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**Doctoral Thesis**

## Traveling Technologies: And Transformations in Health Care

PhD Series, No. 36.2010

**Provided in Cooperation with:**

Copenhagen Business School (CBS)

*Suggested Citation:* Juul Nielsen, Annegrete (2010) : Traveling Technologies: And Transformations in Health Care, PhD Series, No. 36.2010, ISBN 9788759384503, Copenhagen Business School (CBS), Frederiksberg,  
<https://hdl.handle.net/10398/8212>

This Version is available at:

<https://hdl.handle.net/10419/208769>

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Traveling technologies and transformations in health care

# Traveling technologies and transformations in health care

Annegrete Juul Nielsen

ISSN 0906-6934

ISBN 978-87-593-8450-3

ISBN 978-87-593-8450-3



PhD Series 36.2010

Doctoral School of Organisation  
and Management Studies

PhD Series 36.2010

# **TRAVELING TECHNOLOGIES** **and transformations in health care**

*Annegrete Juul Nielsen*



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Thesis submitted for PhD  
Department of Organization  
Copenhagen Business School

Annegrete Juul Nielsen  
Copenhagen, September 2010

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*Traveling technologies and transformations in health care*

1st edition 2010

PhD Series 36.2010

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ISBN: 978-87-593-8450-3

ISSN: 0906-6934

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## **ACKNOWLEDGEMENTS**

This dissertation is the outcome of three years of research on traveling technologies and transformations in health care. During this period I was fortunate to meet and work with a large number of talented and encouraging people who have shaped this work's making.

My sincere thanks go, first and foremost, to all of the informants of this study. In particular I would like to thank Nikolaj Holm Faber, Danish Committee for Health Education and Britta Ortiz, Region Zealand.

I thank the Department of Organization, CBS and the members of the Region-project for scholarship, ideas and critiques and a stimulating working environment.

For discussions, comments, and readings, I would in particular like to thank Nelly Oudshoorn, Marianne De Laet, Roland Bal, Mette Nordahl Svendsen, Morten Knudsen, Kristian Kreiner, Peter Kjær, Anne Reff Pedersen, Eva Sørensen, Brit Ross Winthereik, Christopher Gad, Nina Boulos and Moeko Saito-Jensen.

I am indebted to all the PhD students who travelled alongside me and made the journey merrier and more stimulating. Especially, I would like to thank my writing group - Sara Malou Strandvad and Susanne Ekman for their

companionship and for reading all the bits and pieces as they were in the making.

Above all, big heartfelt *thank yous* to my supervisors Casper Bruun Jensen and Signe Vikkelsø, who have taught me a lot about doing research without imposing dogmas. Throughout, their constructive critique and encouragements were invaluable.

Last but not least, thanks to my dear family and wonderful friends. In particular, thanks to Trine Roelsgaard for proof reading and providing rock-solid moral support. Mads and Hannah's lives and my love for them make up the fabric on which I build my work. Hannah's joyous embrace of a new day and Mads's generous and confident approach to life and myself has been and remains a daily inspiration. For that I am most grateful.

Annegrete Juul Nielsen

Copenhagen, September 2010



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# PART I

## INTRODUCTION

The ‘health society’ is a mainstream reality Kickbusch (2007) argues: “Health, as we understand it and live it today, is not only an outcome of other social and economic developments but a significant defining factor” (ibid: 144). Indeed, it seems difficult to disagree on the general relevance of health to the constitutive dynamics of contemporary societies and organizations. Plenty of policies, politics and programs preoccupied with the health of the worker, the patient, the children, the old or society at large are being launched. The success of these programs is related to their geographical spread. If a health care program does not leave the desk where it first saw light, its chances of influencing those it would like bear down on is bound to be minimal. For a health care program to have an effect it must be able to travel or move between practices. Some health care programs successfully accomplish this task. They come to be widely adopted, apparently having global relevance, as for example the Chronic Disease Self-Management Program, which has been adopted by countries as diverse as Japan, Australia and Denmark. But how does this happen and which effects does traveling have on a health care program and its place of arrival? This question is the starting point for the following text.

In this introduction I start out introducing my approach to health care programs as traveling technologies. Then I very briefly introduce the reader to the two health care programs, *Joint Health Plans* and the *Chronic Disease Self-Management Program*, which have served as case studies for the thesis. Finally, I outline the content of the thesis chapter by chapter.

**Successful health care programs travel - with travel expenditures**

When a health care program is successful in traveling and spreading geographically it is often explained with reference to the program's effective design, because it offers valid or proper solutions to a given problem or because it legitimizes the organizations adopting it as competent or pro-active. The implicit argument is that the program is able to move between practices because it simply is the best (evidence-based) solution to a given problem (Berg & Timmerman 2003) or because it is an unavoidable solution to almost any problem (Brunsson 1989). As a health care program's possibility of influence is related to its geographical spread, the circumstances and factors influencing a program's ability to travel is key to understanding how some programs become successful and others do not. The programs' *traveling* is thus in itself interesting, in terms of the effects it has in doing and undoing the technology as well as the travel expenditures and place-making effects involved in this process.

With inspiration from science and technology studies (STS) I approach this subject through the notion of traveling technologies. With traveling technologies I refer to the translations that occur when an object travels from one place to another, but with an explicit focus on the expenditures involved in this translation (Czarniawska 2005, De Laet & Mol 2000; Jensen 2008). By including an explicit focus on travel expenditures the notion of traveling technologies is also to provide space for more than the strong network and thus avoid privileging the managerial account (Star 1991). The notion of traveling technologies entails that I am primarily concerned with the articulations the health care programs enables, not to be confused with

realizing the programs. Instead I am interested in what the programs realize, what they make people do, the networks they build and the effects they have on their destination. Secondly, tracing health care programs as they travel to new practices is also a way to learn more about the orders which the programs embody. Even the simplest of machines like a water pump is dependent for its operation on a network of elements, which need to be in place for the machine to function (De Laet and Mol 2000; Morita 2010). Similarly a health care program depends on a network of elements to be able to influence the ensuing activity. Following the health care programs as they travel to new places, is a way of learning more about this order as it sticks out in a way that is not visible at its point of origin (Akrich 1992; De Laet 2002). Approaching health care programs as traveling technologies can thus also be described as a “contextualized” approach in that it asks where the programs come from, where they go and with what effects.

### **Joint Health Plans and Disease Self-Management**

Here I describe the two health care programs, *Joint Health Plans* (JHP) and the *Chronic Disease Self-Management Program* (CDSMP), I have studied. I strive to present them as they present themselves to those unfamiliar with joint health planning and disease self-management, the aim being to give the reader a temporary outline of the programs and some names to refer to. It should be pointed out that in the thesis the ontology of the two programs in question is not taken for granted, but is described in terms of the processes and practices through which they are put into existence and their identity evolve. Readers familiar with the programs (however diminutively), can skip this section, as

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more substantial introductions to the programs will be given in the analytical papers.

Joint health plans are formalized efforts within the health sector and/or adjacent sectors of coordinating health services delivered across organizational, disciplinary and political boundaries such as the primary-secondary sector interface. In Denmark the contracting parties in joint health plans consist of the regional authorities running the hospitals and the municipalities in charge of local health services such as home care, nursery homes and health promotion. The legislation on joint health plan was revised in 2006 in relation to a major Danish local government reform, which came into effect in 2007. According to the Danish health act joint health plans must be elaborated once every election period (four years) and in relation to six mandatory areas, pointed out by the minister of health. The plans are to be approved by the Danish National Board of Health, who has the right to reject the plans. Furthermore joint health planning is to be anchored in consultative committees with regional and municipal representatives and general practitioners. The committees are to create the basis for a continuous dialogue about the planning effort (Health act nr. 546, 2005). In short, joint health plans brings the involved actors together and make them plan how the organizational interfaces within the health system are to be managed and bridged. In doing so, joint health plans is believed to build coalitions of stakeholders who pro-actively handle their interdependencies to meet common objectives (Strandberg-Larsen et al 2007). Joint health plans can thus be described as a traditional planning instrument characterized by rationalistic

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ideas of the relation between policy goal and the means to achieve it, such as information and objective methods.

The second health care program that I study is a disease self-management program for patients with chronic conditions, called the Chronic Disease Self-Management Program (CDSMP). The Chronic Disease Self-management Program is an American developed patient-education concept imported by the Danish National Board of Health. The program trains patients with chronic conditions in performing e.g. self-care, symptoms-monitoring and communicating effectively with health professionals. The aim of the CDSMP is, among other things, to provide chronically ill people with skills to coordinate their own care trajectory. For instance they learn how to communicate with health professionals and how to prepare for a consultation with the doctor. The program is developed by Professor Kate Lorig and colleagues at Stanford University in the 1990ties (Lorig et al. 1999). The program is based on cognitive therapy, especially psychologist Alfred Bandura's notion of self-efficacy. Rather than focusing on the medical aspects of disease and treatment, the disease self-management program is concerned with teaching patients problem solving (Lorig 2000: 14). The program is organized as a practical workshop given two and a half hours once a week for six weeks. 10-12 persons with different chronic health problems attend together. In order to sustain the idea of role models, the workshop is facilitated by two trained leaders themselves patients with a chronic disease (ibid.). The CDSMP has been implemented in numerous countries in different parts of the world. According to the developers of the program, the program has evidence based effect. Participants of the CDSMP demonstrate significant



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improvements in exercise, cognitive symptom management, communication with physicians, self-reported general health, health distress, fatigue, disability, and social/role activities limitations and they spend fewer days in the hospital. The developers of the program also argue that the program has a cost to savings ratio of approximately 1:4 and that many of the results persist for as long as three years (Lorig et al 1999; Lorig et al, 2001a, Lorig et al, 2001b). Thus proponents of the program argue that it is not only the individual patient, but also the health care system at large, which benefits by training the patient in self-management (Department of Health 2005c, 2006a).

### **Outline of the thesis**

In PART I: ANALYTICAL FRAMEWORK, I discuss the analytical framework with which I analyze the health care programs as they move through practices, and the transformations that emerge as an effect of this travel on both traveler and place. Inspired by science and technology studies I propose the notion of traveling technology as an analytic approach for examining how health care programs successful at moving between different sectors of life, including the intimate and the transnational, building networks, at the same time produce their own marginalization or fragility. I discuss how this approach makes it possible to do more than account for the strong network of successful (circulating) health care program, by explicating the travel expenditures that goes with its circulation and translation.

In PART I: METHODOLOGY AND RESEARCH PRACTICE, I present the methodology for my practice as an empirical researcher of health care programs, and reflect on how certain choices, resistances and pragmatics have

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propelled my research. Moreover, I describe how and why I understand the study I have conducted as a *translocal ethnography*. I argue that the study is translocal as it traverses a range of spatiotemporal boundaries: Over a period of almost two years I traced the health care programs as they travelled through and across various geographical, institutional and social networks. However, apart from being translocal in a literal sense, I also argue that translocal does not refer to an intermediate scale of circulation conveniently nestled between the local and the global. Instead it designates an approach in which e.g. traveling technologies are regarded as *made through rather than prior to* various translocal encounters and from discrepant locations

PART II: DOCUMENTS ON THE MOVE is the first of the three analytical papers in the thesis. The paper follows the joint health plans as they move between different practices within the health sector, investigating how documents-on-the-move (possibly) perform in or even achieve a variety of socio-material networks. The paper shows how the joint health plans are place-making - they transform the place where they travel to, for instance through shaping the boundaries between what is primary and secondary care. However the plans also assume new tasks and become new things themselves, when entering a new place: The plans both work as a technical device, a political tool for boundary construction and as a shared object facilitating inter-organizational communication. In pointing to the plans' place-making effects, the analysis also makes the price of successful (traveling) policy documents visible. The traveling documents involve a never-ending need to tinker, to work around, to articulate loose ends. However, the paper also shows that these emerging properties and effects, which is referred to as *travel*

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*expenditures*, sometimes and in some circumstances surprisingly turn out to be valuable assets in and of themselves. For instance the plans also bring about the formation of new coalitions and forums between region and municipalities, which may not have emerged had the two authorities not have to conform to and elaborate local joint health plans.

PART II: TRAVELING COMPARISONS analyses how the Chronic Disease Self-Management Program has become globalized and how the program manages to become localized once again, as it is introduced into e.g. a Danish health care setting. The paper approaches these questions by considering the program a travelling technology engaged in ongoing efforts of negotiation and stabilization. The paper shows that far from a simple process of dissemination, the program's means of successful globalization comprise *theorizing*, *evidence-basing*, and detailed *scripting*. Secondly, the paper shows how the program manages to maintain *local* coherence through negotiating the differences between its global claims and local specificities. Several assumptions are embedded in the program, including views on what is an individual, what is a patient, and what is a health care system. These are brought to light as the program enters different contexts and meets other perspectives. The paper argues that the success of the program relates to its ability to hold together the tensions generated by the disjunction between the assumptions of the program and the Danish context, which are rendered explicit in encounters with Danish practice.

In PART II: AUTHORIZED EXPERTS AND NON-USING USERS, I describe how the disease self-management program lends itself as a “prime”

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example of a governmental program which targets and aims to shape social relations with reference to obtaining the full potential of patient-health care relationships. However, in this paper I show how the program's configuration of the patient as self-reflecting, extrovert and adaptable makes authority available to only a *small* group of participants, whose way of handling and coping with disease is thus authorized as "competent" and "expert". I also show how the authorization of one group of participants as expert patients can only take place via a simultaneous de-authorization of another group of patients. In this case making power itself appear considerably more distributed and fluctuating than often supposed. Through analytically including both the *authorized experts* and the *non-using users* the paper outlines an analytics of power, which on the one hand does not deny the disciplining effects of initiatives such as the Chronic Disease Self-Management Program, but which at the same time includes the fragility of an authority which has to be performed and reiterated to be just that.

In PART III, I argue that approaching health care programs as traveling technologies can be seen as a strategy for de-familiarizing oneself with the familiar, e.g. the trivial structure of governmental policy documents or the ways governmental programs aim at shaping social relations and identities. Observing the technologies as they enter new places, where they are cut off from their usual network elements, provides an opportunity for exploring relations embodied yet previously less visible. Analysing health care programs as traveling technologies can thus call attention to processes, routes, and uneven fields of power often neglected in health political discussions of new modes of government and subject formation. Furthermore the thesis suggests

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traveling technologies as an approach which is able to empirically flesh out how global and local healthcare not are opposites, but rather mutually implicated.

## **ANALYTICAL FRAMEWORK**

As described in the introduction this thesis is about health care programs moving between different sectors of life, including the intimate and the transnational and how they while doing so among other things (re)produce differences and stratifications among people. In this chapter I develop the notion of traveling technologies as an analytical approach and strategy for examining how health care programs successful at moving between practices and thus also in building networks, at the same time produce their own marginalization or fragility. The three papers, which comprise the thesis, all relate to this theme and in doing so draw on the same theoretical perspectives. All three papers place themselves within science and technology studies (STS), combined with, and contrasted to, other theoretical perspectives; organizational studies on coordination, policy studies on the transfer of technology and medical sociological studies on patient-professional relationships. The analytical framework which I describe in this chapter therefore, besides explicating the notion of traveling technologies, sums up on some of the fundamental orientations within STS, which I work with in the papers. Accordingly I start out describing my understanding of technology.

### **Technology as network**

My approach to studying health care programs subscribe to an understanding of technology-as-network (Latour 1999). Applying the insights from STS, technology-as-network entails that a technology is an outcome of an association of human and non-human actors in an aligned network. Consequently, technology is a *performative* achievement of many rather than a singular entity (Mol 2002). With an understanding of technology-as network,

technologies emerge in and through the practices they are embedded in. Technologies as network are inseparable from practice and receive their qualities in practice just as they in return shape those very practices in emergent, non-determinist ways (Latour 2005). Moreover, when technologies are considered accomplishments of a network and thus that technology *is* a network, then a well-functioning technology is also the achievement of a *particular local* practice.

The definition of technology which I subscribe to is thus different from a common understanding of technology as a bounded, discrete and de-contextualized entity with specific intrinsic qualities. Technologies are according to Berg often considered as neutral tools that are shaped and determined by their users and with ex ante functions, which it's performance is measured relative to (Berg 1998). This approach cuts away those interrelations which are important for understanding how the specific characteristics of the technology in question have emerged and are changing (Latour 2005). Accordingly I do not regard a technology as something which is realized, but as an enabling entity. The question is what a technology realizes, what it makes people do and articulate. Neither technology, nor humans or the organization exist separated from each other, but are fundamentally enmeshed with each other.

### **Translation and traveling**

Latour defines translation as an actors' ability to interpret objects and to influence others in different ways according to their strategies and interests (1987: 117). The principle of translation entails that technologies are always in the hands of their users and are thus employed, used and abused, changed etc.

in and through the practices of use (Oudshoorn et al. 2003). Because of acts of translation, a health care program is susceptible to transform in spite of the original intentions or purposes of policy makers (Latour 1986). Thus a “functioning” technology is by no means a trivial task.

So how does translation differ from traveling? Both have as already stated several times, transformative effects on both the object being translated and those who perform the translation. I use the notion of traveling technologies as a way of talking of the translations that occur when an object travels from one place to another, but with an explicit focus on the expenditures involved in this translation. By including an explicit focus on travel expenditures the notion of traveling technologies is to provide space for more than the “strongest story” and thus avoid privileging the managerial account, which Latour has been criticized for (Haraway, 1997; Star, 1991). However, instead of explicitly incorporating the marginalized or those left out of the strongest story, I show how even the “strong” actors are fragile, when the travel expenditures of their travel is taken into account. The notion of travel expenditures also allows me to encompass power dimensions in the travel of the technologies (cf. Part II Authorized experts and non-using users).

### **Studies of technology transfer**

The relational ontology of actor network theory (ANT) has raised the question of how technical artifacts are transformed when they travel to new places, where they are cut off from the physical, social and conceptual relations, which previously have stabilized their forms and functions (Morita 2010). STS inspired studies on the travel or transfer of technologies have



shown how these transformations reveal the ontological multiplicity of science and technology (cf. Zhan 2009, Langford 2003). Within STS, studies on the transfer of technologies was first initiated by Madeleine Akrich (1992), who eloquently argued that studying transfer of technology is a valuable occasion to explore the relations that a machine embodies. The interactions between the aspects of the technical object and the heterogeneous entities surrounding it (or the inside and the outside of the object) are usually invisible in an established technology since the two fit with each other seamlessly. Thus Akrich argues, technology transfer, where the inside and outside of a technical object do not match each other, is a valuable occasion to explore the relations that a technology embodies. Since Akrich seminal study STS scholars has further developed this line of thinking and delineated how a specific technoscience or knowledge regime travels and with what effects (cf. De Laet & Mol 2000; De Laet 2002; Zhan 2009; Langford 2003; Tzing 2005). Approaching the health care programs as traveling technologies I place myself within this tradition, but with the difference that I do not study technologies traveling from a developed to a less developed setting.

## **METHODOLOGY AND RESEARCH PRACTICE**

In this chapter I describe how I have tried to construct empirical complexity in my research practice. Doing empirical, qualitative research is about becoming caught up in the world, practicalities and resistances that force one to change plans and re-write the storyline of the dissertation. As Winthereik *et al.* (2002) argue, there is generative potential to be found in the resistances met; they are important opportunities for the researcher to question and consequently change her “preset ideas and research questions” (Winthereik *et al.* 2002: 47). Winthereik also argues that rather than understand this merely as messy work to be deleted from subsequent descriptions of the research process, the description of these kinds of resistances and the researcher’s need to change her assumptions should be seen as traits of “good” science (Winthereik *et al.*, 2002, p. 55). Accordingly, I start out reflecting on how the project’s analytical focus on traveling technologies came about.

### **Crafting the Analytic Question in the Field**

Research field and research objects are never just there. They are continually being constructed from before the research starts, whilst proceeding after data has been collected (Winthereik, de Bont, & Berg, 2002). The scholarship that I applied for is part of a larger project that investigates the effects of a major local government reform in Denmark, which came into effect 1<sup>st</sup> of January, 2007 – half a year after I began my project. One of the requirements was that a part of the analysis concerned the effects of this reform on integrated care. My preliminary research-interests circled around an interest in unpacking the discourse on integrated care. Integrated care generally means: the “bringing together of inputs, delivery, management and organization of services as a

means [of] improving access, quality, user satisfaction and efficiency” (Gröne & Garcia-Barbero 2004). It is also frequently equated with managed care in the US, shared care in the UK, transmural care in the Netherlands, and other widely recognized formulations such as comprehensive care (Kodner & Spreeuwenberg 2002).

Integrated care has an interesting mode of existence as everyone seems to agree that ensuring integrated care is one of the main challenges in modern health care. At the same time there is much less agreement about what kind of problems integrated care is to solve or, indeed, what it is all about (Kodner & Spreeuwenberg 2002; Bodenheimer 2008; Grone et al 2001). Inspired by insights from science and technology studies (STS) on the performative effects of technologies and organizational programs, I was interested in unpacking the notion of integrated care by analysing how integrated care technologies participate in and possibly transform care practices and patient-professional relationships. Another requirement in my scholarship was that I would collect my data in Region Zealand<sup>1</sup> as this region served as case for the larger project that I was part of. This meant that the choice of where - in the crude geographical sense - to study integrated care technologies had already been decided.

On this basis I started investigating kinds of integrated care technologies that would make a good case, by doing preliminary observations in the reformed regional-municipal health system. This can be seen as an initial and *minimal*

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<sup>1</sup> As part of the local government reform of the Danish public sector 14 counties was merged into 5 regions. One of the regions' main tasks is to run the local hospitals and supervise the independently organized general practitioners.

way to try to encompass the ambiguity, diversity and complexity, which at closer look characterize the discourse on integrated care. I decided to choose two different technologies and follow their enactment. I was interested in technologies which were associated with substantive hopes of creating integrated care and which were therefore widely disseminated in health care systems. Furthermore, I wanted technologies which - at least at the outset - seemed to disagree on how integrated care was to come about. Finally I wanted technologies which were about to be introduced. The 'inside' and 'outside' of a technology is often invisible in an established technology, where technology and context fit seamlessly with one another (Akrich 1992). Choosing technologies not yet established I thought would make it more likely for me to be able to observe how means and ends are co-produced in integrated care.

As in most research, however, the actual selection of technologies was also influenced by pragmatism. In relation to the local government reform a new Health Act was being implemented, which sought to enhance integrated care by standardizing the collaboration between municipality and region through mandatory Joint Health Plans (JHP). Joint health planning is formalized efforts within the health sector and/or adjacent sectors of coordinating health services delivered across organizational, disciplinary and political boundaries such as the primary-secondary sector interface. The legal demand to elaborate the JHPs made it likely that a substantial amount of effort and resources would be put into the process. A study of the JHP would not only fulfil the requirement for my scholarship, they would also provide me with an

opportunity to follow the introduction and making of the technology from the very beginning. All in all the JHP seemed a reasonable choice.

The second technology that I chose to follow is a disease self-management program for patients with chronic conditions. Approximately three months into my project, Region Zealand and its municipalities decided that the *Chronic Disease Self-Management Program* (CDSMP) would meet the demands for the joint health plan within the area of health promotion and disease prevention. This entailed that the disease self-management program over the coming months would be introduced in the 17 municipalities within Region Zealand. The region on its part would take on the role as coordinator and network initiator of this process. The CDSMP represents a completely different approach than the JHP and as with the JHP, I had the opportunity to follow the introduction and organization of the technology from the very beginning. Finally and importantly, I was allowed access to all meetings, negotiations and enactments of the two programs. Thus the *Joint Health Plans* and the *Chronic Disease Self-Management Program* ended up as the technologies of choice.

So far so good. However, what had first spurred my interest in integrated care, its interesting mode of existence, soon emerged as a problem in my own project. As I started tracing the JHP and CDSMP, integrated care seemed to evaporate or take on other, less demarcated, forms than I had expected. Increasingly, integrated care appeared to be a ‘garbage can’ for all kinds of problems and solutions within health care. The category simply dissolved into a myriad of things at closer inspection, very loosely (and conveniently) connected in the term integrated care. It seemed to be a “partially existing object” (Jensen 2004). Now, researching partially existing objects may pose some special challenges, but this does not mean that it

cannot be done. In this case, however, claiming integrated care to be the object of study, in my view, entailed that I would have to bend and break the empirical material that was under construction to make it fit into a counterintuitive category. Even more, there were other things at play in the empirical material, which called on my attention and that I came to view as increasingly interesting.

At the same time the technologies that I was following were quite successful in traveling. They were both able to build strong networks. Yet, while tracing the JHP and the CDSMP, I also observed them *being done* in a variety of ways and with different implications from place to place. Thus, although they were able to move between practices and therefore could be labeled as “strong” actors, both programs also exhibited a surprising *fragility*. As a consequence I increasingly found *traveling* of these technologies to be an interesting focus of analysis. Gradually, I came to consider more closely the effects traveling has in terms of doing and undoing the technology as well as the travel expenditures and place-making effects this involved. Traveling technologies, the networks they build and the overflows they give rise to thus became the central attention of my research. As part of this process I decided to re-write the storyline of my project around the notion of traveling technologies. During this phase of conceptual re-orientation I kept doing what I had been doing throughout: seeking out places, practices to which the JHP and the CDSMP traveled. Yet, the shift in focus has had the effect that I have used some parts of my data more intensively than others and even completely discarding other parts. In the following I elaborate on the approach and assemblage of methods I have used for gathering empirical material on traveling technologies.

### **A translocal ethnography**

The study I have conducted can be described as a *translocal ethnography* (Zhan 2009). In the following I elaborate on my understanding of translocal and ethnography, starting with the former. Referring to my study as *translocal* instead of e.g. multi-sited (Marcus 1995), I wish to highlight that I understand the programs I have studied as simultaneously transformed as they enter new places, while at the same time being *place-making* themselves. In this way a translocal ethnography differs from a multi-sited one. While a multi-sited and a translocal approach may both track a subject across spatial and temporal boundaries, e.g. follow a particular technology or a knowledge regime as it travels to different places (Latour 1987) the two approaches differ in terms of their understanding of e.g. the global and the local. According to Marcus, a multi-sited approach assumes that the global (or knowledge regime, technology, program etc) has *effects on* the local. In an article on the nature of comparison in the work of anthropologist Marilyn Strathern, Martin Holbraad and Morten Pedersen sum up her critique of multi-sited ethnography in the following way:

The problem with George Marcus (1993) and others' attempts to 'modernize' the ethnographic fieldwork is the pluralist assumptions behind the notion that the limited scale of 'the local' is automatically overcome by conducting fieldwork in several different places. The assumption seems to be that by 'following the people', the multi-sited ethnographer gains a new perspective from which different 'local' phenomena can be brought together into a single, albeit fragmentary, narrative, by someone whose perspective

(scale) is sufficiently ‘global’ to do so. (Holbraad & Pedersen 2009: 383).

In contrast the translocal approach studies the global (or knowledge regime, technology, program etc) as something which is *made through rather than prior to* various translocal encounters and from discrepant locations (cf. Ferguson 2006, Tzing 2005, Langford 2002). Thus as Zhan describes, translocal does not refer to “an intermediate scale of circulation conveniently nestled between the local and the global”. “Translocal” is not the same as “trans-local” and “trans-national”, which are suggestive of an ontological and analytical priority of places and practices of dwelling over place-making projects and processes” (Zhan 2009: 8).

The present study is translocal in several ways: In a literal sense it is translocal because it builds on fieldwork conducted in various places: inside and outside of Danish bureaucracies and clinics of health care while also tracing the programs to places outside Denmark, especially in the United States. However, it is also translocal in the sense that it focuses on processes of entwinement, rupture and displacement in the formation and deployment of knowledge, identities and communities in health care. Developing the translocal as a methodological approach entails that I have not collected the empirical material by a certain amount of months at specific hospital departments or in a geographical region. Instead my field traverses a range of spatiotemporal boundaries. For approximately two years I have gone in and out of the field, visiting a number of geographically scattered sites and settings. In the two years that I followed the health care programs, they



travelled through and across various institutional and social networks. The physical and virtual sites to which I travelled with the disease self-management program were: Stanford Patient Education Research Center (US); Danish National Board of Health; Danish Committee for Health Education<sup>2</sup>; local health center in the Copenhagen area; CDSMP Trained leader workshop (DK); regional network of trained leaders & municipal coordinators of CDSMP (DK); the Expert Patient Programme Community Interest Company (UK); Funksjonshemmedes Studieforbund (Norwegian Association of Disabled) (NO).

With the Joint Health plans I travelled to the Danish National Board of Health; Local Government Denmark; The regional administration in Region Zealand; Medical Association Zealand; Local Government Regional Council Zealand; a hospital and a municipal health unit in Region Zealand. On these journeys I met and talked to patients, relatives, doctors, nurses, physiotherapists, psychologists, social workers, municipal, regional and

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<sup>2</sup> The secretariat for the patient education program is outsourced to The Danish Committee for Health Education by the Danish Ministry of Health. The committee authorizes the use of the program, coordinates and arranges start-up meetings, patient-instructor courses, supervise patient-instructors and head the evaluation of the program. The committee is a non-profit non-governmental organization with close working relations with public authorities and private organizations in the health field. Besides being in charge of the patient education program the Committee develops and produces health promotion material on a number of themes, e.g. child and maternity health, sexually transmitted diseases and alcohol problems ([www.sundhedsoplysning.dk](http://www.sundhedsoplysning.dk)).

governmental officials, members of NGOs and politicians. I did this not in order to be able to tell a coherent, single story of how the JHP and CDSMP, respectively, influence diverse places, but rather in order to highlight how the programs are done – enacted -- differently at different places and have different effects and costs. As can be seen from these lists the two health care programs had multiple (expected and unexpected) encounters. At the same time they were initiated and approved by the same Board of Health, discussed in the same political-administrative forums, coordinated and managed by some of the same bureaucrats and used by some of the same patients and health professionals. As such the account of the disease self-management program is not *outside of or a parallel to* the account of the joint health plans. The two programs have disparate routes, but in some instances they connect and even entangle.

In order to trace the two health programs I have relied on a combination of ethnographic methods: Observations, participant observation, interviews and written materials (cf. Lofland & Lofland 1995; Spradley 1979). My preference for ethnography as data generating strategy comes with my research interest centering on practical, everyday enactments and effects of the two programs. Using ethnographic methods means that writing is an intricate part of generating empirical material through the making of field notes. Field notes are not accurate representations of reality ‘as it really is’, (Clifford and Marcus 1986), but are made valid through explicit reference to analytical agendas and theoretical assumptions. As Brit Ross Winthereik explains:

Within ethnography ‘accurate description’ can thus be replaced with ‘adequate description’. This refers to how well the researcher makes probable the link between field notes and transcripts and analytical and theoretical resources. Description, therefore, is the tool that enables the researcher to construct data for analysis, not the end-result of a well-developed and well-tested research design (Winthereik 2004: 12). Field notes help the researcher re-adjust the study design along the way, as analysis takes place during data-generation. Both my study of the JHP and the CDSMP are characterized by a translocal approach using ethnographic methods and trailing a network of technologies, people, stories, etc, that the programs have been moving in and performing. However, there are also some important differences in the way the material on the two cases has been collected. The empirical material on the Joint Health Plans is primarily collected between September 2006 and July 2008. It is chiefly organized around three sites: The first is the Danish National Board of Health, the second is primarily the administrative steering committee within Region Zealand and the third relates to the management of one of the larger hospitals within the region. (A detailed list of observations and interviews, which the study encompasses, can be found in Appendix A). Through observations in these sites I came to meet a significant amount of informants who did not mind phone calls with follow up questions and who sent information they thought would be relevant for my project of their own accord. Still it would be fair to characterize the ethnography on the JHPs as one made up by *appointed observation* (Staunæs 2004). I did not just arrive at these settings, but came when I had been invited to do so because there was a meeting or a negotiation that was relevant for me to observe.

In contrast I relied mainly on *participant observation* in the collection of data on the CDSMP. Participant observation refers to researchers' role as 'double agents' at the same time observing and participating in the practice under study, in which the researcher aims at experiencing the practice 'through the eyes of the participants' (yet, simultaneously all positions constantly are reconfigured, which is itself an object for analysis (Haraway 1991:201)). The empirical material on the self-management program was mostly collected between November 2006 and July 2008 (when I went on a 1-year maternity leave), and again in the fall of 2009, when I made additional observations and interviews. I did participant observation in the following places: First, the program itself, which I (as a relative to a person with a chronic condition) attended in a municipal health centre in Copenhagen. Second, the CDSMP trained leaders-program, which was held at a conference centre and gathered to-be-CDSMP-trained leaders from all of Denmark. Third, I (as a trained leader) participated in two networks in relation to the CDSMP: a regional network within Region Zealand, in which trained leaders and municipal coordinators exchange experiences with various issues related to the CDSMP such as recruitment, "hiring out" of trained leaders between municipalities etc. Another network is administered by the Danish Committee for Health Education in charge of the Stanford license, which organize a yearly national workshop and meeting for CDSMP-coordinators and trained leaders. These differences in how the material on the two programs has been collected have influenced how I have been able to seek out resistances and complexity while gathering the material.

### **Becoming affected and cultivating resistance**

Earlier in this chapter, I discussed how I met resistance in determining my object of study and analytical questions. Apart from the resistances met, be they e.g. acquiring access to the field (Law 1994) or delineating the network, there were also resistances, which I thought fruitful to “cultivate”. For the material also to acquire complexity, resistance must also be actively incorporated by the researcher (Despret 2004ab; Gomart 2004). An important element in this process involves the researcher learning to become affected by previously differences that she was previously unable to take into account (Latour 2004). In the following I describe these cultivated resistances.

While doing participant observation of the CDSMP, I experienced mixed emotions - to say the least. In the beginning my relationship with the program was strained. In particular I was bothered with the way criticism was handled. A common criticism often put forward by the participants was that the program’s time structure is too rigid, not allowing room for exchanging experiences or asking questions. To this criticism the trained leaders would respond that their experience with a less rigid time structure was that participants would leave the program because the workshops became too long or too much time was spend on participants telling their own story. However, not all points of critique or questions were dismissed so convincingly with reference to the suggestions already having been tried and failed. When this was not the case, the critique was most often met with an ‘appreciative dismissal’ which can be paraphrased as follows: We understand your concern, we have even thought of this issue ourselves and the program certainly is not perfect, it has its flaws and does not meet all the needs of the patients equally

well. Remember that you always have the opportunity to send your suggestions for revisions of the program to the Danish administrators of the Stanford license, who will consider them when the course material is to be updated. However, the program has been thoroughly tested and validated over a longer period of time, in different settings and with the participation of health professionals and patients with chronic conditions as well as being successfully adopted worldwide and this really is the best way to organize and structure the program.

To me it seemed that only criticism, which the program itself deemed valid (for instance alternative solutions which the program developers themselves had experienced) was allowed - or certainly taken seriously. All other criticism -- for instance of the program's knowledge claims or its ideas of old age, the healthy life or the pro-active subject -- was politely but effectively dismissed. The notion of brainwash occurred to me. It was for this reason I decided, to test how the program responded to critique. I did this while doing participant observation of the program that teaches participants to become trained leaders. Primarily in one-on-one sessions with one of the master instructors I criticised different aspects of the program and gave examples of how, in my opinion, the program accepted only its own criticism. After a couple of these sessions I was told either to quit the course or remain silent. The explanation I was given was that, first of all, the master instructor had never experienced participants raising the questions I – the researcher - was raising, and therefore she did not find them interesting or relevant. Secondly, she was afraid that the other participants would hear of my criticism. According to the master instructor, a questioning of the program would be counterproductive

for the participants as they needed to believe in the program in order to teach it properly. Initially, I took these answers as a confirmation of my own hunch: Although presented as an evidence-based, scientifically developed program, the program was as much about *having faith in the program*. It was by believing in the program as a vehicle for change and personal fulfilment that the participants came to experience it as an effective and appropriate device for patients with chronic conditions. This was why there was no room for questioning the fundamentals on which the program was built, as it risked harming participants' faith.

However, having been confirmed in it being a matter of belief and trust, I realized that my endeavour with questioning and criticising the program was effectively closing down any possible resistance to my own agenda. If, to recall Latour, engaging in an empirical study involves being *ready to be affected*, to *change preset assumptions*, and to *cultivate resistance* so that the object of study can *raise its own questions* against the agenda of the researcher, then the risk I faced was becoming insensitive to those demands.

While analyzing my material I thus increasingly began working with ideas of 'becoming affected' and 'cultivating resistance' (Despret 2004ab; Latour 2004). The overall ambition outlined by Vinciane Despret and Bruno Latour is that we need to learn to be able to become "affected" by what we study, precisely in order to learn to be able to register the differences that we would otherwise fail to notice. In a description of "the training of noses for the perfume industry" Latour discusses the empirical researcher as a subject that gradually becomes "more articulate" (Latour, 2004: 210). Latour describes how perfume trainees -- or rather their noses -- use special odor kits, "malettes à odeurs" to

learn to discriminate among a large range of odors. It is with the kit the “noses” become able to “be affected” by the smells they meet. Latour uses the description of trained noses to show how the ability to be affected neither resides within the individual trainee’s body nor in the properties of the odor kit, but rather is a relational quality. The kit is not just an intermediary between the otherwise definite essences of the subject and the odor. Instead it participates in shaping both the body of the “nose” and the quality of the odors. In analogy with the trained nose, the empirical researcher must become able to register and describe new differences. For Latour, this is an ability which depends on the ability to relate to and be affected by something external to the questions and hunches that initially guide research (Latour, 2004: 210). Engaging in an empirical study should thus involve being ready to be affected, to change preset assumptions, and to seek resistance so that “the phenomenon at hand [can] raise its own questions against the original intentions of the investigator” (Latour, 2004: 219).

Drawing on studies in ethology<sup>3</sup> (the scientific study of animal behavior) Vinciane Despret elaborates on the necessity of inducing resistance in one’s empirical set-up. She distinguishes between ‘being available’ and ‘being docile’ and explains the difference by describing an experiment by the famous primatologist Harry Harlow (Despret 2004a:123). In order to disclose “the vital necessity of attachment” in monkeys, Harlow built a device, which prevented a newborn monkey from establishing relations with its mother and peers. The effects of separation (self-destructive behavior, despair and deep

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<sup>3</sup> Classical ethology focuses mainly on relations with and around food: who eats what, how do animals organize themselves around resources, etc.



depression) according to Harlow, clearly showed that attachment is a primal need (Despret 2004a: 132). Despret's point in discussing this experimental set-up, however, is that the newborn monkey is left no other choice than to fulfill Harlow's expectations and 'self-destruct'. The device is literally '*designed to create despair*' and *nothing else* (Despret, 2004a: 123). Put differently, the experimental set-up renders the newborn monkey docile and as such only produces domestication. Despret makes use of this example to argue instead that what should be strived for is research that makes the subject or object of study 'available' in new ways. "Making available" thus entails giving the object of study the possibility to resist what the experimental set-up is offering the object of study (Despret 2004a: 123). In another article Despret exemplifies with the point with a study conducted by primatologist Thelma Rowell, who investigates social life of sheep by considering how they compete for food. (Despret 2004b). Rowell's set-up was simple. She gave the sheep one bowl of food too many: Instead of 22 bowls corresponding to the number of sheep she served 23 bowls. Despret explains the effect of the seemingly innocuous addition of a 23<sup>rd</sup> bowl of food in the following way:

The twenty-third bowl is meaningful in relation to this problem [competition for food]. It is intended not only to avoid disrupting relations but also, above all, to expand the repertoire of hypotheses and questions proposed to the sheep. The idea is not to prevent them from entering into competition around the supply of food; it is to leave them the choice to do so, to ensure that competition is not the only possible response to a constraint but rather a choice in response to a proposition. If the sheep choose competition, the hypotheses of scarcity of a resource can no longer account for their behavior.

It is then necessary to conceive of other, more complicated explanations, and to ask the sheep other questions on their social behavior. (Despret 2004b: 367-68).

The following is an example from my fieldwork, which describe how I have tried to incorporate this line of thought while collecting and analysing data. That is, how I have tried to become affected and cultivate resistance or putting in “an extra bowl of food”.

Becoming affected and thus cultivating resistance on behalf of my object of study in this situation did not involve critique but belief (Gomart 2004). My fellow participants at the course for trained leaders were excited with the opportunities they experienced the program offered them. Not least they were excited by with the opportunity to share what some termed the life turning event (as some called it) of chronic disease with their equals. If I wanted my informants to be able to resist my research agenda, I had to try to become affected as they were by this opportunity. Thus, instead of standing on the sideline and deliberately not engaging in the practice and therefore not experiencing its meaningfulness, I had to try to understand why the program did not seem to these people as the kind of sect that I had imagined. Why, indeed, was the program approached as a highly meaningful and much in demand device for managing chronic disease? Laying my reservations aside, I committed to the program and all its activities the best I could. I listened intently to my fellow participants’ reflections on why and how they found it so helpful. And what became evident was that if you do believe in it and do commit yourself wholeheartedly to action plans and problem-solving, it actually does work – at least for a while, at least for some.

What the latter qualifications mean is that a crucial point in this account of learning to become affected and cultivating resistance is that the program's approach to critique continues to be equally important for understanding what the practice of the disease self-management is about (cf. the paper "Authorized experts and non-using users" on how both belief and disbelief play a role in the enactment of the disease self-management program). Nevertheless, in cultivating resistance I have aimed at not constructing knowledge behind the backs of those I am studying, through adopting the same demand and exploring how what counts for them has allowed changes in my own approach to the program (Despret 2004b). If learning and striving to become affected and cultivating resistance is about acquiring taste "for the small concrete causes that produce unexpected effects, original hypotheses, things through which – as she [Rowells] often stresses – "differences arise", without any need to refer to grand theories, influences, representations, ideology, etc.", then, sometimes, as Despret says, "a bowl is enough" (Despret 2004b: 361). The issue is finding *the right bowl for the job* (Fujimura and Clarke, 1992).

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## PART II



## DOCUMENTS ON THE MOVE

### Challenges and travel expenditures in standardization of *joint health plans*

#### Practices of documentation

As anthropologist Annelise Riles points out, documents are paradigmatic artefacts of modern knowledge practices:

Practices of documentation are without a doubt ubiquitous features of late modern life. From bus tickets to courtroom transcripts, employment applications to temple donation records, election ballots to archived letters, documents appear at every turn in the constitution of modern bodies (Scarry 1987), institutions (Ferguson 1990), states (Lass 1988), and cultures (Forster 1995) (Riles 2009: 5).

In this paper I am particularly interested in one special form of documents: policy documents. Their number and the amount of work that goes into elaborating them, alone make policy documents an unavoidable, ever present character in any bureaucratic play. However, when measured against the goals they set out to accomplish, policy documents are often judged as failures rather than strong agents in socio-political change. Street level bureaucrats (Lipsky 1980) working with turning policy programs into practice often criticize them for being too vague in their suggestions of both problems and solution or too far flung from what goes on “in reality”. Critical scholars on their part often criticize policy documents for an inconsistent argumentative

structure and for being based on assumptions difficult to sustain. Riles, as well, quotes Bruno Latour who calls documents: “the most despised of all ethnographic subjects” (Latour 1988: 54 in Riles 2009: 2). Seen from the point of view of the policy document, this critique is not devastating. Policy documents themselves do not claim to be more than provisional accounts of a reality that is not completely governable (Gad 2009). A far worse destiny, in the eye of the policy document, is to be ignored all together, to be given no part what so ever. However, according to Latour, being ignored is precisely the most common problem that a document or text encounters (Latour 1988). Documents are ignored or more precisely fail to circulate even among those they would like the most to interest. As such it is the exception rather than the rule when a document actually succeeds in being heard or more precisely circulated (Latour 1999). Despite a policy document’s small chances of making a difference, it’s all too familiar, or indeed, trivial argumentative structure, the protagonist in this paper is exactly such a policy document. In the following I embark on a two-year-long journey with a set of Danish policy documents, *joint health plans* (JHP), which have previously been described as suffering the sorry fate of being ignored (Seeman 2003). The plans have been criticized for not being able to commit counties and municipalities to collaborate on ensuring coordinated care and, as a consequence, for not making any difference in health care practices (Strandberg-Larsen 2007).

Joint health planning is a policy tool for coordinating care across organizational interfaces in health care systems and used in a variety of Western health care systems. The plans can be described as a “contract” between health institutions, most often between primary and secondary sector, on how the organizational interfaces are to be bridged. The aim of my

journey is to give an alternative account of what policy documents and more specifically joint health plans are *made up of* and what they *do*. Instead of a critical account of the assumptions embodied in the plans and their allegedly missing effects, I trace the plans as they move between different practices within the health sector. I am interested in how documents-on-the-move (possibly) *perform in* or even *enact* a variety of socio-material networks. This approach entails that I am not investigating whether the joint health plans have intended effects, but more broadly examine how the plans acquire agency and of which kind. The paper shows how the joint health plans, when entering new locations, assume new properties. These plans, I argue, do new things in new places; they create effects that cannot be controlled by better forecasting or planning. Sometimes, in some circumstances, these emerging properties and effects turn out to be surprisingly valuable assets in and of themselves. Below I refer to them as the *travel expenditures* of policy (Jensen 2008).

### **Analyzing “the most despised of all ethnographic subjects”**

With the aim of describing how there can be something strange and surprising even in the most trivial of policy documents, I draw inspiration from and combine different types of studies from the field of science and technology studies (STS). The first type of studies is concerned with the interdependence of the material and the semiotic (Latour 1987; Bloomfield & Vurdubakis 1994; Haraway 1997). The second type of studies analyzes what happens when a technology travels from one place to another often from a developed to a less developed country (Mol & De Laet 2000; De Laet 2002; Morita 2010).

In STS the analysis of text starts with an insistence on documents' materiality. That is, the document is taken at face value as a *material object*. By connecting descriptions (documents) to day-to-day operations and action (practice), the aim is to explain how the material and the semiotic are always intertwined and interdependently constructed (Latour 1999). Donna Haraway uses the notion of *materiel-semiotic actors* to designate how documents in their circulation overflow their textual functions (Haraway 1997). But what does it mean to say that a document transgresses its textual function? Wherein consists the agency of a document? A basic premise in much STS is that an actor only becomes such at the moment when that someone/thing is able to act in relation to specific others in a given network. Likewise, a document cannot create an effect *by itself* but only in relation with other actors. Effects might take the form, for example, of bringing about the production of (yet more) policy documents, setting new agendas or stabilizing status quo. In terms of document analysis this approach entails a focus on the effects of a document and an immersion in worldly material-semiotic practices, rather than a critique of a document's content (Jensen & Lauritsen 2005). For this reason my approach begins by taking the joint health plans at face value as a material object. They are furthermore objects that travel: in the same way as for example a bush pump or a rice combine harvester travels from developed to less developed countries as part of development aid (Mol & De Laet 2000; Morita 2010). Empirically, this means that I trace the joint health plans as they cross geopolitical boundaries and enter new spaces and describe what they do while traveling (De Laet 2002). However, documents are not simple representations of different organizational or technical phenomena. As well, they are analytically situated accounts (Gad 2009). Like a water pump or a rice

combine harvester has specific relations to their use environments, the users and non-users implicated in their design, so do the policy documents (Akrich 1992; De Laet 2002). The joint health plans, for instance, deliver an account of the interfaces in the regional-municipal healthcare system in a way that makes it possible to act in a specific way in relation to the coordination of care. This means that the JHPs, like the water pump or rice combine harvester, are dependent for their operation on a network of distributed elements, which needs to be in place for them to function as intended in the design. Water pumps, harvest machines and policy documents, we may say, are all inscribed within specific orders (Berg & Timmerman 2000). In order to be able to enter into a discussion with the order that the document sets up, the order must also be accounted for if the analysis is to avoid becoming a privileged account of the document's effects (Gad 2009). Moreover, the document's order is destabilized, unfolded and potentially transformed when the document travels to a new place where the network on which it depends is not yet in place. Following a document's travel is thus also a way to learn more about its implicated order (and its others). Traveling with the document might bring to light emergent complications, which were not visible at its point of origin (De Laet 2002). This is not only important because it makes it possible to analyze the effects the document might have on ensuing activity. It is equally productive in terms of unfolding of the document's implicated relations and the travel expenditures they may give rise to (Jensen 2008). Consequently, the described analytic approach both concerns what the joint health plans *do* on their journey through Danish health care, as well as what the plans *say* with the aim of offering an alternative account of the efficacy of policy texts in the construction of political reality. Methodologically, the

implications of this approach are that I have travelled with the joint health plans for a period of 2 years.

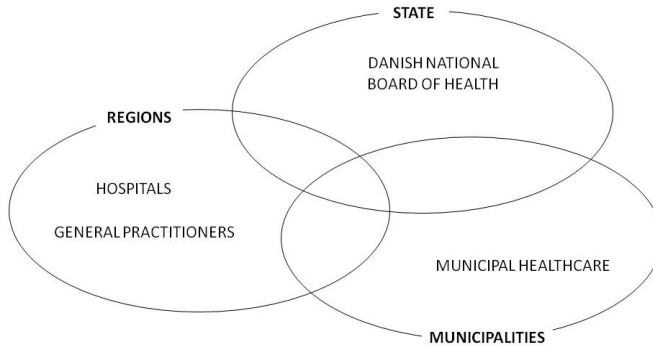
### **Traveling with joint health plans**

Tracing a document's effect gives rise to a number of methodological challenges. First, we can ask, how to identify the specific effects of a document, as these might not be stable and show only over longer periods of time? In reality, however, this challenge proved manageable. By tracing the JHPs over a period of two years, I acquired a thorough knowledge as to the "where, who and how" of the networks, which the JHPs came to form part of. Secondly, within my analytical approach the plans have an effect when they are able to interest other actors and circulate (Latour 1999). Thus, it is not decisive whether the effects of the plans are stable or not. Actually (in line with sociology of translation) I assume them not to be, at least not over a longer period of time (Latour 2005). Concretely, I have traced the JHPs in the period from September 2006 until August 2008. In the first 1½ year the most intense data collection took place. Here I mainly relied on observations and interviews. I observed meetings and negotiations on the JHPs in and between state, regional and municipal administrations. I read mail correspondences, minutes, reports, guides and other written material on or related to the JHP; and I interviewed relevant national, regional and municipal officials, health professionals and politicians, which I met while traveling and who most often recommended me other people they thought it would be relevant for me to talk to. During the second part of my travel I relied on the network I had build during the first period. Thus I was able to follow the continued discussion of the JHP. I was given access to e-mailing lists, received records of

proceedings and made use of newsletters, press releases, and minutes to keep me up-dated on the JHP.

The material collected during this journey has been organized around three settings or “stopping points”. The first “stop” is the Danish National Board of Health, the second the regional-municipal collaboration on JHP in Region Zealand and the third the management and clinical practice at one of the larger hospitals within the region. In the first part of the analysis I examine the *order* inscribed into the “Guideline for Joint Health Planning” developed by the *Danish National Board of Health*. In the second part of the analysis I follow the “Guideline to Region Zealand” and examine the process of development and negotiation of local JHPs between the region and the seventeen municipal councils of Region Zealand. In the third and last part of the analysis I follow the approved local joint health plans into clinical practice and examine how the plans are enacted in the regional-municipal health care organizations. This organization of the analysis might give the impression that it is a top-down form of analysis, which moves from the national authority at the top and works its way down the system to local health practices. However, as will become clear in the analysis, this is not the case. Because regarded as top and down (also) changes as the plans travel to new settings. The three settings are illustrated below.

## PART II: DOCUMENTS ON THE MOVE



The plans, or rather different versions of the JHP, indeed manage to circulate and become part of various socio-political networks. In the following section I briefly describe the health political discourse, which these socio-political networks form part of.

### **Coordinating care with joint health plans**

Today health care is practiced within a highly specialized and widely distributed organizational network. Health care systems differentiate their units to handle the scope and complexity of their practice resulting in highly interdependent and specialized units and wards. Patients often experience receiving complex technology-assisted treatment at one unit, care and follow up treatment at another, rehabilitation at a third and check-up at a fourth unit (Ouwens et al 2005; Bodenheimer 2008). Making sure that the right information and treatment is provided at the right time and place is thus a daily challenge and a demanding task in most health care systems (Mur-Veeman et al 2008; Grone et al 2001). In the best case, lack of timely coordination is known to produce low cost-efficiency and quality in care (Shortell et al 1993). At worst, lack of timely coordination is believed to cause



adverse events or sub-optimal clinical results. Problems with coordinating care are therefore also a hot health-political topic that receives widespread attention (Kodner & Spreeuwenberg 2002; Glouberman & Mintzberg 2001).

Health systems in countries such as the United Kingdom (Glendinning 2003; Rummery & Coleman 2003), the Netherlands (Mur-Veeman et al 1999), Denmark (Strandberg-Larsen 2008) and managed care organisations in the United States (Mitchell & Shortell 2000) have policies on joint health planning. Joint health planning is a formalized effort within the health sector and/or adjacent sectors of coordinating health services delivered across organizational, disciplinary and political boundaries such as the primary-secondary sector interface. Joint health planning brings the involved actors together and makes them plan how the organizational interfaces within the health system are to be managed and bridged (Strandberg-Larsen et al 2007).

Until 2007 joint health planning in Denmark<sup>4</sup> was partly formalized through legislation enacted in 1992, which required that counties<sup>5</sup> and municipalities elaborated joint health plans once every election period (Sygesikringslovens kapitel 6a, 1994). The 1992 legislation only vaguely indicates how joint health plans are to ensure coordinated care and the pre-2007 JHP's were characterized by being very different in scope and content

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<sup>4</sup> Denmark has a Beveridge-type health system based on general taxation covering all inhabitants and with most services produced by public providers at the regional or local level. An important exception to this is the general practitioners (and gatekeepers), who are self-employed, but reimbursed for their services by the regional authorities through a combination of capitation and fee-for-service. Laws and formal regulation imposed at the state level have traditionally been sought to be minimal due to the decentralized structure of the Danish health care system.

<sup>5</sup> Before the local government reform was enacted in 2007 the Danish administrative system consisted of 14 counties (reduced to 5 regions with the 2007 reform) and 271 municipalities (reduced to 98 municipalities in 2007).

between counties (Strandberg-Larsen 2007). As an effect of the criticism of the JHP's lacking effect, it was decided to revise the legislation on joint health planning in relation to a major local government reform<sup>6</sup> which came into effect in 2007. The local government reform handed over more health services to the municipalities, who after the reform became responsible for rehabilitation outside hospitals and for disease prevention and health promotion (Strandberg-Larsen 2007). Together with health care services being more widely distributed than before the reform, the challenge of coordinating care were amplified by an increasing share of elderly and chronically ill. Thus it was argued that the need for an ambitious regulation on joint health planning is imperative (Strandberg-Larsen 2007).

### **Standardizing joint health plans**

The "Guideline for Regional Consultative Committees and Joint Health Plans" (the Guideline) describes the aims and requirements for the content and form of the post-reform joint health plans (Danish National Board of Health 2006). True to the "traditional" style of policy documents, the Guideline starts out defining a worthwhile aim for the revised JHPs. They are to contribute: coherent and coordinated patient trajectories across primary and secondary sector; an unequivocal division of labor between the different health institutions; effective and appropriate communication; planning and management of capacity across institutions; reduced waitlists and patient trajectories of a high quality. The Guideline also specify that JHPs must be elaborated in relation to six mandatory areas: 1) Discharge of weak elderly

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<sup>6</sup> Besides reducing the number of counties and municipalities, the local government reform moves a number of assignments in different policy areas from regional to municipal authorities.

patients, 2) Admissions to hospital, 3) Rehabilitation, 4) Assistive technologies, 5) Health promotion and disease prevention; and 6) Patients with psychiatric diagnoses. Furthermore, the Danish National Board of Health is granted authority to reject plans which do not live up to the requirements put forth by the Board itself. Moreover, the JHPs are now to be anchored in consultative committees consisting of regional and municipal representatives and general practitioners. The committees are to create the basis for a continuous dialogue about the planning effort (Health act nr. 546, 2005). According to the authors of the Guideline, the detailed requirements to joint health planning are made in order to ensure that all five regions and 98 municipalities have gone through the same thorough and detailed planning whatever the specifics of treatments offered, patients served, health professionals employed etc. To illustrate the magnitude and detail of the way the Guideline seeks to govern regional-municipal coordination and collaboration, I describe some of the requirements set up by the Guideline in more detail.

The Guideline lays down a detailed template for each of the six mandatory joint health plans. The Guideline lists five overall requirements for all six JHPs: 1) Description of division of labor; 2) Coordination of the joint effort, including how communication between health actors and patient/citizen is secured; 3) Planning and management of capacity; 4) Development and quality assurance of the cross-sectional effort; 5) Follow-up on the JHP (Danish National Board of Health 2006:15). These requirements are further specified for each of the six mandatory areas. For instance, the following requirements apply to the JHP on *Discharge of elderly week patients*:

- How the parties secure in-time clarification of the individual patient's physical requirements after discharge, including how the time of discharge and services in relation to discharge is coordinated between municipal home care and regional hospital of time and services in relation to discharge
- How the parties make sure that relevant information is communicated in-time to the patient and potential relatives as well as the patient's general practitioner, the municipality and other relevant actors in relation to discharge. Furthermore, how the parties are available for further dialogue and questions from the patient
- How the parties in coordination of capacity etc make sure that the patients can be discharged from hospital as quickly as possible after they have finished treatment
- How the parties will follow-up on the joint health plan (Danish National Board of Health 2006:24)

In short, the notions of optimal regional-municipal collaboration and coordination advanced in the Guideline emphasize uniformity and *standardization* in terms of transparent and detailed specifications of the division of assignments and responsibility between the two local health authorities. According to the authors of the Guideline, the problem with lack of coordination and coherent patient trajectories arises due to work practices that remain implicit, hidden and non-reproducible. Incoherent patient trajectories, they argue, is a consequence of identical situations being treated, recorded and evaluated differently. Therefore the revised JHPs are designed as a tool for better forecasting and standardization of work practices. As such

both the problem of lack of coordinated care and its solution are constructed as relatively clear cut: It is a matter of the regional and municipal institutions agreeing on a clear, detailed and well thought through alignment and division of labor.

In constructing “the formalized” as privileged compared to “the informal”, the Guideline places itself within the general movement of standardizing medical practices, which has swept through health care the past decades (Berg & Timmerman 2003). However, as Berg and Timmerman (2000) have noted elsewhere, the very listings of instructions create the possibility of new disorders emerging: those activities that do not correspond with the order inscribed in the standards:

In addition, these orders do not emerge out of (and thereby replace) a preexisting disorder. Rather, with the production of an order, a corresponding disorder comes into being. [...] Moreover, the intimacy of this connection does not stop here: not only does an order perform its own disorder – it also always *contains* it.[] The order and its disorder, we argue, are engaged in a spiraling relationship – they need and embody each other. These relationships can only be seen as paradoxical from a view that labels them as opposite (Berg & Timmerman 2000: 36).

Thus, the Guideline embodies and carries conventions, orders and disorders that is key to the effects the JHPs might bring about. A critical reading of a policy document would often at this point move on to examine how the conventions and assumptions inscribed to the Guideline resonate with current

health care organizations and practices. For example, organizational theorists Sholom Glouberman and Henry Mintzberg (2001) are among those who have criticized the type of order and standards put forward in the Guideline, for being unduly simplistic in the face of the complexity of medical situations. Glouberman and Mintzberg argue, among other things, that standards and similar technologies can only stifle coordinating efforts, not support or enhance them (Glouberman & Mintzberg 2001):

All kinds of efforts have been made to achieve integration, yet few seem to have seriously penetrated the clinical operations. Many have taken place above the great divide, for example in the administrative reorganizations that shuffle boxes on charts but not much else, the “strategic planning” exercises that avoid the difficult tradeoffs by reducing serious problems to insatiable “wish lists” (or empty “mission statements”), and the government restructurings that evoke all manner of administrative frenzy in order simply to reduce budgets. (Glouberman & Mintzberg 2001: 70).

However, as described, I take a different approach in this paper: I try to capture the liveliness of the Guideline by tracing it as it travels. Traveling is crucial here: the guideline has to literally move between practices, because its success is related to its geographical spread. For the same reason, tracing the Guideline to new practices is also a way to learn more about its order. Following the document as it travels to a new setting is a way of learning more about this network (De Laet 2002: 217-18). Or put differently, by tracing the document when it travels to new practices, new aspects of its order become

visible; as does the document's *resistance to transfer* to new places. Now let us travel to the negotiations on local JHPs in the capital of Region Zealand, an hour's train ride from the National Board of Health in Copenhagen.

### **Politics of coordination**

For decades the Danish health care system has cherished the principle of decentralized health care. For this reason it is not easy for regional and municipal authorities to accept the wisdom of “centralized guidelines”. Not only must the local authorities have their collaboration approved by the Board of Health, like a child needs its approval from her parents. Collaboration to ensure regional-municipal coordination is also governed down to the last detail by the requirements set up in the Guideline. According to the local authorities the Guideline is constructed as an authority that must simply be accepted.

In September 2006 Region Zealand's newly set up *Regional Consultative Committee* on JHPs decided to establish a steering committee with representatives from the regional and municipal administrations. As the Guideline's requirements for the JHPs are comprehensive, it is expected to be a quite laborious job to elaborate these plans. The political Consultative Committee hands over the responsibility of translating the Guideline into six local sets of joint health plans (one for each mandatory focus area) to the steering committee. On their part, the steering committee decides to set up a task group consisting of relevant health professionals and administrators for each of the six plans. The task groups are to elaborate drafts for the joint health plans, which can be discussed in the steering committee. The two new organizations, the steering committee and the task groups, both of which

come into existence as an effect of the Guideline, turn out to be decisive in the ensuing activity relating to the local JHPs; indeed, more so than the Consultative Committee.

The Guideline's notion of the JHPs as a tool for better forecasting, standardization and alignment of work practices is quickly challenged. In the work of the steering committee and the task groups, the "technical" task of elaborating standardized procedures on how coordination come to be interwoven with local political, health professional and economical agendas (Jensen 2008). In the following I illustrate how the elaboration of the local JHPs on the basis of the Guideline activates these agendas. First, the task group's elaboration of the JHP on rehabilitation gives rise to heated discussions on *economical* aspects of the plan. With the local government reform, rehabilitation has been divided in ordinary and specialized rehabilitation with the municipalities being responsible for the former and the regional hospitals for the latter. However, the municipalities must co-finance the specialized training their citizens receive at hospitals. Rather than revolving around coordination of rehabilitation services, the task group's discussions concern the question about who can order services and who is to pay for them. Below one of the regional representatives explains how the task group elaborating the joint health plan on rehabilitation handled the emerging economical agenda:

*The discussion is on when rehabilitation is specialized and when it is not. As specialized rehabilitation takes place at the regional hospital but is co-paid by the municipality, the municipality is interested in avoiding this service. It is*



*cheaper for them to provide the patient with rehabilitation themselves. The municipalities want to know if they can do this or if there is legislation, which they have to comply with. As a consequence we have made a catalogue [of all types of rehabilitation services provided] in this region and categorized them as specialized and ordinary, respectively. However, now we discuss the content of the catalogue again, because there is a lot of money involved in this. The municipalities question whether they can trust that the hospitals only refer the necessary amount of patients to specialized training.*

From a municipal point of view the problem is that the region has an economic incentive to refer more patients than necessary to specialized rehabilitation as this will give the region a higher income. The municipalities try to handle this challenge by transforming the joint health plan into a *warranty* type of document, which states that the region cannot place expenditures on the municipalities in relation to rehabilitation without the approval of the municipalities. Or put differently, the municipalities handle the fact that the joint health plan does not include financial obligations by introducing financial demands themselves. The economical quarrel in relation to the JHP on rehabilitation also leads the municipalities to demand that it is clearly stated in all of the joint health plans that the region cannot set the patients' expectations as to the amount or type of municipal services they will receive when discharged from the regional hospitals. In short, the elaboration of standardized procedures on coordinating rehabilitation becomes as much a negotiation of which authority is to bear the burden of the expenditures arising from the tasks that are decided. Not surprisingly, what the region and

municipality can agree upon when elaborating the plans depends to a very large extent on whether or not it involves increased expenses on their part.

However, the economical agenda is not the only agenda activated in the elaboration of the local joint health plans. Elaborating the joint health plans also activates a *health professional* discussion of which authority can claim to have the professional expertise and experience to provide a given health service. According to regional health professionals, patients currently wait longer than before the reform before they can begin rehabilitation. The regional health professionals find the long wait unacceptable from a medical perspective and question whether the municipalities have the necessary expertise and experience to perform the task they have been given with the local government reform. As a consequence the regional health professionals put forward the demand that the joint health plan on rehabilitation not only lists the standard content and cost of each rehabilitation service, but also lists professional standards, i.e. the maximum waiting time before a patient must start receiving (municipal) rehabilitation.

Similarly, a professional dispute arises in the negotiations of the joint health plan on hospital admission: The municipalities want the plan to encompass municipal out-patient clinics, which they plan to establish in the future. The municipal out-patient clinics are to be an alternative to hospitalization for elderly medical patients who suffer from minor problems that require regular attention such as dehydration. The municipalities expect the out-patient clinics to be cost-saving by preventing inappropriate acute hospitalizations among the elderly. However, the regional health professionals do not support the establishment of municipal out-patient clinics. They do not think that the municipalities have the necessary professional expertise to

deliver such a service. As a consequence, the regional authority argues, in the worst case municipal out-patient clinics can lead to patients not getting the right treatment in due time. Thus, the elaboration of the local JHPs also becomes a discussion of how the boundaries between the primary and secondary sector are constructed and maintained. The municipalities enter this discussion with an interest of taking over more assignments and services from the region, whereas the region enters the negotiations with an interest of keeping as many assignments and services within their domain. Contrary to that is assumed in the Guideline, the distribution of responsibilities and tasks are not just technicalities, which the two local authorities have to agree upon for the common good. It is also a political and professional negotiation of where the boundaries between the two organizations are to be drawn. Thus, the Guideline becomes an actor in the setting up of new orders in the reformed political-administrative landscape of Region Zealand. Not only does the Guideline give rise to new type of complications. In initiating economical and professional negotiations, the Guideline also participates in re-shaping the municipal-regional boundaries on health care. These *travel expenditures*, involved in the Guideline's travel from the Board of Health to the local authorities in Region Zealand, are both negative and positive. On the one hand they make the process of elaborating the local JHPs more laborious as boundary negotiations and working out compromises are time consuming and resource demanding. These expenditures are made invisible at the Board of Health through its exclusive focus on the technical aspects of standardizing coordination using JHPs. On the other hand, the steering committee and the task groups also turn out to be assets in themselves. During the ten months that it took to elaborate the first draft of the local JHPs, the committee and

task groups facilitate networking among municipal and regional administrators and professionals working within the health area. As one municipal administrator put it:

*Now we know each other, we know the person we are calling when some problem has to be fixed. It is not possible any longer just to blame the bad guys from the regional administration if something goes wrong or information gets lost. We know they also have a heavy work load and we know that we can find a solution, which both parties can live with.*

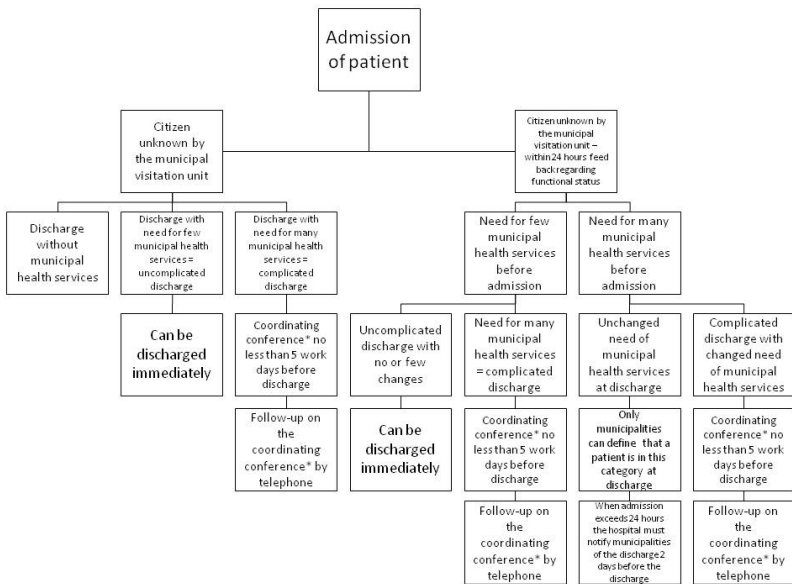
In short, the politics of coordinating care, which arises when the Guideline travels, in some instances also turn out to be valuable assets in and of themselves. The Guideline is not adequately described as a set of statements about bureaucratic reality. Rather it contains a whole implicit analytical account, which emerges through the description of it and which performs in re-shaping the municipal-regional boundaries on health care. Region Zealand's joint health plans are handed in for approval by the Danish National Board of Health on April 1<sup>st</sup>, 2007. In May 2007 the Board of Health announces that the plans are approved with some revisions and take effect as from June 1<sup>st</sup>. In the following I travel with the approved JHPs to a major hospital and the neighbouring municipal health units. The aim is to see what happens when hospital and municipality start trying to organize themselves in keeping with the plans<sup>7</sup>.

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<sup>7</sup> In order to facilitate this process the steering committee decides to elaborate leaflets for health professionals, which briefly sums up every joint health plan. However, these leaflets are not ready to be handed out before ultimo 2008.

### Coordinating coordination

The steering committee and task groups have gone lengths in order to make the local plans systematic, simple and easily applicable descriptions of the distribution of responsibility and assignments between regions and municipalities. Despite these efforts regional hospitals and municipal health units do not find it straightforward to align their practice with the standardized procedures of the plan. In fact, the plans cause quite a number of problems and challenges. The flow chart below is from the JHP on discharge of elderly, weak patients. In the following the standardized procedures summarized in the flow chart below serve as an example.



\*meeting between hospital and municipal nurse to plan and coordinate discharge of a weak elderly patient

## PART II: DOCUMENTS ON THE MOVE

With the enactment of the JHP, hospital staff is required to contact the municipality *before 11am* on the day before a weak elderly patient is to be discharged from hospital to municipal home care. The time deadline is to give municipal home care time to prepare receiving their citizen and ensure coherent patient trajectories across the two sectors. However, several hospital departments find it difficult to adhere to the time deadline. One hospital department is not able to get in contact with the relevant municipal health worker during these hours. When the hospital nurses do get in touch with the municipal health worker outside the agreed timeframe, they refuse to receive the patient, as the hospital has not kept their part of the agreement. Another hospital department experiences problems as rounds typically are made *after* 11am and it is therefore impossible for them to stick to the agreed timeframe. At a third department, where patient admissions are very short, there is a similar problem as patients are often hospitalized after 11am the day before but ready to be discharged the following day. The municipal health workers on their part experience problems with the discharge conference, which also has been made standard procedure with the joint health plan. As the patients' conditions change rapidly, what is agreed upon at the discharge conference therefore quickly becomes irrelevant for the municipal health workers.

Bal *et al* (2007) have shown how information in standardization attempts is made into a *product*. What this means is that instead of viewing information exchange as an ongoing communicative process, in which information is updated and adjusted and thus made relevant, information is turned into a format, in which only the final wording matters (hence it is a “product”). Similarly the local JHPs conceive coordination as a product. Information on

the division of work is elaborated at one place and then *passed on* to another. Yet, as the examples from the JHP on discharge of elderly patients show, the plans do not enter into static organizations but rather very lively ones. For this reason, the coordination of elderly patients' care trajectories also demands a process rather than only a product. So at first glance it would seem that Mintzberg was right in his critique: The JHP's standardization of work procedures indeed prove unduly simplistic. They are constantly overridden by unforeseen activities and courses of events. Even though the standardized work procedures have been developed with painstaking care, they are incapable of traveling to other practices without change. However, Mintzberg's analysis does not account for all relevant aspects of this situation. It is less attentive to the fact that the local JHPs also form *a new shared object*, which -- exactly because of its "too simplistic" representation of health care practices -- facilitates coordinating activity. As a consequence of the problems with aligning their work to the JHPs, the hospital management decides to organize meetings with the relevant regional and municipal staff where they can agree on a common translation of the JHPs. These meetings prove a success, but they also make it clear that the need for adjustment and adaption of the JHPs cannot be settled once and for all. Therefore, the steering committee decides to establish a number of local fora, in which adjustment and coordination of the joint health plans can be discussed ad hoc. These forums called Regional Collaboration on Joint Health Plans (RCJHP) are established at each of the three large hospitals in the region. Below, a head nurse at one of the large hospitals in the region describes the rationale for another coordinating forum:

*I experience the RCJHP as a very positive place to meet. We have decided that the forum is to consist of representatives from hospitals and municipalities who have decision-making authority to do something about the problems. At the same time we have other fora where the idealists can meet. If it is going to be an equal collaboration we need people in the forum who can make decisions*

As was the case with the Guideline, the local JHPs not only give rise to new type of complications, in terms of the health workers having to integrate the product and process versions of the plans - they also participate in network building in the reformed municipal-regional health care system. Following Bruno Latour, we can say that the JHPs also come to work *as mediators*. The plans bring about the formation of new coalitions between the two parties who, without their confrontation with the JHPs, would have found less reason to speak and collaborate (De Laet 2002).

The travel expenditures, involved in the JHPs travel from the political-administrative authorities in Region Zealand to the health care practices at hospitals and in home care, are also both negative and positive. On the one hand, the travel of JHP's to new places initiates time consuming and resource demanding translations and adjustment processes despite the painstaking care with which they have been developed. On the other hand, the need for adjustment of the plans also builds up new networks in a health care system where many previous networks were split up due to re-arrangement of units and organizations due to the local government reform. As such the local JHPs actually succeed in coordinating care. By being a shared object that all parties have to conform with, the plans bring municipal and regional health workers to work together. In the discussion of differences and disagreements of how



the plans should be translated an adjustment and tinkering of routines and work practices take place in both organizations. The analysis thus suggests that coordination is not something inherent to coordination instruments such as JHP. Coordination, instead, is a timely situated effect of the attuning, adjustment and adaptation, which the instrument brings about among related actors. The analysis also illustrates how much effort and how many resources it takes to coordinate. All of which implies that there is no guarantee that connections established – coordination today will remain active or unchanged tomorrow.

### **The JHP's flexible endurance**

Although the Guideline was presented as authority to accept and the local JHPs as procedures to be followed, the analysis shows how even more flexibility and transformation are required by the JHPs as they travel and attempt to do their job of coordinating care. The need for flexible endurance is materialized in the establishment of the three forums (RCJHP) for continual up-date and adjustment of the local JHPs. The order based on standardized action and uniformity, which was setup in the Guideline; reiterated in the local JHPs, and given as reason for a revising the legislation of the JHPs was thus challenged. Indeed, not only is the order challenged, its presumed *other* – an ad hoc, improvisatory, processual approach, is incorporated in the network through the RCJHPs. The JHP thus exemplifies how it is by bringing the disorder of plans into existence that plans are themselves able to continue to circulate and extend their spheres of effect (Berg & Timmerman 2000: 58). Throughout the process of elaborating, implementing and adjusting the JHPs, the local authorities on several occasions state their discontent with the

inflexibility and demanding requirements inscribed by the National Board of Health into the JHPs. As a consequence, in September 2009, the board issues a revised version of the Guideline (Danish National Board of Health 2009). The revised Guideline reduces the required level of detail and gives regions and municipalities more freedom in their collaboration on the JHPs. The revised Guideline also reduces the formal requirements in the template that the local authorities have to use when they submit plans for approval. The submission template is revised to make it more usable for the local authorities in their subsequent work with the JHPs. In short, the revised Guideline places more emphasis on local collaboration and less on standardization and uniformity by listing fewer steps and fewer conditional instructions. In the revised Guideline stability is to a lesser degree to spring from more precise instructions, but from the plans' flexible endurance when traveling to new places (De Laet and Mol 2000).

### **Concluding remarks: Travel expenditures**

Early in this paper I suggested that policy documents have to move between practices because their success is related to their geographical spread and adoption. By connecting performance and space the analysis of the JHPs has shown how the JHPs can be described as place-making - they transform the places to which they travel, for example by shaping the boundaries between what is primary and secondary care. Moreover, the JHPs assume new tasks and become new things themselves when entering new places. The plans both work as a technical device, a political tool for boundary construction and as a shared object facilitating inter-organizational communication and thus acquire a heterogeneous nature.

In pointing to the plans' place-making effects, the analysis also makes visible the price of successful (traveling) policy documents. The travel expenditures involved in the "transfer" of the documents are substantial. Numerous health professionals, national, regional and municipals representatives have spent (disproportionate) amounts of time elaborating, negotiating, interpreting and working around different versions of the JHP. At the Board of Health employees spent more than six months elaborating the Guideline. Yet another month was spent commenting on and approving the 98 JHPs produced (one per municipality). In Region Zealand regional and municipal administrators and health professionals spent ten months elaborating and negotiating the first draft of the local JHPs, after which they had to continue making adjustment and re-negotiating the plans. When seen in this context the JHPs are by no means indifferent or neutral pieces of paper. The JHPs cannot be understood solely as a matter of technical improvement of the primary-secondary sector interface. According to the Board of Health, the JHPs are to build a shared domain of care in which a transparent and standardized division of tasks is ensured. However, as we have seen this neglects the competition built into a decentralized health care system, which is made up of several independent units which all serve their own political agendas, professional and economic interests (Bal et al 2007). As it enters these complicated networks, the traveling of policy documents involve a never-ending need to tinker, to work around, to articulate loose ends. One general question is thus whether the costs (in terms of time and energy spent to *coordinate coordination*) exceed the benefits (the new coalitions and forums for dialogue that also emerged). Perhaps unsurprisingly I would suggest there is no clear-cut answer to that question. However, what the analysis does make

clear is that if a policy document is measured strictly against preset goals, then the evaluation is likely to miss out on many of the most important effects brought about – negative as well as positive (De Laet 2002). For even if a policy document does not accomplish preset goals, this does not entail that it hasn't had any effect. By traveling along with JHPs as they move between practices, the ambition of this analysis has thus been to facilitate a more broadminded analysis of the socio-technical costs and benefits of the enactment of a new policy on standardized JHPs. These costs and benefits tend to be forgotten when the introduction of new policy tools are discussed politically (Jensen 2008). On this basis I suggest that evaluating the effects of a policy document by the travel expenditures it gives rise to, both those who turn out to an asset and those who do not, provides a more adequate picture. This approach also involves a shift away from analyses which affirm existing power arrangements between policy and practice, towards one that shows how these arrangements are made and sustained and, more importantly, identifies where they are beginning to show cracks.

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## TRAVELING COMPARISONS

### Globalizing and localizing the chronic disease self-management program

*Co-authored by Casper Bruun Jensen*

#### Global and Local Health Care

Those who make a practice of comparing human actions are never so much at a loss as to put them together in the same light; for they commonly contradict each other so strangely that it seems impossible that they have come from the same shop (de Montaigne 1943: 117, in Ezrahi 1990: 15)

Western health care today is dominated by a discourse revolving around the ‘burden’ of chronic disease. The burden of chronic disease is described as creating rapidly rising cost by ageing populations, high levels of hospital utilization among those with chronic conditions and primary health care systems that are unable to respond to this demand (Dwyer *et al.*, 1998). Across the world health care politicians, policy-makers and other actors are preoccupied with finding cost-effective solutions that can meet this challenge. In this situation some health care initiatives come to be widely adopted, having apparent global purchase. But how does this happen? How do global health care practices emerge? How do they become global? And how do they become localized once again, as they are introduced into specific health care settings? Far from a simple process of dissemination, the globalization of particular health care initiatives involves complex processes relating to

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evidence and legitimacy, to agency and its distribution among health care workers and patients and to the organization and institutional frameworks in which health care operates. The paper addresses these questions by analyzing the *Chronic Disease Self-Management Program* (CDSMP).

The CDSMP is interesting because it has effectively framed itself as a global health care solution to the pressing issue of dealing with chronic patients. Originally developed at Stanford University in the 1990s the program has since been implemented in numerous countries in different parts of the world. The developers of the program argue that it is not only the individual patient but also the health care system at large, which benefits by training the patient in self-management (Lorig *et al.* 2001). On the one hand, they suggest, the program empowers the individual patient to act informed, pro-actively and competently in collaboration with the health care system. In this respect the program contributes to putting the patient at the center of the care process. Thus, the quality of life among chronically ill has increased. On the other hand, when the patient through training emerges as an active, responsible, self-caring patient, the program argues, it also frees resources to be spent on so-called weak or less resourceful patients (Danish National Board of Health 2005c, 2006).

Now if one considers worldwide adoption, the CDSMP has succeeded beyond all expectations. Why is this? To account for the global success of the program, its developers refer to the fact that it is an ‘evidence-based’, ‘cost efficient’ solution to the challenge facing all Western health systems today. Occasionally (e.g. Lorig *et al.* 2005:71) they refer to Rogers’ (1983) analysis of the ‘diffusion of ideas’ to account for the program’s success. Yet from an analytical vantage point inspired by constructivist work in e.g. STS, medical

sociology and organization theory (e.g. Timmermans & Berg 1997; Czarniawska & Sévon 2005), the global popularity of the Stanford Disease Self-Management Program appears less straightforward. As ‘sociologies of translation’ (Latour 1986) these approaches have been particularly attentive to the *efforts and difficulties* involved in getting ideas, facts, or, indeed, programs of action, widely distributed and adopted. The broader question we must ask is thus double; we query both how the CDSMP has become globalized and how it has still managed to become localized in diverse health care settings.

In the following we explore this double process. First we ask how it has been possible for the CDSMP program to achieve *global* success. Our way of approaching this question is to consider the program as a traveling technology engaged in ongoing efforts of negotiation and stabilization. Its means of successful globalization comprise *theorizing*, *evidence-basing*, and detailed *scripting*.

Second we explore how the program has managed to maintain *local* coherence. Here we analyze the implementation of the program in the Danish context with specific attention to the way in which the program has to negotiate the differences between its global claims and local specificities. Several assumptions are embedded in the program, including views on what is an individual, what is a patient, and what is a health care system. These are brought to light as the program enters different contexts and meets other perspectives. The disjunction between the assumptions of the CDSMP and the Danish context is explored by considering the program as embodying *traveling comparisons* that are rendered explicit in encounters with Danish practice. The success of the program relates to its ability to hold together the tensions generated by these comparisons.

### **The Making of the Chronic Disease Self-Management Program**

The current global focus on patient involvement is often discussed as a response to the recognition that health strategies have failed to recognize how people can play a positive part in building healthy lives for themselves and others (e.g. Department of Health 2001). Various policy solutions have aimed to empower patients to perform self-care and participate in care and treatment. The CDSMP is one of the most flourishing of these initiatives.

The CDSMP was invented in the laboratory of Dr. Kate Lorig at Stanford University during the 1990s. Lorig came to Stanford in 1979 to develop and research an educational program that emphasized self-help skills for people with arthritis. She created the Arthritis Self-Management Course, which became the prototype for the CDSMP, which was eventually developed as a collaborative research project between Stanford University and the California based health organization, Kaiser Permanente.

Traditionally patient education targets specific groups of patients such as diabetics, asthmatics or heart-patients. Diagnosis based patient education has been part of Western health care systems since the 1980s (Lorig 1996). These programs, often organized in a hospital setting, aim to increase patient compliance by providing patients with knowledge of their disease, medication and symptoms (Danish National Board of Health 2005b). Diagnosis based patient education is taught by health professionals and developed according to relevant medical perspectives on disease and treatment (Danish National Board of Health 2009:49).

However, according to Lorig and her colleagues this type of patient education did not address the issues that really mattered to patients. For example, traditional arthritis education programs focused on preventing disability and

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disability management, while the major concern of patients was pain. With reference to the work of medical sociologists Juliet Corbin and Anselm Strauss's (1988) on patients' perception of their condition, Lorig and colleagues argued that arthritis education programs should teach information about *managing* disability in the context of pain management. Using Corbin and Strauss' research, Lorig also went further and argued that patient education programs should relate to problems *as they were perceived by patients*. Thus, it was argued that although most health promotion and patient education programs dealt with medical and behavioral management, most did not systematically deal with the three central tasks identified in Corbin and Strauss' research: medical and behavioral management, role management, and emotional management (Lorig, 1996).

On the basis of the experience with the Arthritis Self-Management Program, Lorig elaborated a number of criteria that self-management education should meet; these also characterize the CDSMP: a) content presentation focused on patients' perceived needs, b) practice and feedback in new skills, including decision making and problem-solving, c) attention to emotional and role management in addition to medical management, d) use of techniques to increase patients' confidence in their ability to manage their conditions, and e) emphasis on the patients' active role in the physician/patient relationship (Lorig 1996: 680)

References to Corbin and Strauss' study aside, the early arthritis studies were avowedly largely atheoretical. They were simply based on the assumption that changes in behaviors are associated with changes in health status. However, Kate Lorig became increasingly interested in theorizing the improvements in health status, gained from participating in the self-

management program. Lorig's experience was that participants viewed the impact of the program as due to their feeling of *being more in control* of their illness. In the interest of accounting for this observation, the team investigated available psychological theories dealing with the issue of control. They were eventually inspired by Albert Bandura's theory of self-efficacy (Lorig, 2003), which argues that "perceived self-efficacy refers to beliefs in one's capabilities to organize and execute the courses of actions required to produce given attainments" (Bandura 1997: 3).

Based on their interpretation of Corbin and Strauss' sociology of chronic illness and Bandura's theory on self-efficacy, the CDSMP can be characterized as a psycho-educational program designed to increase the capacity of people with chronic conditions to self-manage. The aim was to improve participants' self-efficacy, thereby enabling them to more effectively manage their health condition. This involved the development of knowledgeable problem-solving skills and the opportunity afforded by the group to exchange ideas and suggestions. Self-efficacy is said to be enhanced by a number of mechanisms, the most effective of which is performance attainment (i.e. mastery or the experience of success following one's actions). The capacity for change is thus seen to lie within the individual, who is gradually rendered more capable as a result of exposure to the self-management program (Lorig and Holman 2003).

### **A Matter of Control: Theorizing the CDSMP**

"The most effective way of developing a strong sense of efficacy is through mastery experiences" (Bandura 1995)

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As noted the CDSMP came originally without an underpinning theory. As time progressed, however, it became increasingly affiliated with Albert Bandura's social cognitive psychology of self-efficacy. In this section we examine some premises of Bandura's theory in order to begin to develop an understanding of why this particular theory appealed to the developers of the CDSMP program and how it had to be adapted, or translated, to become part of it. Of course, Kate Lorig and colleagues have their own explanations for this. According to them, the theory was chosen because it fits better with patient's experiences than alternatives. Also according to them, this has subsequently been verified through scientific tests since the CDSMP has become evidence-based.

Even if participants expressed a need to feel in control, other theoretical options than self-efficacy were available that could account for this. To understand the preference for this theory, we need therefore engage in a closer examination of self-efficacy. It is perhaps little surprise that Albert Bandura's theory would be brought to the attention of Lorig and colleagues since he had developed and propounded the theory from his base at Stanford University for years at the time when the CDSMP was established. His famous *Social Foundations of Thought and Action: A Social Cognitive Theory* from 1986 offers a wide-ranging – indeed sweeping – statement on thought and action, situated within psychological theory that relates to what Bandura called 'models of human nature and causality' (Bandura 1986: 1-47). *Social Foundations* examined and criticized a variety of such models, psychodynamic theory, trait theory and radical behaviorism, and defined its own -- the social cognitive model. This model has since been refined and renamed as self-efficacy theory.



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The intellectual context for the development of self-efficacy theory was one in which many psychologists were wary of the excess ‘environmental determinism’ affiliated with radical Skinnerian behaviorism. Studying people, pigeons and rats in a similar manner, radical behaviorism accounted for human action in terms of operant conditioning, based on environmental stimuli. As critics began complaining, the behavioral universe left little space for human cognition, volition, intention or motivation.

Bandura, however, did not completely retreat from the implications of behaviorism. Rather he aimed to put cognition back into the picture. In *Social Foundations* he proposed a model in which “human functioning is explained in terms of a model of triadic reciprocity in which behavior, cognitive and other personal factors, and environmental events all operate as interacting determinants of each other” (Bandura 1986: 18). Humans, in this view, can be characterized by a set of basic capabilities: symbolizing, forethought and vicarious. This characterization raises questions: How can the environmental determinism of behaviorism be connected with cognitive notions such as symbolization and forethought? Bandura’s solution was to argue that behaviorists failed to extend the environment *far enough*. People act in response to their environment, to be sure, but this environment includes *even their own minds*. Thus, even though: ‘self-regulatory functions are fashioned from, and occasionally supported by, external influences’ (Bandura 1986: 20), it must be emphasized that an act ‘includes among its determinants self-produced influences’ (20). The combined theoretical picture offered here is thus one of ‘reciprocal determinism’. Determinism refers to the fact that human functioning is the effect of the sets of forces just mentioned. That it is

reciprocal means that neither the individual agent nor the environment is determinant alone.

Yet, this interactive argument faded to the background as the argument of *Social Foundations* unfolds. A series of chapters describe types of motivators and self-regulatory mechanisms all of which focus primarily on individual agents. The last two chapters radicalize this tendency in their discussions of self-efficacy and cognitive regulators to make the argument that ‘perceived self-efficacy’; that is, the belief a person has in his or her ability to accomplish a feat, is an *especially* generative capability often allowing subjects to *overcome environmental obstacles*. This aspect of social cognitive theory was particularly inspiring for the CDSMP. As we shall discuss in more detail, it has been operationalized in different ways, including in weekly action plans made by participants, which are “a little like making a New Year’s resolution”, but of shorter duration and much more specific.

These plans are used to identify tasks that the planner feels confident she is able to carry out, such as: “This week I will walk around the block once before lunch on Monday, Tuesday, and Thursday.” Concretely, ‘perceived self-efficacy’ is measured on a scale from 0 (completely inconfident) to 10 (completely confident). According to program guidelines, if the answer is 7 or higher, there is a “good chance” that the action plan will be accomplished. If the answer is less than 7, then the participant has to perform problem-solving to make the plan more realistic and to avoid failure. In the program, self-efficacy is thus linked to individual control as expressed in the ability to determine tasks that are accomplishable and to conduct these tasks.

The way in which self-efficacy theory renders the issue of control central to psychological understandings of “thought and action” has been

criticized. In “The Psychology of Control: A Textual Critique”, Henderikus J. Stam (1987) argued that self-efficacy theory was capable of making the case for the special importance of establishing personal control only by separating individual agency from a host of other factors and influences. Thus, Stam suggested, self-efficacy works by ‘desocializing’ individuals from their social contexts, by ‘deproblematizing’ the relation between structures of social relations and individual autonomy, by ‘deinstitutionalizing’ through lack of attention to interactions between agents and institutions, and by ‘dehistoricizing’ the question of social agency and control (Stam 1987: 143-8). Centered on individual control, self-efficacy theory is deeply infused with a common-sense Western perception of agency, famously designated ‘possessive individualism’ (MacPherson 1962), according to which a persons’ agency is expressed through individual autonomy. In this ‘version of agency ...self-contained agents who ‘own’ their actions, and demand to be accorded a series of rights and responsibilities’ (Brown, Ashmore & MacMillan nd: 24).

As well, these observations can be juxtaposed with the CDSMP. First, as in the recent manifestations of self-efficacy theory, individual agency and control is of central importance to the program. Thus it is central to the CDSMP that participants learn how to do problem-solving. As the participant’s manual states:

“When trying to overcome obstacles, the first plan is not always the most workable plan. If something doesn’t work, don’t give up. Try something else; modify your short-term plans so that your steps are easier, give yourself more time to accomplish difficult tasks, choose

new steps to your goal, or check your consultants for advice and assistance” (Lorig *et al* 2000:21).

Problems are thus defined as having one of two states. Either they are solvable by the individual, or they must be accepted. Bandura’s original observations on the ‘reciprocal determination’ of internal and external influence provide some kind of answer to the criticism that self-efficacy provides for a ‘desocialized’ and ‘deinstitutionalized’ theory. However, precisely this aspect of the theory has not made much headway into the CDSMP. Instead, the program has thrived precisely by emphasizing individual control. Arguably, the program thus falls into the trap identified by Bandura himself as ‘one-sided determinism’ (Bandura 1986: 22), locating all relevant agency in an autonomous self (although a self that is *struggling to be in charge* of its own actions rather than already controlling them).

For the same reason it requires little strain of the imagination to relate each of Stam’s four critical points to the CDSMP. First, while the program is built around group interaction and activities, it remains *desocialized* because individual action is highly circumscribed and all activities predetermined. In this way, the program *deproblematizes* relations between societal structures and individual participants, focusing exclusively on the latter. It likewise *deinstitutionalizes* chronic disease management by advocating use of identical processes and procedures irrespective of the health care and socioeconomic structures in which the program is implemented. Finally, it could be said, the program *dehistoricizes* or *deculturalizes* social agency by assuming that Western possessive individualism is a universal form of agency. As these points

suggest, each of the translations of social cognitive theory into program principles in the CDSMP can be problematized.

Yet, in spite of the relative ease with which these problems can be identified the fact remains that the program has become an astounding practical success. This suggests – somewhat unsurprisingly – that analytical coherence is not what determines the success global health care initiatives. Indeed, we would go further and suggest that operationalizing self-efficacy theory by focusing on only a few rather simplified key principles has *facilitated* success. If this is the case, criticism of the social and psychological theories embedded in the program must be complemented with an account of other reasons why self-efficacy theory has helped the program to travel.

Two empirical observations provide entry-points for further analyzing this issue. The first is that the CDSMP has put significant efforts into becoming *evidence-based*. The second is that the program has worked to produce a program of action, or a *script* to which all licensees must rigidly adhere.

### **Evidence-Basing**

“The evidence-based movement, as some have described it (Pope 2003), has been met with remarkable enthusiasm on the part of the elites in academic medicine” (Mykhalovskiy & Weir 2004: 1060)

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Evidence has become a key word in the medical vocabulary (Timmermans & Berg 2003). As Eric Mykhalovskiy and Lorna Weir observe, evidence has gone well beyond the confines of medicine proper. Indeed, it has become central for multiple health care stakeholders in:

Nursing, the allied health professions, health administrators and policy makers are all fast at work rearticulating their areas of practice as evidence-based domains. Research and policy institutes committed to EBM have been established across the globe, and evidence-based decision making has emerged as a recurring organizing theme of health-care policy conferences (Mykhalovskiy & Weir 2004: 1060)

In this context it is little surprise that evidence-basing became a crucial factor in allowing the CDSMP to travel globally. For the developers this raised the thorny question of how it is in fact possible to evidence-base a chronic disease management program. Bandura's work on self-efficacy provided a set of hypotheses and experiments that provided both an analytical foundation and a practical inspiration for accomplishing the evidence-basing of the program.

Now as we saw in the previous section, Bandura in fact argued for the reciprocal determination of several external and cognitive factors that together influence human agency and control. The problem with this expansive view is that it is difficult to make testable. Bandura's own experiments have been much more specific, concentrating on measuring the effects of self-efficacy. Self-efficacy as such, however, is also hard to specify since it is a quality of the mind. However, by focusing on *perceived* self-efficacy, it is possible to

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circumvent the problem. Thus, individuals can estimate their ability to be able to accomplish some task (holding a snake, for example) and this estimation can be compared with their subsequent ability to actually do so. The effects of self-efficacy are thus demonstrated if the perception of ability to accomplish the task is correlated with actual capability.

Lorig's experiments proceeded in a similar manner, by aiming to determine whether changes in self-efficacy were associated with changes in health status. In the mid 1990s, while the program was under development, a randomized controlled trial evaluating the effect of CDSMP was conducted. Approximately 1,000 people with heart disease, lung disease, stroke or arthritis participated in a controlled test of the program and were followed for up to three years. When compared to those who did not follow the program, the participants demonstrated significant improvements in exercise, cognitive symptom management, communication with physicians, self-reported general health, health distress, fatigue, disability, and social/role activities limitations. They spent fewer days in the hospital, and there was also a trend toward fewer outpatient visits and hospitalizations. Lorig and colleagues argued that these data yielded a cost to savings ratio of approximately 1:4 and that many of these results persisted for as long as three years (Lorig *et al* 1999; Lorig *et al* 2001a, Lorig *et al* 2001b). The CDSMP was reviewed by the Centers for Disease Control & Prevention (CDC) in 2008, which also found evidence that the program results in reductions in healthcare expenditures.

As the theoretical underpinning of self-efficacy theory have been challenged by critics, so too has its evidential basis. In response to Bandura's own presentations of evidence, critics argued early on that 'self-efficacy theory is conceptually problematic', especially in the sense that 'the central concept of

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efficacy expectations is not unambiguously differentiated from outcome expectations' (Eastman & Marzillier 1984: 213). If these concepts were interrelated rather than independent, perceived self-efficacy could not be measured in the way proposed by Bandura. Criticisms were raised against the self-efficacy assessment scale used by Bandura in the original experiments. This scale defined the score 10 as 'quite uncertain', 50 as 'moderately certain' and 100 as 'certain'. Eastman and Marzillier suggested that 'placing the label "moderately certain" at the 50 point results in a scale in which the conceptual "distance" from "quite uncertain" to "moderately certain" is much larger than the corresponding "distance" from "moderately certain" to "certain" (Eastman and Marzillier 1984: 223). They also pointed to the methodical problem of designating the scale a "probability" scale, indicating that the numbers estimate the probability that a subject will carry out a given task since "it includes no zero point and the labels are inappropriate in the context of probability assessment" (Eastman and Marzillier 1984: 223). Eastman and Marzillier concluded that the scale in fact does not measure self-efficacy and produce skewed evidence for the theory. Bandura blankly rejected these criticisms.

It is noteworthy that identical criticisms have been raised against the evidence base of the CDSM program. Thus, Brady (1997) argued that studies that purport to measure self-efficacy levels in relation to managing arthritis, in fact rather measure outcome expectations. Like Bandura's dismissive response to the criticism from Eastman and Marzillier, Lorig and Holman (1998: 155-7) rejected Brady's comment by arguing that it simply misunderstands self-efficacy. They refer back to Bandura's original work but refrain from noting that the same criticism was raised against this work.



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Critics have raised a number of additional methodological and analytical concerns (Greenhalgh 2009; Taylor & Bury 2007). They note, for example, that Lorig attributes positive effects of the self-management programs to enhancement of participants' levels of self-efficacy rather than learning specific information or techniques (Taylor & Bury 2007). They suggest that, contrary to the claims of the CDSMP, there is little evidence that 'lay-led trainers' have a greater effect than professional trainers (Chodosh *et al* 2005; Griffiths *et al* 2007; Taylor & Bury 2007). They problematize the suggestion that implementing the CDSMP would lead to a reduction in the use of health care services (Gately *et al* 2007; Greenhalgh *et al* 2005). Finally, they also argued that the randomized trials were based on carefully selected patients and biased towards wealthy white patients (Greenhalgh 2009)

As far as we are aware, none of the criticisms have been accepted or had any significant influence on the subsequent development and testing of the CDSM program. In the perception of health care administrators and policy-makers, the program has been sufficiently evidence-based (Danish National Board of Health 2009). In turn, this has vastly improved the ability of the program to travel (Danish National Board of Health 2005; Department of Health 2001). Evidence-basing the program has allowed its developers to simultaneously present scientific credentials *and* use research articles as a platform for telling the story of the importance of CDSMP in multiple venues. As a testament to this strategy, a selected list of publication on the program's homepage counts 65 articles and 11 books on the program. These include articles and commentaries in renowned medical journals like *JAMA*, *BMJ* and *The Lancet*. The fact that the program has generated vigorous debate

has helped it gain even more visibility and authority (see also the paper “Authorized experts and non-using users” for a discussion of this argument).

### **Scripting Global Health Care: Training, Licensing and Selecting**

We also have to move between the inside and the outside of technical objects. If we do this, two vital questions start to come into focus. The first has to do with the extent to which the composition of a technical object constrains actants in the way they relate both to the object and to one another. The second concerns the character of these actants and their links, the extent to which they are able to reshape the object, and the various ways in which the object may be used (Akrich 1992: 206)

We have argued that a particular translation of self-efficacy theory *into* the CDSMP and a subsequent effort to evidence-base the program facilitated the ability of the program to travel. If evidence of effect is a key feature of the program, it is necessary to ensure that the program *remains the same* even as it leaves the laboratory and is transported into “natural” health care settings. To understand this process, we draw on Madeleine Akrich’s analysis of the *scripts* embodied by technical objects. As Akrich suggests, articulating the script of an object means asking both about the kinds of use it facilitates and the kinds it constrains. It also entails a consideration about the extent to which the object – or program - can be changed, or reconfigured, by those who use it. How, then, has the CDSMP been scripted?

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As mentioned the CDSMP was developed as a collaborative research project between Stanford University and Northern California Kaiser Permanente Medical Care Program, an integrated health-care system that serves over 8 million members in various regions across the United States. In 1997 Kaiser Permanente decided to implement the CDSMP in the entire organization. It was decided to disseminate the program through a top-down approach in which individual regions and sites were not permitted to change or adapt the program. The Garfield Foundation, which was established to evaluate innovations within Kaiser Permanente, funded a 3-year process evaluation of the dissemination process (Lorig *et al.* 2005). In 1998, approximately 750 patients from Kaiser Permanente participated in the program; in 2002, approximately 2500 people participated. Based on the results of the process evaluation study and experience with widespread dissemination of the program, Lorig and colleagues developed a number of recommendations for disseminating the CDSMP. These were later turned into an implementation manual by Stanford Patient Education Research Center (2008).

The implementation manual is a very detailed description of all aspects of the program that organizations need to implement. It describes the process of training expert patients to run the program, it outlines how each part of the program is conducted and it details how patients should be selected and managed within the program. Rigid adherence to the manual is presented as crucial in order to make sure that each dimension of efficacy enhancement takes effect (Lorig 2003). Increased capacity of individual participants is thus based on standardized exposure to sessions that revolve around problem-solving, decision-making, resource utilization, action planning and partnership

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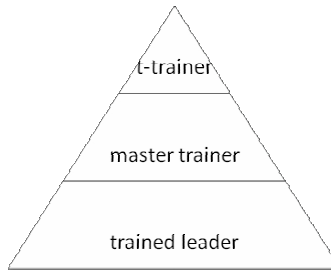
with health care providers. According to the developers, it is this specific process that makes the program work. Careful scripting ensures that it remains evidence-based, and therefore effective, no matter where it moves.

The general process is one in which participants inspire and help each other to find and test alternative ideas for how to solve common as well as serious problems. Concretely, the program is organized as a series of practical workshops that run for six weeks. Workshops are attended by ten to twelve people with different chronic health problems. They all follow a pre-determined format. The instructors use detailed manuscripts, in which every activity is given a time code. Subjects that must be covered include: techniques to deal with problems such as frustration, fatigue, pain and isolation; appropriate exercises for maintaining and improving strength, flexibility, and endurance; appropriate use of medications; communicating effectively with family, friends, and health professionals; nutrition, and how to evaluate new treatments (Lorig *et al.* 2000).

The program works as well with a notion of role models. The role models are two trained leaders who are themselves patients with a chronic disease. These trained leaders, too, follow a tightly scripted “Leaders Manual”. Every minute of the course is organized using this manual, which covers content as well as the interactions between leaders and workshop participants. Leaders must follow the script to the letter except during the period when Stanford staff is in the process of revising the manual. This happens approximately every 5 years. If special circumstances suggest the need to change the program, permission must be granted.

How does one become a trained leader of the CDSMP? The program is built around a hierarchy of certified trained leaders:

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At the top of the pyramid are the so called t-trainers (trainers of trainers), who are allowed to teach and certify master trainers (at a five-day workshop). T-trainers are educated by leading a master trainer course while receiving supervision from another t-trainer. The t-trainer can only be certified at Stanford University. In the middle row we find master trainers. The master trainer is allowed to train patients who lead the program. In these four-day workshops, the ‘master trainer aspirant’ leads a trained leader workshop and reflects on the purpose of each of the activities. Master trainers make it possible to sustain the CDSMP in their own organizations since they can recruit and certify trained leaders. Finally, at the lowest ladder, we find trained leaders. At trained leader workshops every activity in the program is examined and rehearsed by participants and master trainers. Each level of training is carefully scripted, as is the relation between them.

Now, if trainers are taught – and in this process standardized – through these courses, they are taught at the same time how to identify patients fit to join the program. This goes for participants with chronic diseases, some of which may be more suitable than others, but it is especially pertinent in relation to the recruitment of patients to lead the workshops. As regards these patients, the manual admonishes the trainer to “be a little cautious” about

inviting certain types of people to become leaders. These types include persons whose ‘main focus in life is their chronic condition’; ‘people who are super achievers despite their chronic condition’ (exemplified by ‘people who have had an amputation and run marathons’), ‘people who are judgmental’, ‘people who have “found the answer” to their disease and want to share it with the world’ and ‘people who are really sick’. The reason for excluding the latter is that sometimes ‘a chronic condition can become all consuming’, which makes some people ‘too sick to teach effectively’ (“This is a hard one on which to make a judgment call”) (Stanford 2008: 7-8).

Although it has been an aim to disseminate, reproduce and distribute the CDSMP for public use and benefit, it has also been an aim to profit on the program. Stanford has copyrighted the content for the training of program leaders and trainers of self-management of chronic conditions. Thus, before an organization can offer the CDSMP it must purchase a license from Stanford. According to the developers, licensing has several purposes. First, it establishes the legal obligations of the organizations offering the program. Second, it protects Stanford’s intellectual property. Third, it enables Stanford to keep track of who is offering the program and thus form a network of all licensed organizations. Finally, it allows Stanford to easily notify organizations when there are program changes.<sup>8</sup>

In combination, these requirements and procedures instantiate what we follow Akrich in calling *the script of the CDSMP*. The script packages together *training* of (patient) leaders, the *structure* of the program and the *selection* of patients via a *licensing agreement* that simultaneously ensures that Stanford is paid for use of the program and is able to control its use elsewhere. Each of

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<sup>8</sup> See <http://patienteducation.stanford.edu/licensing/>.

these requirements is bound up with the need for the program to *remain evidence-based* thereby enabling its travels. Thus, self-efficacy, evidence-basing and scripting are all tightly interconnected in a way that facilitates the CDSMP in becoming a global health care program. Scripting is a precondition for traveling globally. In the next section we consider what happens to the script *as* the CDSMP travels.

### **Traveling Comparisons: Frictions between the Global and the Local**

”The relationship between the environment inscribed in the machine design and that of the Thai farmer’s field are evoked *comparatively*. In this case, comparison resides within the machine itself, which at the same time implicates relations with Japanese environment and required to establish new relations” (Morita 2010 “Ethnographic Machine”)

The CDSMP has been carefully scripted in a way that enables it to travel globally, to countries as diverse as Denmark, Sweden, Austria, Singapore, Japan and Taiwan. Yet, the end-point of these efforts is the insertion of the program into local health care settings (cf: Lengford 2002; Zhan 2009). This creates numerous potentials for friction (Tsing 2005). From the point of view of the developers the aim is to maintain the global coherence of the program *even though* it travels. From the point of view of the “users”, however, the aim is to make sure that the program can be properly localized. Atsuro Morita’s (2010) analysis of Thai indigenous engineering shows how Japanese harvesting machines embody ideas about work practices and environmental conditions

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that are challenged in rural Thailand. The machines literally evoke comparisons as they travel from the Japanese to the Thai context. Analogously, we ask in this section about the traveling comparisons articulated as the CDSMP encounters Danish health care. Thus we are interested in how the traveling CDSMP come to function as a *comparative device*. An apparatus that facilitates comparisons to be made between the assumptions built into the program and the health care realities it encounters. As we show, the program facilitates comparisons relating not only to the common psychological constitution of mankind (assumed by the CDSMP) but also to questions such as why and how culture, society and institutions matter for health care initiatives, and what it means to be a patient and a health care professional according to the program.

In the early years of the millennium the American HMO Kaiser Permanente began to receive much attention in Denmark on account of their model for handling the ‘burden’ of chronic disease. At the time, the Danish National Board of Health was writing a number of white papers on this issue. In the period 2005-2008 approximately 130 people, representing different levels of the Danish healthcare sector and various interest groups, visited Kaiser Permanente. Visitors included the Minister of Health, members of the Parliament and local politicians, groups of health professionals, and administrators (Frolic *et al*, 2008). At the initiative of the Danish Arthritis Association, the Danish National Board of Health in 2004 acquired a 5-year national license to use CDSMP from Stanford University<sup>9</sup>. Initially they carried out a demonstration project.



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This pilot test was conducted by a partnership consisting of the arthritis association, the counties of Copenhagen and Ribe, and the National Board of Health. In conjunction with the pilot test, a number of workshops were held during which Connie Davis from Stanford Patient Education Research Center described and demonstrated the CDSMP. Managing doctors, nurses and occupational therapists participated in these workshops. As part of the same process the course book was translated into Danish, and seven people were educated as master instructors at Stanford. The project group also conducted site visits in Norway and the UK in order to explore other experiences with the CDSMP. The pilot was followed by an evaluation, carried out by a consulting company, Rambøll Management on behalf of the National Board of Health. The evaluation was to provide input on whether the CDSMP was acceptable in a Danish cultural, social and health context (Rambøll 2005: 5).

Before considering this report in more detail, it must be noted that the CDSMP does not in fact claim complete universalism. Indeed, it is at pains to ensure cultural appropriateness. How is appropriateness conceived by the CDSMP? The implementation manual (Stanford, 2008) takes a great deal of care to note special considerations for working with the program in different cultural settings – as it is said: “even your own”. It is explained that program activities are:

designed to be as near as possible culturally neutral. This means that they are usually acceptable in any cultural setting as long as the leaders and participants are from the same culture (and sometimes

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<sup>9</sup> This license covers all actors within the national health system until the end of 2010. Danish patient associations are allowed to offer the program using the same license against paying a fee of 250 dollars to Stanford.

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socioeconomic status) and the workshops are offered in a site and at a time that is culturally acceptable for the population being served. (Stanford 2008:23).

According to the authors, there is often as much diversity within a culture as there is between cultures. In the implementation manual the concept of cultural humility designates an approach to cultural issues, characterized by avoiding stereotypes since: “One size seldom fits all.” (Stanford 2008: 24).

The manual also gives examples of how the CDSMP successfully has been adapted to different cultures or minority groups. In all cases this has happened without major problems or changes; what has usually been required is “minor adjustments”. As an example is offered the case of working with First Nations People in Canada:

We have been surprised at how well some of the exercises worked with tribal people who I'd have thought would be reluctant. When we held a focus group with rural First Nations People in Canada, they wanted longer sessions so that they would have time to sit around and talk before the program started. They quickly reminded us that their diet was mostly wild animals and berries. They wanted few other changes. When we did the same thing with urban Indians in the United States, they changed the symptom cycle to a Native symbol and added a short prayer. With Native American communities, either prayer or silent reflection is added to the beginning of most classes and more emphasis is placed on low fat low salt foods. (Stanford 2008: 24).

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Admittedly, there is quite a way from Native American communities to Danish health care. In the latter case, too, however, cultural diversity issues have been raised and answered with reference to ‘minor adjustment’. The Rambøll report provides an entry point for analyzing the traveling comparisons embodied by the CDSMP.

Rambøll defined a number of indicators to determine whether the program was appropriate for the Danish context. They related to such themes as relevance, the quality of course materials and cultural transferability. The overall conclusion was that the program was indeed transferable and that patients with chronic conditions would benefit from it. However, despite the general recommendation to disseminate the program in Denmark, the evaluation also gave comparative testimony that translation to the Danish setting did not go entirely smoothly. A quote from the evaluation report illustrates some of the issues:

On the two first days of the workshop the master instructors experienced some resistance against the program, which was perceived as too rigid, blunt, inflexible and impersonal. According to Kate Lorig, this is common, as the program breaks with ordinary teaching principles and requires adaptation. It is Kate Lorig’s experience that resistance disappears as the participants experience on their own body that the process works for them and as they see that it works for other participants. This also happened during the third day of the demonstration project’s trained leader workshop. (Danish National Board of Health 2005: 14).

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The evaluation report mentioned several problems and challenges. Participants questioned different aspects of the program including the length of the program, particular activities and effects. In the evaluation report, however, each line of criticism is rebutted in the way illustrated by the quote above. The recurring answer is that the program rests on many years of experience and has been thoroughly tested. Each criticism has thus been encountered before and is therefore already taken into account. Readers are assured that resistance will eventually disappear.

A particularly interesting example is afforded by the response to the question of the cultural applicability of CDSMP in a Danish setting. A number of participants from the demonstration project carried out in Ribe County responded that they regarded some aspects of the program to be problematic in the Danish setting. The evaluation report interpreted these answers in the following way:

It is thus possible that attitudes towards the program's applicability come from a generally sceptical attitude among the provincial participants towards applying American concepts in a Danish setting rather than a concrete sceptical attitude toward this program. However, to determine whether this is the case goes beyond this report (Rambøll 2005: 23).

On the one hand, the evaluation report thus treats the question of cultural applicability as important. On the other hand, concrete questions about or reservations with regard to the appropriateness of the program is dismissed, or, as in the last case, somewhat paradoxically explained away with reference

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to peculiar cultural tendencies. The only noteworthy cultural adaptation is the removal in the Danish context of an activity in which participants have to elaborate “A durable power of attorney”, “a document that appoints another person to act in your place if you are unable to do so” (Lorig *et al.* 2000). This requirement was found by Danish participants to be ‘too American’, for the Danish context which is comparatively uncommitted to litigation.

That the Rambøll report found few cultural discrepancies and paid only limited attention to those it did find is perhaps not surprising. Danish officials used broadly the same strategy – to emphasize the necessity of appropriateness while finding no concrete problems. Thus, they defined as premise for Danish implementation that:

As regards the transferability of the concept to a Danish setting, the four partners [performing the pilot test of the program] agree that it is doable as long as the translation of the program, adjusts the concept to Danish circumstances and culture, while at the same time being loyal to the [program’s] method. However, it has been necessary to “peel off” the American approach, but the opinion is that the concept as such is generalisable (Danish National Board of Health 2005: 41).

Since the report does not elaborate on what is meant by the ‘American approach’, it can be assumed that it takes for granted the readers to compare and distinguish this approach from a Danish one. Comparisons at this level give rise only to ‘minor adjustments’. Aside from the question of the attorney they can be exemplified by the removal of an activity in which participants are

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to write a life testament. Trained leaders realize that the Danish participants finds the activity of ‘preparing for dying’ very American and explain that participants experience negative emotions.

Such minor adjustments aside, however, the qualities of the ‘American approach’ as perceived by Danish patients and health care personnel, is comparatively evoked and specified in a number of substantive ways. First of all, trained leaders struggle with the rigid timeframe and structure of the program. The problematic involved in the rigid timeframe and structure of the program is the cause of continual debate at the annual meeting for trained leaders of the program. Trained leaders remark that participants persistently question this aspect of the program. The explanation is offered that this is because the format provides for a very “un-Danish” learning setting. The Danish teaching tradition is based on the allocating time to what is deemed important in the situation. This contrasts with rigid adherence to a predefined schedule. This teacher wants free hands to adapt teaching depending on the needs of patients. Additionally, she argues that little time is allotted to the problem-solving sessions. In consequence they become less valuable as there is not time to elaborate on different ideas. For her, the rigorous scripting of the sessions comes across as distinctly and problematically alien.

The distinct American imagination guiding the program is also comparatively evoked at a more institutional level. Whereas American health care is based on private health insurance mainly organized through Health Maintenance Organizations, the Danish health care system is a so-called Beveridge type system based on tax based universal health coverage. As we have seen, the CDSMP enacts a strongly individualized version of patient-doctor relationships. Yet, as it travels to Denmark (as elsewhere), it is required to

manoeuvre in a quite different setting. Danish participants note and remark on the incongruence by characterizing the program as a “typically American” self-help paradigm. They see this most clearly articulated through the way in which it is the task of the individual patient to take responsibility and control. For some, this health philosophy (based on Bandura’s psychology) breaks with a “Danish welfare mentality”, according to which the “system” is assumed to take responsibility for vulnerable social groups.

One trained leader exemplified the problems that may follow from this comparison, with an experience from one course, in which a participant kept obstructing the activities because he was provoked by the exaggerated emphasis on how individuals can help themselves. By pointing to the differences between welfare health care as they know it and their perceptions of American health care, participants thus make clear that the CDSMP embodies quite specific assumptions about patients and their relations to themselves, the health care system, and even society. Whereas developers view the CDSMP as basically culturally neutral, Danish participants experience it as carrying distinctly American baggage. Viewing the CDSMP as a set of traveling comparisons has thus allowed us to get “under the skin” of the global claims of the developers and to highlight some of the frictions that arose as the program travelled into Danish health care.

### **Holding Together the Global and the Local: The Success of the CDSMP**

Our interest in this paper has been to account for the global success of the CDSMP. The case is of course specific, but we suggest that it offers insights of more general currency into the emergence of global health care programs.

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If the aim of the CDSMP is to travel widely, our analysis suggests that careful scripting of a diverse set of elements enables this. Scripting is, thus, a precondition for globalization. Yet, globalization always means localization in multiple settings. Considering processes of localizing the CDSMP in the Danish context, we proposed to view the program as a device that articulates differences between health care practices comparatively as it travels. Thus, we have asked the double question of how the CDSMP has become and remained globalized while also becoming localized. Global and local healthcare are here not opposite; rather they are mutually implicated. The global and the local, however, do not necessarily co-exist harmoniously, but may exhibit friction. The success of the CDSMP can thus be described as its ability to continue *to hold the global and the local together*.

The CDSMP has been constructed as a tightly scripted program comprising a number of interrelated components. In combination they have turned chronic disease management into a 'do-able problem' (Fujimura 1987) on a worldwide scale. This requires ongoing efforts and continuous vigilance. In the present case it involved transforming the program from an un-theorized, experiential entity, into a theorized, evidence-based one. Subsequently, it involved a detailed scripting in which all elements of the program were interrelated in a coherent whole.

The making of this interrelated whole was a precondition for global traveling but was also challenged due to the traveling. Outside of the Stanford manuals and the confines of the laboratory, other actors become part of the CDSMP, and they may have different interests in and interpretations of the program. In the Danish context the program evoked a series traveling comparisons. They related to issues such as the format and organization of



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the workshops, questions of death and attorneys, and involved challenges to the American health care paradigm that participants perceived within the program. This points to the pertinence of de Montaigne's suggestion, with which we began the paper that: "comparing human actions are never so much at a loss as to put them together in the same light; for they commonly contradict each other so strangely that it seems impossible that they have come from the same shop".

In light of these challenges it is particularly fascinating to observe that the script of the CDSMP has continued to operate. The program continues to globalize. Local challenges and comparisons are successfully handled with reference to 'minor adjustments'. The global and the local co-exists in friction but is held together by the CDSMP. The program emerges as a global health care platform not because chronic disease is everywhere the same but because the program script *turns chronic disease into the same problem*, globally.

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## **AUTHORIZED EXPERTS AND NON-USING USERS**

### **On the authorizing effect of expectations and the fragility of power in disease self-management**

#### **Re-configuring the patient**

“Today, the debate (or the polemic) is no longer set in terms of medicine and anti-medicine. The questions revolve around whether health is a matter for private or for public provision; around whether and how the market for health should be regulated; and around the conditions for participation, for inclusion or exclusion, in the opportunities generated by an ever growing health industry.” (Greco 2009: 17).

In today’s healthcare the question is not whether or not the patient should have an active role and be heard in medical treatment and care. The Parsonian notion of the passive sick role has lost its bearing (Parsons 1951). The question rather is *how* and *under which conditions* the patient is to participate in his or her medical trajectory and treatment (Greco 2009). Already partly performed and partly idealized and shaped through discursive practices, patients are increasingly expected to be self-managing and technologically empowered citizens able to access, produce and manage health-related information, administer treatment trajectories and make informed choices (Department of Health 2001). Globally various governmental programs and technologies have been launched, which aim at teaching patients these new required skills and engage them in treatment and care, for instance patient



education programs, telemedicine and online support-communities such as [patientslikeme.com](http://patientslikeme.com).

These “humble and mundane mechanisms by which authorities seek to instantiate government” (Rose and Miller 1992: 183), have been a favored object of socio-political research since the 1990 (Greco 2009; Maravelias 2007). Inspired by a Foucauldian notion of power, these studies have led to valuable insights on how governmental strategies and technologies which aim at shaping institutions and subjects in particular ways operate and reproduce power in practice (Rose 1999, Dean 1999). Governmentality studies, as these studies are often termed, has convincingly shown how the neoliberal state, with reference to freeing the full potential of the citizen, produces more discrete and efficient forms of social control, and how classic hierarchies in turn are reproduced in new forms in contemporary relations between citizen and the state (Rose 1999). Within medical sociology governmentality inspired studies have analyzed new forms of involving patients in treatment and care (Wilson 2001; Fox et al 2005). These studies show how governmental programs have shifted their traditional focus on controlling the patients’ behavior (compliance with medical treatment) to a focus on controlling the selves of patients. It is shown how governmental programs on patient empowerment seek to make commitment to and identification with ‘the responsible self-managing patient’, a norm that is enforced and controlled by the patients themselves (Cruikshank 1999).

In this paper I stand on the shoulders of the valuable insights generated by this approach, but with the aim of giving an alternative account of the intricate power relations at play in programs for patient empowerment. I find

the need for an alternative account primarily for two reasons: Firstly, as Greco notes, it might be argued that the critical function, initially offered through the notion of governmentality, has become somewhat redundant. Greco argues: “Through the concept of ‘governmentality’, scholars in a range of disciplines offered early critical analyses of health promotion discourse in the specific context of neo-liberalism, highlighting some of its paradoxical features. To the extent that such paradoxes are now more widely articulated as an explicit subject for public debate through the notion of a ‘health society’” (Greco 2009:13). Secondly and more importantly, although probably few scholars today would argue that the internalization of power is something that is done to individuals who, as it is, succumb to it (Knights and McCabe 2000), within health care analysis the efficiency of social control in determining how patients relate to themselves is often less problematized (Jensen 2008). Moreover, failures in determining how patients relate to themselves are often only explained in terms of resistance or social inequality, leaving out other possible reasons for failure. For these reasons I focus on the fragility of power, on how power easily fails at being just that, instead of on the discreteness and efficiency of social control. Drawing on scholars within the field of Science and Technology Studies (STS), I will show how the plans of the putatively powerful in the form of governmental public health programs are often transformed as they are enacted and how “power failures” can take other forms than resistance (Gomart 2004; Wyatt 2003). The aim is not to deny the (possible) subjugating and disciplining effects of governmental programs, designed to mobilize patient responsibility, but to question the effectiveness and extent with which they operate.

Empirically this aim is pursued using ethnographic data<sup>10</sup> on the *Chronic Disease Self-Management Program*, a program which aims at teaching patients with chronic conditions, how to handle their life-condition in what the program refers to as a pro-active way. The disease self-management program lends itself as a “prime” example of a governmental program which targets and aims to shape social relations with reference to obtaining the full potential of patient-health care relationships. In the following I will show how the disease self-management program’s configuration of the patient as self-reflecting, extrovert and adaptable makes authority available to only a small group of participants, whose way of handling and coping with disease is thus authorized as “competent” and “expert”. I will also show how the authorization of one group of participants as expert patients can only take place via a simultaneous de-authorization of another group of patients. In this case making power itself appear considerably more distributed and fluctuating than often supposed. Through analytically including both the *authorized experts* and the *non-using users* the paper outlines an analytics of power which on the one hand does not deny the disciplining effects of initiatives such as the CDSMP, but which at the same time includes the fragility of an authority which has to be performed and reiterated to be just that.

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<sup>10</sup> The analysis of the CDSMP is based on ethnographic material generated over a longer period of time. The collected material is based on participant observation of the six week long program, the workshops which educate and license former participants (and patients) to become trained leaders of the program and of follow-up meetings among a group of patients just having completed the program; interviews with former participants, instructors, supervisors and administrators of the Stanford license as well as the municipal health workers coordinating and administrating the programs being held; observations of network meetings among trained leaders of the program; and written material such as course material, mail-correspondences, news-letters on the program etc.

### **The Chronic Disease Self-Management Program**

Globally, various policy solutions have been launched with the aim of making patients perform self-care and participate actively in their care and treatment. One of the most influential is the *Chronic Disease Self-Management Program* (CDSMP) or *The Expert Patient Initiative* as the British version of the program is called. Developed at Stanford University in the 1990ties, but adopted in 23 countries worldwide, the CDSMP has effectively framed itself as a win-win situation (see PART II: TRAVELING COMPARISONS for an elaboration of this argument). It is not only the individual patient, but also the health care system at large, which benefit by training the patient in self-management (Lorig et al. 2001). On the one hand, the program empowers the individual patient to act pro-actively and competent in collaboration with the health care system, thereby contributing to putting the patient at the center of the care process. On the other hand, the patient emerges through training as an active, responsible, self-caring patient and this leaves more resources to be spent on encounters between health care professionals and so-called 'less resourceful patients' (National Board of Health 2005c, 2006a). In the UK more than 50.000 patients have attended the program so far<sup>11</sup>. In Denmark where the program has been running since 2006 more than 1500 patients have completed the CDSMP in 2009 (Danish Committee for Health Education 2009). The CDSMP is organized as weekly practical workshops held over a period of six weeks and facilitated by two trained leaders who are themselves patients with a chronic disease. Ten to twelve persons with different chronic health problems attend at a time (Lorig 2000).

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<sup>11</sup> See <http://patienteducation.stanford.edu/licensing/>.

The goal of the disease self-management program goes considerably beyond increasing patient compliance with medical treatment, which traditionally has been the object of patient education (Danish National Board of Health 2005b). The program is concerned with what its developers call the social and mental aspects of living with a chronic disease. Rather than teaching patients how to solve particular problems, the aim of the program is to teach the participants *methods and techniques of problem solving* (ibid.: 14). According to the developers of the program, it is the process in which the program is taught that makes it effective. Participants and trained leaders are to inspire and help each other find and test alternative ideas for how to solve common day as well as serious problems (Lorig, 1996).

### **Governing the (dis)empowered patient**

“Yet by simply accepting these powers as real, rather than empirically investigating them, it becomes exceedingly difficult to adequately understand the complexities of health care practices – just as it becomes correspondingly harder to imagine alternative ways of doing health care.” (Jensen 2008: 365)

The empirical field of patient education and patient involvement is dominated by an empowerment discourse: The self-managing patient denotes a more democratic patient-centric perspective, as it is believed to renegotiate the terms on which patient participation in health care infrastructures has taken place so far. According to policy-makers and politicians, programs as the CDSMP and the self-managing patients these produce, challenge traditional

medical research in the creation of new ways of knowing disease. Rather than a meeting between authoritative professionals and vulnerable patients, the aim is to make space for a meeting between experts.

However, the claim of patient empowerment put forward by the program's developers and its adopters has been questioned by medical sociologists (Taylor and Bury 2007; Wilson 2001; Fox et al. 2005). These scholars argue that despite the more democratic appearance of the program, the supposedly empowering and emancipating initiative is in fact a subtle way of subordinating the subjects to governmental powers (Gastaldo 1997; Thorne et al. 2000; Henwood et al. 2003). In this description, the CDSMP does not aim at controlling the patients' behavior, but the selves of patients, and as such lends itself almost too easily to a description as a discrete form of neoliberal social control (Rose 1999). The participating patients are governed as they assimilate the demands and expectations of the CDSMP and make them their own (Fox et al. 2005). Rather than encouraging a new model of health and illness, this analysis argues that self-care and patient participation initiatives serve to reinforce a biomedical model of disease. Thus, Wilson argues that although the CDSMP focuses on the rights and responsibilities of those with chronic illness, it does not at the same time challenge professionals' assumptions toward those with chronic illness (Wilson 2001: 134). The patient might gain more decisional autonomy, but this is only to be used in certain situations and is followed by increased responsibility for illness and treatment (Fox 1999, Lupton 1995). The inherent conflict of interests between health professionals and patients, this position argues, is not dealt with by the program. Rather the biomedical perspective on healthy lifestyle or appropriate treatment is reinforced alongside patient rights and as health professionals

continue to be the legitimate gatekeepers of health care resources (Tang & Anderson 1999; Thorne et al 2000). Despite the program's apparent empowering intentions, it is thus argued that the program reproduces classic hierarchical relations between citizen and the state albeit in new forms.

While governmentality studies have led to valuable insights on the intricate power play in programs by which health authorities seek to instantiate the "self-managing responsible patient", Greco argues that there also is a need to move beyond this type of accounts (Greco 2009). For one, the analytical insights generated by governmentality studies, are not only well-known within an academic milieu, they have also (as a testament to their merits) travelled into the empirical field, in this case health care practices. For instance some health care professionals and policy makers use of governmentality studies types of argument in discussions about how much health care policy should interfere in the private sphere of patients (ibid.). In short the medical sociological reflex of describing programs like the CDSMP as a conflict of interest between authoritative health professionals and vulnerable patients, who become more vulnerable as more responsibility is put on their shoulders, is no longer a solely critical academic argument.

Secondly and more importantly, in relation to governmental programs on patient involvement, the effectiveness of the governmental intentions in determining how patients relate to themselves is often not substantially problematized in empirical studies. Both the empowering and disempowering position seem to treat social control as something that flows down a pre-given hierarchy, from the seat of power to the diverse practices of health care (Jensen 2008). For instance the (dis)empowering effect of the

CDSMP is regarded an intrinsic quality of the program that diffuses from program to patients when the latter is exposed to the former. The problem with analyzing power as a repressive substance, is that disease self-management is seen as a question of *simply having the power to change the way patients relate to themselves*.

A central point within STS is that technologies or other types of policy solutions are always in the hands of their users, who use, abuse, abandon and change the technology or program in and through their practices of use (Latour 2005). Achieving “power” is thus by no means a trivial task. On the contrary, to realize a given health care solution, depends not solely or primarily on the intrinsic qualities of the design of the health care program, but on a network of both material and human actors. Accordingly, the introduction of technologies or programs involves not only a reconfiguration of those who are the objects or subjects, but also of the plans of those supposed to have power (Callon 1998).

In an analysis of women in IVF treatment, Charis Cussins challenges accustomed ways of thinking of the patient as the disciplined subject par excellence and objectification as only entailing loss of agency and alienation (Cussins 1999). Cussins shows how women in IVF treatment exercise agency, and how at times this is expressed by their active participation in their own medical objectification. Women undergoing IVF treatment objectify their own infertility so that they may move through medical diagnosis and treatments in a way that brings about desired changes in a long-range identity i.e. become pregnant or a mother. Cussins argues that agency and objectification are co-constitutive rather than distinct, social processes;



each moment of objectification exists with an associated form of agency. Adding an ontological connection between selves and technology, Cussins uses the spatiotemporal metaphor of *ontological choreography* to capture the cycles of objectification involved in the distribution and redistribution of activity among people and things in the infertility clinic: “The patients do not so much let themselves be treated like objects to comply with the physician as comply with the physician to let themselves be treated like objects” (Cussins 1999:179).

In this paper I pick up on Cussins’ analysis. I use the notion of authority instead of power to elaborate on how technologies work to articulate subjectivities and how patients in the process rework their own identities as users in relation to the health care program. In order to encompass other possible reasons than resistance or social inequality for failures in the program’s plans to determine how patients relate to themselves, I also use the notion of non-use (Wyatt 2003). Thus my approach is to study in detail how the program’s plans are continually transformed in interactions between the disease self-management program and the participating patients. This allows me to account for the specificity that occasions each actual occurrence of power.

### **The authorizing effect of expectations**

In this section I propose to analyze the effects of health care programs as processes of authorization. Drawing on psychologist and philosopher of science Vinciane Despret’s notion of expectations as processes of authorization, I propose to analyze the relation between the disease self-

management program and the participants as a relationship based on authority rather than power.

Drawing on Gregory Bateson's authority figure and experiments from ethology (the scientific study of animal behavior) Despret examines how expectations and authorization are related and interlinked. In elaborating this argument Despret quotes Bateson: "a person is said to have authority when anyone who is under the influence of that authority does everything possible to make whatever this person said to be true" (Despret, 2004a: 118). However, in line with a STS position, Despret turns Bateson's subject-bound definition around, and makes authority a relational effect of expectations being fulfilled. This means that for a person to acquire authority, the ones authorizing that person must be interested in aligning their action with the expectations of the (potential) authority. Or put differently, there must be a will to achieve what is expected of them, trust and interests must be shared, even though for different stakes. Despret notes that what is most important for this process is the emotion of trust. "Indeed, the whole matter is a matter of faith, of trust, and this is the way I suggest we should construe the role of expectations, the role of authority, the role of events that authorize and make things become." (Despret 2004: 121). What does this mean for health care programs, which seek to determine how patients relate to themselves? It means that for the programs to have effect the participants must trust or believe in the patient configuration set up by the health care program. Otherwise the participants will not be willing to fulfill the health care programs expectations as to what it means to be e.g. a responsible self-caring patient. In this way the emotional relations creating authority, made of expectations, belief and trust, can also propose new ways to behave, new

identities and transform both e.g. the CDSMP and the participating patient (Despret 2004: 122). In fact, the proposal of new interesting ways of being e.g. patient, can serve as a motivation for aligning one's behavior with the expectations set up by the program.

A crucial point is that to fulfill the expectations of another, what Despret also terms to make one self available to others beliefs, is not identical to simply obeying that person. As authority comes about relationally, a person may resist what is expected of him or her or transform the expectation of e.g. the CDSMP into new ones. That is, there is no determinism inscribed into authority as processes of expectations. Gaining authority are *reciprocal* processes of delegation of authority based on expectations and belief. Despret's notion of authority as a relational effect of expectations being fulfilled also implies that authority is an experienced effect and as such the relation between fulfilled expectations and authority stabilizes authority. Or put differently authority authorizes.

With Despret's understanding of expectancies as processes of authorization, it becomes important to observe who guides whom and who authorizes whom in the practice of the disease self-management program? Who sets the expectations potentially leading to authority and how? In STS terms this can be formulated as a matter of how the program's design *configures* the user (Woolgar 1991, Oudshoorn and Pinch 2003) and how this configuration is transformed when enacted by the assemblage of participating actors.

### **Configuring the expert patient**

“The gender distribution is 70/30 [female/male, ajn] like at the general practitioner and we have a hard time getting hold of the weakest 20% of patients with a chronic condition, but that critique goes for the whole system and not just us.” National coordinator of the CDSMP

Users play an active role in shaping socio-technical change during their domestication of technologies (Oudshoorn and Pinch 2003). Given the heterogeneity of uses, designers will, consciously or unconsciously, privilege certain expectations of users and use over others, e.g. expectations of the intended users’ interests, competences, skills, responsibilities, actions etc. Expectations are thus inscribed and materialized in the program’s design (Woolgar 1991:69, 89). Such user configurations facilitate, but also confines who and how a given technology can be used and abused. In the following I go into the nitty gritty details of how the CDSMP configures the patient, in order to examine the expectations of ideal practice and patienthood that the program sets up. As will become clear later on, this configuration involves an inclusion or authorization of some groups of patients, but also an exclusion or de-authorization of others.

The CDSMP is based on the idea that all patients pass through a process of coming to terms with having a chronic condition of differing intensity and length. In order for the patient to gain from participating in the program the patient has to be at a stage in this process where feelings of apathy, anger or

self-pity are left behind and the person is ready to take responsibility for getting the most out of life with a chronic disease. As one of the national coordinators of the program in Denmark puts it, the disease self-management program must not be offered too early nor too late. The patient has to be “ripe for learning” how to take responsibility for her own health. On the other hand, the patient should still be in need of help. If a patient is already a good self-manager before participating in the program, it can be a problem to have to learn to do things in the program’s way. Equally important, such patients also become a problem at the workshops because they obscure the process the rest of the participants have to go through. According to the national coordinator, the good self-managers’ do not experience the same thrill of acquiring agency as the rest of the participants and as an effect it becomes more difficult to build up the right atmosphere of success in the class.

In order to make sure that the patient is able to benefit from the program, some of the municipal coordinators perform a screening of the patient’s readiness. The screening is not only concerned with finding out whether the time is right, but also whether the patient is in a physical condition that allows the person to participate in the 2½ hour long workshops. On this the national coordinator comments:

”In relation to mental illnesses there is a problem. We just started the program in Østerbro, where many of the participants come from an institution, which works with brain injuries. In this case the screening was very hard and a lot of patients did not get to participate in the program, because they would not be able to pull it

through. Before the program there was no offer to this group of patients, so they are not worse off than they were before.”

Some patients who have a chronic condition also suffer from mental illnesses such as depression. According to the national coordinator these patients are not excluded from the program if they have started treatment. However, as was the case with the majority of the patients suffering from brain injuries, not all kinds of diagnoses go well with the program. The municipal coordinators give different examples of patients that they now choose to not include in the program. For example one municipal coordinator tells of a Parkinson patient, who was prone to tears and made it difficult to retain the positive group dynamic among the rest of the participants. The profile of the patients who complete the program also gives testimony to the selection process preceding the program. Patients, who complete the program, are characterized by being, mainly, educated married women with an ethnic Danish background (The Danish Committee for Health Education 2008).

On the first workshop the participants agree to a number of obligations: Daring to ask about everything, reading the course material and trying out new activities for at least two weeks, making and going through with a weekly action plan and finally calling a fellow participant once a week (Lorig et al 2000). The participant is configured as someone ready to share personal thoughts and experiences with the other participants as the program assumes that sharing thoughts leads to a reduced feeling of isolation and stigma. A central part of the program is to teach participants to communicate ‘openly and effectively’ with their surroundings. “As uncomfortable as you may feel about expressing your feelings and asking for help, chances are that others are

also feeling this way. It may be up to you to make sure the lines of communication are open” (Lorig et al 2000: 141). Thus the program also configures the patient as a person who is conscious that e.g. the way expectations, doubts and wishes are communicated is crucial for the dialogue with health care professionals. When encountering frustrations and barriers during communication with health care professionals the person is expected to learn or at least appreciate how feelings can be communicated in a constructive manner.

Most activities in the program include readings and so called mini lectures, in which the trained leaders instruct the participants about the significance of eating a healthy diet and being physically active. Learning objectives state what the participants should be able to complete after each of the six workshops. For instance, the goals for the first workshop is that the participants should be able to: define at least three differences between acute and chronic illnesses, to identify common problems due to chronic illness, to identify elements in the circle of symptoms, to mention at least two tools to self-help from the self-help tool box, to practise distraction as a means of self-help, and finally to work out an action plan for the coming week (Danish Committee for Health Education 2009). Another activity teaches the participants how they can prepare a resume of symptoms since their most recent consultation, and to prepare questions regarding treatment before meeting with their doctor. According to the program, the general practitioner meets many patients during a workday, and seldom has the time to prepare for a consultation. As a response the participants are taught to take control of the consultation through e.g. symptom resumes and in this way assist the general practitioner

improve their treatment. This activity ends with the trained leader giving the following two mini lectures:

“To receive the right treatment and care can be difficult at times. The health care system is complex and often it is hard to foresee where challenges arise. For instance, reaching the doctor over the phone can be hard and understanding him/her can be difficult.”

”In the back of your mind remember that health care personnel are working under difficult conditions e.g. lack of time and information (which is why it is so difficult to inform about one’s condition). They can be just as frustrated as the rest of us” (Trainers manual 2009: 120).

The program also configures the participant as a person who handles her illness in an aorganized systematic way and who constantly looks for ways to expand her possibilities of action. The corner stone of teaching the participants to act systematically is the so called action plans, which must be elaborated each week. At the coming workshop the participants must tell whether they have completed their action plan, and if not what made them fail. The weekly action plans are used as a means of practising to break down large goals into smaller achievable aims. They are meant to inspire participants to increased action, offer them a greater feeling of control over their own situation and to make them trust that they can take care of their treatment and course of disease. Seen from a traditional perspective on the doctor-patient relationship, the program’s configuration of the patient is expanded in the



sense that the patient is expected to be highly involved in the treatment and control of the course of disease. The program's configuration of the patient as a self-reflecting, extrovert and adaptable person entails that the problems a patient may meet are always problems which the patient can (and must) act upon.

### **Co-authorizing expert patient and the Chronic Disease Self-Management Program**

"No, it hasn't had a great impact as such, but it has had the impact that I mentally have benefitted from it and it has done me good to make that [positive thinking] present again. Basically I am confirmed that what I do is the right thing, but I wasn't really doubting that anyway." Participant of the CDSMP

In this section I argue that the disease self-management program's configuration of the patient as self-reflecting, extrovert and adaptable makes authority available to a *small* group of participants who already self-manage their disease trajectory and perform self-care before attending the CDSMP. The way in which these expert patients' handle and cope with their disease is thus authorized as "competent" and "right". In turn, I suggest that the authorized expert patients make authority available to the program - authorizing it as an indispensable and competent device for patients with chronic disease.

”So actually it is a little difficult for me to take daily medicine, because if it has those side effects, then it doesn’t really help that much. So I have had to work out other strategies. This may also be why I am more motivated for attending such a self-management program, because when my options aren’t that... you get more motivated for saying: ‘For fucks sake, then what I am to do? Give me some tools, so I can navigate and do as best as possible’. And actually I think my doctor is quite happy with that.” Trained leader of the CDSMP

The majority of the authorized patients have developed a self-caring or self-managing approach before attending the CDSMP. They have developed this approach out of an experience with the health care system as a burdened organization. Health care is viewed as an organization that is not able to create overview of its own production and that cannot adapt its procedures to the needs of the individual patient. This is precisely why these participants choose to attend the CDSMP – it is their experience that if they want to get the best out of things they need to take on the responsibility of their patient trajectory themselves. As the trained leader explains in the quote above, the program complies with her experience with the health care system and not least with the kind of tools which patients like herself demands. The expectations that the health care system will take care of everything only puts the patient in a worse situation. The only “way out”, as the trained leader in the quote states, is to take the matter in one’s own hands. In the understanding of the participants (one of) the solution(s) to the challenges in living with a chronic condition lies in the patient’s own agency and experiences with living with a

chronic disease. Throughout the program it is reiterated that participants themselves have the answers to how to cope with disease and treatment. No health professionals are present at the workshop who might correct or have an alternative view on the participants' suggestions on a given matter. All suggestions or views that the participants share with the group, are accepted as valid and are received unquestioned, as prescribed by the program's manuscript. The program believes and trusts in the resolution and experience of the participants, and the expert patients reward this trust and faith with an equal amount of trust and belief in the program. Put differently, the program offers an interesting new identity as patient to these participants in terms of making their practice as expert patients more articulate - and authorized.

The CDSMP offers the patients a chance to be articulated rather differently from the role of either disciplined patient or disabled unemployed citizen. The trained leaders not only lead the disease self-management workshops and are entitled to authorize other patients (ask *them* to become trained leaders) they also enter regional and national networks for trained leaders. A middle-aged female trained leader, who is a disability pensioner, explains how she has experienced becoming a trained leader like "getting a job and being useful again". To her, the CDSMP has offered the opportunity of making her experiences with being a patient an asset to society instead of a burden. The annual national meetings and the regional network of trained leaders provide an opportunity to discuss experiences with her colleagues and develop further her expertise in leading the workshops. In Denmark where the program has been running since 2006, some of the most experienced trained leaders have run more than 20 workshops during the last couple of years. Being a trained

leader is thus both the means and the goal of living with a chronic condition. The emotional and authorizing relation linking this group of patients and the CDSMP is also expressed when the trained leaders take on the role as enthusiastic advocates of the CDSMP. In Denmark as elsewhere, the CDSMP has received a substantial amount of attention from the media with trained leaders being interviewed on television and for local newspapers about their “new” life with chronic disease after having attended the CDSMP. Thus the trained leaders are not only the motor that keeps the practice of the CDSMP running, they are also crucial in terms of authorizing the program as tantamount to living with a chronic disease. Thus it facilitates the program’s ability to continually perform itself as a success. In Despret’s words, the program proposes to the patient, while the patient proposes to the program, a new manner of becoming together which offers new identities: The program gives the patients the chance to add new meaning and ways to behave as a patient (e.g. being an *expert* patient and not just any patient), while the patients give the program the chance to disclose itself as a proper and authorized self-management tool for patients with chronic diseases. “Both are active and both are transformed by the availability of the other. Both are articulated by what the other ‘makes him make’.” (Despret 2004: 125). The emotional relations made of expectations, faith, belief, trust that are so established and that link patients to the program and vice versa, show that it is not only a practice, which proposes new ways to behave and new identities. In doing so it also transforms and articulates both the patient and program in new ways. Because these patients have faith in the propositions of the program, they can fulfill the expectations of being motivated, competent, action oriented, flexible and so on and make these expectations their own. It matters to these patients that

the program's expectations are "true", something they can believe in and trust. For them it is a way - if not out, then beyond the all too well-known role as passive objectified patient. A corner stone in this process is that both patient and program willingly make themselves available to this transformation.

Despret distinguishes between set-ups or programs which *make available* and those that *make docile*. The difference is that the first allows the participants the possibility of resisting what is expected of them, whereas the latter does not (Despret 2004: 123). Thus to fulfill the expectations of others is not the same as obeying expectations<sup>12</sup>. The CDSMP allows these participants to resist its practice, as we shall see more clearly in the next paragraph. Indeed, one of the strengths of the program is precisely that it is not constructed in a way which makes the participants docile, i.e. it does not determine how the participants relate to themselves. The participants and the program *choose* to make themselves available to an authorizing event they create *together*. The real power of the Chronic Disease Self-Management Program lies thus not so much in being able to determine how the participants relate to themselves, but in its authoritative proposal of a new way of being an expert patient.

However, as a young female trained leader explains below, inherent in the authorization of the expert patients and the CDSMP is also the expectation that some are *not* able to live up to the expectations that some are unable to become expert patients:

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<sup>12</sup> Cf. Cussins' (1999) analysis of women in IVF treatment, who objectify their own infertility so that they may move through treatment in a way that brings about desired changes in a long-range identity i.e. become pregnant.

”It is not for the deprived to be frank. That is, they don’t have to be as good at taking care of themselves as I am. A lot can be learned by coming here. Now, I knew a lot already, but it is not for someone with few resources or with no education. They will opt out completely, it is way too difficult, and it goes way too fast.”

At the end of the final workshop when people were saying good-bye to each other, the trained leaders told a young female participant that she had been extremely valuable for the group and the program with her enthusiasm and active engagement in the activities. They also told her that if she wanted, they were sure she could become a good trained leader of the program. The female participant, an educational assistant on sick leave, was surprised but happy to receive praise from the trained leaders. No one else from the program received this praise or was asked to become trained leaders. According to the trained leaders, it had not been one of the good groups of participants. There had been too many participants who did not bring any energy to the group and who did not participate in building up the right group spirit of success and agency. In short the program’s failure to capture and engage the participant was explained with the participants not being the right kind of participants. But what happens to a patient who is not able to live up to the expectations of being keen on making changes in lifestyle and take responsibility for his or her patient trajectory?

### **Processes of de-authorization: The non-using users**

In this section I argue that the effectiveness of the CDSMP as authorization device is premised on a simultaneous de-authorization of another group of

participants which I refer to as the *non-using users*. Not all participants comply with the program's expectations, nor does the program comply with all participants' expectations. Through including those instances when the authorization of both program and participants fail in the analysis, it becomes possible to show how the assemblage of program and participants is not enacted uniformly and how power as a consequence is distributed unevenly among those involved in the enactment of the CDSMP.

As a group the non-using users are characterized by having made it through the explicit selection process and received seats in the CDSMP. Some users drop out during the program, because they don't like the program's format, they do not find it useful or they just stop showing up<sup>13</sup>. However, a large part of them complete the course. Yet, they do not get authorized as expert patients and none of them are invited to become a trained leader at the end of the program. According to the trained leaders, this may be due to that the non-using users are not at the right stage in acknowledging their disease and their own agency in living a healthy life with a chronic condition. Or they may be too depressed or too busy doing other activities to invest the necessary amount of energy in the program. And sometimes, the trained leaders explain, there is no explicit explanation other than some participants just not being "right" for the program. In the following I describe the processes of de-authorization of a young male participant and an elderly widower and how

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<sup>13</sup> Currently there is no Danish data as to how big the dropout rate is as only participants who have completed the program forms part of the national evaluation surveys. However, an evaluation is under elaboration, which will provide data on the dropout rate ([www.dsi.dk](http://www.dsi.dk)).

these participants in turn de-authorized the CDSMP as a proper and effective device for patients with chronic illnesses.

A young male participant, referred to the CDSMP by his general practitioner, very strongly wanted to lose weight, but had so far been unsuccessful, as he found it very difficult to quit his habit of eating large amounts of sweets at lonely evenings in front of the television. While attending the CDSMP his weekly action plans all revolved around trying to lose weight and getting rid of what he considered his bad habits. The first action plans that he developed were rather unrealistic: He would stop eating sweets altogether or he would start eating a completely different diet. During the rounds in which everybody told of their action plan for the coming week, the trained leaders failed to get him to make a more realistic plan as he was very determined on this goal. When he showed up the next week, not having been able to adhere to his plan, the trained leaders did as the program prescribes: They asked the group to do a problem solution session. In these sessions all participants are asked to come up with ideas and tricks that could help the participant adhere to his plan. People came up with all sorts of ideas: Make sure you don't have any sweets in the house; buy chocolates that are wrapped in small portions; exercise and allow yourself one sweet as a reward. After the round the trained leaders asked him whether he liked any of the suggestions; if there were some that he would like to try out. His response was rather negative. He had already tried them all many times and he was not able to fool himself with those kind of tricks. If he didn't have any sweets and he felt like them, he would just go to the nearest 7-11 shop and buy some. The chocolates being wrapped in small portions did not stop him from eating the whole bag. Presented with this failure of the program, the trained leaders tried to calm things down, by



suggesting that maybe he should write some of them down after all and try them again. This got the participant quite agitated. Again he explained that he had already tried the suggestions and they were no help to him. Frustrated with not being understood the young male reiterated that what he was in search of were other kinds of tools or advice. Again the trained leaders response was to suggest that he at least could try one or two out, but when he again responded very negatively, they decided to move on to the next activity. According to the trained leaders the problem with this participant was that he did not grasp the concept of the program. By refusing to try out any of his fellow participants' suggestions and by insisting on his lack of agency in relation to losing weight, the participant did not "play along" and allow the program a chance to show how effective and helpful it could be. The trained leaders' explanation was that the young male participant was not *ready and properly motivated* to benefit from the program. The trained leaders let him stay on the program, but he was not praised for his efforts or contributions to the group. The young male participant saw himself as very motivated for making a lifestyle change, specifically losing weight, and he very explicitly asked for help to accomplish this change. However, he did not do so in the manner prescribed by the program. As he had already tried out the tricks and suggestions made by the other participants, he explicitly asked for other kinds of advice. When the program was not able to deliver what he requested, he stopped believing and as a consequence did not make himself available to the transformation into an expert patient proposed by the program. In short, the negative expectations on part of the trained leaders de-authorized the young male participant as an expert patient, while his negative expectations of the program de-authorized the program as an effective device for lifestyle change.

As a *non-using user* the young male participant embodies resistance but also exclusion. He only engaged in some of the activities of the program and resisted the usefulness of the others. He started out playing along, but upon finding the program ineffective resisted aligning his actions in the way expected by the program. Thus he only began resisting after experiencing the program as unable to help him in the desired way. This young male participant did not manage to change his diet or weight while attending the program. When we met again, a month after the program had finished, he was still struggling with overweight, with guilt coming from his sweet-eating habits and with negative thoughts as he blamed himself for being unable to lose weight. Instead of facilitating an increased sense of agency, the program seemed to have confirmed his view that he was unable to lose weight. Clearly he was not one of the pro-active and resourceful patients, capable of changing their lifestyle.

Another participant who was de-authorized as an expert patient was an elderly widower, referred to the CDSMP by his physiotherapist, who worked at the local health centre where the course was held. During the program the elderly widower made the action plans as required, all of which concerned things he usually did. When the participants share their action plan with the group, they have to do so by answering four questions: 1. Is it something you would like to do? 2. Is it realistic? 3. How often will you do it? 4. How confident are you that you can do it? Question 4 is answered by using a scale from 1-10. Plans rated below 7 must be revised so as the participant's confidence in accomplishing the plan increases. Being able to rate an action plan with a high number is well looked upon, as it is taken as a sign of the participant getting

hold of the idea of making action plans and starting to be more realistic in her or his planning. At the same time the plans must contain actions, which are new to the participant or something the person does not usually do. Now, the elderly widower's action plans did not comply with this format. All his plans concerned things he usually did: Play bridge Monday evening; buy coffee for the bridge club; train with the physiotherapist etc. He rated all of them 10 as he said he was confident that he would continue his daily routines. The first couple of weeks the trained leaders when presented to these plans asked him instead to come up with an activity that he wouldn't have done had he not attended the course. In response the widower replaced the first routine with another equally standard one and when pressed again for a non-routine activity, came up with a third of his usual activities. The trained leaders ended up giving up on him and letting him make his "routine plans".

As the young male participant, the elderly widower was also de-authorized as an expert patient, but for quite different reasons. The elderly widower conscientiously showed up at each workshop, did his homework and like a devoted student engaged in the action plans eager to demonstrate to the leaders that he was able to accomplish his plans. Still, the trained leaders considered him as dragging down the group spirit, with his liking to routines and status quo. Rolling their eyes, the trained leaders explained that no matter how hard they tried to explain the concept to the elderly widower, he simply did not get it. While the ideal participant inscribed into the program is keen to take action, experiment with new activities and experience change, the widower was quite happy with the way things were. He had no inclination to change his habits and no desire to engage in new activities. Being de-

authorized as expert patient did not seem to trouble him much. Although puzzled by the program and its format, he did not engage in open discussion with the trained leaders, but settled with an occasional headshake.

As a non-using user the elderly widower passed through the program without leaving any traces. He was neither empowered nor disempowered by the program. On the one hand, he did as was expected of him engaging in all the activities. On the other hand, he did not what was expected of him and had no intention to change his way of life. In this respect the elderly widower silently de-authorized the program as an effective device for patients with chronic conditions. Like the young male participant, but for different reasons, the program did not offer the elderly widower something that he found valuable. As a consequence he did not make himself available to being transformed into an energetic, pro-active elderly man keen on trying out new activities and changing habits.

Like the authorized expert patients, the stories of the non-using users illustrate how the processes of (de-)authorization are created or rejected relationally. Rather than being able to project the intentions of the powerful, the program ends up being judged as useless, not relevant or as illustrated by the lacking support at the reunion meeting, merely trivial: During the program the trained leaders several times emphasised, how much they themselves had benefitted from the program when they first attended it and how they still met up with their now fellow trained leaders. Even though they would not organize it, they strongly encouraged the group to continue meeting after the program had ended. All twelve participants shared phone numbers and e-mail addresses

and decided on two dates that we would meet in the first half year following the ending of the official part of the program (in the spirit that the rest of the dates could be arranged later). However, when the date for our reunion arrived, apart from myself, only two others showed up. Upon realizing that nobody else would turn up the other two were keen to go home, as they had mainly shown up out of conscience due to the promises made a month prior. However, they agreed to let me take the opportunity of conducting an informal group interview about their experiences with and use of the CDSMP. The participants merely shrugged upon realizing that what had been organized as a social event, ended up as a research episode. In short, not only did the program not authorize the non-using users as expert patients, but neither did the non-using users authorize the program as the effective and proper device for patients with chronic disease.

However, the de-authorization of one group of participants is also an indispensable element in the authorizing process of some participants as expert patients. In fact, I suggest that it is built into the program. The authorization of the expert patients is premised on the notion that not all participants are able to fulfill the program's expectations to what constitutes an expert patient. The reason for that the authorization of the expert patient would not work as effectively if all participants were asked to become trained leaders and thus represent the program<sup>14</sup>. The program needs to be able to distinguish between the "true" self-managing, pro-active and learning oriented participants and those who are not, as the differentiation gives weight to the authorization of the expert patient. The authority of the expert patients

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<sup>14</sup> If all participants were to become trained leaders the organization of the CDSMP would furthermore breakdown as the trained leader- workshop ratio would go awry.

among other things lies in being entitled to authorize others, but not everyone.

The de-authorization of the *non-using users* demonstrates how power is distributed unevenly among those involved in the enactment of the CDSMP. As such the analysis of the non-using users exhibits the *fragility* of the supposedly powerful program, as it is not able to accomplish what it sets out to do namely to determine how patients with chronic conditions relate to themselves. Upholding power (in the sense that the participants internalize the expectations of the patient as self-reflecting, extrovert, flexible and learning-oriented conveyed by the program) proves much more difficult than assumed in governmentality inspired studies.

However, as described in depth in paper 1 the CDSMP has been successful in traveling the globe and framing itself as an effective and appropriate device for handling the increasing “burden” of chronic disease. Clearly the fragility of the CDSMP personified in the non-using users does not form part of the official narrative of the program. At first this may seem as a paradox: the CDSMP is a rather fragile governmental program, but worldwide received as the opposite, namely as a success in terms of handling the “burden” of chronic disease. However, in effect the success of the program can also be explained by how authority is distributed unevenly among participants in the enactment of the CDSMP. The effective de-authorization the non-using users is in fact what makes the program able to appear so successful, as it excludes the non-using users from taking part in the authorized representation of the CDSMP. It is the authorized experts and thus most often trained leaders who represent the program in the media, in

the workshops, at the annual meetings etc. The non-using users figure in the number of patients with chronic diseases which have attended the program, but the fact that their experience with the program differs from that of the authorized experts is made invisible. In this sense the non-using users can be described as detached from the network of the CDSMP (cf. Star 1991). They end up as the losers in the network representation and is left out of history and made invisible once the black box has closed.

### **The pervading effect of authority**

Using insights from STS scholarship on the distributed character of power, the configuration of non-users and Despret's notion of expectations as processes of authorization, the present paper has presented an alternative account of the (dis)empowering effect of a welfare program, designed to increase patients' ability to self-manage their disease trajectory pro-actively. On the basis of ethnographic data, the paper has empirically demonstrated how the intentions inscribed into the program when enacted are transformed into co-constitutive processes of authorization and de-authorization of the program participants.

The first point made in the paper is that the CDSMP makes authority available to a small group of already self-managing patients, whose way of handling and coping with disease thus is rendered as "expert" and "competent". In turn, the expert patients authorize the program as a proper and useful device for patients with chronic disease. In this way, it can be argued that the program further strengthens a small group of resourceful patients. This contributes to displacing the traditional patient-doctor

asymmetry. Yet in doing so the program does not construct symmetry. Rather it contributes to a new form of asymmetry in which the authorized 'expert patient' as he or she is enacted within the program potentially becomes capable of demanding and getting more or better treatment than other patients. This leads to the second point made by the paper. By including a focus on participants who are configured as non-using users, the analysis has made visible how the co-construction of users and program involves an uneven distribution of authority among involved actors. Crucially, however, the processes of authorization described above work so effectively that even though the non-using users' are enrolled in the program they are at the same time excluded from the CDSMP network, which come only to be represented by the authorized experts.

This analysis qualifies ongoing debates within medical sociology. Governmentality studies criticize that programs such as the CDSMP by program developers and politicians are described as a democratization of the patient-professional relationship. In reality, this position argues, it still is a power relation in which the patient subjugates her or himself to a biomedical perspective on disease and its handling (Wilson 2001; Fox et al 2005). However, I suggest that the critical account in itself facilitates the ongoing authorization of the CDSMP as a powerful program for societal change (Bowker 1995). These critical accounts contribute to a process of authorization in which the governmental perspective is reproduced in reverse. In believing that the CDSMP is able to determine how patients relate to themselves in an almost unproblematic way, be the effects empowerment or disempowerment, the critical accounts implicitly further the assumption that the CDSMP is an unstoppable governmental intervention (Jensen 2008). As



the analysis of the empirical enactment of the program and the processes of authorized expert patients and the non-using users have shown, this is far from the case. Although the authorized expert patients align their actions with the expectations conveyed by the program, they choose to do so because the behavior prescribed by the program to great extent resonances with how they handled their disease before entering the CDSMP. The non-using users, on the other hand, choose not to do so for many other reasons of which the urge to resist the program is only one of them. In Despret's terms the expectation of the powers of the CDSMP that are built into the critical accounts, thus contributes to authorizing the disease self-management program precisely as powerful. Commenting on the researcher's share in the processes of authorization, Despret talks of *the pervading effect of authority*: "we may see, therefore, the pervading effect of authority: to have the authority to authorize is to make the one who is authorized gain authority, and thereby, to be entitled to authorize, in his/her turn, someone else." (Despret 2004: 132). Accordingly this analysis also participates in processes authorizing the disease self-management program as an authority in policy solutions to the "burden" of chronic disease. Yet, by including those instances when the processes of authorization fail, the analysis has also pointed to the fragility of health care programs such as the CDSMP in bringing about societal change. The non-using users are neither heroic nor irrational, but their actions cannot be categorized simply as resistance or incompetence either. Approaching the authorized experts and the non-using users in a symmetrical manner, the paper has thus outlined an analytics of power, which does not deny the disciplining effects of initiatives such as the CDSMP, but which, at the same

time, includes the fragility of a power or authority which has to be performed and reiterated to be just that.

I opened this paper with a quote by British scholar Monica Greco, in which she diagnoses the debate on health today as dominated by questions revolving around the conditions for patient participation and inclusion and exclusion (Greco 2009). On the basis of the empirical analysis of the CDSMP I tend to agree with Greco. The analysis has shown how the conditions for patient participation as they are conveyed in the CDSMP involve several processes of in-and exclusion. Not only in terms of who is granted a seat at the program, but more importantly also among those participants enrolled in the program. These in- and exclusion processes disappear in detail, if the analysis does not transgress the official empowerment version of the CDSMP. For the developers and organizers of the CDSMP, the question becomes how to develop the CDSMP so to make it a *better* program for *more* patients? That is, a program, which in the vocabulary of this paper, produces less de-authorized users and more authorized experts. One obvious suggestion would be to elaborate the configuration of the patient, so as to allow for more diversity among users and the aims these users pursue.

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## PART III

## CONCLUSION

For a health care program to have an effect it must be able to travel or move between practices. As its possibility of influence is related to its geographical spread, the circumstances and factors influencing a program's ability to travel are key to understanding how some programs become successful and others do not. With inspiration from science and technology studies (STS) this thesis has approached this subject through the notion of traveling technologies. 'Traveling technologies' is developed as an analytical approach and strategy for examining how health care programs successful at moving between practices and thus also in building networks, simultaneously produce their own fragility, referred to as travel expenditures. In the following I explicate the contribution of the PhD as a whole cutting across the contributions of the individual analytic papers.

### **Technology transfer re-visited**

The relational ontology of actor network theory (ANT) has raised the question of how technical artifacts are transformed when they travel to new places, where they are cut off from the physical, social and conceptual relations, which have previously stabilized their forms and functions (Morita 2010). STS-inspired studies on the travel or transfer of technologies have shown how these transformations reveal the ontological multiplicity of science and technology (cf. Zhan 2009, Langford 2003). Studies on the transfer of technology from one place to another have often been done in relation to technologies being transferred from a developed to a less developed setting (cf. Akrich 1992; De Laet & Mol 2000; De Laet 2002; Morita 2010). This thesis has tried to refresh interest in this kind of STS-inspired studies, but by

tracing technologies being transferred from a developed to an equally developed setting. The thesis suggests that this approach is equally relevant and analytically productive when studying technologies traveling within what is regarded a similar cultural setting (relatively to differences between north-south or developed-developing). PART II: DOCUMENTS ON THE MOVE and PART II: TRAVELING COMPARISONS suggest that the interaction between the inside and the outside of a technology is also charged with friction, despite that the technology has travelled only a very short distance (the JHP) or a longer distance but within similar cultural settings (the CDSMP). Approaching health care programs as traveling technologies can be seen as a strategy for de-familiarizing oneself with the familiar, e.g. the trivial structure of governmental policy documents or the ways governmental programs aim at shaping social relations and identities. Observing the technologies as they enter new (albeit in some sense also familiar) places, where they are cut off from their usual network elements, provides an opportunity for exploring the embodied relations previously rendered invisible. As unfolded in PART II: AUTHORIZED EXPERTS AND NON-USING USERS approaching health care programs as traveling technologies can thus call attention to processes, and uneven fields of power often neglected in health political discussions of new modes of government and subject formation.

Moreover, as unfolded in PART II: TRAVELING COMPARISONS, approaching health care programs as traveling technologies also provides a possibility for exploring how the programs *evoke* comparisons as they travel from one place to another. That is how traveling technologies come to

function as a *comparative device*. A comparative device can be described as an apparatus that facilitates comparisons to be made between the assumptions built into the program and the health care realities it encounters. As PART II: TRAVELING COMPARISONS described, the CDSMP facilitates comparisons relating to the distinct American imagination guiding the program. Danish participants of the CDSMP point to the differences between welfare health care as they know it and their perceptions of American health care, making clear that the CDSMP embodies quite specific assumptions about patients and their relations to themselves, the health care system, and even society. In the case of the CDSMP, viewing the program as a comparative device, is a possibility for getting “under the skin” of the global claims of the program and to highlight some of the frictions that arise when health care is globalized. This leads me to the second contribution of the thesis.

### **Globalizing health care**

Although the two health care programs studied in this thesis are of course specific, they also offer insights of more general currency into what makes health care programs travel. Both programs are tightly scripted packages of relations and the analytical papers suggest that their ability to travel widely is closely tied to this scripting. At the same time, for the programs to travel, they must also be flexible as their careful scripting is constantly challenged as they travel. These challenges, which are referred to as travel expenditures, involves the programs constantly negotiating their own order, as other actors become part of their network. These actors have different interests in and interpretations of the programs and for the programs to be able to keep

moving between practices, these interests must be incorporated. In the case of the JHPs this process takes place quite openly, with the establishment of new collaborations, which negotiate the order of the JHPs. In the case of the CDSMP local challenges and comparisons are successfully handled with reference to 'minor adjustments'. The CDSMP makes a fascinating example of how despite these challenges the script of the CDSMP continues to operate. The program continues to globalize.

This leads to the final concluding remark, which only pertains to the case of the CDSMP, namely the part which the program plays in globalizing health care. As mentioned the CDSMP has successfully travelled the globe, being adopted in countries as diverse as Taiwan, the United States and South Africa. As PART II: TRAVELING COMPARISONS shows, this is not because chronic disease is everywhere the same, but rather because the program's script turns chronic disease into the same problem, globally. Or perhaps more precisely, the program turns chronic disease into the same 'do-able problem' (Fujimura, 1987) on a worldwide scale. The program emerges as a global health care platform, in which the global and the local co-exist in friction (ongoing efforts and continuous vigilance is required), but is held together by the CDSMP. Approaching the CDSMP as a traveling technology thus also makes visible how global and local health care not are opposites, but rather mutually implicated. In a Scandinavian context health care is closely tied to the *welfare* state and therefore traditionally considered a very local or Scandinavian phenomenon. However, studying the CDSMP as a traveling technology, shows how 'Danish welfare' actually is patched together by different entities, some of them coming from countries with traditions very different from the

### PART III: CONCLUSION

Scandinavian welfare model (as the comparisons evoked in the enactment of the CDSMP in a Danish health care setting also gives testimony to). Not that this in itself necessarily is a problem or a bad thing. The point this thesis makes is rather that to understand the globalization of health care, it calls for an approach which is able to empirically flesh out how the global and local are mutually implicated and detail the effects of this process. In this thesis I modestly believe to have suggested one such approach.

## ENGLISH SUMMARY

When a health care program is successful in traveling and spreading geographically it is often explained with reference to the program's effective design, because it offers valid or proper solutions to a given problem or because it legitimizes the organizations adopting it as competent or pro-active. The implicit argument is that the program is able to move between practices because it simply is the best available solution to a given problem or because it is an unavoidable solution to almost any problem. As a health care program's possibility of influence is related to its geographical spread, the circumstances and factors influencing a program's ability to travel is key to understanding how some programs become successful and others do not.

Inspired by science and technology studies the thesis propose the notion of traveling technology as an analytic approach for examining how health care programs successful at moving between different practices, at the same time produce their own marginalization or fragility. It is argued that this approach makes it possible to do more than account for the strong network of successful (circulating) health care program, by explicating the travel expenditures that goes with its translation. The thesis is based on what is referred to as a *translocal* ethnographic study of two health care programs, *Joint Health Plans* (JHP) and the *Chronic Disease Self-Management Program* (CDSMP). The study is referred to as translocal as it traverses a range of spatiotemporal boundaries: Over a period of almost two years the two health care programs are traced as they travelled through and across various geographical, institutional and social networks. Apart from being translocal in a literal sense,

it is also argued that the study is translocal as it investigates how the traveling technologies are *made through rather than prior to* various translocal encounters.

The thesis comprises three analytical papers. The first paper follows the joint health plans as they move between different practices within the health sector, investigating how documents-on-the-move (possibly) perform in or even achieve a variety of socio-material networks. The paper shows how the joint health plans are place-making - they transform the place where they travel to, for instance through shaping the boundaries between what is primary and secondary care. However, the plans also assume new tasks and becoming new things themselves, when entering a new place: They both work as a technical device, a political tool for boundary construction and as a shared object facilitating inter-organizational communication. In pointing to the plans' place-making effects, the analysis also makes the price of successful (traveling) policy documents visible. The traveling documents involve a never-ending need to tinker, to work around, to articulate loose ends. However, the paper also shows that these emerging properties and effects, which is referred to as *travel expenditures*, sometimes and in some circumstances surprisingly turn out to be valuable assets in and of themselves.

The second paper analyses how the Chronic Disease Self-Management Program has become globalized and how the program manages to become localized once again, as it is introduced into e.g. a Danish health care setting. The paper approaches these questions by considering the program a travelling technology engaged in ongoing efforts of negotiation and stabilization. The paper shows that far from a simple process of dissemination, the CDSMP's



means of successful globalization comprise *theorizing*, *evidence-basing*, and detailed *scripting*. Secondly, the paper shows how the program manages to maintain *local* coherence through negotiating the differences between its global claims and local specificities. Several assumptions are embedded in the program, including views on what is an individual, what is a patient, and what is a health care system. These are brought to light as the program enters different contexts and meets other perspectives. The paper argues that the success of the program relates to its ability to hold together the tensions generated by the disjunction between the assumptions of the CDSMP and the Danish context, which are rendered explicit in encounters with Danish practice.

The third paper starts out describing how the disease self-management program apparently lends itself as a “prime” example of a governmental program which targets and aims to shape social relations with reference to obtaining the full potential of patient-health care relationships. However, the paper shows how the program’s configuration of the patient as self-reflecting, extrovert and adaptable makes authority available to only a *small* group of participants, whose way of handling and coping with disease is thus authorized as “competent” and “expert”. The paper also shows how the authorization of one group of participants as expert patients can only take place via a simultaneous de-authorization of another group of patients. In this case making power itself appear considerably more distributed and fluctuating than often supposed. Through analytically including both the *authorized experts* and the *non-using users* the paper outlines an analytics of power, which on the one hand does not deny the disciplining effects of initiatives such as the

CDSMP, but which at the same time includes the fragility of an authority which has to be performed and reiterated to be just that.

Although the two health care programs studied in this thesis are of course specific, they also offer insights of more general currency into what make health care programs travel. Both programs are tightly scripted packages of relations and the analytical chapters suggest that their ability to travel widely is closely tied this scripting. At the same time, for the programs to travel, they must also be flexible as their careful scripting is constantly challenged as they travel. These challenges, which are referred to as travel expenditures, involves the programs constantly negotiating their own order, as other actors become part of their network. In the case of the JHPs this process takes place quite openly, with the establishment of new collaborations, which negotiate the order of the JHPs. In the case of the CDSMP local challenges and comparisons are successfully handled with reference to ‘minor adjustments’. The CDSMP makes a fascinating example of how despite these challenges the script of the CDSMP continues to operate.

This leads to the final concluding remark, which only pertains to the case of the CDSMP, namely the part the program plays in globalizing health care. The CDSMP has successfully travelled the globe. This is not because chronic disease is everywhere the same but because the program’s script turns chronic disease into the same ‘do-able problem’ on a worldwide scale. The program emerges as a global health care platform, in which the global and the local co-exists in friction, but is held together by the CDSMP. Approaching the CDSMP as a traveling technology thus also makes visible how global and local

healthcare not are opposites, but rather mutually implicated. As such, the notion of traveling technologies can also be described as a “contextualized” approach, as focus is put on where health care programs come from as well as where they go. In a Scandinavian context health care is closely tied to the *welfare* state and therefore traditionally considered a local phenomenon. However, studying the CDSMP as a traveling technology, shows how ‘Danish welfare’ actually is patched together by different entities, some of them coming from countries with traditions very different from the Scandinavian welfare model. Not that this in itself necessarily is a problem or a bad thing. The point this thesis makes is rather that to understand the globalization health care, it calls for an approach which is able to empirically flesh out how the global and local are mutually implicated and detail the effects of this process.

## DANSK RESUME

Når et sundhedsprogram med succes rejser og spredes geografisk forklares dette ofte med reference til programmets effektive design, med at programmet tilbyder fornuftige løsninger på et givent problem, eller fordi programmet legitimerer de organisationer som anvender det som kompetente eller proaktive. Det implicitte argument er at programmet kan bevæge sig mellem praksisser fordi det er den bedste løsning på et givent problem eller fordi det er en uundgåelig løsning på nærværende alle problemer. Eftersom et sundhedsprogramms mulighed for indflydelse er relateret til dets geografiske udbredelse, er omstændigheder og faktorer som har indflydelse herpå essentielle i forståelsen af hvorfor nogle programmer bliver succesfulde mens andre ikke gør.

Inspireret af science and technology studies foreslår afhandlingen anvendelsen af *traveling technology* som en analytisk tilgang til at undersøge hvordan sundhedsprogrammer med succes bevæger sig mellem praksisser mens de samtidig skaber sin egen marginalisering eller skrøbelighed. Der argumenteres at denne tilgang tillader mere end at redegøre for netværket bag succesfulde (cirkulerende) sundhedsprogrammer ved at eksplicite de rejseudgifter der følger med deres oversættelse. Afhandlingen baserer sig på hvad der refereres til som en translokal etnografi af to sundhedsprogrammer, *Sundhedsplanerne* og *Lær at leve med kronisk sygdom*. Studiet refereres til som et translokalt etnografisk studie eftersom det krydser en række spatio-temporale grænser. Over en periode på næsten to år følges de to sundhedsprogrammer i geografiske, institutionelle og sociale netværk. Foruden at være et translokalt etnografisk studie i litterær forstand, argumenteres det også for at studiet er translokalt da

det undersøger hvordan *traveling technologies* skabes gennem, snarere end for translokale møder.

Afhandlingen indeholder tre analytiske studier. Det første følger sundhedsplanerne i bevægelsen mellem forskellige praksisser i sundhedssektoren, og undersøger hvordan dokumenter i bevægelse (muligvis) agerer i eller skaber forskellige socio-materielle netværk. Studiet viser hvorledes sundhedsplanerne er *place-making* dvs. at de transformerer det sted de rejser til f.eks. ved at skabe grænser mellem det primære og sekundære sundhedsvæsen. Sundhedsaftalerne påtager sig også nye opgaver og bliver selv fornyet når de tages i brug. De fungerer både som tekniske indretninger, politiske redskaber for opstilling af grænser og som delt objektskabende interorganisationskommunikation. Ved at pointere planernes *place-making* effekt anskueliggør analysen også omkostningerne ved succesfulde (rejsende) policy dokumenter. De rejsende dokumenter involverer et uophørligt behov for tilpasning, men analysen viser også at disse egenskaber, som refereres til som rejseudgifter, i nogle henseender overrasker ved at være værdifulde værdier i sig selv.

Den anden analyse viser hvorledes Lær at leve med kronisk sygdom er blevet globaliseret, og hvordan programmet håndterer at blive lokaliseret igen f.eks. ved implementering i det danske sundhedsvæsen. Analysen adresserer disse spørgsmål ved at anse programmet som en *traveling technology* i igangværende forhandlinger og stabiliseringer. Arbejdet viser at trods en indviklet dissemineringsstrategi, skyldes programmets succesfulde globalisering teoretisering, evidensbaseret og detaljeret scripting. Derefter

viser arbejdet hvorledes programmet vedligeholder lokal sammenhæng ved at forhandle forskelle mellem dets globale krav og lokale specificiteter. En række forudsætninger er indlejret i programmet, heriblandt syn på individer, patienter og sundhedssystemer. Disse anskueliggøres i og med at programmet entrerer forskellige kontekster og møder andre perspektiver. Arbejdet argumenterer at programmets succes afhænger af dets evne til at sammenholde de spændinger der skabes af adskillelsen af programmets forudsætninger og den danske kontekst programmet møder.

Afhandlingens tredje artikel starter med at beskrive hvordan selvhjælpsprogrammet åbenbart sandsynliggør sig som et fortrinligt eksempel på et offentligt program som retter sig mod at skabe sociale relationer under henvisning til at opnå det fulde potentiale af relationen mellem patient og sundhedssystem. Ikke desto mindre viser artiklen hvordan programmets konfiguration af den selv-refleksive, ekstroverte og foranderlige patient kun giver autoritet til en lille gruppe af deltagerne hvis håndtering af sygdommen autoriseres som kompetent. Artiklen viser også hvorledes autorisationen af denne gruppe af deltagere som eksperter kun kan foregå via en samtidig de-autorisation af en anden gruppe patienter. I dette tilfælde viser magten sig at være mere spredt og fluktuerende end ofte formodet. Ved analytisk både at inkludere de autoriserede eksperter og de ikke-brugende brugere skitserer artiklen magtanalytik, hvilket på den ene side ikke bestrider disciplinerende effekter af initiativer såsom Lær at leve med kronisk sygdom, men som samtidig

Inkluderer skrøbeligheden ved en autoritet som skal udformes og reitereres for at være netop en sådan.

På trods af at de to programmer som studeres i denne afhandling er specifikke, giver de indsigt i hvad der får sundhedsprogrammer til at rejse. Begge programmer er pakker af relationer, og den analytiske del foreslår at deres evne til at rejse vidt omkring er tæt forbundet til disse. For at rejse må programmerne på samme tid være fleksible eftersom deres scripting konstant udfordres under rejsen. Disse udfordringer, som refereres til som rejseudgifter, involverer programmets konstante forhandlen med deres egen orden eftersom andre aktrører bliver en del af deres netværk. I sundhedsaftalerne tager denne proces sted i det åbne med oprettelsen af nye samarbejder, som forhandler sundhedsaftalernes orden. I Lær at leve med kronisk sygdom håndteres lokale udfordringer og sammenligninger med reference til småjusteringer. Lær at leve med kronisk sygdom er et fascinerende eksempel på hvordan scriptet heraf forsat opererer trods disse udfordringer.

Dette leder til den sidste konklusion som kun vedrører Lær at leve med kronisk sygdom, nemlig den rolle programmet spiller i at globalisere sundhed. Lær at leve med kronisk sygdom har med succes rejst jorden rundt. Dette skyldes ikke at kronisk sygdom er ens alle steder, men at programmets scripts forvandler kronisk sygdom til det samme håndterbare problem i hele verden. Programmet opstår som en global sundhedsplatform, i hvilket det globale og det lokale co-eksisterer med gnidninger, men som sammenholdes af Lær at leve med kronisk sygdom.

Ved at anse Lær at leve med kronisk sygdom som en traveling technology viser hvordan global og lokal sundhed ikke er modstykker, men gensidigt

implicerende. Som sådan kan traveling technologies også beskrives som en kontesktualiseret tilgang, eftersom fokus lægges på hvor sundhedsprogrammer kommer fra og hvor de rejser til. I en Skandinavisk kontekst er sundhed tæt forbundet til statens velfærd og anses derfor traditionelt som et lokalt fænomen. Men ved at studere Lær at leve med kronisk sygdom som en traveling technology viser hvorledes dansk velfærd er lappet sammen af forskellige entiteter af hvilke nogle kommer fra lande som adskiller sig markant fra den Skandinaviske velfærdsmodel. Dette er ikke i sig selv skidt eller et problem. Denne afhandling pointerer at frem for at forstå globaliseringen af sundhed, er det nødvendigt med en empirisk tilgang som kan illustrere hvordan det lokale og det globale er gensidigt impliceret, og som kan udspecificere effekter af denne proces.



## CO-AUTHOR DECLARATION

København,  
23 September 2010

### Forfattererklæring

Undertegnede erklærer hermed medforfatterskab med Annegrete Juul Nielsen på kapitlet "Travelling Comparisons: Globalizing and Localizing the *Chronic Disease Management Program*".

Kapitlet beror på empirisk arbejde udført 100% af Annegrete Juul Nielsen.

Undertegnede og Annegrete Juul Nielsen har bidraget med 50% hver til de metodiske, teoretiske og analytiske dele af kapitler.

  
Casper Bruun Jensen

### English translation of Danish co-author declaration

I hereby declare my co-authorship with Annegrete Juul Nielsen regarding the chapter "Traveling Comparisons: Globalizing and Localizing the *Chronic Disease Management Program*".

The chapter is based on empirical work conducted 100% by Annegrete Juul Nielsen.

Annegrete Juul Nielsen and I have each contributed with 50% to the methodological, theoretical and analytical parts of the chapter

Casper Bruun Jensen

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