakeholders were more actively invited to engage in the debate concerning the new technology. I agree that this is a fruitful tool to use in

CTA workshops, especially when people with different backgrounds in terms of education, socioeconomic status and relation to the technology are involved. By this I mean that an engineer probably has a different view on technology than a medical professional, and that a medical professional's view can be very different from that of a patient. Having these actors work together on a design activity is then a profitable manner to "probe each other's worlds" (Rip & Te Kulve, 2008, p. 50).

Like Timan I argue that "things to think with" (2013, p. 199) can play a role in enhancing communication between different types of stakeholders. One can extend this method by having stakeholders explain how and why they used the objects in the design activity and ask what the reasons for their choices were. This way the analysis of the design activity works in two ways. The CTA agent can analyze the discussions among stakeholders within the design activity but also analyze the arguments they give when they explain their design choices to each other.

6.3 Methodology

In this chapter I apply CTA as a research methodology. I therefore organized two CTA workshops with different stakeholders involved in the design and development of telecare technologies for COPD patients. The first workshop took place on January 11, 2011, at the University of Twente, and the second one was on June 27, 2013, also at the University of Twente. For the first workshop I applied a so-called top-down approach by inviting stakeholders who were professionally involved in the development of a telecare technology. For the second workshop I applied a bottom-up approach by inviting, in addition to professionally involved stakeholders, end-users to the event. The two workshops had different setups and contained different forms of interaction.⁹² Data was collected by making audio recordings of the workshops and by using notes made by CTA agents during the workshops. Both the recordings and the transcriptions were stored on a secure server of the University of Twente, which could only be accessed by me.⁹³

⁹² See appendix V for the program of the first workshop and appendix VI for the program of the second workshop.

⁹³ For details about the methods used in the individual workshops, I refer to sections 6.4 and 6.5.

6.4 The Telecare at Home CTA workshops

In the foregoing sections I presented the theoretical framework for this chapter by introducing CTA as an approach for responsible innovation. I elaborated on different workshop approaches, how to prepare for a workshop and what discussion tools I used for the workshops. In this section I give an overview of how the actual Telecare at Home CTA workshops took place. I present what the research questions for the workshops were and how they were setup.

6.4.1 Research questions for the Telecare at Home CTA workshops

The two CTA workshops described in section 6.3 were aimed at answering the following three sub-questions:

- How do participants of the workshop conceptualize good care?
- What are the main differences between stakeholders on how to organize a telecare system for COPD patients in terms of self-management, and how can we understand these?
- What are the major differences in insights gained from CTA workshops using different tools:
 - i) working with questions, scenarios, propositions and design research methods
 - ii) working with only professionals vs working with professionals and patients

The first and the second questions will be answered by analyzing stakeholders' arguments and interactions used during participation in the four CTA activities I introduced in the previous section, namely, the use of questions, scenarios, propositions and the design assignment. I will answer the third question by comparing the different research methods and approaches I used for the workshops.

6.4.2 Setup of the Telecare at Home CTA workshops

The first workshop

In the first workshop I applied the top-down CTA approach. The stakeholders that were invited for the first workshop included technical engineers, researchers, project leaders of the research and development institute, as well as project members of the local hospital, including a nurse practitioner, a lung specialist and two epidemiologists. Unfortunately, only the research coordinator of MST, the electrical/biomedical engineer, the biomedical technology engineer and the nurse practitioner could attend the first workshop. The CTA agents at the workshop were professor of Technology Dynamics and Health Care, Nelly Oudshoorn (UT) (referred to as the second CTA agent) and the author of this thesis (referred to as the first CTA agent).

Pre-engagement activities for the first workshop

As already noted in section 6.2.2, in order to have a successful CTA workshop it is important to meet the pre-engagement requirements as described by Te Kulve (2010). In my case these pre-engagement activities were:

- Reviewing literature of the emerging science and technology, in my case of emerging telecare applications, especially those aimed at COPD treatment.
- Studying websites, the COPDdotCOM research protocol, received notes on the project from different stakeholders and other relevant literature.
- Visiting relevant conferences.⁹⁴
- Conducting semi-structured interviews with all of the invited stakeholders prior to the workshop. As an extra pre-engagement activity, all stakeholders received a map containing the program of the workshop, the scenarios and the propositions (see appendix V).
- Locating the relevant stakeholders for the project was achieved through “snowball sampling.” At each of the interviews stakeholders were asked if they knew other people that played a role in the development of the

⁹⁴ E.g. EFORTT conference on aging with technologies, Barcelona, September 2010; Conference on the Establishment of Centre for Care Technology, Eindhoven, October 2010.

telecare technology. In the end twelve participants were selected for the workshop.

- Considering broader developments that might become relevant for the emerging technology in the development of the methods used during the workshop (i.e. in scenarios and debates).

Program of the first workshop

The first workshop consisted of three sessions. In the first session participants were asked to react to questions on what the telecare system should (not) bring about for COPD patients. In the second session three scenarios were presented. The scenarios varied in terms of autonomy patients would have when using a COPD telecare application. The scenarios were based on the distinction of three dominant forms of self-management present in contemporary telecare technologies, as described by Schermer (2009). In the last session of the workshop participants were asked what dominant form(s) of self-management were underlying the telecare application and what design decisions were based on these forms. The complete program of the first workshop, including a detailed description of the scenarios, can be found in appendix V.

The second workshop

In the second workshop I applied the bottom-up CTA approach. While at the first workshop only professionals that were involved in the development of the telecare technology were invited, at the second workshop end-users in the form of patients were also invited. The patients that were invited were all diagnosed with COPD. They had used the telecare system as part of a randomized controlled trial (see chapter 5). In addition to patients, professionals involved in the development of CoCo were invited as well. These were the same people that were invited for the first workshop, minus the research engineer,⁹⁵ and also two physiotherapists who participated in the Coco trial.

The eventual participants of the second workshop were the daily supervisor, the electrical/biomedical engineer, the human media interaction engineer, the biomedical technology engineer, the software engineer, the nurse

⁹⁵ The research engineer was no longer involved in the project.

practitioner, a physiotherapist and two patients (Patient A and Patient G).⁹⁶ The CTA agents at the workshop were professor Nelly Oudshoorn (UT) (referred to as the second CTA agent), Dr. T. Timan (UT) (referred to as the third CTA agent) and the author of this thesis (referred to as the first CTA agent).

Pre-engagement activities for the second workshop

For this workshop I could largely depend on my pre-engagement activities executed for my first workshop. However, additional preparation for this workshop included the following:

- Conducting semi-structured interviews with the invited patients and two physiotherapists prior to the workshop. Selecting patients was done by contacting the researchers of RRD who were in charge of the CoCo trial at MST. They asked patients of the trial if they would like to participate in the interviews. Approval for the interviews was granted by the medical ethics committee of the MST hospital. During the interviews I asked patients whether they would be interested in participating in the CTA workshop. In the end eight patients were selected for the workshop.
- Keeping up-to-date with current developments in literature on emerging telecare applications, especially those aimed at COPD treatment.
- Studying websites, CoCo research protocol, received notes on the project from different stakeholders and other relevant literature.
- Visiting relevant conferences.⁹⁷
- Considering broader developments that might become relevant for the emerging technology in the development of the methods used during the workshop (i.e. the design activity and propositions).

⁹⁶ Four patients had agreed to come to the workshop. For various reasons two patients did not show up.

⁹⁷ E.g. Congress COPD Chain care, Utrecht 2011; Congress Society for Philosophy and Medicine, Leiden 2012; Symposium "Ambulatory monitoring and feedback at daily physical activity," Saxion Enschede 2013.

Program of the second workshop

As with the first workshop, the second workshop also consisted of three sessions. In the first session patients, and after that the other participants, were asked to react to seven propositions concerning a telecare device. The propositions were developed based on findings collected during the pre-engagement activities with the patients. Through the interviews patients mentioned several pressing issues related to the telecare device they had used. The findings were combined with opinions on forms of self-management as discussed in the first workshop. Recurring issues included in the propositions were whether patients based decisions on how to deal with their disease on knowledge of their own body or on knowledge based on automatically generated advice of the telecare application. Furthermore, propositions were about how rigid the script of a telecare system should be and whether patients wished to share information other than pure medical knowledge (like psychological, social or circumstantial experiences and insights) via the telecare system with their health-care professionals and/or maybe other patients.

In the second session participants were asked to design a telecare application for COPD patients that would facilitate “good care” for patients. I will explain the assignment in detail in section 6.5.4. In the third session each group had to give a short presentation of the result of their assignment for the other groups. After the short presentation the groups were asked what principle was used for their “telecare system.” The different groups could ask questions about each other’s design choices. In this way mutual learning could occur among the different stakeholders. The complete program of the second workshop, including a detailed description of the scenarios, can be found in appendix VI.

6.5 Assessing telecare technologies

In this section I present an analysis of the interactions between the participants of the two workshops. What did they think a telecare application should (not) do for COPD patients? And how did they see these functions in light of enhancing patient autonomy? These questions will be answered by analyzing stakeholders’ arguments and interactions used during participation in the four CTA activities I introduced in the previous section, namely, the use of questions, scenarios, propositions and the design assignment. I used questions and scenarios in the first CTA workshop,

where only professional stakeholders were present. The use of propositions and the design assignment originate from the second workshop where professional stakeholders *and* patients participated. After analyzing each of the four activities separately, I will bring my findings together to answer the research questions of this chapter.

6.5.1 What telecare technologies should and should not do

As mentioned earlier in this chapter I used questions about the technology at hand to trigger discussion among stakeholders on their opinion of care through a telecare system for COPD patients.

The first question I presented to the participants of the first CTA workshop was what the telecare system should offer COPD patients. This question triggered a lively debate among the participants in which they expressed their views on telecare technologies. According to the nurse practitioner, by using the system patients should become more reflexive and should also receive more confirmation regarding their actions. The technology should be supportive of making the right decisions. She also mentioned the monitoring aspect of the technology, namely, that patients could be monitored from a distance to check whether they were doing okay. In contrast to the nurse practitioner, the other participants of the workshop predominantly focused on what the activity monitoring application should bring about for patients using the telecare system. They agreed that by using the activity monitoring and feedback application, patients should become more aware of their activity levels during the day. Referring to how people in general listen to their body when it comes to how active they are, or can be during the day, they emphasized that for COPD patients it is important to spread their energy over the entire day instead of being active during a specific part of the day. Using the activity monitoring application (i.e. a technological intervention) could help them to achieve this goal. Patients would be enabled to receive the relevant knowledge about their activity pattern, become aware of it, and get the opportunity to change it. The nurse practitioner added that face-to-face consults in the hospital could also bring about change in activity behavior of patients, but that the activity monitoring application could deliver feedback more often and more regularly.

In a consultation you can discuss with people what they have done during a day, or you can have people keep a diary of their activities, but the advantage of a device is that it can generate feedback directly.

(Nurse practitioner, first CTA workshop, January 11, 2011)

The research coordinator emphasized another aim of the application: it could function as a tool to collect information on the patients' activity, which then could be used by specialists to adapt their treatment program. The information could then also be shared with other specialists using the system.

Reflecting on this discussion, I conclude that it focused predominantly on how the activity monitoring and feedback devices could make patients aware of their imbalanced activity level during the day, which would enable them to change their behavior. Creating awareness was thus considered as the kind of care the telecare system should provide to patients. However, the nurse practitioner also mentioned the possibility of the telecare system to monitor patients and to intervene when things go wrong. In contrast, the research coordinator stressed the importance of gathering information about the patient's condition and sharing treatment information among health-care professionals through the system in order to fine tune a patient's treatment. She, thus, considered disease management by health-care professionals as a major contribution of the telecare system. Most importantly, all stakeholders adopted a medical point of view in reflecting on what the telecare system should bring about for patients.

The second question I presented to the participants to stimulate further discussion regarded what the telecare system should not bring about for COPD patients. All participants agreed that the advice of the electronic diary should be just that, advice. Patients should not follow the automatically generated advice blindly. Their own bodily experiences should be their guidance in the end. Patients should not delegate the responsibility for their treatment completely to the telecare system. This concerned both the advice of the electronic diary and the feedback message of the activity monitoring application. According to the stakeholders, these parts of the telecare system should not be considered as technologies that determine patients' actions completely but as tools that guide their action. The

research coordinator also referred to her experiences during a previous trial with a telecare technology in which she observed that patients were inclined to follow the advice of the system too strictly. Therefore, they decided to include information on how to contact health-care professionals in the electronic diary. Patients needed instructions on how to use the system. The electrical/biomedical engineer emphasized that the same was applicable for the activity monitoring feedback advice. It should be regarded as an *advice* and not as a *command*. The research coordinator added she would not suggest this system to every patient, because history had shown that some people simply are not able or willing to work with technological devices.

When I see how some patients deal with their medications, I would certainly not let them treat themselves. There is certainly a difference in which patients you can, or cannot, hand this over to. You should have a good look at this.

(Research coordinator at MST, first CTA workshop, January 11, 2011)

Summarizing, this part of the discussion during the workshop shows that all participants agreed that the system should definitely not overrule patients' own judgment about the treatment of their illness. The generated advice should be complementary to patients' own perception and experiences. This view largely reflects the third form of self-management, namely that patients are enabled and stimulated to find their own way of living with their condition. The generated advice should be used for enhancing relevant knowledge, but patients should be able to make their own decisions and choices.

6.5.2 The degree of autonomy of patients

The scenarios I presented to the participants of the first workshop also triggered lively debates. As mentioned before, the scenarios varied on the degree of autonomy patients would have when using a virtual COPD telecare application. In this section I present the participants' reactions to the scenarios and my analysis of the underlying arguments.

The first scenario

To open the discussion I asked the participants what kind of care for COPD patients would be desirable. Why should they receive a specific kind of care or why not and what are the advantages and/or disadvantages? Do they approve or disapprove with the self-management model presented in the scenario? In my analysis I tried to look for the arguments underlying the participants' reactions.

Box 6.1: The first scenario about a telecare system for COPD.

SCENARIO 1: MANDATORY SELF-MANAGEMENT (COMPULSORY COMPLIANCE)

Patients take over a number of practical tasks of their caregiver. They become an "extension" of their caregiver and have no personal responsibility for their care: surveillance by automated devices.

Herman is a 54-year-old truck driver who has been an inveterate smoker since he was fourteen. As a result, he suffers from severe chronic COPD and has been forced to give up his job. The doctor at the hospital proposed for him a remote treatment using telecare equipment to keep Herman's condition under surveillance for 24 hours a day. Through a simple procedure a chip was implanted in his arm that can measure his blood values and activity level every 5 minutes. This treatment was necessary because it has been found that Herman does not realize that his unhealthy lifestyle is the cause of the disease. His wife was also asked to keep an eye on this. With the help of special software on his phone, Herman can now see his own values with a delay of one minute. In his house, equipment was installed to read out the sensor 24/7. When Herman leaves the house his data are sent to the hospital using the wireless telephone network. A computer in the hospital keeps an eye on Herman's activity level. The doctor and nurse at the hospital, as well as his physical therapist and his general practitioner have access to his file. If the computer detects that Herman's data exceeds a preset level, Herman and his caregivers receive a message saying that he needs to adjust his activity level or that he has to take medicine. Using specially developed equipment it is verified that Herman indeed has taken the pills (i.e. he has taken them out of the pillbox). If it turns out he did not, Herman is called within 12 hours by a nurse asking him why he did not take his pills. If there are signs of a serious deviation in Herman's blood levels, indicating an upcoming exacerbation, a computer at the hospital automatically calls in an emergency service. An ambulance is sent to the place where Herman is located since the chip is equipped with GPS functionality. His doctor and a close family member would also receive a text message were Herman hospitalized. The most important part of his treatment is for him to stop smoking. If he smokes, this is immediately measured by the sensor on the basis of his blood values. There is a direct signal to the computer in the hospital where his file is stored. Furthermore, his doctor, his nurse, his general practitioner and a close family member receive a text message that Herman has smoked. This is to help him stop smoking. If it turns out Herman cannot keep his hands off cigarettes within a month, Herman's treatment is stopped automatically. The health insurance company receives a message that Herman does not cooperate with the treatment of his disease, and therefore the allowance for this would stop. The allowance for the special physical therapy that Herman had would also be stopped.

The discussion on the first scenario (Box 6.1) was opened by the nurse practitioner. Punishing patients for “unhealthy activities” (e.g. smoking) in order to achieve a change in behavior would not work, according to her:

I really want to start by saying that change of behavior of patients cannot be achieved by punishing wrong behavior.

(Nurse practitioner, first CTA workshop, January 11, 2011)

Although she considered monitoring patients as important to create feelings of safety and to prevent crisis situations, the use of an implantable chip for this purpose was inappropriate, she argued:

...dogs wear chips...

(Nurse practitioner, first CTA workshop, January 11, 2011)

She was disappointed that patient autonomy was absent in this scenario. The research coordinator focused on how much burden this scenario would entail for caregivers (e.g. the nurse practitioner having to call patients when medicine is not taken or the alarm service sending ambulances when things are wrong). In response to the research coordinator, the electrical/biomedical engineer tried to ease her worry by emphasizing that the activity monitoring application of the telecare system (his role on the project) was not meant as an alarm service. COPD is not the kind of disease, like heart failure or epilepsy, that calls for acute intervention by medical professionals; an argument on which the nurse practitioner and the research coordinator agreed. The electrical/biomedical engineer did see potential in the monitoring aspect of the scenario that caregivers could check on how their patients were doing on their activities or medication compliance. However, he did not think the consequences of unhealthy behavior should be as tough as the scenario sketched. Patients’ autonomy would be restricted so much that the telecare service would work reversed, he argued.

The biomedical technology engineer mentioned that the only positive element of the first scenario was the amount of information available on the patient in this situation. She disapproved of the fact that there was no

responsibility for the patient in this scenario and that creating awareness should be the idea of a telecare system. She argued that changing patient behavior was impossible if everything was determined beforehand by a technological system. The nurse practitioner added that in this scenario only “hard” patient data was monitored. According to her, COPD was about more than just hard data, like feelings of wellbeing for instance. The research coordinator agreed that COPD was more about the symptoms of patients than factors like blood levels. COPD symptoms could not be measured easily because they varied per person and were experienced differently by each person. Therefore, before using the telecare system patients should decide for themselves what feelings are normal for them. This should then be the reference when filling out questions about their health. She did not know how to translate these feelings into hard numbers, which is what the scenario suggested doing.

Reflecting on the discussion about the first scenario, we see an important difference in perspective adopted by the different stakeholders. The research coordinator adopted the perspective of the health-care organization. Both engineers welcomed the ability of the system in this scenario to gather much information on the patient but rejected the absence of patients’ own responsibility for their condition. Thus, they emphasize the role of the telecare system as a means to collect data and execute disease management. However, this should not interfere negatively with patients’ agency to remain responsible for the treatment of their disease. All things considered, the stakeholders identified more negative than positive aspects in this scenario, particularly the restricted autonomy of patients.

The second scenario

Compared to the first scenario, the second scenario (Box 6.2) triggered more positive reactions. According to the biomedical technology engineer this scenario was much better than the first because it focused on creating insight about the disease and supporting awareness among patients. Moreover, in this scenario the feedback messages were “neutral,” so patients were not “punished” for their bad behavior. However, she disapproved of the limited role of health-care professionals, because regular guidance in the form of motivation, confirmation and explanation by professionals was important, according to her. The nurse

practitioner mentioned the danger in this scenario to give too much trust to devices, because there could be something going on that the devices would not detect. The biomedical technology engineer argued for a significant role for health-care professionals when implementing a telecare system. The research coordinator largely agreed with them by emphasizing that telemedicine should not replace professionals but should be an addition to existing care. She and the nurse practitioner also agreed that patients should be allowed to have a certain degree of freedom.

Box 6.2: The second scenario about a telecare system for COPD.

SCENARIO 2: AUTONOMOUS SELF-MANAGEMENT

Patients learn to manage their illness autonomously, including monitoring and interpreting measurements and making decisions about their care (“proto-professionalization,” De Swaan, 1990).

Peter is a 54-year-old painter who has been told recently he has COPD. This is probably not due to excessive smoking, because he was a moderate smoker, but from working for years with harmful solvents in paints. Attention to these adverse effects came in the 1990s, but by then it was too late for Peter. Recently, Peter received an activity meter for the treatment of COPD from his lung specialist that he must wear five days a week and which communicates with his cell phone. On the phone, he can easily see whether he should take a rest or just go for a walk. He also received a computer to keep an electronic diary on a daily basis, which can generate advice about his condition. Peter understands the measured data and can also act according to it, for example, by adjusting his food or exercising. Peter follows any medical directive and any advice and thus, in a practical sense, becomes less dependent on his caregivers. Thanks to the equipment compliance is enhanced, and Peter can live a longer “healthy” life.

The electrical/biomedical engineer emphasized that the use of the activity monitoring application should help patients learn how to spread their activity over the day. He argued that patients, not health-care personnel, should be responsible for their wellbeing. During the discussion the question emerged whether all patients would be able to manage their disease. The nurse practitioner emphasized that proactive patients were perfectly capable of self-managing their COPD. The research coordinator agreed and added that through plain conversations with patients she could rather easily assess whether they would be capable of self-management of their COPD. She said that she would not have patients try something new, who seemed unable to comply with a medication protocol:

I'm not going to send these patients home with something new that I do not know of whether they abide to it, whether they are compliant with the protocols. You can anticipate that, a kind of compliance with a protocol that you think they have to follow.

(Research coordinator at MST, first CTA workshop, January 11, 2011)

The nurse practitioner shared her experience that during a medical trial some patients surprised her by being able to follow triage diary instructions.⁹⁸ Based on this experience, she concluded that it was worthwhile to give people a chance in similar cases.

It is certainly worthwhile to give people the chance, let me put it this way.

(Nurse practitioner, first CTA workshop, January 11, 2011)

When I asked the nurse practitioner whether she advised patients (in the self-management courses) to follow medication advice based on medical arguments, she responded that psychological, social and emotional aspects were also important in this regard. The second CTA agent participated in the discussion by asking how strict the medication advice should be. There was consensus among the participants that it was not about whether patients did or did not follow the advice strictly. They argued that the activity devices were meant to create *awareness* about their activity, and that education about how to use the devices was therefore very important. At this point in the discussion, for the first time, the distinction was made between the advice of the activity monitoring and feedback devices and the electronic triage diary. There was consensus among the stakeholders that it was unnecessary for professionals to be involved in the management of patients' activity levels all the time. However, when it concerned medication (advice), a telecare system should always involve professional guidance.

Summarizing, I conclude that the stakeholders considered the second scenario more acceptable than the first one. Stakeholders particularly embraced the foreseen role of the (activity monitoring and feedback) devices, namely to

⁹⁸ The medical trial was part of the COPE II study. In this trial COPD patients were trained in self-treatment of exacerbations with the help of a symptom diary (Effing et al., 2009).

create awareness among patients of their behavior. In this scenario, patients were more responsible for their wellbeing than in the first one, which was considered as a positive aspect. The participants agreed that the degree of autonomy that could be delegated, with respect to medication, depends on individual patient characteristics in relation to their condition.

The third scenario

All stakeholders emphasized that the third scenario (Box 6.3) conflicted with the intended use of the telecare system they were developing.

Box 6.3: The third scenario about a telecare system for COPD.

SCENARIO 3: SELF-MANAGEMENT BASED ON COOPERATION

Patients are encouraged to collaborate with their caregivers, in which their own knowledge and experiences with their illness is equally important to the medical knowledge of caregivers.

Petra is a 68-year-old widow and lives off her state pension and a small retirement income. Since she was 18 she has smoked two packs of cigarettes a day and suffers from severe COPD as a result. The doctor at the hospital has proposed remote treatment using telecare equipment. The activity level of her muscles is measured by a pedometer, which fits in her back pocket. Furthermore, she has to fill in an electronic diary once a week. If she wants, Petra can look at the screen of the electronic diary to check how her recent activity level has been and decide if she wants to change this. The data are only for own use. Furthermore, she may choose to see if there is advice to use certain medication, if she feels a bit worse and has noted this in the diary. Petra is not obliged to always wear the pedometer, but may do so if she wants. She can also use the electronic diary as she wants. She believes that she herself feels best when something is going on. If she wants she can bring along a printout of her activity level to her physiotherapist or doctor for further advice or exercises. If she has an exacerbation or feels one is coming on, she calls her doctor who then sends her to the hospital. Additionally, Petra visits the hospital twice a year to determine her condition and to discuss this with her doctor or nurse practitioner. Finally, she knows that when she is not doing well, she can always call her doctor, who can refer her to the hospital if necessary.

The discussion began with how the telecare system would not work if it was used as described in this scenario. The algorithms as developed for the COPDdotCOM system (both for the activity monitoring and feedback application and for the electronic triage diary) were based on a more or less continuous stream of data over a certain period of time. Therefore it should be used in the prescribed manner and not depend on patients' own preferences. The biomedical technology engineer

remarked that in case of selective use, patients' conditions would not be verifiable for professionals.

I think it is not binding for the patient. There is no need for them to do something, which may lead to a situation where they don't do anything at all. Then it is no longer verifiable for the professional anymore.

(Biomedical technology engineer at RRD, first CTA workshop, January 11, 2011)

The research coordinator added she would not give patients medication if she did not know what they would do with it. When the first CTA agent asked whether it would be possible to think of a telecare system where medical and nonmedical arguments about care could be treated equally, the nurse practitioner answered this would be possible, but not without the consequences of "unhealthy" behavior, from a medical point of view.⁹⁹

Reflecting on the discussion of the third scenario, I conclude that all stakeholders emphasized that the telecare system would not contribute to what they considered as "good care" from a medical point of view because of the degree of freedom patients had in its use.

6.5.3 Patients' use of telecare technologies

In addition to the use of questions and scenarios about the COPD telecare system, I used propositions to trigger discussion among stakeholders on their understanding of the use practices and preferences of COPD patients. I used this approach in my second workshop, where both professionals and patients who had used the telecare system were invited to participate. In order to let them speak openly (i.e. not influenced by professionals' opinions) about their experiences, all seven propositions were first addressed to the patients. Afterwards the floor was open for reactions from professionals as well. My analysis will also be presented in that order. The propositions I used are depicted in Box 6.4.

⁹⁹ E.g. refusal to take certain medication can be justified from a patient's perspective, but might not be the most optimal choice from a medical point of view.

The first two propositions are about how patients (should) interpret the advice generated by the activity monitoring and feedback devices and the electronic triage diary. Do patients prioritize the advice of the system over their own bodily feelings? Or do they think of themselves as the more suitable person to know what is best for them? The third, fourth and fifth propositions are about the possibility to share information and/or communicate (for different purposes) with professionals via the web portal. Proposition six is about the degree of freedom patients (should) have to follow the rules on the frequency of use of the system. The seventh, and last, proposition entails the opportunity to share experiences with other users of the system.

Box 6.4: Propositions about a telecare system for patients with COPD.

Propositions

- 1) I always follow the medication advice of the electronic diary and the advice of the activity devices, because my doctor knows what is best for me.
- 2) I do not always follow the medication advice of the electronic diary and the advice of the activity devices, because I know my own body best.
- 3) I would like to have the opportunity to ask for support via the web portal when deciding on medication or my activity level. Also, I would like to do so outside office hours.
- 4) I would like to have the opportunity to add some of my own experience-based knowledge about my lung disease to the electronic diary.
- 5) I would like more opportunities for emotional or psychological support via the web portal.
- 6) I want to decide how often I fill in the diary and use the activity devices.
- 7) I would like to share my experiences with my lung condition with other users of the system.

In their reactions, both patients mentioned the second proposition reflected their opinion best with regard to the electronic diary. They both argued the advice of the electronic diary did not always correspond to their bodily feelings. For example, for one patient his body sometimes “advised” him to take medication, while the diary did not generate this advice (yet). For the other patient the diary sometimes advised her to take medication while she felt her condition was already

improving. She then called her health-care professional and did not follow the advice of the diary blindly. Both patients disagreed on the functioning of the activity monitoring and feedback devices. It turned out this related to trust in the correct workings of the device. One patient did not trust the devices at all. It did not reflect his bodily feelings correctly, which lead to ignoring the generated advice and eventual nonuse of the application. The other patient commented that the devices helped her spread her activity behavior more evenly over the day. She did trust the working of the devices and they reflected her bodily feeling correctly.

Both patients reacted approvingly to the third proposition. One of them mentioned that the web portal of the telecare system did not contain information on whom to call for advice on health-related or other matters. The portal did not provide contact information of any kind at all. Although he did have the phone number of his doctor, this did not mean he could call him outside office hours. There lacked information in the system to contact professionals to discuss his condition. Furthermore, he mentioned he also expected the opportunity to receive feedback from professionals on his situation while using the system.

Now you have to indicate yourself when something is wrong; that is not how I see care, to be honest.

(Patient A, second CTA workshop, June 27, 2013)

The other patient added she missed the possibility to add extra information to the system, like an explanation for her condition. She disapproved of the use of multiple-choice questions to give voice to her condition and indicated she wanted the opportunity to communicate with professionals, especially when “usual” contact with her regular health-care professionals was not possible, like on the weekends.

Professional emotional support could be an added value to the telecare system, both patients argued, especially when patients’ conditions deteriorate. However, they added this should not take place via the telecare application but more in the form of face-to-face contact. However they would like the opportunity to communicate their call for help via the system. Remarkably, in their reaction to proposition six, both patients mentioned they did not know whether or how often

the diary was being reviewed by professionals. They had not received information about this. They both agreed that knowledge on this was crucial for them to decide how often to fill in the diary or use the activity devices. Apparently they expected that their situation would be monitored continuously or at least regularly by their professionals and not (only) by computer systems. Both patients reacted positively to the seventh proposition to include some kind of exchange of information between patients on how to deal with certain disease-related matters. One of them stressed the telecare system could offer a place for this, to avoid an open forum on the Internet where a lot of the posted information could concern “nonsense.”

After listening to patients’ reactions to the propositions the first CTA agent asked the professionals to give their reactions. The health-care professionals agreed on the fact that patients who were considered less capable of assessing their health condition might benefit from a telecare system, but that such a system would be unnecessary for patients who did have a good perception of their health status. The last group would be capable to manage their condition quite well already.

Another point of discussion was whether the aim of telecare to reduce health-care costs could be in conflict with extending the telecare system to support patients sharing individual experiences of living with their disease. The physiotherapist mentioned the telecare system should be accommodating to health-care professionals and not lead to an increase in work pressure. He opted for using warning signals, like flags, as a solution for health-care professionals to trace patients in trouble. The nurse practitioner added it should be the patients who should ring the alarm bell and inform professionals if they experienced problems. The idea to add a forum for “tips and tricks” to the telecare system for COPD was embraced by both patients and professionals.

Reflecting on the discussion to the propositions, I conclude that the patients reject following the instructions of the telecare system blindly, because their bodily feelings do not always correspond to the generated advice. When in doubt they prefer to call a health-care professional. This behavior reflects the third form of self-management, where the relationship between professional and patient is based on collaboration or concordance (Schermer, 2009, p. 690). Trust in the correct workings of the devices and applications seem to be crucial for how patients

use the telecare system. When telecare technologies work in accordance with patients' bodily experiences, they trust its workings and are willing to domesticate the devices in such a way that they become adjusted to patients' daily routines. However, when the devices do not resemble patients' bodily experience, patients distrust their working, which eventually leads to nonuse of the devices.

A reoccurring theme in the discussion on the telecare system was the lack of options to communicate with health-care professionals through the system. Moreover, patients experienced a lack of feedback by professionals and seemed to have expected that the data they (whether or not automatically) share via the system was regularly monitored by their professionals. For them, this was (extra) motivation to keep using the system regularly. These remarks can be interpreted as a wish for more self-management of the third form to be incorporated in the telecare system. However, health-care professionals stressed that a telecare system should not lead to more work for them. Consequently, they delegated the responsibility for arranging communication between patients and health-care professionals and giving feedback on patients' conditions to the telecare system and/or patients. Equally important, they emphasized that not all patients will benefit from using the telecare system. They argued that patients, who know their body well, can manage their disease on their own, already.

6.5.4 The design of telecare technologies

Up to this point I have presented the results of the text-based methodologies used during the workshop to stimulate discussions among stakeholders. I will now turn to the design assignment that was part of the second workshop. Prior to the workshop, a poster (see Figure 6.1) was printed containing nine rows and six columns. The headings of the columns were as follows (translated from Dutch):

1. Device to be included in the system.
2. How often should patients use it?
3. Share data automatically with caregiver?
4. How often should caregivers check the data?
5. What action should be taken?
6. How important is this part? Why?

I also printed pictures of (devices often included in) contemporary telecare systems. Pictures were selected based on information patients gave me during the interviews about their views and wishes for a helpful telecare system. To examine whether workshop participants experienced already existing parts of the CoCo application useful, I also selected pictures of these. Finally, I selected pictures of parts that I thought could be relevant for a COPD telecare system in the future. For an overview of the parts participants could choose from see Table 6.1 and Table 6.2. In addition to the pictures of (devices of) contemporary telecare systems, I made colored cards on which choices were depicted relating to the questions in the headings of the columns two to five (Figure 6.1). For an overview of what cards stakeholders could select during the design assignment, see Figure 6.2, Figure 6.3, Figure 6.4 and Figure 6.5.

To answer column six of Figure 6.1 I handed out Post-it notes on which participants could write down their own notes. For the assignment three groups were put together out of the participants of the workshop. The first group consisted of two COPD patients who had used the CoCo telecare system plus the nurse practitioner. I will call this group the “patients/nurse” group. The second group consisted of three professionals who had been closely involved in developing the CoCo application. These were the cluster manager Technology Assisted Pain Rehabilitation at RRD and professor in Technology Supported Cognitive Training at the UT,¹⁰⁰ the biomedical technology engineer and the physiotherapist. The biomedical technology engineer was also the principal investigator of the CoCo trial. The physiotherapist had actively contributed to the CoCo research proposal and was one of the cooperating physiotherapists in the CoCo trial. I will refer to this second group as the “research professionals” group. The third group consisted of engineers working for RRD who were also involved in the CoCo project, namely the electrical/biomedical engineer, the human media interaction engineer and the software engineer. I will call this group the “engineers” group

¹⁰⁰ In chapter 3 I referred to her as daily project supervisor because of her role in the COPDdotCOM project. For this workshop I will refer to her as cluster manager at RRD.

Figure 6.1: Poster for the design assignment of the second CTA workshop.

Onderdeel	Hoe vaak moet de patiënt het gebruiken?	Gegevens automatisch delen met zorgverlener?	Hoe vaak controle van gegevens door zorgverlener?	Welke actie moet worden ondernomen?	Hoe belangrijk is dit onderdeel? Waarom?

Table 6.1: Parts 1–10 of a telecare system for the design assignment of the second CTA workshop.¹⁰¹

<p>Heart rate meter</p>	<p>CoCo physiotherapy exercise module</p>
<p>Blood pressure meter</p>	<p>Implantable lab on a chip</p>
<p>COPD patient forum</p>	<p>Analog diary</p>
<p>Mobile ECG telemonitoring device</p>	<p>Telephone</p>
<p>Online diary</p>	<p>Spirometer (lung function)</p>

¹⁰¹ For the sources of the pictures: see references.

Table 6.2: Parts 11–20 of a telecare system for the design assignment of the second CTA workshop.¹⁰²

<p>Urine meter</p>	<p>Website for psychological support</p>
<p>Camera</p>	<p>Smoke detector</p>
<p>Motion detector</p>	<p>CoCo activity monitoring and feedback device</p>
<p>CoCo electronic triage diary</p>	<p>Pulse oximeter (oxygen saturation)</p>
<p>Medication adherence device</p>	<p>Digital weighing scale</p>

¹⁰² For the sources of the pictures: see references.

Figure 6.2: Overview of cards to be used in column two.

How often should patients use it?	
Original text	English translation
24 uur per dag	24 hours a day
alleen overdag	during daytime only
anders, nl:	other:
elke dag	every day
elke maand	every month
elke week	every week
elke werkdag	every working day
n.v.t.	not applicable
patient bepaalt zelf wanneer	patient decides when
tijdens regulier consult	during regular consult

Figure 6.3: Overview of cards to be used in column three.

Share data automatically with caregiver?	
Original text	English translation
ja, want:	yes, because:
nee, want:	no, because:

Figure 6.4: Overview of cards to be used in column four.

How often should caregivers check the data?	
Original text	English translation
24 uur per dag	24 hours a day
alleen op werkdagen	during working days only
alleen overdag	during daytime only
anders, nl:	other:
elke dag	every day
elke maand	every month
elke week	every week
elke werkdag	every working day
hulpdienst wordt ingeschakeld	emergency service is called
n.v.t.	not applicable
tijdens regulier consult	during regular consult
zorgverlener bepaalt zelf wanneer	caregiver decides when

Figure 6.5: Overview of cards to be used in column five.

What action should be taken?	
Original text	English translation
anders, nl:	other:
automatische feedback	automatic feedback
familie/naasten worden gebeld	family/loved ones are called
hulpdienst wordt ingeschakeld	emergency service is called
metingen worden besproken tijdens regulier consult	measurements are discussed during regular consult
n.v.t.	not applicable
patient wordt gebeld	patient is called

Each group was accompanied by one of the CTA agents of the workshop. The composition of the groups was thus based on different backgrounds, involvement and roles the participants had in relation to the telecare system. By making groups based on their different backgrounds and roles, I tried to distil differences in the design choices they made.

Furthermore, the composition of the groups was in line with the distinction between what CTA scholars call “insiders” and “outsiders” of a technological development (Garud & Ahlstrom, 1997), or as Rip and Te Kulve (2008) call them, “enactors” and “comparative selectors” of technologies. According to Rip and Te Kulve, enactors are “technology developers and promoters who try to realize (enact) new technology,” whereas comparative selectors “can compare the option with alternatives... [and]...can range more freely because they are not tied to certain methods, and to accountability” (2008, p. 52). Additionally they make a distinction between professional and amateur comparative selectors. In my workshop the research professionals group and the engineers group can be considered as enactors because they indeed were the promoters and developers of the technology who try to implement it. The patients/nurse group can be considered as comparative selectors of the telecare technology because they indeed were selectors of the technology and had multiple options regarding if and how to use it. If we draw this line further, the nurse practitioner might be called a *professional* comparative selector and the patients might be called *amateur* comparative selectors. By this I do not mean that patients have less knowledge

than the nurse practitioner of the telecare technology, but that their knowledge originates from a different source. Patients have experience-based knowledge by using the telecare technology, while the nurse practitioner's knowledge originates from her work experience with the technology and with COPD patients who used the technology.

The assignment for the participants was to design a telecare system that would provide “good care” for its users. Each group could use up to eight of the preselected parts I described above. There were more than eight parts available for the assignment so the participants were forced to choose between them. For each chosen part the participants needed to answer some questions using the colored cards. The questions were the following: How often should patients use the selected part (column 2), whether the collected data should be shared automatically with a caregiver (column 3), how often caregivers should check the data (column 4), what action should be taken (column 5), and finally, how important was this part for the system and why (column 6). The time reserved for the assignment was approximately one hour, after which each group had to present and explain their design to the others. The assignment resulted in three colorful posters depicted in Figure 6.6, Figure 6.7 and Figure 6.8.

Figure 6.6: End result of the design assignment of the patients/nurse group.¹⁰³

¹⁰³ Photograph taken by the author (June 27, 2013).

Figure 6.7: End result of the design assignment of the research professionals group.¹⁰⁴

Onderdeel	Hoe vaak moet de patiënt het gebruiken?	Gegevens automatisch delen met zorgverlener?	Hoe vaak controle van gegevens door zorgverlener?	Welke actie moet worden ondernomen?	Hoe belangrijk is dit onderdeel? Waarom?
anders, nl:	Ja, want: - snelle behandeling - geen wait	Verspreiding van gegevens - snelle behandeling - geen wait	anders, nl:	een item zoet eigenlijk niet Onderdelen zijn gekoppeld we zien het als samenhang
elke dag	Ja, want: om behandeling of te voorkomen in de toekomst	elke dag Ja, want: - snel - goed	Automatische feedback
elke maand	Ja, want:	elke maand Ja, want: - snel - goed	Metingen worden besproken tijdens regulier consult
elke maand	Ja, want:		Patient wordt gebeld
anders, nl:	Ja, want:
anders, nl:	Ja, want:
patient bepaalt zelf wanneer	Ja, want:
24 uur per dag	Ja, want:			

¹⁰⁴ Photograph taken by the author (June 27, 2013).

Figure 6.8: End result of the design assignment of the engineers group.¹⁰⁵

Onderdeel	Hoe vaak moet de patiënt het gebruiken?	Gegevens automatisch delen met zorgverlener?	Hoe vaak controle van gegevens door zorgverlener?	Welke actie moet worden ondernomen?	Hoe belangrijk is dit onderdeel? Waarom?
elke dag	Ja, want: graag beschikbaar	tijdens regulier consult	Metingen worden besproken tijdens regulier consult	Ja, in de eerste
elke dag	Ja, want: automatisch met zorgverlener	tijdens regulier consult	Automatische feedback	Ja, in de eerste
anders, al	Ja, want: elke keer wanneer de patiënt het gebruikt	tijdens regulier consult	Automatische feedback	Ja, in de eerste
elke maand	Nee, want: niet nodig	zorgverlener bepaalt zelf wanneer	n.v.t.	Ja, in de eerste
patiënt bepaalt zelf wanneer		zorgverlener bepaalt zelf wanneer	n.v.t.	Ja, in de eerste
anders, al	Ja, want: elke keer wanneer de patiënt het gebruikt	tijdens regulier consult		Ja, in de eerste

¹⁰⁵ Photograph taken by the author (June 27, 2013).

Analysis of group discussions and presentations

In this section I will present what devices the groups selected to be part of the telecare system. I will give an analysis of the discussion that took place between the participants of each group and what arguments the groups used during the presentation of their telecare system.

The patients/nurse group

The nurse practitioner and the two patients decided that many of the choices regarding the use of a chosen telecare device as depicted in Figure 6.2, Figure 6.3, Figure 6.4 and Figure 6.5 should be negotiated between the caregiver and the patient. The need for communication in a telecare system was stressed again. The nurse practitioner added that whenever action should be taken in case of deviating measurements, patients should be responsible for this, because she did not think caregivers could live up to this responsibility when discussing which telecare devices and applications they preferred. When discussing which telecare devices and applications they preferred, both patients mentioned they would support the use of an implantable lab on chip that could measure any COPD-related data. Patient G emphasized she would not like the use of the oxygen saturation device (pulse oximeter) because the repeating confrontation with this data would only worry her. At this point the nurse practitioner added there are more patients that dislike the continuous confrontation with personal health-related data, while others seem to like to have as much as possible information about their own body.

In the end, this group chose the following eight devices: CoCo physiotherapy exercise module, CoCo activity monitoring and feedback device, pulse oximeter (oxygen saturation), implantable lab on a chip, telephone, COPD patient forum, website for psychological support and the CoCo electronic triage diary. The frequency of use depended on how often a measurement would produce relevant data for the health-care professionals. The group chose to automatically share data with health-care professionals, but argued it should not be mandatory to use all the devices. (E.g. if a patient did not want to use the implantable lab on a chip, this should be allowed.) Relevant data should be discussed during regular face-to-face consults, including what actions should be taken. The nurse practitioner added to be careful with sending too many alarm “flags” to health-care

professionals, because they would not be able to live up to processing too much data. Moreover, this would lead to unrealistic expectations among patients who would use the devices.

When the group had to explain their design to the other groups it became clear that they focused on *collaboration* between health-care professionals and patients on how to use and implement the devices of the telecare system, because “each patient is different” (Nurse practitioner, second CTA workshop, June 27, 2013). In addition to collaboration, the nurse practitioner emphasized she would prefer a telecare system focus on gathering *richer* information on patients’ wellbeing (e.g. not only “hard” data), for instance through the use of validated questionnaires about quality of life. This would improve her ability to give feedback to patients on their condition.

The research professionals group

In this group the discussion focused on which devices would generate relevant data for the treatment of COPD. The cluster manager at RRD and the biomedical technology engineer continuously asked the physiotherapist what devices he could use for his work on treating COPD patients. Apparently he was regarded as the expert on this matter, and implicitly as the main user. The group agreed to use the CoCo electronic diary instead of the analogue or Internet diary because of the triage system behind it. They preferred not to measure patients’ activity level 24 hours a day because of the lack of user friendliness of the current technology. However, from a medical perspective continuous measurement of these data could be relevant, the physiotherapist argued. Since the pulse oximeter (blood saturation) could also measure patient’s heart rate and blood pressure it was not necessary to include devices that could measure these variables individually. The cluster manager remarked she learned from the CoCo trial that the choice of whether to use each telecare system device should be much more flexible for patients and caregivers, because the protocol for the CoCo trial was too strict on this point and the end result of such a trial would be meaningless.

My biggest learning experience of CoCo is that patients and professionals should be able to play with the modules they want to use and how to use

them and leave that up to them. We just do not have enough knowledge to decide that for them. As a researcher, you can try to accomplish a wonderful RCT [randomized controlled trial], but then I get unwanted care that I evaluate, which would only give me meaningless results.

(Cluster manager at RRD, second CTA workshop, June 27, 2013)

When the discussion came to the point about what responsibility caregivers should have when using a telecare system, the physiotherapist said he did not want patients to know whether he had checked their data because this could lead to unrealistic expectations for them, which caregivers could not live up to. However, patients should be aware that he could have checked their data in order to stimulate compliance. The group agreed the system should generate feedback to the patient but should only notify caregivers if the collected patient data would show “worrisome” information. Moreover, they mentioned they did not prioritize one device over another because they regarded the system as a whole as a relevant unit.

The discussion resulted in the following devices for the telecare system: CoCo physiotherapy exercise module,¹⁰⁶ website for psychological support, CoCo electronic triage diary, spirometer (lung function), digital weighing scale, pulse oximeter (oxygen saturation), CoCo activity monitoring and feedback device, telephone and the implantable lab on a chip.

During the presentation of their design, the group stressed that patients and health-care professionals should agree on what devices would be useful for each individual patient from a medical point of view. The group also stressed they regarded the system as a whole and that they saw a large role for software in the system to monitor the data and only inform (via the use of flags) health-care professionals when data deviated from normal values. Again, they stressed they did not want patients to know when or whether health-care professionals are informed about or monitor their status because they did not want to create unrealistic expectations. Moreover, in this way the responsibility for their condition would still

¹⁰⁶ Because the group could not immediately find the accompanying picture, they chose to use a white note paper to write down their choice and stick it to the poster.

be on the patient's side. Furthermore, the group mentioned they would like the opportunity to have information on patient compliance through the use of gray flags. The use of different feedback to patients and health-care professionals should support patients to manage their disease themselves as much as possible and professionals to take action when things go wrong.

The engineers group

Like the research professionals, the engineers also focused on how to collect COPD-related data from patients for professionals. However, applications like the CoCo activity monitoring and feedback devices or the digital weighing scale could also be used by only patients to monitor themselves without necessarily sending data to health-care professionals. Moreover one of them mentioned he disliked the implantable lab on a chip, because it might disclose too much information and violate patient privacy.

This one is too much [like] Big Brother ...

(Electrical/biomedical engineer, second CTA workshop, June 27, 2013)

However, later on he mentioned he thought privacy was not a big issue for patients if they knew the reason certain data were collected. The engineers agreed that in the end patients were responsible for their own wellbeing and that proper education about how or whether health-care professionals would monitor them was an important aspect of a telemonitoring system. They also paid attention to how patients would experience the feedback by health-care professionals.

You do not want someone to call you when your activity level is too low, you would immediately get the feeling you're under surveillance.

(Human media interaction engineer at RRD, second CTA workshop, June 27, 2013)

This group chose the following devices for the telecare system: the CoCo electronic triage diary, CoCo activity monitoring and feedback device, telephone, COPD patient forum and the pulse oximeter (oxygen saturation). In their explanation of the design this group focused on creating insight into the disease for both patients

and health-care professionals. Education was emphasized as important and patients should know whether and when their data would be checked by a professional or that feedback was generated automatically.

Reflecting on the discussions between the stakeholders and the choices they made during the design assignment, we see that all three groups choose the CoCo activity monitoring and feedback device, the pulse oximeter (oxygen saturation), the telephone, the COPD patient forum and the CoCo electronic triage diary as devices to be part of a COPD telecare system. The heart rate meter, blood pressure meter, mobile ECG telemonitoring device, online diary, analogue diary, urine meter, camera, motion detector, smoke detector and the medication adherence device were not selected for various reasons. Some devices were not selected because COPD patients were not considered “incapable” of making informed decisions in contrast to, for example, patients suffering from severe Alzheimer’s disease. Furthermore, COPD was not regarded as a life threatening disease. That is why stakeholders considered it unnecessary to automatically call an emergency service in case of worrying signals.

During the group discussion and the presentation of their results, it becomes clear that each group had a different focus on what the telecare system should bring about if it would be implemented in health care. The patients/nurse group focused in its design largely on a strong collaboration between individual patients and caregivers. This preference is in line with Schermer’s third form of self-management based on collaboration.

The focus in the design of the research professionals group was on how to gather as much relevant data as possible to do research on the course of a disease in order to fine-tune treatment of COPD patients. They did consider patients’ views on the use of some devices, however, only from the point of view that the lack of user friendliness of some devices could lead to selective or nonuse, which in its turn could lead to a loss of useful data. In other words, they only considered some devices unsuitable from a medical point of view, not on how the (non) use of devices could lead to a better quality of life for patients. The same argument was used in the discussion on whether health-care professionals should continuously check patient data. They did not seem to ask the *moral* question of who in the end should be responsible for patients’ wellbeing. They argued that it was not possible

in practice for health-care professionals to be responsible for patients' wellbeing. However, the cluster manager nuanced this idea by arguing the system should have a twofold feedback application focusing on supporting patients to self-manage their disease, and supporting health-care professionals to monitor patients with the use of software and to alarm them if data would indicate serious health-related problems (i.e. a telecare system should contain "smart" software to process the collected data differently).

The engineers group focused on gathering *useful* data for health-care professionals. In addition, some devices could be helpful for self-management purposes for patients, but the measured data would not necessarily have to be useful for health-care professionals from a medical point of view (e.g. a weighing scale could be used for patients to keep an eye on their weight, but the measurements would not have to be shared with third parties). Moreover they also seemed to consider some devices undesirable from a moral point of view (e.g. the implantable lab on a chip).

Reflecting on the discussions between the stakeholders within each group, I conclude that dividing the groups based on the enactor/comparative selector relation to the technology (as discussed earlier) appeared to be fruitful. Also, the suggested differentiation between amateur and professional comparative selectors emerged to be a useful approach.

Each group found different aspects of the technology to be relevant. The patients in the patients/nurse group predominantly discussed what would be helpful for them in their daily live practice of living with or treating COPD. They articulated the comparative selector perspective on the technology. They chose the devices they thought could work for them, without being bothered by the overall question of whether telecare could contribute to a solution for (future) health-care demands, as it is often stressed by policymakers (e.g. see Oudshoorn, 2011, p.13). The nurse practitioner listened carefully to the patients and repeatedly asked whether they regarded several devices as useful to treat and/or handle their condition. She, thus, articulated the same *amateur* comparative selector perspective on the technology as the patients did. However she also thought about what the use of some devices would mean for her work as a caregiver. Hence, in these situations she articulated the role of *professional* comparative selector.

The research professionals positioned themselves as enactors of the technology. They focused on how the telecare devices could enhance empirical knowledge in order to improve the treatment of COPD. It seemed they regarded “treatment of COPD” to be a synonym for “care for COPD patients.” The engineers articulated the enactor perspective of the technology as well. Like the research professionals, their focus was to gather as much relevant data as possible. However they sometimes took on the role of spokesperson for the patients. They not only focused on instrumental arguments (e.g. lack of user-friendliness of the technology) for using certain devices, but also considered what the use of certain devices would mean for patients. In these situations the engineers articulated the role of comparative selectors of the technology.

6.6 Conclusions

My research questions for the workshops were as follows:

- How do participants of the workshop conceptualize good care?
- What are the main differences between stakeholders on how to organize a telecare system for COPD patients in terms of self-management, and how can we understand these?
- What are the major differences in insights gained from CTA workshops using different tools :
 - working with questions, scenarios, propositions and design research methods
 - working with only professionals vs working with professionals and patients

6.6.1 Participants’ views on good care

In this section I will answer the question of how the participants of the two workshops conceptualized “good care” supported by a telecare system based on the analysis of stakeholders’ arguments and interactions during participation in the four CTA activities (questions, scenarios, propositions and design research methods).

The participants of the first workshop (one nurse practitioner, one research coordinator, two engineers) seemed to agree that creating awareness among patients, about the influence of their own behavior on their condition and generating feedback on how to change this, would be considered good care that a telecare system could provide for patients. The stakeholders argued that feedback by a telecare system should not overrule patients' own judgment of their illness and that in case of doubt professionals should be (or able to be) consulted. If the system would (automatically) generate health-related advices, these should be complementary to patients' own perceptions. For some patients automatically generated medication advice could be helpful.

During the second workshop, patients argued that good care by a telecare system is about being supported by trustworthy devices, having the freedom to give their own interpretation to the generated advice and having the opportunity to communicate about their personal experiences with health-care personnel face-to-face or by telephone, also outside office hours. Moreover, they want to know what happens to the data that are collected through the devices of a telecare system. Implicitly, they argued that being in charge of their own lives was an essential part of good care for them.

Caregivers and research professionals stressed that in the end patients themselves are responsible for their wellbeing. They considered it would be too much work for caregivers to check patients 24 hours a day. Moreover this would lead to unrealistic expectations on the patients' side. Remarkably, caregivers and research professionals only gave practical reasons for this argument. The fact that having personal responsibility (i.e. more patient autonomy) could also be good for patients' wellbeing seemed to have been ignored.

Research professionals and engineers emphasized the collection of data to do medical research on the disease (in order to improve treatment) as an important contribution of a telecare system for improving health care. Monitoring patients and generating feedback to them automatically should enhance self-management strategies of patients and give caregivers the opportunity of surveillance. This would entail different feedback loops for patients and professionals. In order to avoid lack of clarity about how the system works and what happens to the data,

education on its workings and its use should be an integral part of a telecare system.

6.6.2 Stakeholders' views on self-management

Stakeholders views expressed during the two workshops not only differed in terms of what they considered as good care mediated by telecare technology but also on how these technologies should support self-management, although there is more convergence with respect to the latter.

The discussion during the workshops indicated that there seemed to be consensus among stakeholders on who in the end should be responsible for patients' wellbeing when using a telecare system as a supporting tool in health care. They seemed to agree that it is the patients' responsibility (while they still can) to notify health-care professionals when they feel bad or a telecare system signals worrying data on their disease status. However, patients seem to have a different rationale behind this argument than (research) professionals. For patients, being in charge of their own wellbeing seems to be related to the (human) right to self-determination over their body, which is in line with the literature in which patient autonomy is considered as an important aspect of contemporary health care (Pols, 2003). The rationale of health-care professionals seems to be that it is impossible *in practice* to keep an eye on every patient's health data and from a moral point of view it would be wrong to create unrealistic expectations for patients using a telecare system.

Equally important, there seems to be a difference in how patients and health-care professionals would like to *implement* the idea of self-management via a telecare system in health care. Patients seemed to prefer a form of self-management where there is a lot of room for collaboration with their caregiver on what telecare system devices to use and what the consequences of the collected data could be. In line with the third form of self-management (Schermer, 2009, p. 690), they argued that the relationship between professionals and patients should be one of collaboration or concordance. Therefore, patients strongly plead for incorporating proper communication tools in the design of the telecare systems.

In contrast, research professionals and engineers implicitly expressed another form of self-management. They stressed that the benefit of a telecare system is the collection of data to do medical research, to monitor patients to

enhance their self-management strategies and to give caregivers the opportunity of surveillance. They see a strong role for the software of a telecare system to divide feedback information between patients and professionals. Furthermore, feedback to patients should be executed automatically as much as possible to release health-care professionals from the workload of managing too much patient data. The fact that caregivers only feel the need to intervene when patient data shows worrying information does not reflect self-management based on collaboration, but a delegation of work and responsibilities to partly automated telecare systems.

However, professional stakeholders in the first workshop argued that feedback of a telecare system should not overrule patients' own judgment of their illness and that in case of doubt, professionals should be consulted. This is in line with Schermer's third form of self-management where the idea is to integrate experience-based knowledge of patients into the prescribed treatment and to cooperate with health-care professionals.

6.6.3 Comparing CTA methodologies and approaches

Reflecting on the different CTA methodologies used in the two workshops, we may wonder whether the different methodologies and approaches resulted in different insights in assessing telecare technologies.

CTA methodologies

In the first workshop I used questions and scenarios to guide the discussion between the present stakeholders. The use of questions can be a fruitful tool for CTA workshops, but I suggest that this methodology only works when CTA agents have enough knowledge of the topic of the workshop to ask the right questions. In this respect executing pre-engagement activities is an essential prerequisite for the success of a CTA workshop, in this case, for asking the right questions.

The scenarios turned out to be productive tools for the first CTA workshop. They are productive because through the scenarios CTA agents can integrate various possible futures about how a technology can have an impact on society. In this way participants are stimulated to think about the effects of the technology beyond the instrumental way, which they might be used to in their role as a

professional.¹⁰⁷ In my case the scenarios varied on the degree of autonomy that was delegated to the COPD patients. By zooming in on this feature of telecare technologies it was possible to provoke reactions of stakeholders and find out what they thought a good level of patient autonomy is for a successful implementation of a telecare system.

In the second CTA workshop I used propositions and a design assignment to stimulate interactions among stakeholders. Similar to the use of questions, proper knowledge of the topic of the workshop is essential for developing useful propositions. In other words, proper socio-technical knowledge is crucial for a fruitful CTA workshop. Interviewing the participants beforehand is therefore very useful, or maybe even a necessary prerequisite for a successful engagement activity, especially when real end-users of a technology are involved. It is very hard to learn about their thoughts, feelings and experiences associated with the use of a technology without some form of personal encounter between researcher and end-user.

As mentioned previously, I used a design assignment in the second CTA workshop, which turned out to be a useful tool to make stakeholders interact regarding the implementation of a telecare technology. By using pictures of possible telecare devices, stakeholders were prompted to actively make choices about how they thought a telecare system could deliver good care for patients. By giving them more pictures of devices than they could use for the assignment, stakeholders were forced to make explicit choices, which could have stayed implicit or unmentioned in a more text-based CTA activity. Through the use of cards stakeholders explicitly had to answer questions on how the telecare system should be implemented in health care. For CTA agents this gave the opportunity to get to know stakeholders' positions regarding certain relevant questions about the technology. In my case it made visible what stakeholders' opinions were on patient autonomy, for instance, by asking (via the columns on the poster) whether patient data should be shared automatically with health-care professionals. By letting stakeholders present their design and give them the ability to ask questions about each other's choices, they could indeed "probe each other's worlds" (Rip & Te

¹⁰⁷ For the development of the telecare technologies in COPDdotCOM, the engineers also used scenarios.

Kulve, 2008, p. 50) so that learning could occur. Furthermore, the design assignment turned out to be a very useful tool to overcome possible language barriers or knowledge gaps between different stakeholders because they all got the same “things to think with” (Timan, 2013, p. 199). Inviting stakeholders with different educational and social backgrounds is a very useful tool.

CTA approaches

In the two CTA workshops that I organized, I used four different CTA methodologies. These were discussed extensively in the foregoing sections. But besides using different methodologies (questions, scenarios, propositions and design research methods), the two workshops also varied in the used approach. The participants of the first workshop were all professionals who were somehow involved in the development of a telecare system for COPD patients. In addition to professionals, the participants of the second workshop were also end-users of a telecare technology (i.e. patients). Moreover, the setup of the second workshop was to have patients be the first to react to the various propositions (in the first half hour), and then have a plenary session where the professionals could also participate in the discussion (the second half hour). The CTA method used in the first workshop was thus based on a top-down approach, while the second workshop was based on a bottom-up approach.

The top-down methodology provided useful insights in professionals’ opinions on the telecare technology. Learning occurred particularly when professionals with different backgrounds and involvement in the technology shared their views. However it is hard to really pinpoint these occurrences in the first workshop. I argue that the bottom-up approach produced more insights in the development of the technology at hand for the participating stakeholders than the top-down approach did. During the second workshop it became clear that even in the limited context of a CTA workshop, learning occurred between end-users (i.e. patients) and professionals. For example, during the discussion on the propositions the patients mentioned they did not know whether the data they shared via the telecare system was checked by health-care personnel. For them this was crucial information that would directly influence their compliance with the advice of the system. The professional stakeholders picked up this information and it became a central theme for them during the design assignment. I therefore agree with

Oudshoorn and Pinch (2003) that knowledge based on the experiences of real end-users is crucial for the development of a technology. User knowledge is very important when the technology at hand is very user-sensitive, which contemporary telecare technologies are. Moreover, experience-based knowledge of patients might even be more important for the development of a telecare technology, since for its use an intimate relationship between a patient's body and the used device(s) is often essential.

6.7 Discussion and reflection

In this chapter I introduced CTA as an approach to broaden the design of telecare systems for COPD patients. The goal of CTA is to support mutual learning between stakeholders that are involved in the development of a technology in order to create a better technology in a better society (Schot & Rip, 1997). To improve the design of telecare technologies for COPD patients I therefore organized two CTA workshops with different stakeholders involved in the design of these technologies. The two workshops produced important insights of what stakeholders considered as important requirements for a COPD telecare system in order to deliver good care for its users. Furthermore, these insights gave me the opportunity to analyze what form(s) of self-management (Schermer, 2009) the telecare system should promote according to the different stakeholders.

The two workshops illustrated that different stakeholders preferred different forms of self-management to be promoted by a telecare system for COPD patients. Patients seemed to prefer to find their own way to live with their condition, and make their own decisions and choices, which sometimes could differ from the advice of a telecare system. Moreover they argued their relationship with health-care professionals should be based on concordance and cooperation. Experience-based knowledge of their body was essential for them to deal with their condition. These characteristics that patients described are in line with Schermer's third form of self-management.

Some professional stakeholders, predominantly the engineers, seemed to agree with the preferences of patients but emphasized that not all patients would be capable of managing their condition this way. For some patients the first or second form of self-management might be more suitable. However, in the end,

patients should remain responsible for their own wellbeing. The research professionals seemed to opt for a more rigid form of self-management to be promoted by a telecare system. Patients could use telecare devices to take over some practical tasks from health-care professionals like taking measurements of health-related indicators. However, they argued that the software of the telecare system should interpret these data, instead of patients. It should generate feedback to patients on how to deal with their condition. This might help improve patients' health status or wellbeing, but does not promote their autonomy. It does not involve any decision-making by patients, nor are patients' own views or wishes involved. The described characteristics seem to be in line with Schermer's first form of self-management.

Reflecting on CTA as an approach to support mutual learning between stakeholders that are involved in the development of a technology, I argue that this exercise turned out to be successful. Stakeholders were enabled to exchange insights on the technology and had the opportunity to probe each other's worlds (Rip & Te Kulve, 2008, p. 50). The difficulty with CTA workshops is that it is very hard to find out whether real learning occurred among stakeholders. A possible way to trace this would be by doing follow-up interviews among the present stakeholders. However, this methodology would be an extra burden for the stakeholders. I therefore chose not to take this up in my research. Fortunately, the discussions during the second workshop illustrate that learning explicitly occurred when remarks from patients prior to the design assignment were literally translated into design requirements by other stakeholders. Of course it still is the question whether this learning effect will have its consequences on the design of a telecare system in real practice, but it could be a start.¹⁰⁸

Besides the usefulness of CTA as tool to broaden the design of a technology, the approach has some limitations. First, it is very hard to get the most important stakeholders in a field to participate in a workshop. As a CTA agent it is important to make clear how the exercise can be of importance to them in order to get these stakeholders enthusiastic about participation. Moreover, as a researcher one has to be aware that opinions of so called non-users (Oudshoorn & Pinch,

¹⁰⁸ In chapter 3 I showed that engineers are highly configured in their design work by other influences than merely user requirements.

2003) are hard to collect, let alone have them participate in CTA workshops. Second, even if these stakeholders are willing to participate, practical reasons might hinder them from showing up at the actual workshop (e.g. sudden illness or traffic circumstances, as happened in the first workshop). Third, as previously mentioned, it is very hard to find out what the real effects of a CTA workshop are in the outside world. There are numerous influences that affect the way a certain technology develops, which might be more influential than insights gained at a CTA workshop.

Moreover, the setup of a workshop might constrain its usefulness. As mentioned earlier, I invited patients to participate in my second workshop. Because of their fragile health, it is sometimes difficult to have them actively participate in these meetings. Even in the case of a relatively “mobile” or “healthy” patient group, this may affect their attendance during a CTA workshop.¹⁰⁹ This problem might be less urgent when the topic of the workshop involves “healthy” end-users.

To conclude, I argue that the setup of a workshop and the methodologies a CTA agent chooses to use are very dependent on the type of technology that is under discussion. In my case the technology was rather mature, giving me the opportunity to invite end-users to the workshop and apply a bottom-up approach towards the technological development. However, many technologies that have been included in CTA workshops (see e.g. Te Kulve, 2011; Parandian, 2012; Lucivero, 2012; Bitsch, 2013) are not matured enough to identify end-users at all. However when CTA agents do invite end-user or users of different socioeconomic and educational backgrounds to their workshops, I argue an approach that is not purely based on discussion but involves other ways to exchange ideas can be a useful extension of the CTA toolbox. The outcomes of the design assignment of the second workshop illustrate this point.

¹⁰⁹ In my case one patient called in sick on the day of the workshop, another cancelled beforehand because of health-related problems.

Chapter 7: Conclusions and recommendations

7.1 Introduction

In the previous chapters I introduced the topic of this research and answered the sub-questions in five empirical chapters. In this chapter I give a recapitulation of the main findings of these chapters and combine them to answer the central research question of this thesis. Next I relate my findings to existing literature in the scholarly field of STS and discuss how this research contributes to new insights. I will end this chapter by suggesting a methodological guideline for designers of telecare technologies.

7.1.1 Recapitulating the research questions

The central question of this research was the following:

How do telecare technologies participate in enabling and/or constraining self-management practices of chronic patients?

I divided my research question into five sub-questions:

1. *Which views of patient self-management are inscribed in telecare technologies?*
2. *How can we understand the design practice of telecare technologies? What are enabling or constraining aspects that shape the design process, and why?*
3. *What understandings of self-management are taught to patients before using telecare technologies?*
4. *How do telecare technologies shape and mediate patients' perceptions of their disease regarding self-management and actions in dealing with the system?*

5. *How can we feedback experiences and insights of developers and users about how telecare technologies should support self-management of patients in the development process?*

The telecare technology investigated was developed within the framework of two consecutive research projects with the aim to design, develop and test a prototype system to support supervised physical training and monitoring from a distance, and improve patient self-management and communication between professionals and patients (Hermens, 2010). In this thesis I focused on the ambition of the projects to improve patient self-management, which included two different strategies: coaching patients in their daily life to improve their activity behavior and applying self-treatment of exacerbations. The telecare technologies that were developed to support this goal were an activity monitoring and feedback application and an electronic triage diary.

7.1.2 Self-management and scripts of a contemporary telecare technology

In the first empirical chapter (chapter 2) of this thesis I performed a script analysis (Akrich, 1992) to investigate what forms of self-management (Schermer, 2009) were inscribed in the design of a contemporary telecare technology for patients suffering from a chronic lung condition (COPD).

To perform the analysis I suggested refining the script approach by pointing out that technologies that are referred to as singular artefacts can incorporate multiple scripts. This refinement applies to the telecare technology at hand for mainly two reasons: First, I suggested that since the telecare technology consists of a system of multiple devices it should not be regarded as a singular technology containing a singular script. I therefore adopted Oudshoorn's (2011, p. 99) argument that telecare technologies incorporate multiple scripts. Second, telecare technologies are composed of information and communication technologies (ICTs), thus consisting of hardware and software components, both incorporating their own scripts. I therefore emphasized the importance of differentiating between hardware and software scripts. Furthermore, I suggested it is important to include the instructions for use of the telecare technology in the

script analysis to improve the understanding of how the technology shapes use practices.

Based on the analysis of the hardware and software scripts of the devices, I concluded that the use of graphs, reference lines, block charts and so on incorporated a science-based representation of data in the telecare technology. I considered this remarkable bearing in mind that COPD patients are on average lower educated older people¹¹⁰ who may be unfamiliar with this kind of data representation. Moreover, I concluded that the telecare technology predominantly made use of science-based medical knowledge instead of experience-based knowledge of patients to support self-management.

The script analysis illustrated a mixture of the first and second forms of self-management inscribed in the telecare technology. The application aimed at improving patients' physical activity (BAN and web portal) reflected both the first and second forms of self-management. The first form of self-management was discernible in the feedback messages on the PDA to improve patients' activity levels. Patients were not expected to interpret the measured data themselves. They were expected to follow the generated advice without incorporating their own views and wishes. The second form of self-management was apparent in the use of graphs to display activity levels. Patients were expected to interpret this information and translate them into healthy activity behavior, a task usually conducted by professionals. This might have enhanced patients' insights into their physical activity but it did not support their autonomy.

The instructions for use of the devices to measure patients' activity levels contained a mixture of both forms of self-management. There were strict rules about how to wear the devices and for what period of time, but patients were allowed to be relatively flexible in when to use them. The telecare application aimed at the self-treatment of exacerbations (the electronic triage diary) predominantly incorporated the first form of self-management. Patients were limited to entering information about their health status into the predefined answers of the multiple-choice questions, which were based on their medical status only. They did not take over practical tasks from health-care professionals. The

¹¹⁰ <http://www.oecd-ilibrary.org/sites/9789264183896-en/01/16/index.html>
(accessed 12-05-2014).

system might have improved patients' wellbeing, but did not increase patient autonomy. A minimum of the second form could be discerned as well because patients had to interpret their condition to fill out the diary and might have developed experience-based knowledge of their disease when viewing the medical history of their condition. Remarkably, the telecare technology did not incorporate the third form of self-management.

7.1.3 Why the third form of self-management was not inscribed in the telecare technology

Based on the script analysis of the telecare devices, I concluded that the first and the second forms of self-management were predominantly inscribed in the telecare technology. In chapter 3 of this thesis I tried to find an explanation for the absence of the inscription of the third form of self-management. I therefore analyzed the design process of the telecare technology.

I used the concept of configuring the user (Woolgar, 1991) to illustrate that among the authors of the research proposal there were ideas to prestructure the future use of the technology by incorporating the third form of self-management into its design. I continued the chapter by arguing that the design process of the telecare technology was not only shaped by designers but that designers were also shaped by the environment in which they work. Designers of the telecare technology had to deal with constraints like time, money, available resources, and the demands of funding agencies. This process was captured by the STS concept configuring designers (Mackay et al., 2000). The chapter described how the designers of the telecare technology were considerably configured by the funding agency ZonMW, which resulted in design processes characterized by bricolage (Disco, 1998; Garud & Karnoe, 2003) and path creation (Garud & Karnoe, 2001). I showed how these design processes resulted in the inscription of the first and second forms of self-management in the telecare technology instead of the third form, which was discernible in the initial ideas of the authors of the research proposal. I concluded the chapter by arguing that the design of a telecare system that supports the third form of self-management requires another design strategy than the bricolage approach. A less restrictive funding regime is needed to enable designers to explore new design approaches aimed at incorporating other ways of supporting self-management.

7.1.4 Educating patients to self-manage their condition

Up to this point, this thesis focused on how technical characteristics of the design of the telecare technology may participate in prestructuring self-management practices of chronic patients. However, as STS scholars have illustrated, a large part of the foreseen use of a technology is not solely in the hands of the designers (Lie & Sorenson, 1996; Oudshoorn & Pinch, 2003, 2008). While Oudshoorn and Pinch predominantly focus on how users co-shape the development of technical objects, I argued in chapter 4 that the self-management practices supported by the telecare technology were also considerably shaped by accompanying *use instructions* of the technology. Therefore I analyzed what views of self-management were taught to patients during a self-management course patients were asked to take before they used the telecare technology as part of a clinical trial. In these courses patients were educated about their disease, how to use the electronic triage diary and how to interpret symptoms.

Based on participatory observations of the self-management course, I described how patients were taught to manage their disease in a quasi-professional way. By answering the prestructured multiple-choice questions of the electronic triage diary, they were taught to take over interpretative tasks of health-care professionals and diagnose their disease status. Patients were thus supported to self-manage their condition according to the second form, where patients are regarded as proto-professionals (Schermer, 2009, p. 689). However, patients were told to modify or reject some parts of the scripts of the telecare technology (e.g. patients were advised not to change their medication automatically if the electronic triage diary advised them to). Instead patients were recommended to contact their caregiver. Patients were also allowed flexibility in using the electronic triage diary. Moreover, patients were advised to treat their condition based on their own bodily knowledge instead of the advice generated by the telecare technology.

I therefore concluded that the views and ideas on self-management taught in the course were predominately based on the third form. However, the contents of the course material and the verbally transferred knowledge were predominantly based on medical expert information.

7.1.5 The role of a telecare technology in shaping patients' actions and perceptions

The aim of chapter 5 was to investigate how the telecare technology shaped and mediated patients' *perceptions* of their disease and patients' *actions* in dealing with the telecare technology to see whether and how the inscribed forms of self-management discerned in the technical characteristics (chapter 2) and the self-management course (chapter 4) of the telecare technology were enacted during the actual use practices of the system.

Since I investigated use practices in a trial setting, I first analyzed how patients were configured by the selection criteria of the trial. I described how the use of specific selection criteria implied that certain groups that have an increased risk of getting COPD are excluded from the trial. This might influence the scientific generalizability of the study's results.

In the chapter I described that the telecare technology shaped patient's actions in various ways. My analysis of the use practices of the telecare devices showed how each patient made his or her own interpretation of the scripts of these devices. The use practices of the activity monitoring and feedback devices showed how patients often followed the generated advice of the feedback messages only when they could adjust them to their daily life routines. Although patients did not follow the advice blindly, they nevertheless changed their activity patterns. The reactions of patients to the electronic triage diary showed a wide variety of interpretations of the script of this device. Some patients strictly followed the advice (i.e. medication advice or advice to contact the doctor) that automatically resulted from the anamnesis questions of the triage diary. In contrast, patients who considered experience-based knowledge of their own body equally or more important than knowledge generated by the electronic triage diary did not always follow the advice of the telecare device. Other patients mentioned they felt more at ease with discussing medication-related interventions with their caregivers instead of following the advice of the electronic triage diary.

The chapter continued by describing how the telecare system mediated patients' perceptions of their illness, themselves and their relationship with health-care professionals. The activity monitoring and feedback devices changed patients' perception of their physical capacities and enabled patients to perceive themselves

as active individuals capable of influencing the constraining consequences of their condition. The use practices of the electronic triage diary also changed patients' perceptions of themselves in relation to their illness. The telecare system enabled patients to become more autonomous regarding the taking of medication. However, patients experienced that the electronic triage diary reduced their illness to predefined multiple-choice questions, based on medical knowledge only. They emphasized they missed the opportunity to share emotional, psychosocial or circumstantial knowledge. Additionally, the telecare system also affected patients' perceptions of their relationship with health-care professionals because it enabled them to become more assertive in their contacts with health-care professionals due to the advice of the electronic triage diary.

Based on my findings I argued that a mixture of the three forms of self-management described by Schermer (2009) can be discerned in the use practices of patients. Patients enacted the first, "compliant," form of self-management when they followed the advice of the electronic triage diary blindly. The second form of self-management can be discerned when patients took over interpretative tasks of health-care professionals, for instance, by diagnosing their health status for the electronic triage diary and using the graphs of the activity monitoring and feedback application. Although the script of the telecare devices was not aimed at supporting the third form of self-management, the use practices of both the activity monitoring and feedback devices and the electronic triage diary reflected this form of self-management as well. Patients used the activity monitoring and feedback devices in such a way that they could be incorporated in their daily lives and they relied on their own experience-based knowledge in using the electronic triage diary. Moreover, patients enacted the third form of self-management when they decided to deviate from the advice generated by the telecare system (i.e. some use practices can be described in terms of "anti-programs") (Latour, 1992). In this respect, the self-management course patients attended prior to using the telecare devices may have encouraged them to rely on their own experience-based knowledge as well.

I concluded chapter 5 by arguing that inscribed forms of self-management in the design of the telecare technology did not necessarily result in corresponding use practices of patients. Which form of self-management eventually emerges is

the result of an interactive process between each individual patient and the telecare devices in which the creativity and personal preferences of patients, their health condition, daily routines, the flexible interpretation of the scripts of the devices and the self-management course play an important role.

7.1.6 Applying CTA to a contemporary telecare technology

Chapter 6 started with the observation that there is a gap between the forms of self-management that designers inscribed into the telecare technology and the perception and enactment of these forms by users. Where in the technical characteristics of the telecare technology the third form of self-management was largely absent, the analysis of the corresponding educational program and the actual use practices predominantly reflected the second and third forms of self-management. To enable patients to develop adequate and morally acceptable self-management practices supported by telecare technologies, a better fit between design and use practices is desirable. The chapter therefore introduced the method of Constructive Technology Assessment (CTA). CTA is a reflexive approach to broaden the development process of technologies. A commonly used approach within CTA is to bring together different stakeholders involved in the socio-technical development process of a technology in a workshop setting so that reflexive learning can occur. The chapter continued by describing two CTA workshops I organized with different stakeholders involved in the design of the telecare technology for COPD patients. The two workshops had different setups, different stakeholders were invited and they contained different methodologies to stimulate engagement among stakeholders.

The two workshops showed that different stakeholders preferred different forms of self-management to be promoted by the telecare technology. Patients wanted a telecare technology that supported the third form of self-management, with opportunities to integrate experience-based knowledge into the telecare technology and possibilities to communicate with health-care professionals about their condition. Research professionals and engineers (the professional stakeholders) were divided over which form of self-management the telecare technology should support. While the engineers acknowledged the importance of incorporating the third form of self-management into the technology, they also emphasized that for some patients treatment would be more successful by a

telecare technology supporting the first or second forms of self-management. The research professionals only focused on compliant self-management to be promoted by a telecare system. Patients could use telecare devices to take over some practical tasks from health-care professionals like taking measurements of health-related indicators. They agreed that telecare technologies can only become successful tools in the treatment of chronic conditions if tasks traditionally performed by caregivers would be delegated to technologies, like processing measurement data.

Reflecting on CTA as a method to support mutual learning between stakeholders involved in the development of the telecare technology, I argued that the approach has been useful for stakeholders to “probe each other’s worlds” (Rip & Te Kulve, 2008, p. 50) and for learning to occur. This was nicely illustrated in the second workshop when remarks from patients on the design of the telecare system were picked up by the engineers and immediately translated into new design requirements.

I concluded the chapter by arguing that the setup of the workshops, the invited stakeholders and the used methodologies should depend on the type of technological development that is at stake. I showed how including patients as participants of the workshop, and applying the so-called bottom-up approach was important, since the technology at hand directly shaped their health-care practices. I furthermore showed that applying methods for the exchange of ideas beyond the scope of written or oral text, like the design assignment, was very useful for stakeholders of different socioeconomic and educational backgrounds to share their views and opinions.

7.2 Broadening of conclusions

Combining the findings of the empirical chapters, I return to the central research question: how telecare technologies participate in enabling and/or constraining self-management practices of chronic patients. My argument throughout this PhD thesis has been that it is important to open the black box of self-management by acknowledging that there are different forms of self-management at play and that the three forms of self-management described by Schermer provide useful heuristic tools for this endeavor. Equally important, telecare technologies themselves should not be black boxed either. I therefore decided to analyze the multiple devices that constitute the telecare system investigated in this thesis. This

approach has been very productive because it enabled me to provide a rich and detailed understanding of how the telecare devices both enable and constrain self-management practices of COPD patients. The empirical chapters show that there are differences between the forms of self-management inscribed in the different telecare devices compared to the self-management enacted during the self-management course and the actual use practices.

I therefore conclude that the ways in which self-management is designed, taught and enacted during use does not follow a linear trajectory. On the contrary, each site in the development of the technology had its own dynamics in articulating and enacting what self-management actually meant. The empirical chapters illustrate as well that there are differences between the different actors in terms of the forms of self-management they prefer. However, in this complexity we can discern a specific pattern. The forms of self-management enacted by the actors involved in the self-management course and the actual use of the telecare devices did not mirror the forms of self-management inscribed in the system by the designers. Whereas the nurse involved in the self-management course and the users themselves preferred and enacted forms of self-management based on concordance and cooperation, and to a lesser extent compliance; the designers, however, prioritized compliant forms of self-management. I therefore conclude that there is a mismatch between the forms of self-management inscribed in the telecare devices and the forms enacted in the learning and use practices of this telecare system.

7.2.1 A possible explanation for the gap between design and use practices

I draw from insights of other STS studies in order to understand the mismatch between the inscribed form of self-management in the design practice of the telecare technology and the enacted forms of self-management by patients and health-care personnel in their use practices.

In her analysis of dominant discourses on telecare technologies, Oudshoorn (2011) suggested that the introduction of telecare technologies is embedded in discourses on problems relating to financing future health care because of demographic changes, the modernization and rationalization of health care and a discourse related to a neoliberal political view on future health care. She

furthermore argued that these discourses reflect and reinforce both a “reductionist” view on health care and a “restricted” view on technology. The reductionist view on health care is reflected by the assumption that telecare can increase the efficiency and reduce the costs of health care, while other changes related to its introduction are largely ignored. By representing telecare technologies as instruments that serve narrow economic interests, these discourses hide important changes in the role of patients, the relationships between health-care providers and patients, and care itself implicated in telecare technologies. The restricted view of technology is reflected in an instrumental understanding that assumes a causal relationship between the aim and effects of a technology. This view has been criticized because it fails to recognize that technologies often transform problems rather than solve them because people use technologies for their own purposes rather than follow their intended use (Oudshoorn, 2011, p. 17). Scholars involved in a large European-funded research project on the ethical and social implications of the introduction of telecare technologies in elderly care (the EFFORT project)¹¹¹ argued in a similar vein, suggesting telecare should not be regarded as an easy technological fix to solve the problems of the current health-care system (see e.g. Mort et al, 2012; Roberts et al., 2012).

I suggest that reductionist views on health care and instrumental understandings of technology also underlie the gap between the inscribed and the enacted forms of self-management of the telecare technology that is central in this thesis. In chapter 3 on the design process of the telecare technology, I described how the development team was highly configured by the funding agency ZonMW to develop a telecare technology to increase the efficiency and reduce the costs of future health care. This resulted in a telecare technology incorporating a rather compliant form of self-management, where the control of the technology and the caregivers over patients was relatively high. Telecare technologies incorporating compliant forms of self-management promise on the one hand to increase the efficiency of health care by assuming patients will strictly follow a prescribed medical regime (resulting in a decreasing demand for health care), and on the

¹¹¹ See www.lanacs.ac.uk/efortt (last accessed 12-05-2014).

other hand, to reduce the costs of health care by redistributing tasks usually conducted by (expensive) health-care specialists to (less expensive) technologies.

However, the assumption that patients would strictly follow the medical regime of the telecare technology studied in this thesis did not seem to work out. The analysis of use practices illustrated that patients challenged the compliant form of self-management of the telecare technology by adjusting the generated advice to their daily routines, or ignoring them by developing anti-programs (Latour, 1992). These practices thus indicate that inscribing a compliant form of self-management in a telecare technology does not automatically result in compliant behavior of patients.

Also, the redistribution of self-management tasks from humans to technologies was less straightforward than assumed. The script analysis of the telecare technology, described in chapter 2 of this thesis, illustrated that tasks and responsibilities usually conducted by caregivers were delegated to technical systems to monitor and take decisions automatically. However, in my analysis of the use practices I described that some patients developed “work-arounds” (Gasser, 1986, p. 216; Oudshoorn, 2011, p. 105) to discuss their health problems with caregivers instead of relying on the technologically mediated advice only. Moreover, the majority of patients mentioned preferring human contact to discuss their treatment (Patient interviews, January 2013). These self-management practices thus suggest that humans cannot easily be replaced by technologies and promises of reduction of health-care expenditures may not be so readily fulfilled.

Both findings are in line with studies of user-technology relations suggesting that technologies often are used differently than designers intended (Oudshoorn & Pinch, 2003, 2008). I therefore agree with Oudshoorn (2011) when she suggests ANT as an alternative to the instrumental view on technological change. ANT does not regard humans and technologies as singular entities with predefined identities (e.g. an *obedient* patient) and characteristics (e.g. a *compliant* telecare technology) that exist independent from each other. They are part of a heterogeneous network where they are mutually shaped and constituted by each other in use practices. Telecare technologies can therefore not be regarded as “isolated instruments that determine economic or socio-cultural change” (Oudshoorn, 2011, p. 18). Thus, tasks and responsibilities regarding patient self-

management cannot be distributed from humans straight to technologies without anticipating how they may transform human-technology relations in multiple ways.

7.2.2 Flexibility in self-management approaches

As previously described, for some patients a telecare technology incorporating a compliant form of self-management might enable them to adhere to a medical regime to improve their health status. Others, however, might feel constrained in their autonomy and develop strong anti-programs (Latour, 1992) to a compliant telecare technology, which might lead to misuse of a telecare service or nonuse of the technology. Of course, this argument also works the other way around. A telecare technology incorporating a form of self-management based on patient autonomy might enable patients to live their lives according to their own views and wishes and improve their wellbeing, while for others a high level of autonomy might lead to misuse of medication or the neglect of a healthy lifestyle (i.e. adequate forms of self-management supported by telecare technologies vary per patient). Oudshoorn (2011) argues in a similar vein: “Based on the insights of research on user-technology relations, we might expect that the heterogeneous users of telecare technologies will not necessarily share the same views of the new technology” (p. 10).

Still, the above arguments for variation in self-management forms are articulated from a socio-technical perspective to contribute to solving the burden of chronic disease in health care. However, I argue that incorporating various forms of self-management in telecare technologies is also important to increase the moral acceptability of telecare technologies. As I described in chapter 1, telecare technologies may create ethical dilemmas. Telecare technologies that only support compliant behavior and partly replace health-care professionals with machines force patients and care providers to prioritize the norms of care inscribed in these technologies over their own norms about how to live a meaningful life or to provide good care. In contrast, telecare technologies that support a variation of self-management forms may enable patients and health-care providers to choose the kind of care they think is best in a given situation.

However, I agree with Mol (2008) that choosing the right treatment should not solely or ultimately be in the hands of patients (according to the logic of

choice). As health-care professionals suggested, not all patients are capable of handling the kind of freedom a telecare technology incorporating an autonomous form of self-management would entail (transcript, first CTA workshop, January 11, 2011). Moreover, Schermer suggests that not all patients will have the ambition to perform self-management to the same degree (2009, p. 690). Especially when self-management incorporated in a telecare technology is coupled with distribution of medication beforehand, it brings along extra responsibility for patients to only use it when necessary. Or, to quote one of the patients: “They [the pills] are not candies” (Patient D, interview, January 22, 2013). I therefore argue that both patients and their health-care providers have a responsibility when it comes to finding the right form of self-management for the treatment of chronic disease using telecare technologies. Deciding on what form of self-management works best for individual patients thus becomes a process of “shared doctoring” (Mol, 2008, p. 56).

To summarize, I conclude that the shared decision-making of health-care professionals and patients could improve the balance between giving responsibility and autonomy to patients on the one hand and delegating control to technical devices on the other. I therefore agree with Schermer that in the development of telecare technologies, “flexible solutions are preferred” (2009, p. 690). These flexible solutions might be accomplished by incorporating multiple scripts supporting various forms of self-management into the design of telecare technologies. Patients and their health-care professionals can then decide what form of self-management is appropriate to employ for each individual patient using the support of a telecare technology. Or, as Pols argues (2012, p. 76): “It makes the question what device to use, and a fitting logic to live by, important for potential users to ask.”

7.2.3 The importance of patient knowledge

Up to this point, this chapter predominantly focused on the process of “shared doctoring” to find out what the best form of self-management for individual patients using telecare could be. However, this research also suggests that the

implementation of self-management support for patients by telecare technologies should not be guided by science-based knowledge only, for the following reasons.¹¹²

First, science-based knowledge does not take individual circumstances of patients into account. This is nicely illustrated by patients mentioning they did not follow the advice of the activity meter or electronic triage diary blindly, but integrated them in their individual circumstances at that moment. One patient mentioned he did not follow the advice of the electronic triage diary to take prednisolone because of his aversion to the side effects of this medication (Patient C, interview, January 31, 2013). Another patient mentioned she did not follow the advice to go for a walk when she was at work. Thus, advice built on science-based knowledge needs to be combined with patients' practical knowledge to be translated into actions. Patients constantly have to improvise on how to interpret the advice of the telecare technology and how to apply the advice into the here and now of their individual situation. Pols introduces the concept "know-now" to refer to this type of practical patient knowledge (2012, p. 84).

Second, science-based knowledge in health care is frequently constructed by mean values of data collected in randomized controlled trials conducted with a preselected group of patients. Based on this knowledge, rules are created for patients regarding how to treat their condition or live with their disease. However, (bodies of) individual patients might behave differently to these rules. Ergo, when the electronic triage diary, which was built on science-based knowledge (Effing et al., 2009), advised patients to start with a course of penicillin or prednisolone this could have worrying (side) effects for individual patients.¹¹³ In a similar vein, one of the patients mentioned, he thought it was not very trustworthy the way the electronic triage diary prescribed him prednisolone without knowing his personal (medical) history (transcript, self-management course, July 18, 2012). In other

¹¹² Also see Pols (2012) chapter 5 on the roles of experience-based knowledge and scientific medical knowledge in living with a chronic condition.

¹¹³ Mol argues in a similar vein when she introduces the difference between science-based "facts" and bodily experience-based "values" in the treatment of diabetes (2008, p. 43).

words, it is important to incorporate individual experience-based knowledge into the science-based knowledge of the telecare technology.¹¹⁴

Third, the reliance on science-based knowledge may constrain the self-management of science-illiterate patients who may be overrepresented among COPD patients because of the demographic characteristics of the disease. In this respect, courses to make patients, both science illiterate and literate, familiar with how telecare technologies can support self-management are crucial to include in the care trajectory for chronic patients. Although patient knowledge was not supported by the telecare devices, the self-management course encouraged patients to rely on their own experience-based knowledge. In the courses patients learned to apply personal bodily related knowledge of their disease when they had to diagnose their disease status when answering the questions of the electronic triage diary. Importantly, patients were taught to put more trust into their bodily knowledge than the science-based knowledge of the telecare technology. I suggest that the experience of nurses involved in these courses may provide a useful resource for the future development of the telecare system investigated in this thesis. In this respect the involvement of one of these nurses in the CTA workshops I organized for this research can be considered as a first step in this direction.

7.2.4 The importance of communication

In order to enable patients to fit the self-management support of telecare technologies to their individual situations and incorporate experience-based knowledge into the generated advice, it is important to include substantial means of communication in the design of telecare technologies.

In my research almost all patients mentioned they wanted the opportunity of communication with their health-care professional while being guided in their self-management by the telecare technology (i.e. most patients preferred to communicate about their health problems with other humans). In other words, in order to achieve successful self-management practices supported by telecare technologies, sufficient communication opportunities for patients should be enabled. In this respect, my research confirms previous studies on contemporary

¹¹⁴ Of course experience-based knowledge can also be unreliable, meaning it does not reflect physical reality. In that case a (tele)monitoring device can correct subjective experiences of a disease (Pols, 2012, p. 67).

telecare technologies that emphasize the importance of communication technologies in providing care at a distance.

Studies on the use of telecare technologies for heart patients, for example, illustrate that the telephone still plays a major role in the contact between health-care professionals and patients (Oudshoorn, 2011, p.101).¹¹⁵ Based on ethnographic studies of telecare practices, Pols has suggested that these care practices can best be portrayed as “together-management” (2012, p. 75). Whereas the term self-management seems to suggest that this kind of care is an individual endeavor, the notion of together-management depicts these care practices as a collective activity shaped by health-care professionals, technologies and relevant others together.¹¹⁶

These means of communication, however, do not have to be limited to contacts with health-care professionals only. Together-management can not only be enhanced by including technologies that support communication between patients and health-care professionals but also by including communication tools to contact other patients, family members, and the Internet. As described in chapter 6, most participants of the CTA workshops also mentioned these communication technologies as relevant to include in future designs.

7.2.5 The importance of an educational program

An important part of the self-management practices of patients using the telecare technology studied in this thesis is prestructured by not only the technical design of the artefact but also by the self-management course patients received prior to testing the system in a trial. Considering the fact that the developers of the self-management course were familiar with the telecare technology and experience-based knowledge of patients, it is not surprising that the educational program incorporated various forms of self-management. The nurse practitioner responsible for the course knew by experience the importance of bodily related

¹¹⁵ E.g. Oudshoorn (2011) describes how telecare nurses used the telephone to employ their practical knowledge (p. 107). In a similar vein Pols (2012) describes how call center nurses develop intimate relationships with patients via the telephone (p. 67).

¹¹⁶ This together-management is adequately illustrated by the fact that patients were invited to bring along significant others to the self-management course.

knowledge for the treatment of a disease and expected that different patients would react differently to the telecare devices.

I therefore suggest that in order to develop adequate and morally acceptable self-management practices supported by telecare technologies, a thorough educational program is important. Besides the importance of making patients acquainted with (medical) knowledge of their disease and instructing them how to use the technology, education is important to prepare patients for the fact that the potential rigidities of telecare technologies allow a more flexible approach in real life use, to inform patients about the importance of embodied knowledge in their self-management and to get patients acquainted with this new care actor entering their private spheres. The latter argument is important considering the transformations the introduction of telecare implies for patients' personal lives (see e.g. Oudshoorn, 2011, pp. 4–5). Moreover, patients almost unanimously mentioned they regarded the self-management course as a useful learning experience to cope with their disease (transcripts, patient interviews, January 2013).

The importance of education to support self-management of chronic patients is not surprising. As already described in the introductory chapter of this thesis, educational programs are important tools in the teaching of self-management tasks and problem-solving skills to patients (Lorig & Holman, 2003). My research suggests that telecare technologies may become important tools to support self-management, or better, together-management of chronic diseases, but that face-to-face educational programs remain important to support these care practices.

7.3 Integrating research results with a design approach for telecare technologies

As described earlier, the research presented in this thesis is part of the NWO program Responsible Innovation. An important aim of the program was to reflect on ethical and social aspects of new technologies from the design phase onwards.¹¹⁷ In this thesis I reflected on ethical and social aspects of telecare technologies and

¹¹⁷ <http://www.nwo.nl/en/research-and-results/programmes/responsible+innovation> (last accessed 12-05-2014).

suggested the approach of CTA (chapter 6) to include them from the design phase onwards. In this section I present guidelines I developed together with my supervisors Valerie Jones and Nelly Oudshoorn, enabling developers to anticipate and build on the insights this research generated for the design of telecare technologies for chronic patients.

7.3.1 Guidelines for anticipating future care in scenario-based design

Based on the insights of this research, I concluded that telecare technologies can become successful and morally acceptable tools to contribute to solving the problem of the growing demand for care only if patients are enabled to develop adequate self-management practices.

This research illustrated that telecare technologies participate differently in enabling and/or constraining self-management practices for chronic patients. Some patients develop adequate practices in living with their disease with the incorporation of a compliant form of self-management in the telecare technology, while others thrive better with a telecare system that supports a more autonomous form of self-management (i.e. adequate forms of self-management supported by telecare technologies vary per patient). This research also illustrated that the moral acceptability of telecare technologies would improve with the incorporation of various forms of self-management. I therefore suggested incorporating multiple scripts supporting various forms of self-management into the design of telecare technologies.

To explore what scripts could be incorporated into the design of a telecare technology, we suggest drawing from insights developed in the field of Scenario-Based Design (SBD). SBD has been defined as “a family of techniques in which the use of a future system is concretely described at an early point in the development process” (Rosson & Carroll, 2002, p. 1032). These design methods have been applied in a variety of ways in the development of telecare technologies and have proven to be effective in user requirements elicitation. Huis in ‘t Veld et al. (2010) for instance adapted the People-Activities-Context-Technology (PACT) framework together with principles of evidence-based medicine to develop a guideline for constructing the content of scenarios to describe new teletreatment services. However, SBD has not been used explicitly in telecare as the prior creative step of imagining alternative future self-management forms for patients. We therefore

propose to extend the reach of SBD with the objective of exploring and discovering new scripts based on various forms of patient self-management, which could contribute to developing telecare technologies containing multiple scripts.

Based on the analysis of the design and use practices described in this thesis, we developed guidelines for an SBD approach to incorporate various forms of self-management in telecare technologies for chronic patients. We distinguish five key features that should be taken into account in the self-management scenarios: 1) frequency of use; 2) presentation of data; 3) feedback on activity level; 4) monitoring health condition; and 5) treatment/medication. To avoid discrepancies between design and use as described in this thesis, we suggest developing telecare technologies that are able to vary the incorporation of these features in their design.

First, explicit consideration of frequency of use of the telecare system is important to take into account because it can be based on different requirements varying from the collection of more or less continuous data, which requires compliant behavior, to adjusting the frequency to the daily routines of patients or patients' free choice, which support respectively the first, second and third forms of self-management.

Second, the design should address the ways in which the monitoring data are presented. A compelling way of presenting data (e.g. directive text messages or alert icons) might enable patient support via the first form of self-management. Science-based presentation of data may be appropriate to support science-educated patients to become proto-professionals, according to the second form of self-management. An interactive system that invites patients to comment on the data is useful to support the third form of self-management.

Third, anticipation of appropriate forms of self-management should include an explicit reflection on the forms of feedback on patients' activity levels. Automatically generated feedback based on algorithms is appropriate to support the first and second forms of self-management because it can discipline patients to comply with activity regimes, without incorporating patients' own views and wishes. Advice generated by an interactive feedback system supports patients in taking responsibility for their behavior and educates them in balancing the advice of the system against their own experience (the third form of self-management).

Fourth, the guidelines we developed include anticipation of the requirements for monitoring patients' health conditions. Monitoring based on multiple-choice anamnesis questions on the physical condition inscribed in a triage system is appropriate to support patient compliance (the first and, to a lesser extent, second form of self-management). Designing a telecare system to support the third form of self-management would require anamnesis questions based on physical, psychological and social parameters as well as creating space for patients to report on their experiences with their illness.

Finally, an anticipation of what form of self-management is most desirable for the targeted patient group should reflect on the requirements for the advice on treatment/medication generated by the system. An automatically generated advice message on medication or other treatment without the possibility to discuss this with health-care professionals is desirable to support the first and second form of self-management because it disciplines patients to follow instructions blindly. In contrast, an interactive software system enables health-care professionals and patients to change medication in a shared decision-making process. This design supports the third form of self-management, because it is based on cooperation between health-care professionals and patients and makes them co-responsible for decisions on medication (thus enhancing their autonomy).

In Table 7.1 we present the full overview of the guidelines. Although the guidelines are aimed at developing telecare systems for patients with COPD, they may be applied to other diseases that require monitoring of physical activity as well.

Table 7.1: Guidelines for incorporating various self-management forms in telecare systems for patients with COPD.

Self-management form	Key features of the telecare system	Guideline	Motivation
	Frequency of use		
1	Frequency of use is based on the requirement to	Describe why continuous use is required	Disease management or research requires more or

2	collect more or less continuous data	Describe what activities need to be executed by patients and health-care professionals	less continuous data. If patients don't comply with the regimen of use, the collected data will be much less useful
	Frequency of use is based on daily routines of patients	Describe the benefits of integrating use into the daily life of patients	If continuous monitoring or data collection is not required, adjustment of system use to daily routines of patients will increase acceptability and use of the system
		Describe what activities need to be executed by patients and health-care professionals	
3	Frequency of use is based on patients' free choice	Describe the relevance of patients' autonomy in deciding on frequency of use	Delegating the choice when to use the system enhances patients' responsibilities. This is preferred over daily use because the latter creates a constant awareness of the disease which may have a negative impact on quality of life
		Describe what activities need to be executed by patients and health-care professionals	
Presentation of data			
1	Science-based presentation of data or directive text messages and/or alert icons	Describe patients' level of education and decide which way of presenting data is most effective	Patients' use of data on activity levels depends on the ability to read and interpret these data,

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		Describe how a help-desk can support patients in interpreting data	which depends on their education. The use of a science-based presentation of data may hamper compliance, particularly among patients who are not educated in science.
2	Science-based presentation of data	Describe the level of education of patients that is required for reading graphs and tables. Explain how the user should read them.	The use of a science-based presentation of data is useful for science-educated patients to support them to become proto-professionals
3	Style of presentation of data on patients' demand and possibility to add comments on the data	Explain to patients why checking data on activity level is useful for self-management and that patients can choose to view graphs and tables, or icons and text messages Describe how patients can add comments	Inviting patients to comment on the data provides an incentive to check the data. The comments provide an extra source of information for health-care professionals
Feedback on activity level			
1	Automatically generated feedback based on an	Describe how feedback on activity levels is	An automated, univocal advice disciplines patients

2	algorithm	inscribed in the telecare system	to comply with the activity regime
	Automatically generated feedback based on an algorithm	Describe how feedback on activity levels is inscribed in the telecare system Explain to patients how the advice is derived from the data	An explanation of how the telecare system generates advice is important in educating patients to become proto-professionals
3	Advice generated by an interactive feedback system	Describe how feedback is based on interactions between the advice of the system and the input of patients	An interactive system supports patients to take responsibility and educates them in balancing the advice of the system against their own experience
Monitoring health condition			
1	Monitoring is based on multiple-choice anamnesis questions on the patient's physical condition and inscribed in a triage system	Describe what questions are used in the triage system and how they can be formulated in a compelling way Describe what activities need to be executed by patients to fill out the anamnesis questions	Monitoring based on a triage system supports patients' compliance

Conclusions and recommendations

2	Monitoring is based on multiple-choice anamnesis questions on the patient's physical condition and inscribed in a triage system	<p>Describe what questions are used in the triage system and how they can be formulated in an educating way</p> <p>Explain to patients why these questions are important for monitoring their health condition</p>	An explanation of the rationale underlying the anamnesis questions enhances patients' knowledge of their disease
3	<p>Anamnesis questions are based on physical, psychological and social parameters</p> <p>The electronic triage diary includes space for patients to report on their experiences with their illness</p>	<p>Describe what questions about the physical, psychological and social wellbeing of patients will be included in the electronic triage diary</p> <p>Describe the activities of patients, i.e. filling out the questionnaire and reporting their own experiences with their illness</p> <p>Explain to patients why it is relevant to report their own experiences</p>	<p>Including psychological and social parameters will enrich the sources for anamnesis and support patients to learn to live with their disease</p> <p>Creating space for reporting their own knowledge and experiences enriches the sources for anamnesis and enhances patients' autonomy in coping with their disease</p>

	Treatment/medication		
1	Automatically generated advice on medication is based on the anamnesis of the triage system	Describe how changes in medication are decided by the telecare system Describe the activities of patients, i.e. that they always have to follow the advice	An automated compelling advice disciplines patients to follow the instructions blindly
2	Automatically generated advice on medication is based on the anamnesis of the triage system	Describe how changes in medication are decided by the telecare system Inform patients about the rationale for taking specific medication Describe the activities of patients, i.e. that they should contact their physician to discuss whether they should change their medication or not	An explanation of the rationale for changing medication enhances patients' knowledge of medication and their disease
3	Changing medication is based on a shared decision by health-care professionals and	Describe how decisions on medication decided by the patients in consultation with their	Making patients co-responsible for decisions on medication creates a positive attitude towards

	patients, supported by an interactive software system	physician	taking medication and enhances patients' autonomy
	The decision on changing medication is based on cooperation between patients and professionals		

7.3.2 But guidelines are not enough

Summarizing, I conclude that a viable future of telecare technologies for chronic patients highly depends on the incorporation of adequate forms of self-management. Incorporation of merely compliant forms of self-management leads to misuse or nonuse of telecare technologies and reduces the moral acceptability of these technologies for future health care. I therefore argue that telecare technologies should be developed in a creative and long-lasting collaboration between designers, health-care professionals and patients in which the experiences of the two latter groups should play an important role. In this respect, the method of CTA developed in this thesis maybe useful because it enhances the reflection and learning of social and ethical issues regarding the design and introduction of these technologies by multiple stakeholders. Kiran et al. (2014) refer to this approach as ethical CTA (eCTA). Yet their conceptualization of eCTA predominantly entails the development of *theoretical* building blocks for the integration of ethical reflections of new technologies with CTA approaches.¹¹⁸ In this thesis, however, I developed an

¹¹⁸ Kiran et al. (2014) introduce four principles for eCTA: 1) a focus on ethical implications of technologies at the micro-level; 2) addressing ethics of technology in terms of technology accompaniment rather than assessment from an outsiders perspective; 3) a focus on the co-shaping of both design and appropriation of technological mediations; and 4) addressing practices of subjectivation, also by nonusers of technologies.

eCTA methodology *in practice*, which may be useful for guiding the development of telecare technologies. This is illustrated from applying a bottom-up approach to the methodology (by inviting patients to the workshops) and by introducing creative design approaches. Nevertheless, in order to be able to apply the suggested approach for the development of telecare technologies aimed at incorporating more adequate forms of self-management, current short-term research funding regimes need to be reconsidered.¹¹⁹

¹¹⁹ This is especially important since research and development projects in an academic setting are highly configured by the rules and protocols of (often European) funding regimes (see chapter 3 of this thesis).

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Samenvatting in het Nederlands

Technologieën van therapietrouw? Telezorg technologieën en zelfmanagement praktijken van patiënten met een chronische aandoening.

Telezorg technologieën zijn technologische hulpmiddelen die ondersteuning bieden bij het leveren van zorg op afstand met behulp van informatie- en communicatie technologieën (ICTs). Beleidsmakers en producenten beloven dat telezorg technologieën een bijdrage kunnen leveren aan het oplossen van het probleem van de groeiende vraag naar gezondheidszorg als gevolg van een vergrijzende bevolking, een toename van het aantal chronische zieken en een veronderstelde afname van personeel in de gezondheidszorg.

Deze beloften zijn gebaseerd op de aanname dat telezorg technologieën de gezondheidszorg efficiënter zullen maken omdat ze bepaalde taken en verantwoordelijkheden die voorheen door artsen werden verricht kunnen delegeren naar goedkopere zorgverleners, technologieën en patiënten. Bovendien wordt er verondersteld dat met behulp van telezorg technologieën patiënten een actievere bijdrage kunnen leveren aan hun eigen zorgverlening.

Nader beschouwd liggen er twee benaderingen aan deze beloften ten grondslag: Enerzijds wordt er verwacht dat telezorg technologieën gedeeltelijk mensen zullen vervangen en zorgtaken van patiënten over zullen nemen om de zorg efficiënter te maken. Anderzijds wordt er verwacht dat door de inzet van telezorg technologieën de verantwoordelijkheid van patiënten zal toenemen om voor zichzelf te zorgen. Deze in potentie conflicterende benaderingen worden zichtbaar in de manier waarop ideeën over zelfmanagement worden opgenomen in telezorg technologieën.

Medisch ethicus Maartje Schermer onderscheidt drie vormen van zelfmanagement die door telezorg technologieën kunnen worden ondersteund. Kenmerkend voor de eerste vorm van zelfmanagement is dat patiënten alleen enkele praktische taken voor hun zorgverlening overnemen die voorheen door een zorgprofessional werden uitgevoerd, zoals het meten van gewicht of bloeddruk. Patiënten worden als het ware een verlengstuk van hun zorgverlener, maar worden niet betrokken bij het nemen van beslissingen over hun zorg. Hierdoor kan de gezondheid van patiënten verbeteren maar ze worden niet gestimuleerd hun ziekte

te managen volgens hun eigen wensen. Met andere woorden, hun autonomie wordt niet vergroot.

Karakteristiek voor de tweede vorm van zelfmanagement is dat patiënten wordt geleerd op een bijna professionele manier met hun ziekte om te gaan. Ze worden niet alleen betrokken bij het doen van metingen maar er wordt hen ook geleerd hoe ze deze meetresultaten moeten interpreteren en welke actie ze kunnen ondernemen om hun gezondheid te verbeteren. Patiënten leren hoe ze medische richtlijnen kunnen volgen en krijgen de bevoegdheid om hun levensstijl aan te passen. Echter, net zoals bij de eerste vorm van zelfmanagement worden patiënten niet gestimuleerd om hun leven te leiden volgens hun eigen inzichten en wensen. Ook bij deze vorm van zelfmanagement wordt de autonomie van patiënten niet vergroot. Ze worden gestimuleerd om richtlijnen te volgen die louter gebaseerd zijn op medische kennis.

Kenmerkend voor de derde vorm van zelfmanagement is dat patiënten worden gestimuleerd om een eigen manier te vinden om met hun aandoening om te gaan, gebaseerd op eigen wensen en inzichten. Deze hoeven niet noodzakelijkerwijs samen te vallen met medische richtlijnen, maar ze kunnen wel de kwaliteit van leven van patiënten verbeteren. Cruciaal voor deze vorm van zelfmanagement is dat op ervaring gebaseerde kennis van patiënten wordt opgenomen in voorgeschreven behandelingen en richtlijnen voor het omgaan met hun chronische aandoening. Daarnaast wordt deze vorm van zelfmanagement gekenmerkt door het feit dat de relatie tussen patiënten en zorgverleners niet alleen is gebaseerd op het bevorderen van therapietrouw maar meer op samenwerking en overeenstemming over de behandeling. In tegenstelling tot de eerste en tweede vorm van zelfmanagement wordt bij deze vorm niet alleen het welzijn van patiënten verbeterd, maar wordt ook hun autonomie gestimuleerd.

Schermer concludeert dat hedendaagse telezorg technologieën vooral vormen van zelfmanagement ondersteunen die zijn gericht op het vergroten van de therapietrouw van patiënten door het volgen van medische richtlijnen te ondersteunen. Hierdoor blijft er weinig ruimte over om de autonomie van patiënten te vergroten. In plaats van het delegeren van taken en verantwoordelijkheden aan patiënten, nemen deze technologieën juist verantwoordelijkheden over van hen.

Echter, vanuit de literatuur is bekend dat er vaak een discrepantie is tussen het geplande gebruik van een technologie en het uiteindelijke gebruik. Bovendien spelen eindgebruikers een actieve rol in het vormgeven van technologieën en kunnen zij deze op andere manieren gebruiken dan ontwerpers in eerste instantie voor ogen hadden. Met andere woorden, terwijl ontwerpers telezorg technologieën ontwikkelen die vooral gericht zijn om therapietrouw van patiënten te ondersteunen (zoals Schermer veronderstelt), kan de uiteindelijke gebruikspraktijk hele andere vormen van zelfmanagement aan het licht brengen. Daarnaast spelen ethische kwesties een rol rond de implementatie en gebruik van telezorg technologieën. Is het wenselijk om technologieën te ontwikkelen in de gezondheidszorg die patiënten ‘dwingen’ om medische richtlijnen te volgen of is het gewenster om deze in te zetten om patiënten hun leven te laten leiden volgens hun eigen wensen en voorkeuren?

Het is dus aannemelijk dat telezorg technologieën alleen succesvolle en moreel geaccepteerde instrumenten in de gezondheidszorg zullen worden als patiënten in staat worden gesteld adequate manieren van zelfmanagement te ontwikkelen. Om dit te bereiken zal de spanning tussen enerzijds het geven van verantwoordelijkheid en autonomie aan patiënten en anderzijds het delegeren van controle aan technische apparaten moeten worden opgelost. De leidt tot de centrale vraag van dit onderzoek:

Op welke manier spelen telezorg technologieën een rol bij het ondersteunen of beperken van zelfmanagement praktijken van chronische patiënten?

Om deze ontwerp- en gebruikspraktijken beter te begrijpen zullen nieuwe theoretische inzichten moeten worden ontwikkeld. Om te analyseren welke vormen van zelfmanagement zijn ingeschreven in het ontwerp en worden gepraktiseerd tijdens het gebruik van telezorg technologieën kunnen inzichten uit het wetenschapsgebied Science and Technology Studies (STS) een belangrijke bijdrage leveren. De concepten *configuratie van de gebruiker*, *configuratie van ontwerpers*, *script* en *actieprogramma* zijn nuttige instrumenten om de mens-technologie relaties die centraal staan in dit proefschrift te analyseren.

De centrale onderzoeksvraag wordt opgedeeld in vijf afzonderlijke deelvragen die elk in een afzonderlijk hoofdstuk van dit proefschrift worden behandeld. Na de inleiding in hoofdstuk 1 wordt in hoofdstuk 2 de eerste deelvraag gesteld, namelijk: *Welke opvattingen met betrekking tot zelfmanagement van patiënten worden er tijdens het ontwerp ingeschreven in telezorg technologieën?* Door het uitvoeren van een scriptanalyse van het ontwerp van een hedendaagse telezorg technologie voor patiënten die lijden aan een chronische longaandoening (COPD) laat het hoofdstuk zien dat er een combinatie van zowel de eerste als de tweede vorm van zelfmanagement is ingeschreven in de telezorg technologie. De derde vorm van zelfmanagement is nagenoeg afwezig. Daarnaast laat de analyse zien dat er een voorkeur wordt gegeven aan een wetenschappelijke representatie van informatie aan de gebruikers wat opmerkelijk is aangezien vanuit de literatuur bekend is dat COPD patiënten over het algemeen lager opgeleid zijn en de ziekte met name voorkomt bij oudere mensen die wellicht niet vertrouwd zijn met deze manier van weergeven van data. Bovendien blijkt uit de analyse dat de adviezen en behandelvoorschriften van de telezorg technologie vooral gebaseerd zijn op medisch wetenschappelijke kennis en niet op ervaringsdeskundigheid van patiënten.

In hoofdstuk 3 wordt onderzocht waarom de derde vorm van zelfmanagement nagenoeg afwezig is in de telezorg technologie, door het stellen van de volgende deelvraag: *Hoe kunnen we de praktijk van het ontwerpen van telezorg technologieën begrijpen?* Welke aspecten spelen een doorslaggevende rol bij het feitelijke ontwerpproces en waarom zijn deze zo belangrijk? Door het interviewen van de ontwikkelaars van de telezorg technologie wordt duidelijk dat er onder de auteurs van het onderzoeksvoorstel in eerste instantie wel ideeën waren om het toekomstige gebruik van de technologie voor te structureren door het opnemen van de derde vorm van zelfmanagement in het ontwerp. Het hoofdstuk maakt echter duidelijk dat deze configuratie van de gebruiker niet automatisch leidt tot een artefact dat aan overeenkomstige ontwerpeisen voldoet. Het ontwerpproces van een technologie wordt immers niet alleen bepaald door ontwerpers. Ontwerpers worden op hun beurt ook gevormd door de omgeving waarin ze werken. In het geval van het ontwerpproces van de betreffende telezorg technologie waren dit met name de instanties die het onderzoeksproject

financierden. Deze configuratie van ontwerpers resulteerde in het inschrijven van de eerste en tweede vorm van zelfmanagement in de telezorg technologie in plaats van de derde vorm.

In hoofdstuk 4 staat de vraag centraal *welke ideeën met betrekking tot zelfmanagement aan patiënten worden geleerd voordat ze telezorg technologieën gaan gebruiken*. Vanuit de STS literatuur is bekend dat niet alleen ontwerpers het toekomstig gebruik van een technologie bepalen, maar dat de eindgebruikers vaak zelf voor een belangrijk deel kunnen invullen hoe een technologie gebruikt gaat worden. In het geval van de telezorg technologie werd het eindgebruik mede beïnvloedt door hoe gebruikers wordt geleerd met de technologie om te gaan. In de analyse van de zelfmanagementcursussen die toekomstige gebruikers van de telezorg technologie volgden kwam naar voren dat patiënten werd geleerd om hun ziekte op bijna professionele manier te managen. Echter, hen werd tevens geleerd niet elke instructie van het telezorg systeem strikt op te volgen, bij twijfel contact op te nemen met hun zorgverlener en hun ervaringskennis met hun aandoening te prefereren boven de adviezen van de telezorg technologie. Het hoofdstuk concludeert dan ook dat de ideeën over zelfmanagement die patiënten werden geleerd voordat ze de telezorg technologie gingen gebruiken voornamelijk gebaseerd waren op de derde vorm van zelfmanagement.

Nadat in de voorgaande hoofdstukken het script, het ontwerpproces en de instructies voor het gebruik van telezorg technologie zijn geanalyseerd richt hoofdstuk 5 zich op de vraag *hoe telezorg technologieën de perceptie van patiënten van hun ziekte mediëren en hun handelingen bij het gebruik van het systeem vormgeven*. Het is vooral interessant om te kijken of deze overeenkomen met de vormen van zelfmanagement zoals deze zijn ingeschreven in het ontwerp van het systeem (hoofdstuk 2) en hoe patiënten geleerd werd de telezorg technologie te gebruiken (hoofdstuk 4). Het hoofdstuk beschrijft hoe de telezorg technologie medieert in percepties van patiënten van hun ziekte, zichzelf en hun relatie met hun zorgverleners. Het centraal stellen van bepaalde fysiologische kenmerken van hun ziekte werd door sommige patiënten als een beperking ervaren. Zij gaven aan mogelijkheden in het systeem te missen om hun eigen, op ervaring gebaseerde, kennis te delen of om overleg te plegen met hun zorgverlener. Verder werd duidelijk dat het gebruik van de telezorg technologie patiënten in staat stelde

zichzelf als actieve individuen te beschouwen die hun eigen welbevinden kunnen beïnvloeden. Daarnaast stelde de telezorg technologie patiënten in staat autonomer te worden met betrekking tot het nemen van medicatie en beïnvloedde het hun perceptie van hun relatie met hun zorgverlener omdat ze zich assertiever durfden op te stellen.

De analyse van de gebruikspraktijken van de telezorg technologie laat bovendien zien hoe elke patiënt zijn of haar eigen interpretatie van het script van de technologie maakte. In die zin kan er een combinatie van de drie vormen van zelfmanagement in het gebruik worden onderscheiden. De eerste vorm van zelfmanagement kan worden onderscheiden wanneer patiënten de adviezen die de telezorg technologie genereert blindelings opvolgden. De tweede vorm kan worden waargenomen wanneer patiënten interpretatieve taken van zorgverleners overnamen zoals het diagnosticeren van hun gezondheidstoestand of het interpreteren van grafieken en meetgegevens. Hoewel hoofdstuk 2 duidelijk maakte dat het script van de telezorg technologie niet was gericht op het ondersteunen van de derde vorm van zelfmanagement, blijkt dat in de gebruikspraktijk deze vorm wel degelijk waarneembaar is. Patiënten integreerden de telezorg technologie in het patroon van hun dagelijks leven en vertrouwden op hun eigen ervaringskennis van hun ziekte bij het gebruik ervan. Bovendien blijkt dat sommige patiënten besloten af te wijken van het advies dat gegenereerd werd door de telezorg technologie. Ze hielden zich niet aan het zogenaamde ingeschreven actieprogramma van het artefact, maar ontwikkelden zogenaamde antiprogramma's in het gebruik ervan. Het hoofdstuk concludeert dat het inschrijven van bepaalde vormen van zelfmanagement in het ontwerp van de technologie niet noodzakelijk leidt tot corresponderende gebruikspraktijken van patiënten. Welke vorm van zelfmanagement uiteindelijk ontstaat, is het resultaat van een interactief proces tussen elke individuele patiënt en de telezorg technologie waarin de creativiteit en persoonlijke voorkeuren van patiënten, hun gezondheidstoestand, dagelijkse routines, de flexibele interpretatie van de scripts en de manier waarop patiënten wordt geleerd met de technologie om te gaan een belangrijke rol spelen.

Naast het genereren van theoretische gefundeerde, empirische inzichten is een belangrijk doel van dit onderzoek deze inzichten terug te koppelen naar de

ontwerppraktijk van telezorg technologieën. Dit leidt tot de laatste deelvraag die centraal staat in hoofdstuk 6: *Hoe kunnen we de ervaringen en inzichten van ontwikkelaars en gebruikers over hoe telezorg technologieën zelfmanagement van patiënten moet ondersteunen terugkoppelen naar het ontwikkelingsproces?* Het hoofdstuk begint met de constatering dat er een kloof bestaat tussen de vormen van zelfmanagement die door ontwerpers ingeschreven zijn in de telezorg technologie en de perceptie en praktisering van deze vormen door gebruikers. Echter, om patiënten in staat te stellen adequate, door telezorg technologieën ondersteunde zelfmanagement praktijken te ontwikkelen is een betere aansluiting tussen de ontwerp- en het gebruikspraktijk wenselijk. Om deze aansluiting en de maatschappelijke inbedding van technologieën te verbeteren is binnen het wetenschapsgebied van STS een reflexieve methode ontwikkeld genaamd Constructive Technology Assessment (CTA). Een veel gebruikte aanpak binnen CTA is het in een vroeg stadium samenbrengen van verschillende stakeholders die betrokken zijn bij het socio-technische ontwikkelingsproces van een technologie zodat zij van elkaars inzichten kunnen leren. In dit hoofdstuk worden twee CTA workshops beschreven waarin betrokkenen bij het ontwerp en gebruik van de telezorg technologie zijn samengebracht. De twee workshops waren verschillend qua opzet, diverse stakeholders waren uitgenodigd en er werden meerdere methoden toegepast om de interactie tussen stakeholders te stimuleren. De workshops bleken nuttige instrumenten te zijn waarin de verschillende stakeholders in staat werden gesteld kennis te maken met elkaars ‘wereld’ zodat men van elkaars standpunten kon leren. Met name het deelnemen van patiënten als eindgebruikers van de technologie aan de workshops, de zogenaamde ‘bottom-up’ benadering, bleek succesvol. Daarnaast lieten de workshops zien dat het toepassen van creatieve methoden, anders dan het uitwisselen van ideeën via (geschreven) woorden, bijzonder nuttig kan zijn om stakeholders van uiteenlopende sociaaleconomische en educatieve achtergronden hun standpunten en meningen te laten delen.

Na een korte recapitulatie van de onderzoeksvragen wordt in hoofdstuk 7 een antwoord geformuleerd op de centrale vraag van dit proefschrift, namelijk: *Op welke manier spelen telezorg technologieën een rol bij het ondersteunen of beperken van zelfmanagement praktijken van chronische patiënten?* Voor de

beantwoording van deze vraag is het belangrijk gebleken om de ‘blackbox’ van zowel het concept ‘zelfmanagement’ als ‘telezorg technologie’ nader te beschouwen. Uit het onderzoek is gebleken dat de onderverdeling van Schermer in drie verschillende vormen van zelfmanagement hiervoor een bruikbaar heuristisch middel is. Daarnaast is duidelijk geworden dat voor de analyse die centraal staat in dit proefschrift het opdelen van de telezorg technologie in aparte apparaten en applicaties een vruchtbare benadering is omdat het heeft bijgedragen aan een zo gedetailleerd mogelijk beeld van hoe de telezorg technologie zowel bepaalde vormen van zelfmanagement mogelijk maakt, maar ook een beperkende werking kan hebben voor andere vormen van zelfmanagement.

De empirische hoofdstukken laten zien dat er verschillen zijn tussen de vormen van zelfmanagement zoals deze ingeschreven zijn in de telezorg technologie en welke zich openbaarden tijdens de zelfmanagementcursus en de uiteindelijke gebruikspraktijken. Dit leidt tot de conclusie dat er geen lineair verband bestaat tussen de manier waarop zelfmanagement is ingeschreven in het ontwerp van telezorg technologieën, hoe het aan patiënten wordt geleerd en hoe het wordt gepraktiseerd tijdens het gebruik. Integendeel, elk deel in de ontwikkeling van de technologie had zijn eigen dynamiek wat betreft het articuleren en praktiseren van wat zelfmanagement eigenlijk inhoudt. De empirische hoofdstukken laten ook zien dat er verschillen zijn tussen de actoren met betrekking tot welke vormen van zelfmanagement hun voorkeur heeft. Waar uit de scriptanalyse blijkt dat de ontwikkelaars prioriteit gaven aan een telezorg technologie gebaseerd op het bevorderen van therapietrouw, laat de analyse van de zelfmanagementcursus en het daadwerkelijk eindgebruik zien dat zowel de verpleegkundige als de patiënten de voorkeur gaven aan vormen van zelfmanagement die meer gebaseerd zijn op overeenstemming en samenwerking tussen patiënten en zorgprofessionals. Dit leidt tot de conclusie dat er een discrepantie heerst tussen de ingeschreven vormen van zelfmanagement in de technologie en de vormen die zich openbaren tijdens het leren omgaan met het systeem en het uiteindelijk gebruik.

Een mogelijke verklaring voor de kloof tussen ontwerp- en gebruikspraktijken van telezorg technologieën is te vinden in een reductionistische visie op gezondheidszorg en een instrumentele benadering van de rol van

technologie. De reductionistische visie op gezondheidszorg betreft de veronderstelling dat telezorg de efficiëntie kan verhogen en de kosten van de gezondheidszorg kan verminderen, terwijl andere wijzigingen in verband met de invoering ervan grotendeels worden genegeerd. De instrumentele benadering van de rol van technologie komt tot uiting in de opvatting dat technologie een neutraal middel is om een bepaald doel te bereiken, terwijl er aan voorbij wordt gegaan dat door de inzet van technologie problemen vaak veranderen in plaats van dat ze worden opgelost.

Door het ontwerpen van een telezorg technologie die eenzijdig gebaseerd is op het stimuleren van therapietrouw wordt enerzijds getracht de efficiëntie van de gezondheidszorg te verhogen door te veronderstellen dat patiënten een voorgeschreven medische regime (resultierend in een afnemende vraag naar gezondheidszorg) strikt zullen volgen. Anderzijds wordt er getracht de kosten van de gezondheidszorg te reduceren door taken, meestal uitgevoerd door (dure) gezondheidszorg specialisten, te verschuiven naar (minder dure) patiënten en technologieën. Dit proefschrift heeft echter aangetoond dat de veronderstelling dat patiënten het medisch regime van een telezorg-technologie strikt zullen volgen niet realistisch is. Ook de herverdeling van taken van mensen naar technologieën blijkt minder eenvoudig dan gedacht. Dit onderzoek illustreert dat professionals in de zorgverlening van chronisch zieken niet eenvoudig kunnen worden vervangen door technologie, waardoor aan de beloften van de vermindering van de uitgaven voor gezondheidszorg niet zo gemakkelijk kan worden voldaan.

Dit proefschrift suggereert om gebruik te maken van inzichten uit actor netwerk theorie (ANT) als alternatief voor de instrumentele visie op technologische veranderingen. ANT beschouwt mensen en technologieën niet als enkelvoudige entiteiten met vooraf gedefinieerde identiteiten en kenmerken die onafhankelijk van elkaar bestaan. Ze zijn onderdeel van een heterogeen netwerk, waarin ze wederzijds worden gevormd en geconstitueerd tijdens ontwerp en gebruikspraktijken. Telezorg technologieën kunnen dus niet als geïsoleerde instrumenten worden beschouwd die economische of sociaal-culturele veranderingen bepalen. Taken en verantwoordelijkheden met betrekking tot zelfmanagement van patiënten kunnen niet worden verschoven van mens naar

technologie zonder te anticiperen op hoe deze herverdeling de relatie tussen mens en technologie ook op andere manieren transformeert.

Om toch een bijdrage te leveren aan de oplossing van het probleem van de groeiende vraag naar gezondheidszorg voor chronische aandoeningen pleit dit proefschrift voor het ontwikkelen van telezorg technologieën die verschillende vormen van zelfmanagement (kunnen) ondersteunen. Deze flexibele oplossingen kunnen worden bereikt door het ontwikkelen van een combinatie van meerdere scripts in het ontwerp van telezorg technologieën. Hierdoor zou de mogelijkheid ontstaan om tot een vorm van zelfmanagement te komen die het beste bij elk individu en zijn of haar zorgsituatie past. Daarnaast kan deze flexibiliteit in zelfmanagement ook bijdragen aan de morele aanvaardbaarheid van telezorg technologieën doordat patiënten niet worden opgezadeld met een telezorg technologie die niet aansluit bij hun wensen. Patiënten zouden in plaats daarvan in samenspraak met hun arts en omgeving kunnen kiezen of en welke ondersteuning ze willen (of in staat zijn te gebruiken) bij het zelf ‘managen’ van hun aandoening. Een gezamenlijk besluitvormingsproces van zorgprofessionals en patiënten zou voor een goede balans kunnen zorgen tussen enerzijds het geven van verantwoordelijkheid en autonomie aan patiënten en anderzijds het delegeren van controle aan technische apparaten.

Naast het belang van een gezamenlijk besluitvormingsproces over welke vorm van zelfmanagement het beste past bij elke individuele patiënt toont dit proefschrift aan dat zelfmanagementondersteuning door telezorg technologieën niet alleen gebaseerd moet zijn op medisch wetenschappelijke kennis. In de eerste plaats omdat er dan geen rekening kan worden gehouden met individuele omstandigheden van patiënten. In de tweede plaats omdat medisch wetenschappelijk kennis vaak gebaseerd is op gemiddelde waarden van gegevens afkomstig van gerandomiseerde gecontroleerde onderzoeken, terwijl individuele patiënten zich heel anders kunnen gedragen of anders reageren op bepaalde medicijnen. Tenslotte is niet elke patiënt in staat om ingewikkelde medisch wetenschappelijke kennis op de juiste manier te interpreteren.

Om patiënten in staat te stellen om de telezorg technologie aan te passen aan hun individuele situatie en de aangeboden zelfmanagementondersteuning juist te interpreteren is het belangrijk dat er voldoende mogelijkheden zijn ingebouwd

in het ontwerp van de technologie voor goede communicatie. Mede gezien het feit dat zelfmanagement in de zorg geen individuele inspanning is maar een activiteit die patiënten samen met professionals, medepatiënten en naasten uitvoeren zijn voldoende communicatiemiddelen noodzakelijk.

Naast het belang van communicatie toont dit proefschrift aan dat voor het ontwikkelen van door telezorg technologie ondersteunde zelfmanagement praktijken een gedegen educatief programma van groot belang is. Immers, een belangrijk deel van de in dit proefschrift beschreven zelfmanagementpraktijken van patiënten werd voorgestructureerd door de zelfmanagementcursus die patiënten kregen voorafgaand aan het gebruik van de technologie. Door middel van educatie is het mogelijk patiënten te onderwijzen over (medische) kennis van hun ziekte, hen te instrueren hoe de technologie te gebruiken en ze te informeren over het belang van ervaringskennis voor succesvol zelfmanagement van hun aandoening.

Samenvattend concludeert dit proefschrift dat telezorg technologieën alleen succesvol en moreel aanvaardbare instrumenten kunnen worden om bij te dragen aan het oplossen van het probleem van de groeiende vraag naar zorg als patiënten in staat worden gesteld om adequate zelfmanagementpraktijken te ontwikkelen. Welke vorm van zelfmanagement adequaat is blijkt per patiënt te verschillen. Bovendien zal de morele aanvaardbaarheid van telezorg technologieën verbeteren met de integratie van verschillende vormen van zelfmanagement. Er wordt daarom gepleit voor het opnemen van meerdere scripts in het ontwerp van telezorg technologieën die diverse vormen van zelfmanagement kunnen ondersteunen. Een mogelijke manier om dit doel te bereiken is het opnemen van deze scripts in de ontwerpmethode Scenario Based Design (SBD). Deze ontwerpmethode is voorheen een succesvol instrument gebleken voor het ontwerpen van telezorg technologieën. Uit het onderzoek komt naar voren dat er voor variatie in vormen van zelfmanagement in het ontwerp rekening moet worden gehouden met: 1) de frequentie van het gebruik van de apparatuur; 2) de manier van (re)presentatie van gegevens; 3) hoe er feedback wordt gegeven; 4) op welke manier de gezondheidstoestand wordt gemonitord; en 5) hoe de behandeling/ medicatie wordt bepaald.

Het proefschrift sluit af met de opmerking dat alleen het opstellen van richtlijnen voor het ontwerp van meer flexibele telezorg technologieën niet voldoende is. Om de mogelijkheden te creëren nieuwere en betere ontwerpmethoden te exploreren moet het huidige regime van korte-termijn financiering van onderzoeksprojecten worden heroverwogen.

Appendices

Appendix I:

Figure 2.8: Screenshot of an overview of COPDdotCOM electronic triage diary (English translation).

Figure 2.8: Screenshot of an overview of COPDdotCOM electronic triage diary (English translation).

You are logged in as: Mr. B. - patient

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Diary

Overview of a Week week 22, 2010 ⏮ ⏪ ⏩ ⏭

Advice of October 11: Do not (yet) start with treatment

	mo 31-5	tu 1-6	we 2-6	th 3-6	fr 4-6	sa 5-6	su 6-6
Complaints							
<div style="display: flex; justify-content: space-between; font-size: 0.8em;"> ■ = normal ■ = slightly more </div> <div style="display: flex; justify-content: space-between; font-size: 0.8em;"> ■ = clearly more □ = empty </div>	■	■	■	■	■	■	■
Prednisolone							
Antibiotics							
Block 1							
More complaints than normal?	■	■	■	■	■	■	■
Block 2							
Shortness of breath	■	■	■	■	■	■	■
Giving up mucus?	■	■	■	■	■	■	■
Color of coughed up mucus	■	■	■	■	■	■	■
Block 3							
Coughing?	■	■	■	■	■	■	■
Wheezing?	■	■	■	■	■	■	■
Runny nose?	■	■	■	■	■	■	■
Sore throat?	■	■	■	■	■	■	■
Metered-dose inhalers?	■	■	■	■	■	■	■
Fever?	■	■	■	■	■	■	■

Source: Hermens (2010).

Appendix II:

**Semi-structured interview question list for developers
COPDdotCOM**

INTERVIEWS Developers COPD.COM

Ivo Maathuis, University of Twente-MB-STePS

I. Introduction

1. What is your professional background (Master's Degree)?
2. What is your current position?
3. What are your current tasks?

II. COPD.COM general

1. How and when did you get involved with COPD.COM?
2. What exactly is your contribution to COPD.COM?
3. What is your current position within COPD.COM?
4. What is the division of labor between you and the other team members?
5. What is the aim of COPD.COM?
6. Can you broadly explain the research trajectory of a project like COPD.COM?
7. To what extent is the content of a project like COPD.COM determined by the funding agency (in this case ZonMw)?

8. COPD.COM is a regional / national project. Does ... also participate in international projects?
9. What are the major differences with EU / international projects in terms of organization / conditions?

III. The design process

1. How does the design of a telemedicine application as COPD.COM look like on paper?
2. How is the design of COPD.COM in practice? What are the main differences?
3. What was / is the main input for the design of COPD.COM according to you?
4. Which users (groups) are all involved in the design?
5. How are these groups assembled?
6. Are (representatives of) patient groups involved?
7. How are / were they involved?
8. Which role do these user requirements have in the design eventually?
9. Are there non-users (e.g. people may experience problems with the use because of their disabilities (visual or hearing disabilities) or age (digital skills)) involved in the formulation of requirements?
10. What considerations dominantly underlie the final design decisions?

11. Which role do (research) results / experiences from previous projects play?
12. Who makes the final design decisions in COPD.COM? Particularly with regard to delegation of tasks between humans / technologies? Does that happen in the design team?
13. Are there sometimes opposing views between engineers and physicians? If so, what happens next? What discipline has the most influence on the final decision?
14. What considerations underlie the design decision to use a BAN in COPD.COM?
15. How do you think the design of COPD.COM influences healthcare practices?

IV. Development team discussions

1. How does the team that develops COPD.COM like?
2. Which people are in there? From what disciplines?
3. How (often) there is a team meeting with all project partners?
4. Which topics are discussed during team meetings?
5. Did you participate in team meetings yourself?

V. Testing

1. How is COPD.COM tested?

2. Tests from which user groups are included in future design? (Patient, nurse-practitioners, specialists, ...)
3. How does user feedback take place?
4. What happens with this feedback? What changes are made to the design?
How does feedback influence future projects?
5. How often do iteration feedback loops take place in the design process?

VI. Surveillance / autonomy

Explanation:

Autonomy of users: The extent to which patients hold responsibility to monitor their disease.

The degree of surveillance of patients by devices in the treatment of their illness: The extent to which monitoring takes place without interference and responsibility of patients.

1. Can you give an example of how patients play a more active role and take responsibility for monitoring their health in COPD.COM?
2. Can you give an example of how tasks and responsibilities are delegated to nurses in COPD.COM?
3. Can you give an example of how monitoring of patients is delegated to devices instead of nurses / doctors in COPD.COM?
4. Can you give an example of how patients and doctors / nurses transfer control over treatment to devices in COPD.COM?

5. Are design decisions taken consciously on, for example, the degree of autonomy of patients in the treatment of COPD in COPD.COM? How? Who makes that decision?
6. Are design decisions taken consciously on, for example, the degree of surveillance devices have on patients in the treatment of COPD in COPD.COM? Which functions are automated within COPD.COM or not? Who makes that decision and based on what?
7. What are important elements in the design of telemedicine devices regarding surveillance by devices and autonomy for patients / nurses?
8. Do you think that the kind of disease influences the design of telemedicine technologies regarding surveillance by devices and autonomy of patients / nurses? If so, how?
9. Do you think the balance between surveillance by devices and autonomy for patients & nurses affects the acceptance of telemedicine by patients and caregivers?
10. Can you imagine that by using COPD.COM patients feel less responsible to take care of their own condition because they are also monitored by others (including technologies) constantly?

VII. Final remarks

1. Do you have documents on the project that are relevant for my research?
2. How do you think the health care for chronic / COPD patients will look like in 10-15 years?
3. Questions / comments?

Appendix III

Observation scheme self-management course CoCo COPD application

Observation scheme self-management course CoCo COPD application

Venue:

Date:

Time:

Main question: What form of self-management (Schermer 2009) predominantly underlies the self-management courses?

General
Attendees (teachers / patients / others) (m / f and age)
Who teaches the course (function)
Course material (brochure / reader / prints)
How is the course given (PowerPoint presentation / movie / oral / class / individual)
What is the physical arrangement?
Contents
How is the course structured?

What are the main topics of the course?
What is taught to patients? (Only how to use the application or also about how to deal with COPD)? Are patients taught to use their own knowledge/ experience How?
How patients are advised to listen to their own bodies? If not, what are they advised?
How can patients consult a professional? If not, what are they advised?
How are patients involved in decision-making? If not, what are they advised?
How do patients' own views and wishes play a role? If not, what are they advised?
How are patients taught to interpret measurements and to act on them? Is there freedom to incorporate patients' own visions / views?
How are patients encouraged to find their way to deal with their condition, based on knowledge of their own body? If not, what are they advised?
How are patients taught to deal with advice on medication of the device?

Appendix IV

Semi-structured interview question list for patients CoCo trial

PATIENT INTERVIEWS COCO TRIALS

Ivo Maathuis, University of Twente-MB-STePS

Main research questions:

- **How do patients configure themselves when they use the CoCo application? Do they accept the script? Do they modify it, or do they develop anti-programs?**
- **How do they feel CoCo affects their lives. Do patients feel their own experience in dealing with their disease is enhanced/decreased?**

I. General

1. Age, gender, occupation and education (nationality/ country of origin)
2. Can you tell something about the background/ history of your lung disease? How did this come about?
3. When/ at what time were you diagnosed with COPD?

II. Experiences using the CoCo application

4. How did you like the treatment of COPD before using CoCo?
5. Which parts of CoCo do you use (and how often)?
 - i. Activity Monitoring and feedback (pedometer + PDA)
 - ii. Web portal with online training program (physiotherapy)
 - iii. Electronic triage diary (PDA + portal)

iv. Web portal to access own data

6. Could you briefly describe or show what daily actions you must perform to use CoCo?

7. Who/ how is the use of the activity meter and PDA explained?

8. What do you think of the feedback from the PDA you get?

- The graphs.

- The messages.

9. Do you always follow the instructions on your activity? (Why/ why not?)

10. How do you feel when you see your daily activity is below the reference line? What do you do?

11. What do you think of the questions of the electronic diary? And the medication instructions of the diary?

12. Do you fill in the electronic diary yourself or with help? From whom?

13. Do you always follow the instructions of the diary? (Why/ why not?)

14. Do you watch your data on the web portal? What do you do with this information?

15 What do you think about the following statements:

i. I follow the advice of CoCo blindly even though I do not always know why.

ii. I follow the advice of CoCo and I know why.

iii. I follow the advice of CoCo not always. By experience I know best what is good for me.

16. What did you think of the self-management course? Was it useful?

17. What is the most important thing you have learned from the course?

III. Dealing with health care providers

18. Do caregivers sometimes give feedback via CoCo?

19. What do you think of the feedback from the specialists using CoCo?

20. Do doctors or nurses ever contact you based on your data in CoCo? What do you think of this?

21. Can you discuss how to deal with certain symptoms with your caregivers by using CoCo?

22. When in doubt, can you contact your health care provider? If so, do you ever do that? Why/ why not?

23. Do you feel extra monitored by your doctors when using CoCo? How do you feel about this?

24. Do you get more or less freedom on how to deal with your condition by using CoCo from your caregivers?

25. Does the use of the CoCo change anything in your attitude/ contact with the lung specialist or nurse?

26. Does the use of CoCo influence for your sense of dependency from your lung specialist or nurse?

IV. Influence on the perception of your disease

27. What is the main difference between the use of CoCo and the previous way of treating your illness? What is most comfortable?
28. Do you feel you play a more active role in dealing with your COPD by using CoCo?
29. Do you feel you can incorporate your experience based knowledge in living with your disease (even if it is medically not always the optimal choice)?
30. Does the use of CoCo improve your understanding of your COPD?
31. Do you feel that you have more or less influence on dealing with your condition by the use of CoCo?
32. How has the equipment changed the way you deal with your illness?
33. Do you think this affects your overall wellbeing/ health?
34. Has this made you more calm/ confident or more restless/ insecure? (Calming effect)
35. Has something changed in the way you experience your illness by the use of CoCo?
36. Are you more or less worried about your illness by using CoCo?
37. Did you feel more or less freedom in your daily behaviour by the use of the equipment (the electronic diary/ by the activity meter)?

38. Would you rather have more flexible devices that better suit your daily life? Or would you prefer strict requirements for use, so it is clear what rules to comply with?

39. Would you rather have had more responsibility for when and how the equipment should be used?

40. What is the role of your partner when using the equipment?

V. Other

41. What are the positives about treating your illness with CoCo? And the negatives?

42. Suppose you can choose whether or not to use the device for a longer time, what you would do?

43. If you could design a similar device for your lung disease, how would it look like?

44. If you could arrange your own healthcare regarding your lung disease, how would it look like?

45. Do you have additions/ comments you want to share?

Appendix V

Program 1st CTA workshop Telecare at Home

Workshop

Telecare at Home

Place and time:

- University of Twente
- Building Ravellijs, room 1315
- Tuesday 11 January, 14.00u – 17.00u

UNIVERSITEIT TWENTE.

What to expect from this workshop?

- Discussion of the aims of the telecare device for COPD patients
- Reflection on scenarios about how telecare applications can support self-management of COPD patients
- Choices in the Design Process

Participants: Mw. Clara van Ommeren, Ir. Dennis Hofa, Ir. Harm op de Akker, Prof. Dr. Hermie Hermens, Dr. Marjolijn Brusse Prof. Dr. Miriam Vollenbroek-Hutten, Ir. Monique Tabak, Dr. Rianne Huls In't Veld, Ir. Thijs Tönls

Organization of the workshop:

Ir. Ivo Maathuis (Phd) and prof. dr. Nelly Oudshoorn, coordinator of the NWO-MVI project Telecare at home

UNIVERSITEIT TWENTE.

Aim of the workshop

Welcome to the workshop on design and development of Telecare applications in healthcare. The workshop is part of the NWO research project Telecare at home

[http://www.nwo.nl/files.nsf/pages/NWOP_87TAGL/\\$file/L_Oudshoorn.pdf](http://www.nwo.nl/files.nsf/pages/NWOP_87TAGL/$file/L_Oudshoorn.pdf)

SUMMARY OF TELECARE AT HOME

The multidisciplinary research team consists of ir. Ivo Maathuis (PhD student at STePS); dr. Asle Kiran (postdoc researcher at the Department of Philosophy, UT) and four senior researchers for supervision, coordination and co-authoring of publications (Prof. dr. Nelly Oudshoorn (STePS); prof.dr. ir. Peter-Paul Verbeek (Dept of Philosophy, UT); Prof. dr. ir. Hermie Hermens (Biomedical Engineering, UT) and dr. Val Jones (Computer Science, UT) .

This research project aims to increase understanding of how engineers can anticipate conflicting norms concerning surveillance and autonomy implied in telemonitoring technologies. These devices can monitor or diagnose patients at home by the use of information and communication technologies (ICTs) and may improve the quality of health care. The adoption of these technologies implies a transition in health care because they challenge existing distributions of tasks and responsibilities, including norms of care. The research team will conduct a constructive, ethical technology assessment to investigate the design and use practices of telemonitoring devices for chronic patients. Based on these insights they will develop tools that can support engineers to find a balance between surveillance by technological devices and control and autonomy of patients and nurses. The research is a collaborative project between social scientists, philosophers, and engineers.

The aim of the workshop is to reflect on the design process of the research project COPD.COM as executed by RRD in collaboration with MST and the University of Twente. Participants are expected to share their experiences with the design.

Rules

The workshop has an informal character. To encourage open discussion as much as possible we propose the following rules: participants to the workshop are free of speech (including organizers) and may not refer to what other participants have said (Chatham rules) for their own purposes. The insights that each of the participants gathers from the workshop are allowed to be used for their own decisions and strategies.

We would like to take up the discussion at the meeting because the workshop is part of the PhD research of Ivo Maathuis. The images will be treated confidentially and will be processed in the thesis anonymously.

PROGRAM of the WORKSHOP

14.00-14.15 Welcome

- Welcome and coffee at Ravelijn, room 1315

14.15-14.30 Introduction

- Welcome by Nelly Oudshoorn
- Round of introductions
- Introduction to the workshop by Nelly Oudshoorn and Ivo Maathuis

14.30-15.00 Session 1: Discussion on aims of the telecare device for patients with COPD.

- Participants of the workshop are asked to react to the following questions:
 1. What should the telecare system, according to you, bring about for COPD patients and what kind of care should it provide for this patient group?
 2. What should the telecare system, according to you, not bring about for COPD patients and what kind of care should it not provide for this patient group?

15.00-16.00 Session 2: CTA-scenario's

- Participants of the workshop are asked to react to the following scenario's:

SCENARIO 1: MANDATORY SELF-MANAGEMENT (COMPULSORY COMPLIANCE)

Patients take over a number of practical tasks of their caregiver. They become an "extension" of their caregiver and have no personal responsibility for their care: surveillance by automated devices.

Herman is a 54-year-old truck driver who has been an inveterate smoker since he was fourteen. As a result, he suffers from severe chronic COPD and has been forced to give up his job.

The doctor at the hospital has proposed him a remote treatment using telecare equipment, to keep Herman's condition under surveillance for 24 hours a day. Through a simple procedure a chip is implanted in his arm that can measure his blood values and activity level every 5 minutes. This treatment is necessary because it has been found that Herman does not realize that his unhealthy lifestyle is the cause of the disease. His wife was also asked to keep an eye on this. With the help of special software on his phone Herman can now see his own values with a delay of one minute. In his house equipment is installed to read out the sensor 24/7. When Herman leaves the house his data are sent using to the hospital using the wireless telephone network. A computer in the hospital keeps an eye on Herman's activity level. The doctor and nurse at the hospital, as well as his physical therapist and his general practitioner have access to his file. If the computer detects that Herman's data exceeds a preset level, Herman and his caregivers receive a message, that he

needs to adjust his activity level or that he has to take medicine. Using specially developed equipment it is verified that Herman indeed has taken the pills (i.e., has taken out of the pillbox). If it turns out he did not, Herman is called within 12 hours by a nurse asking him why he did not take his pills. If there are signs of a serious deviation in Herman's blood levels, indicating an upcoming exacerbation, a computer at the hospital automatically calls in an emergency service. An ambulance is sent to the place where Herman is located since the chip is equipped with GPS functionality. His doctor also receives a text message that Herman is hospitalized and also a close family member receives this message. The most important for his treatment is that Herman stops smoking. If he smokes, this is immediately measured by the sensor on the basis of his blood values. There is a direct signal to the computer in the hospital where his file is stored. Furthermore, his doctor, his nurse, his general practitioner and a close family member receive a text message that Herman has smoked. This is to help him stop smoking. If it turns out Herman cannot keep his hands off cigarettes within a month, Herman's treatment is stopped automatically. The health insurance company receives a message that Herman does not cooperate with the treatment of his disease, and therefore the allowance for this stops. The allowance for the special physical therapy that Herman had is also stopped.

Question: Is this way of treating COPD patients desirable? Why / why not? What are the advantages? What are the disadvantages?

15.20-15.35 Break: Coffee/ tea/ refreshments and candy bars

SCENARIO 2: AUTONOMOUS SELF-MANAGEMENT

Patients learn to manage their illness autonomous, including monitoring and interpreting measurements and making decisions about their care ('proto professionalization', De Swaan 1990).

Peter is a 54-year-old painter who has been told recently he has COPD. This is probably not due to excessive smoking, because he was a moderately smoker, but by working for years with harmful solvents in paints. Attention for these adverse effects came in the 90s of the last century, but then it was too late for Peter. Recently, Peter received an activity meter for the treatment of COPD from his lung specialist that he must wear five days a week and which communicates with his cell phone. On the phone, he can easily see whether he should take a rest or just go for a walk. He also received a computer to keep an electronic diary on a daily basis, which can generate advices about his condition. Peter understands the measured data and can also act according to it, for example by adjusting his food or exercising. Peter follows any medical directive and any advice and thus, in a practical sense, becomes less dependent on his caregivers. Thanks to the equipment compliance is enhanced, and Peter can live a longer 'healthy' life.

Question: Is this way of treating COPD patients desirable? Why / why not? What are the advantages? What are the disadvantages?

SCENARIO 3: SELF-MANAGEMENT BASED ON COOPERATION

Patients are encouraged to collaborate with their caregivers, in which their own

knowledge and experiences with their illness is equally important to the medical knowledge of caregivers.

Petra is a single widow of 68 years old and lives from her state pension and a small retirement income. Since she was 18 she has smoked two packs a day and suffers from severe COPD as a result. The doctor at the hospital has proposed remote treatment using telecare equipment. The activity level of her muscles is measured by a pedometer, which fits in her back pocket. Furthermore, she has to fill in an electronic diary once a week. If she wants, Petra can look at the screen of the electronic diary to check how her recent activity level was and decide if she wants to change this. The data is only for own use. Furthermore, she may choose to see if there is an advice to use certain medication, if she feels a bit worse and has noted this in the diary. Petra is not obliged to always wear the pedometer, but may do so if she wants. She can also use the electronic diary as she wants. She believes that she herself feels best when something is going on. If she wants she can bring along a printout of her activity level to her physiotherapist or doctor for further advice or exercises. If she has an exacerbation or feels one is coming up, she calls her GP who then sends her to the hospital. Additionally, Petra visits the hospital twice a year to determine her condition and to discuss this with her doctor or nurse practitioner. Finally, she knows when she is not doing well she can always call her GP, who can refer her to the hospital if necessary.

Question: Is this way of treating COPD patients desirable? Why / why not? What are the advantages? What are the disadvantages?

16.00-16.45 Session 3: Design choices

Participants of the workshop are asked to respond to the following questions:

1. Which "model" of self-management underlies the design of the telecare system for COPD patients?
2. Which design decisions are based on this?

16.45-17.00 Summary and conclusion

- Closing remarks by the chairman and reactions of participants

Concepts:

Autonomy of users: The extent to which patients themselves hold responsibility to monitor their disease.

Surveillance by devices: The extent to which monitoring takes place without interference from equipment and responsibility of the patient.

Acknowledgements:

Hereby, the organizers of the workshop would like to thank Haico to Kulve and Clare Shelley-Egan for the drafts and texts of the CTA workshops organized by them.

References:

"Chatham House Rule". Chathamhouse.org.uk.

<http://www.chathamhouse.org.uk/about/chathamhouserule/>. Accessed 07/06/2013.

Schermer, M. (2009) Telecare and self-management: opportunity to change the paradigm? *JMedEthics* 2009; 35:688-91

Swaan, A., & Hendriks, H. L. W. (2004). *Zorg en de staat: welzijn, onderwijs en gezondheidszorg in Europa en de Verenigde Staten in de nieuwe tijd*. Bert Bakker., Amsterdam (zesde druk)

Acknowledgements:

A special thank you goes to the workshop participants for providing their valuable time and attention.

Appendix VI

Program 2nd CTA workshop Telecare at Home

Workshop

telecare

Time and place

University of Twente
Building Ravelijn, room 1315
Thursday 27 June 2013, 9.30u – 13.00u

UNIVERSITY OF TWENTE.

Welcome to the workshop on experiences with the use of telecare services in health care. The workshop is part of the NWO research project Telecare at home.

[http://www.nwo.nl/files.nsf/pages/nwop_87tagl/\\$file/l_oudshoorn.pdf](http://www.nwo.nl/files.nsf/pages/nwop_87tagl/$file/l_oudshoorn.pdf)

Telecare at home

The telecare at home research aims to increase understanding of how engineers can anticipate conflicting norms concerning surveillance and autonomy implied by the use of telemonitoring technologies. These ICT technologies can be used to monitor or diagnose patients at home and are widely claimed to have the potential to improve the quality of health care. Telemonitoring technologies are an important innovation because they can contribute to closing the gap between the growing demand of care and the scarcity of health-care professionals by delegating certain tasks, normally conducted by doctors, to nurses, to patients and their informal networks of carers and to ICT systems. The adoption of these technologies implies a transition in health care because they challenge existing distributions of tasks and responsibilities, including norms of care. On the one hand, telemonitoring technologies aim to increase the responsibility of patients and nurses for monitoring diseases, thus bringing more control and autonomy to patients' lives and nurses' work. On the other hand, telemonitoring applications are expected to replace people and take over responsibilities and control for monitoring diseases. These conflicting norms play an important role in the acceptance of these innovative technologies. The central question of the proposed research is therefore: How can telemonitoring technologies be developed to achieve a careful balance between surveillance by technological devices and control and autonomy of patients and nurses? To answer this question, we will conduct a constructive, ethical technology assessment in which we investigate the design and use practices relating to use of telemonitoring devices in chronic care that are currently developed and implemented in Europe. Based on these insights, we will develop tools that can support engineers to find a balance between these conflicting norms.

The aim of the workshop is reflect on the design of the CoCo (Conditie coach) project, a telemedicine project for the chronically ill, coordinated by Roessingh Research and Development. We try to investigate how this design shapes patients' experiences of illness. Participants are expected to share their experiences with the design with each other.

Rules

The workshop has an informal character. To encourage open discussion as much as possible we propose the following rules: participants to the workshop are free of speech (including organizers) and may not refer to what other participants have said (Chatham rules) for their own purposes. The insights that each of the participants gathers from the workshop are allowed to be used for their own decisions and strategies.

We would like to take up the discussion at the meeting because the workshop is part of the PhD research of Ivo Maathuis. The images will be treated confidentially and will be processed in the thesis anonymously.

PROGRAMME OF THE WORKSHOP

9:30 to 9:45 Welcome and Introduction (Ivo)

- Reception and welcome
- Introduction of the workshop

9:45 to 10:45 Session 1: Patient responses to statements about telecare (Nelly)

- Patients are asked to respond to statements about the importance of personal experience of their disease with the use of a telehealth service.

10:45 to 11:00 Explaining Session 2 (Ivo)

- Explanation of the components from which participants can choose when designing a telehealth service for COPD patients.

11:00 to 11:45 Session 2: Self-Designing a telecare device (N, T & I)

- The participants are divided into two or three groups. Each group will be tasked to design a telehealth service for COPD patients. They receive different parts in the form of pictures (eg a camera, a chip, an electronic diary, internet forum, etc.), but they may also contribute ideas themselves. By each selected item, they must also choose from a few instructions that come with the component on how often it should be used, how long, when, etc.

11:45 to 12:00 Break: Coffee, tea and pastries

12:00 to 12:45 Session 3: Discussion on the design of the telehealth service (Tjerk)

- Each group is asked to explain the choices for its design

12:45 to 13:00 Summary and conclusion

- Closing remarks by the chairman and reactions of participants.

Concepts:

Telecare: Care at a distance using electronic devices.

Telemonitoring: Using electronic devices to remotely monitor the patient's condition.

Autonomy of users: The extent to which patients themselves hold responsibility to monitor their disease.

Surveillance by devices: The extent to which monitoring takes place without interference from equipment and responsibility of the patient.

Self-management: The ability of patients to detect symptoms, manage treatment and physical and psychosocial consequences, including lifestyle changes (...) resulting from living with a chronic illness (Schermer 2009).

Acknowledgements:

Hereby, the organizers of the workshop would like to thank Haico to Kulve and Clare Shelley-Egan for the drafts and texts of the CTA workshops organized by them.

References:

"Chatham House Rule". Chathamhouse.org.uk.
<http://www.chathamhouse.org.uk/about/chathamhouserule/>. Accessed 07/06/2013.

Schermer, M. (2009) Telecare and self-management: opportunity to change the paradigm? JMedEthics 2009; 35:688-91

Swaan, A. (2004) Care and the state. Welfare, education and health care in Europe and the United States in the new age. Bert Bakker, Amsterdam (sixth edition)

Acknowledgements:

A special thank you goes to the workshop participants for providing their valuable time and attention.

The background features large, abstract, 3D-style geometric shapes in blue and red. A large blue shape is on the left, and a large red shape is on the right. They are partially overlapping and have a slight shadow, giving them a three-dimensional appearance. The text is overlaid on a semi-transparent white rectangular area in the upper half of the image.

Telecare technologies are instruments that enable care at a distance via the use of information and communication technologies (ICTs). One of the aims of telecare technologies is to support self-management strategies of chronic patients. However, the ways in which self-management is articulated in the design and use of these new technologies is largely unaddressed. This thesis focusses on how telecare technologies participate in enabling and/or constraining self-management practices of chronic patients by questioning what forms of self-management are inscribed and enacted in design and use practices of a contemporary telecare technology for COPD patients. The research illustrates that telecare technologies participate differently in enabling and/or constraining self-management practices for chronic patients. Some patients develop adequate practices in living with their disease with the incorporation of a compliant form of self-management in the telecare technology, while others thrive better with a telecare system that supports a more autonomous form of self-management. In order to develop a successful and morally acceptable tool to enable care at a distance the thesis therefore suggests incorporating flexible scripts supporting various forms of self-management into the design of telecare technologies, including the integration of experience based knowledge of patients. Moreover, the telecare technology should provide sufficient means for communication, education and shared decision making. To support this goal the approach of Constructive Technology Assessment (CTA) is applied and guidelines for anticipating future care in scenario based design (SBD) are developed.