Standardizing healthcare practices

Experimental interventions in medicine

and science and technology studies

Teun Zuiderent-Jerak

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Promotoren: Prof.dr. M. Berg

Prof.dr. R. Bal

Overige leden: Prof.dr. P. Meurs
Prof.dr. S. Timmermans
Prof.dr. A. Mol

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Introduction

Experiments with Situated Standardization and

Interventionist Science and Technology Studies

"If you want to truly understand something, try to change it."

Kurt Lewin

"The academic vocation requires a vacation
from more common modes of engagement"

Mike Lynch

A recent study by Italian physicists (Cardillo, Scellato et al. 2006) has shown that the distance one has to cover to get from any particular point within a city to any other point within that city – the 'minimum spanning tree' – is strikingly similar for cities with very different characteristics. Through their analysis of the street patterns in twenty cities around the world they have shown that the minimum spanning tree in a medieval city like Ahmedabad (figure 1.1) is similar to that of a grid-iron city like New York (figure 1.2). This means that when getting from a to b in a highly structured city like New York one has to span on average the same distance as when doing so in the much less rigorously planned streets of Ahmedabad[1].

I propose this counter-intuitive finding to be illustrative of two positions on the study of medical practices that will be discussed and questioned in this thesis. The first approach stands for the celebration of the organically grown, messy, professional, complex practices of healthcare. I will critically analyze the role medical sociology, ethnography and science and technology studies (STS) at times plays in the uncritical appraisal of sociotechnical complexity while (at times) lacking sensitivity for the particular problems that this complexity engenders. The second approach stands for the continuous pleas for a thorough rationalization and structuring of medical decision making and healthcare delivery and the elimination of practice variation by healthcare professionals. Some sections of the healthcare quality movement, in particular the branch specialized in developing integrated care pathways, are partly responsible for this 'grid-ironing' of

Figure 1.1: Ahmedabad
Source: Google Earth
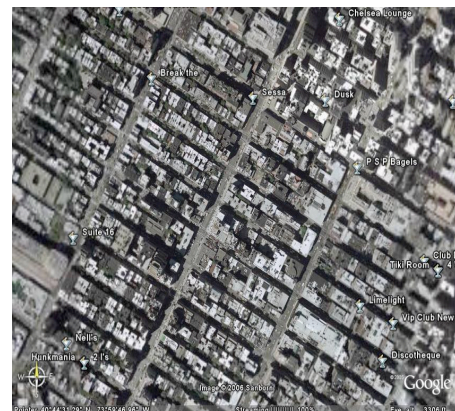
Figure: 1.2 New York
Source: Google Earth

medical work. I suggest the striking consequential similarities between Ahmedabad and New York to be illuminating for the potential limitations of celebrating complexity and of rationalizing medical work. Both may fail to lead to situated improvements that seem needed in healthcare systems that at times cause substantial suffering to both patients and healthcare professionals.

Fortunately, the physicists have studied more locations. The results for Paris (figure 1.3) are of particular interest here since this city can be qualified as 'hybrid', meaning it is heterogeneous in its composition, drawing on qualities from both locales mentioned above. On the one hand Paris can be seen as an ancient city with a substantial 'organic' development whereas at the other some parts have been thoroughly structured through the 19th century Hausmanisation which involved the development of *grande* connections through *allées* and *boulevards*. And, as the physicists have calculated, this type of city has a much lower minimum spanning tree than any of its more homogeneous counterparts. Getting from a to b in a hybrid city requires a journey over less distance than in either a medieval or grid-iron type city[2]. The hybrid qualities of Paris thereby provide an interesting metaphor for a position towards healthcare improvement that is central in this thesis: the experimental approach of coming to, what I would like to call, *situated standardization* of medical practice.

Rationalization, complexity and situated standardization

The advocates of Evidence Based Medicine (EBM) have gone a long way in stressing the high rates of medically inexplicable practice variation and the importance of privileging data over judgment in clinical practice. Claiming that "the best guideline is only a good intention unless it degenerates into clinical care" (Dilts 2005, pg 5881) EBM proponents generally strive to achieve maximal implementation of clinical guidelines. The notion that non-standardized ways of working are to be seen as a problem per se have however been critiqued by social scientists, in particular by ethnomethodologists.
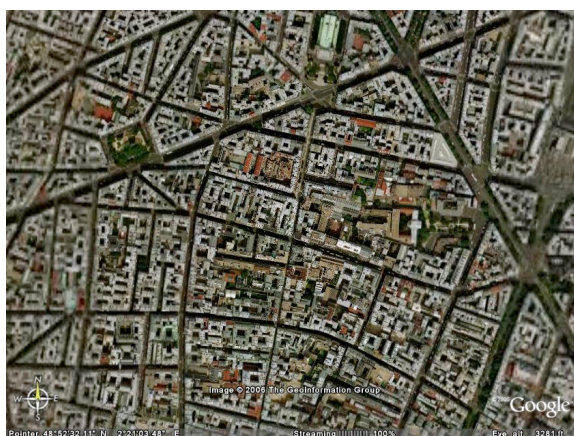
Figure 1.3: Paris
Source: Google Earth

The idea that ethnographic understandings of the complexity of (care) practices can be used for their improvement is dominating scientific fields such as Participatory Design (PD), Computer Supported Cooperative Work (CSCW) and Action Research (AR). Drawing on ethnomethodological approaches as developed by Harold Garfinkel (Garfinkel 1967b), many publications claim to have come to 'better' technologies that really support work practices, rather than support or automate idea(l)s of work practices that would e.g. be found in a (clinical) guideline (Blomberg, Suchman et al. 1996; Button 2000; Luff, Hindmarsh et al. 2000; Procter and Williams 1996; Suchman 2000).

The work of Garfinkel and of authors from CSCW, PD and AR is mostly inspiring due to the strength of its detailed analyses. This work is both empirically fascinating and has been very helpful in counter-arguing the continuing accusations that medical records are "carelessly kept" (Garfinkel 1967a, pg 192) and that practice variation between medical professionals is "irrational" (Lennarson Greer 2002). Thereby, these studies have been crucial for questioning the implied cognitive psychological 'solutions' of 'disciplining' and 'educating' medical professionals[3]. I will however explore in this thesis to what extent both the rationalization of medical practices *and* celebrating complexity are theoretically and practically problematic. Where I will show that the unchallenged epistemological status of EBM creates its own 'implementation problems' through largely situating medical knowledge production outside of the complex sociomaterial practices of care delivery[4], I will also claim that the critiques of EBM often seem to display an awkward inherent conservatism. They tend to privilege a fascination for complexity over a sensitivity for possible problems that follow from intricately working sociotechnical arrangements and end up with extremely modest notions about the way in which things could be different. As I will explore in the empirical chapters of this thesis, celebrating sociotechnical complexity at times leads to the somewhat bizarre consequence that an unprecedented trust is put in the actions of professionals. In the case of healthcare delivery this results in the highly conservative position of trusting traditional medical expertise.

Interestingly, the focus on sociotechnical complexity is often combined with claims about the ability to define what the practice really 'is', rather than exploring ways of elucidating the multiplicity of sites through ethnographic research. For these reasons Paul Atkinson indicates that such researchers tend to "a sociology which is behaviorist and empiricist" (Atkinson 1988, pg 441). Practically, this approach thereby seems unable to adequately address the *problems* that may arise for patients and care professionals from particular practices and their – what Garfinkel called – "'normal, natural' troubles" (Garfinkel 1967a, pg 191) in healthcare. By locating ethics in an extremely localized, complex work practice, ethnomethodology does not seem to have a conceptualization of normativity that is also partially connected to *other* practices than the *work* practice under study nor to the observation that there are *different work practices* taking place simultaneously (cf. chapter 1).

I will explore in this thesis how ethnographically inspired practices of science and technology studies (STS) can lead to the elucidation of *particular possibilities* of *how things could be different*. As I will analyze in chapter 4, the pragmatist philosophical work of John Dewey, particularly his seminal work *The Public and its Problems* (Dewey 1927) on the role of *issues* in constituting publics, is a prime source of inspiration for this emerging approach of experimenting with situated standardization in healthcare. Such research enacts the interventionist researcher as someone with "expertise based not so much on solutions as on defining the problem space, where the 'problem' is understood in realtime" (Brown 2004, pg 9). By elucidating such 'problems' through ethnographies of healthcare practices, but also through the analysis of data from hospital information systems, through interviews with care professionals and through collaborative practices with e.g. people specialized in healthcare logistics, the researcher is enabled to situate the 'solution' of particular interventions to standardize healthcare practice into specific issues. Hereby standardization does not become a solution per se, which would lead to a grid-ironing of medical work, nor a solution to be merely critiqued for its lack of sensitivity to complexities of prevailing work practices, which would lead to an appreciation for complexity while lacking sensitivity for the way in which this particular problems remain unaddressed. I will explore how articulating issues through ethnographically inspired STS research of medical practice offers spaces for experimenting with standardization in action. I will argue in chapter 4 that situating standardisation in particular problems which draw together collectives of care professionals, management and patients, is a way of doing issue politics that refigures both what it is to 'standardize medical practice' and what it means to 'provide patient-centred care'.

I will also explore what the consequences of this approach are for a refiguration of one of the core issues of research in STS: the issue of normativity of research practices.

Normativities and intervention in STS

In the early 1990's, STS researchers started analyzing how their research on controversial technoscientific practices got them entangled in their objects of study in unforeseen ways. Non-intervention seemed to become an impossibility through the observation that "an epistemologically symmetrical analysis of a controversy is almost always more useful to the side with less scientific credibility or cognitive authority. In other words, epistemological symmetry often leads to social asymmetry or nonneutrality" (Scott, Richards et al. 1990, pg 490). The notion of the scientist as a detached observer of epistemic practices seemed not merely worthy of critique in the natural sciences, it also created interesting tensions for STS researchers studying technoscientific controversies[5] thereby making intervention no longer a problem per se but an empirical domain worth exploring[6] (cf. Blume 2000).

Where these observations were somehow performed as dealing with 'unintended consequences' of doing STS research and engaging with practices, John Law, among

others, has made it compellingly clear that social investigations are involved in the construction of worlds rather than their mere description. Since STS researchers are involved in "ontological politics" (Law 1998)[7] this opens up the question *which* worlds they would like to enact (Law and Urry 2004). And one would expect, this would also raise the question *how* they could be involved in the enactment of such worlds.

However, the range of ways in which this issue is addressed is strikingly limited. Authors who are interested in pursuing normative agendas through their contributions to enacting the social, explore the possibly "productive *metaphors*" that come from complexity theory (Law and Urry 2004, pg 390 italics added), plea for "deliberate efforts to structure *inquiry, description*, and *explanation* to serve social purposes" (Woodhouse, Hess et al. 2002, pg 298 italics added), "argue for a strategic *dialogue*" (Kember 2003, pg ix italics added) between critics of scientific practices and scientific practitioners or claim the need to organize "*public debates* on standards" (Callon 2004, pg 131 italics added). It is striking that many STS authors thereby restrict themselves to largely *discursive* ways of doing ontological politics, despite the fact that it has generally been taken as one of the main accomplishments of STS that it assumes a "radical indeterminacy of the actor" (Callon 1999, pg 181) through which it opened up the social sciences to non-humans. Reducing normative acting space to largely discursive interventions sits uncomfortably with the strong appreciation for the importance for material agency (cf chapter 2). Furthermore, these approaches all are rather proceduralist, without explicating how the content of issues is accounted for, nor how these procedures can contribute to outcomes these authors aspire for.

In contrast to these proliferating examples of pleas for more discursive STS engagements, the specificity of the approach I develop in this thesis explores the socio-*material* refiguration of (medical) practices as a site for doing ontological politics. This approach is inspired by authors who indicated the need of STS researchers to get into the heart of sociotechnical developments as "a crucial, never fully predictable and potentially creative force" (Berg 1998b, pg 478). The approach therefore explores what it means to embrace a "*substantive* position, and with that, embrace the newly found political actors [i.e. materialities] for what they are: active entities who might be seduced into joining – temporarily and partially – the shaping of a differently organized work practice" (Berg 1998b, pg 480 italics in the original). This position continuously articulates issues about who benefits and who is silenced through specific sociotechnical arrangements (Star 1991, pg 43)[8].

The approach of explicitly experimenting with the co-construction of (medical) work practices while constantly creating partial connections (Strathern 1991) and partial *dis*-connections between those practices and critical STS, is what I would like to call interventionist Science and Technology Studies (iSTS). Before turning to how this concept will be explored empirically, a few words on the notion of 'intervention' seem appropriate, though a more elaborate historical analysis of the concept will follow in

chapter 2. 'Intervention' is of course a highly layered concept that, following the performativity of researchers in enacting certain worlds, in some subtle forms cannot be avoided. The counterpart of this notion – non-interventionist STS – therefore seems unimaginable and posing it possible would be critiqued for following a naïve yet not harmless (Haraway 1991b) conceptualization of scientific practice. 'Intervention' is certainly not introduced here to re-iterate a descriptive/useful dichotomous understanding of STS. It is however proposed because of the potentially productive tensions it raises – particularly in a medical setting. When STS studies the work of healthcare professionals, 'intervention' is generally reserved for the objects of study. The notion of iSTS therefore is a partial attempt to reclaim some of the ideas about 'where the action is' from the field of medicine[9]. The notion also articulates what Casper Bruun Jensen and I have called the dual fear of STS researchers being either too detached, combining strong normative sensitivity with a powerless position vs. being 'merely' useful and involved in practices in which one gets subsumed in normative agenda's of actors, thereby making STS scholars a puppet on a string of those they claim to 'act with'[10] (Zuiderent-Jerak and Jensen 2006). The aim of stubbornly sticking to the notion of intervention is thereby partly to reconceptualize the fear 'intervention' invokes by empirically unpacking the conceptual and practical consequences of experiments with iSTS.

The questions that are to guide this experimental journey through interventions in practices of standardizing healthcare therefore are:

What are the consequences of iSTS engagements with the standardization of healthcare work for the sociomaterial arrangements of medical practices?

Which theoretical/practical tools can be fruitfully (mis-)used by iSTS researchers to enable them to 'act with' the actors they encounter?

Which tricks are played by and on the iSTS researchers through the complex and partly uncontrollable process of 'intervening'?

In which ways do these experimental iSTS practices lead to translations of theoretical a priori's and normativities within the field of STS, and in particular, how does engaging with the normative complexity of medical practices relate to the practical ethical acting space of iSTS researchers?

Structure of this thesis

The chapters of this thesis deal with different issues of iSTS, drawing from three empirical cases. The first case comprised the development of a hemophilia care centre in a Dutch university medical centre, the second case was a project on the development of standardized care pathways in a large hematology/oncology ward and the third case involved the development of the approach of situated standardization in a national quality collaborative improvement program for hospital care and its consequences for the development of regulated competition in Dutch healthcare.

Though the cases and the analysis may seem to progress from empirically detailed practices of the individual actions of patients in a healthcare setting and 'move up' to the level of market developments in Dutch governance arrangements, I will not analyze these cases as proceeding from a 'micro' to a 'macro' level. Such ethics of scale would re-introduce the notion that there is a pre-existing 'top' and a 'bottom' of the social (Latour 1997), where I will rather focus on specific themes that emerge in the three cases in relation to situated standardization.

In *chapter 1* I analyze the methodological issue of the relationship between ethnographi-cally-inspired analyses of work practices and the complex potential this engenders for intervention. Whereas ethnography has been identified as an important method for de-veloping situated (information technological) solutions for specific workplaces by neigh-bouring fields like participatory design, action research and computer supported cooperative work, I claim that its political pertinence and fuzzy practice have been underexposed. I challenge the oft-encountered notion that ethnography leads to 'better' material interventions. In this context 'better' is often seen as 'more appropriate for a workplace'. However, I will show on the basis of fieldwork in a hemophilia care centre (HCC) of a Dutch university hospital, that what this workplace is, and therefore what materiality is desired, is equivocal. I will also show that 'doing fieldwork' cannot be sepa-rated from 'informing design' or 'intervening'. 'Intervention' is a subtle, layered concept and a continuous activity. Based on these insights I develop the iSTS approach as being geared towards interweaving fieldwork and informing the design of material interventions in an intentionally ad-hoc and non-sequential way. The advantage of this articulation of iSTS is that it sensitizes the fieldworker to the located and strategic multiplicity of a site, to the data that can be found in roles and epistemic authorities that are being ascribed by various actors resulting from their 'view from somewhere', and to the acting space that is constantly emerging and changing in an iSTS project. I will claim that the approach can lead to sensitized interventions situated in politicized ethnography.

In *chapter 2* I discuss the notion of 'intervention' as it has historically developed in STS. I analyse how it has become attached in 'critical STS' to normative agenda's of social activism and propose that, though this is one way of addressing the criticism that con-structivism is 'normatively deficient', this critique can be rebutted through interventionist research without embracing activism as a strategy. Drawing on the same case of being involved in the development of the HCC, I indicate how the practice of hemophilia home-treatment benefits from STS insights on the issue of compliance and making work visi-ble. Non-compliance has often been conceptualized as a problem per se in the quality of care literature, resulting in a plethora of equally unsuccessful compliance enhancement initiatives and cognitive interventions. STS researchers have questioned the aim of full compliance, realizing patients have to live in many different worlds simultaneously –

worlds which at times may challenge their role of being a 'patient'. By shifting their focus from trying to understand irrational non-compliance to the study of achieving compliance in practice they have indicated interesting acting space for situating compliance enhancement initiatives in the complexity of the live-worlds of patients. I explore the interventions this insight has led to and relate them to the possible gains for iSTS to *do normativity* through practices of *artful contamination* of research practices. I claim this move to be of value for overcoming the normative deficit STS has been accused of and propose iSTS research as a fruitfully risky business.

After having discussed the value of empirically scrutinizing compliance by patients to treatment regimes, I turn in *chapter 3* to the study of compliance by clinicians to pre-scribed guidelines. Following a very similar rhetorical structure as the compliance debate about the actions of patients, the low adherence rates of healthcare professionals to clinical guidelines is often seen as highly problematic by health scientists and policy makers. However, as in the debate on patient adherence, the common 'solutions' to improve the success rate of implementation initiatives tend to leave the epistemological status of aggregated medical knowledge untouched. Such initiatives therefore tend to be practically cumbersome, politically desensitized and conceptually problematic. I will analyze the experimental interventions with standardization of medical care practices in a second case, a healthcare improvement project at a hematology / oncology outpatient clinic of a university hospital. I will show that this iSTS project is a form of doing politics through standardization. Rather than following the above mentioned extremes of striving for the full rationalization of medical practice, or of celebrating complexity that boycotts being standardized, I will articulate the value of iSTS experiments *and* of much early work from the integrated pathway movement to come to situated standardization of healthcare practices. Through finding frictions within discussions on evidence based practice and amplifying those, I propose that the relevance of iSTS projects here exceeds the care practice under study and provides ground for articulating a 'processual' approach to pathwaying.

In *chapter 4* the same case of iSTS at the hematology/oncology outpatient clinic and treatment centre is explored to intervene in discussions on the relation between stan-dardization and patient-centeredness. In the medical sociological literature, 'standardi-zation' and 'patient-centred care' have been positioned as perfect conceptual opposites. In this chapter I explore what the specificities of this opposition are, what their limitations are, and in which sense a re-conceptualization of both concepts could lead to their pragmatic commensurability. Drawing empirically upon the development of patient-centred care trajectories and conceptually on the pragmatist philosophical work of John Dewey and his reappraisal of issues in democratic theory, I indicate that recent debates within political science are helpful for reconfiguring discussions and practices on patient-

centred care and standardization. Through putting the issues patients, care professionals and organizations face centre stage in the process of 'pathwaying' healthcare, situated standardization can be attained which is helpful in making care patient-centred in more substantial ways.

Having started at the empirically detailed level of the treatment practice of patients, having moved through the practice of adherence to guidelines by medical professionals, and having covered the development of situated care pathways for an entire ward, *chapter 5* deals with the possibilities for iSTS in enacting emerging healthcare markets. The social study of markets has experienced challenging theoretical developments through the work of Michel Callon on 'the performativity of economics' (Callon 1998c). This notion has opened up the construction of markets to many previously excluded actors. However, Callon's focus on the role of materialities in performing spaces of calculation and the role of economics in creating materialities easily leads to over enthusiasm for active engagement by social scientists. Drawing on the third case of the development of situated standardization through process redesign in a national healthcare quality collaborative, I analyze the possibilities for enacting healthcare markets as value- rather than cost-saving-driven. I pose that iSTS involvements in the construction of market laws may however be more risky than suggested by Callon. Since markets can 'work' despite the absence of well functioning materialities it seems important to sensitize the interventions by STS researchers for prevailing market regimes and market practices as 'forms of the probable' (Thévenot 2002) that are highly consequential for the acting space of social scientists in performing markets.

In the *conclusion* I will return to the questions raised in this introduction and will address the consequences for the practices iSTS engaged with and the issues this has articulated for practices of STS. Exploring some 'ecologies of intervention' I will claim that the active involvement of STS researchers is helpful for finding frictions within (Kember 2003) medical practices and for elucidating normative complexity. This complexity will prove not to be a situation that problematizes normative interventions, enacting a 'normative deficit' that STS research has been accused of. Rather it opens up stale normativities that have too easily assumed who are 'inappropriate/d others' (Haraway 1991a, pg 2). Following the work of Michael Lynch (Lynch 2004) on the surfeit of public understanding of social science, I will similarly claim that there is a normative surfeit, rather than a deficit to be dealt with in (interventionist) STS research. The strength of iSTS in elucidating this normative complexity will prove fruitful for the productive interplay of loyalties and betrayals and for coming to what I will call an *ethics of specificity*.

Chapter One

Blurring the Center

On the politics of ethnography

> 'Reality' is not compromised by the pervasiveness of narrative;
> one gives up nothing, except the illusion of epistemological transcendence,
> by attending closely to stories.
>
> *Donna Haraway, "Mice into Wormholes"*

1.1 Introduction: first aid for technology development

On December 21st 2000, Jacques Chirac, President of France, opened a hospital that was to change hospital administration and patient care around the world. The *Hôpital Européen Georges-Pompidou* would be the first paperless hospital, with complete electronic registration of patient data, and small operations being performed by robots. However, the hospital has been called a fiasco in many respects by French media (Le Monde, 22nd December 2000, Le Monde, 10th January 2001)[11].

First, the aim of paperless care was not achieved and has led to the need of developing paper medical records as an emergency call – without the logistics for this being in place. Second, out of the 24 high-tech surgery theatres, only 4 were being used a few months after the opening due to a lack of skill and training for healthcare professionals in operating the complicated technology needed (Anon. 2001).

The unworkable situation in this high-tech hospital does not just beg the question why the implementation was carried out so carelessly. It also makes a more fundamental issue pertinent; why would such goals be set at all? The rationale behind such a layout and development of a high-tech hospital can be seen as one of the causes of its failure. Though the scope of this failure – being a € 273 million project – is extraordinary, the conceptual mistakes that form its foundation are widespread among policymakers and technology developers. Even more than being sacrificed to a French liking for *grandeur*, the hospital has fallen victim to the dual myth of the possibility of standardizing care work (Berg 1997; 1998a) and technology leading to inherent progress[12].

This dual myth – which is the foundation of a substantial part of the management literature (Ciborra 2001a) – lies at the heart of top-down approaches for IT in health care that have proven problematic and unfruitful. With the exceptionally high failure rates of such projects and the growing insight that the 'technological' cannot be separated from the organizational context of a working practice that is inherently complex (Berg 2002), there has been a tendency to look in other directions for realizing IT development in particular settings. Ethnography has been identified as an approach that can be used for elucidating sociotechnical complexity (Lloyd 2000) by unraveling the tacitly present practices that make workplaces function properly. Whereas initially researchers trying to make ethnographic approaches relevant for design settings: "used the most outdated version of anthropology" (Latour 1990b, pg 146)[13] of trying to be a 'fly on the wall', there has been a substantial development in which the interpretation has shifted to participant-observation. Here the definition of ethnography is much closer to that used by contem-

porary anthropologists: "Ethnography means talking to and interacting with people, and ultimately attempting to understand their symbolic worlds and *social action*" (Hess 1992, pg 4, italics in the original). I would like to stress here that the symbolic is not merely a result of humans attributing meaning but of a sociotechnical interplay[14]. With this definition in mind, cases have been described where a thorough understanding of the sociotechnical character of work was translated into the development of meaningful situated technology in a specific workplace setting[15]. But a methodological question that soon had to be addressed was how ethnographic findings can be successfully translated into the realm of technology development. Various authors realized that this translation was being hindered by structural matters such as: "The discontinuities across our intellectual and professional traditions and associated practices", due to which: "[ethnographers] could not simply produce 'results' that could be handed off to [designers]"(Suchman 2002). This meant that the working relations between ethnographers and designers had to be altered to come to: "mutual learning and partial translations" (ibid.). An important consequence of this observation is that the chronological separation of first 'doing fieldwork' and only then 'informing design' or 'intervening' is problematic.

      In this chapter I will underline this argument by showing that these activities are not sequential since 'intervention' is a highly layered term that is part and parcel of doing fieldwork. Moreover, by not realizing the inappropriateness of the dichotomy, one faces the risk of remaining insusceptible to opportunities for subtle interventions during the period of fieldwork, thereby reducing the acting space that is dearly needed in interventionist research.

      The issue of how ethnography and technology development can be brought together has led to a considerable amount of reflection amongst some researchers working on the crossroads of ethnography and technology design or computer supported cooperative work (CSCW)[16]. They have pointed out various seemingly promising ways to deal with this issue, but these approaches share being geared towards creating better technology by means of ethnography. However legitimate this as a principle may seem, they hereby fail to deal with the politically highly relevant issue whose version of 'better' they support[17].

      In this chapter I will analyze this *problematique* of the political implications of doing ethnographic studies of workplaces and technology design by presenting fieldwork from an ongoing IT development project in a Dutch university hospital. I will claim that 'viewpoints' tend to vary substantially in a highly dynamic working environment, and that ethnography can function as a method to bring to light these differences – rather than finding commonalities on the basis of which 'better' technology can be developed. This insight has normative implications for the role of the ethnographer and begs for a conceptual framework that enhances sensitivity for the politics of practice in order to avoid instrumentalist concepts for referring to the researcher's design-informing work. This framework can be partly provided by the work of researchers working on feminist tech-

nology studies, such as Donna Haraway. Though it has been stated that the work of Haraway cannot be 'followed' because of her: "idiosyncratic, hybrid style of speech and writing … [that] cannot be easily reduced to a package of methodological guidelines" (Prins 1995pg. 362), I will see it as a source of inspiration to reflect on the political nature of ethnographic interventions in technology design and, coming to my second and related aim of this chapter: to outline some aspects of an emerging interventionist approach that is geared towards interweaving fieldwork and IT design in an intentionally ad-hoc and non-sequential way with a continuous sensitivity to the issues of account-ability and situatedness of the researcher. Thereby intervention is made a strategic and located activity manifesting throughout a research project, rather than being its closing phase.

1.2 Beyond Better: the politics of ethnography

In the search for ways of communicating ethnographic findings to engineers, various roads have been pursued. Besides a rather scientistic solution that is seen in an enhancement of methodological rigor (Avison, Baskerville et al. 2001)[18], more creative approaches have been proposed. Peter Lloyd (2000) focuses on the importance of cre-ating a common language among engineers through storytelling. He claims that ethno-graphy is a fruitful way of acquiring insight into the social mechanisms that facilitate the emergence of a common frame of reference by narrative agreements. This insight can then lead to the support for these mechanisms, which Lloyd sees as an indicator of 'good design'. What he actually means by this concept, and for whom it will be good, is a question that remains unaddressed.

Hughes et al. (2000) deal with the issue of communicating ethnographic findings to engineers more explicitly by developing an approach for: "bringing ethnographic field studies more systematically into the design process" (ibid. pg 188). One of the important features of this method is a tool that is used to: "allow the structured ethnographic record to be used for the development of requirements, prototype designs, design variants and so on" (ibid. pg 189). This device is an IT application called The Designers' NotePad (DNP), and its main feature is that it combines model-based representations of a work-site with underlying links to text notes. The claim of the authors is that they hereby merge the two worlds of designers (who are said to think in models) and ethnographers (living their professional lives in text). Though the possible conflicting desires of actors are recognized by Hughes et al., an essential feature of their method is that it is designed not to focus on the antithetical viewpoints encountered during ethnographic research, but to represent: "generic features" (ibid.) that can be made useful to design. They hereby not only explicitly avoid a positioning in the battle being fought in techno-logy design, but also delegate the choices that need to be made in the design process to the DNP and thereby to the designers. This is a stance that I will prove to be lacking po-litical relevance in the remainder of this chapter and that has been shown to be prob-lematic in a substantial body of literature from the field of (feminist) technology studies

on design. Following Lucy Suchman's (2000) distinction of various forms of design prac-tices, the DNP faces the risk of contributing to 'design from nowhere' by which: "design-ers are effectively encouraged to be ignorant of their own positions within the social rela-tions that comprise technical systems" (ibid.). Furthermore, Hughes et al. maintain the chronological dichotomy between ethnography and intervention to a large extent, thus failing to admit the complexity and interventionist richness of 'doing fieldwork', and remaining largely insensitive for opportunities to intervene that emerge – possibly for a short period – during fieldwork.

This dichotomy is largely absent in the third solution that I wish to discuss here. Hartswood, Procter, Rouncefield and Sharpe (2000) present an approach that deals with many issues raised in the discussion on ethnographically informed design and develop-ment. They find their counterpoint in participatory design (PD) approaches that tend to be 'user centered' rather than 'user led'.[19] They state that PD hardly ever transcends the design phase to provide guidance during development and implementation. This results in the failure to include requirements that cannot be identified outside of the context, and more subtle observations on the way in which applications are or should be implemented in work practice. Hartswood et al. wish to solve these problems by: "taking the technical work of IT design and development into the users' workplace" (2000, pg 97). For this they introduce the concept of the 'IT facilitator'; an individual that is to help the users realize their needs in whatever way required. This implies a combination of roles such as design consultant, ethnographer, programmer, troubleshooter, handyman, etc. that are to be acted out during a prolonged stay in a specific site. While the clear-cut chronology in the activities of doing fieldwork and intervening is abandoned in this approach, a problem may arise resulting from the array of roles requiring a substantial amount of accompanying qualifications. This implies that the IT facilitator is asked to be a rooster that also lays eggs, and therefore Hartswood et al. see the need to raise: "issues of skill repertoires and the possibilities of overloading" (ibid. pg 104), a point I will return to at a later stage. Through their ad-hoc intervention strategy, an 'over-formalised' way of par-ticipation is transformed into: "a situation where participation, through the routine, in-formal interaction between users and IT facilitator, becomes a part of the daily activities of both parties" (ibid. pg 100). A major advantage of this approach is that the design and development activities, that normally remain opaque, are rendered visible, thus giving the users a sense of which demands are time-consuming and which are simple. This forces users to define specifically which features they desire in, for example, a database, thereby preventing an overload of work for the IT facilitator, and more importantly, not asking for a 'comprehensive' database that will be cumbersome to use (ibid. pg 101).

However elegant a solution this may be to some of the problems encountered by PD and ethnographically informed design strategies, it still leaves some of the issues that I focus on in this chapter unaddressed. Hartswood et al. aim at optimizing the process of involving users in technology development, which is: "universally recognized

as the key factor in guaranteeing more usable and effective IT-based systems and arti-facts" (ibid. pg 96). As with the approaches of Lloyd and Hughes et al. it remains obscure what is actually meant by 'more usable', 'effective', or 'better' technology. Hartswood et al. state that the IT facilitator may find him or herself: "dealing with conflicts of opinion" (ibid. pg 103) and read this as a result of the ad-hoc nature of the interactions between the users and the IT facilitator. Based on this problem-definition, they propose the solution of organizing more formal interactions, but they also state that the facilitator needs to be able to explain the road that was taken to the present situation. Making understandable: "'how things have come to be this way' when alternatives are proposed" (ibid.) should suffice – at least methodologically – as a solution to the conflicting opinions.

Besides the practical problems this solution will pose for the IT facilitator of being in a direct discussion with several users having to justify – and thereby becoming responsible and accountable for – 'how things have become this way', the framing of the problem may also be questioned. The present problem definition seems to stem from an underproblematized and unsophisticated concept of 'better' technology design. This concept can be found in all three described approaches dealing with the issue of informing design by means of ethnography. The possible conflicts of opinion between users are either dismissed by focusing on the 'generic features' in research findings (Hughes et al.) or marginalized by stating that: "So far, instances of this have been few" (Hartswood et al. 2000, 103).

An alternative way to frame this issue is to state that conflicts are the quintessence of technology development. There is a large volume of research from the field of Science and Technology Studies (STS) focusing on precisely this theme[20]. More-over, authors on the crossroads of STS and feminist studies have shown that design incorporates and factualises values in technology which has been a reason to argue in favor of opening the 'black box' of technology production (Wajcman 1991). Drawing upon these insights and siding with the political agenda proposed in these fields of research, the conflicts of opinion are not to be taken as something to be marginalized during design and development, but can form a focal point for interventionist ethno-graphic fieldwork. It is exactly by means of detailed empirical fieldwork that stories on the dynamic multiplicity of a specific site can be told. Focusing on this aspect of technology design sensitizes the ethnographer to possible political implications of his or her activi-ties and for various opportunities to intervene, including their political consequences for the various actors involved. These will not be crystal clear and predictable, but some of their contours can be taken into account. Meanwhile, this focus will prevent the ethno-grapher to withdraw into a position that Donna Haraway has called: "unlocatable, and so irresponsible" (Haraway 1991a, pg. 191) and facilitates taking a: "*substantive* position" by which the various actors that are encountered in a site – not excluding oneself – can be embraced as: "active entities who might be seduced into joining – temporarily, and

partially – the shaping of a differently organized work practice" (Berg 1998b, pg 480; Vikkelsø 2007).

I will present the interventionist approach that is emerging on the basis of these insights by describing my entry into a hemophilia[21] care center (HCC) in a Dutch university hospital. In this ongoing project I have not taken a perspective identical to that of the IT facilitator, but certainly kept an actively involved stance. The difference between a position as IT facilitator and my own approach was not just that I am not much of a programmer; it also stemmed from my different positioning in the academic landscape. Since an IT facilitator – as proposed by Hartswood et al.[22] - is involved primarily in the IT design, it also means that the agenda for the kind of solution that is proposed has to be relatively fixed – it will have to be an IT application. As Randi Markussen has pointed out: "Designers describe the work of the users from the point of view of the technological solution they have in mind" (Markussen 1996, pg 136). Of course this also implies that I do not transcend these situated solutions. I entered the site with the explicit aim of being a 'change agent' supporting and bringing about transformation, without the problem, nor the solution having been framed rigidly yet. From my professional position at a research group with a focus on sociotechnical issues of IT in healthcare I offer certain 'affordances': there is obviously a wish to include IT developments in the change process, or rather, because the medical center asking for our assistance perceived IT to be an important factor in solving their organizational problems they approached us in the first place. As will become clear from the remainder of this chapter the alterations that were proposed and instigated where not all involving IT in a narrow sense. This is to be seen in the light of the observation that organizational and social issues are highly relevant for IS research[23].

My interest in the positioning of the change agent and the politics of intervention in design is another substantial difference between the position of the IT facilitator and the approach laid out here. Markussen stresses the importance of a sensitivity for the specific positionings of technology designers, and in my view this insight can easily be extended in a reflexive way to the position of the change agent: "As long as you focus on the historical and social conditions of the users and their organizations without including the historical and social conditions of the designers and the technology, you cannot account for the designers' location and historise their experiences"[24] (ibid.), and to come to a research approach that does not play the god-trick of hiding in a scientific 'culture of no culture' (Haraway 1997) this very positioning of research is vital.

From this methodological starting point I entered the department of the hospital providing care for hemophilia patients. This department had been subjected to a dramatic policy change when being appointed as a HCC. The Dutch ministry of health laid down a policy document (Borst-Eilers 1999) that set the standards for the desired care. Demands such as integrated care in a multidisciplinary care team[25] had to be met and therefore substantial organizational changes were due for the HCCs. This situation

made an internist-hematologist at the HCC under study approach the department for which I work, to ask for assistance when realizing these changes on an organizational level, and on the level of the development of IT that he and his colleagues at other centers deemed necessary. The strategy of entering as a change agent implied that my role in the scene was not narrowly defined in advance; rather, what I would be doing – or would be expected to do – was kept fuzzy and left open for situated construction, within the limits – and sometimes beyond – of my interest and competence. My position of being a 'change agent' did imply a positive definition of 'change'. First of all, there was a clearly defined and imposed need for change in a particular direction pointed out by the minister of health. But besides this externally imposed alteration of the site, 'change' is not something the minister introduced into an otherwise static setting. Change is a state that is: "already and always in progress" (Blomberg, Suchman et al. 1996, pg 260, original in italics). This reality of continuous 'redesign' accommodates continuously asking the politically pertinent question who benefits from a certain regeneration of a site or, following Susan Leigh Star *cui bono?* (Star 1991, pg 43). This sensitivity for the political importance of change helps "put the boundary between the technical and the political back into permanent question" (Haraway 1997, pg 231) but also includes the risk of being marginalized[26] because of it's inherent preference for siding with 'inappropriate/d others' and a lack of sensitivity for the limited number of interventions that actually seem feasible – based on all kinds of 'sensible' considerations. Interventions therefore had to be both politically sensitized, as well as highly pragmatic since I was not in any way positioned 'above' the practice, but was continuously situated.

Without a narrow, identified focus, I was present at the HCC with the aim of identifying acting space, assessing where interventions would be possible and trying to remain sensitive for the way in which the regeneration of a site would influence the positions of various actors. This activity in itself already consisted of more subtle forms of intervention and it is not to be seen as 'preparing the ground' for the 'real' intervention of developing IT for the center. Of course the cherished fuzziness raised similar problems as those pointed out by Hartswood et al. in relation to the competencies of the researcher and the risk of being overloaded with demands, but I will also show (in the section 'Many Lives in a Hospital') how the various expectations and roles that were attributed or adopted were turned into an important source of data in both the research and the interventions, and thereby became part and parcel of the methodology.

But before turning to this aspect of the approach, I will first question the concept of 'better' technology, by showing that 'the' HCC that I expected to encounter was a rather equivocal and multiple entity.

1.3 Countless Care Centers

Important concepts that have been coined within feminist technology studies are 'diffraction' and 'situated knowledges' (Haraway 1991a). They indicate the inherent partiality of perspectives on a 'practice', a 'fact' or a 'site'. Questions that proved to be illustrative of

the diffracted nature of the HCC were: 'What is the HCC?' and 'How do we make the HCC work?' It was when focusing on these matters that the multiplicity of 'the' HCC would easily come to the fore. The clearest, and most explicit answer to this question came from a representative of the Dutch Association of Hemophilia Patients. This informant reacted as if she had been stung by a bee: "What do you mean 'to make it work'? It is already there! The ministry has appointed them, so they already exist." For her, discussing the present functioning of the care center was out of the question: it *already existed*. All the aims were laid down, and now it was just up to the care providers to live up to these standards.

Initially, a rather opposite reaction came from the internist-hematologist, who was my key contact at the center. He stated that we had to be very careful, because: "if we don't make the care center work, we may be closed down. I think that is a real risk, and the more so for some smaller centers. The only center that would then remain would be the Van Creveld[27]". The fear of being closed down, and the resulting perception of the HCC as a *threatened unit* was initiated by the way the implementation of the policy by the ministry was presented. The initial demands were that a formal examination with direct consequences for the continuation of the status of HCC would follow within one year. Since the problems were substantial, this informant seriously doubted the chances of passing the exam.

The perceived viability of the center altered after a powerful reaction came from medical professionals. They expressed in strong words to the ministry their discontent with the state of affairs on the implementation of the policy. This changed the ministerial aim of 'examining' the centers into drawing up an inventory, which diminished time-pressure to shape the HCC substantially. This also seemed to transform the perception of the internist-hematologist on the HCC. Instead of the center being threatened, he became eager to present it as an *efficient unit* in the hospital. This situated idea of what the center was came to the fore when we were discussing an internal document I had prepared for the hospital pharmacy to indicate the amount of money that went astray due to sub-optimal registration and logistics of medication[28]. I carried out this investigation in order to generate a budget to employ an extra person at the HCC dealing with medication, and to increase my credibility at the site (see section 'Many Lives in a Hospital'). The internist-hematologist was called to the Board of Directors of the hospital after they received a copy of the survey that he had filled out and sent to the ministry as part of the inventory. He had filled it out quite strategically, focusing more on problems than on achievements and now assumed he would have to justify himself for the way he had represented the hospital. He said: "I would like to bring this paper along to the Board of Directors. It is good to show them that we do quite a bit more than just filling out inventories here!" The very changes that were taking place in the setting 'redesigned' the HCC, and enabled him to state that the care providers and I were turning it into an efficient unit.

When I arrived, the '*multidisciplinary care team*' that I expected to find turned out to be nothing but a number of individuals, not meeting at all, not knowing what procedure to follow in case a hemophiliac would show up; not showing any characteristics of a 'team'. During my stay there, the care providers of the team started meeting up, and discussing patients together. Meanwhile, a protocol folder was created for all disciplines. This turned out to be a highly constitutive activity for healthcare providers since it made the HCC all the more tangible in the hospital environment. Even though it proved difficult to implement the protocols they did give guidance to the discussion among the various disciplines. For the professionals from other disciplines, this way the HCC was starting to work: the care team started functioning.

When I started the project in the HCC, one of the important activities of the hemophilia nurse was her dealing with all the contacts with pharmaceutical companies. She would maintain her own stock of medication, acquire product information, place orders directly with the companies and receive the sales managers when they came to visit. She stated that this was definitely improving the quality of care, and was a task that should be carried out by her. She also realized that most patients hardly ever saw a doctor, and in general administered their own medication. Therefore providing them with the proper medication and product-information was the most important function of the HCC. It made her situation in the outpatient-clinic – of which the HCC is part – special, and it defined the working of the HCC as operating an *own shop*, i.e. a separate place in the clinic that she was running herself with a substantial amount of autonomy with respect to the hospital pharmacy and her superiors.

This definition was a thorn in the flesh of the head-nurse of the integrated outpatient-clinic hematology/oncology. When giving me a reprimand after a meeting (see section 'Many Lives in a Hospital'), she stated that it was of utmost importance that: "we shouldn't return to the situation where hemophilia is something completely different, with different privileges and all. That was the case when I came here, and I was told that was exactly the problem with this clinic!". For her, making the HCC work was to keep it as an *integrated unit*, i.e. as part and parcel of the hematology/oncology clinic. She tried to install this interpretation by rotating the nurses as much as possible to the other positions in the clinic, and by stressing in meetings that officially there doesn't exist such a thing as a 'hemophilia nurse' in the Netherlands. She also insisted on the fact that there was no permanent function for a nurse dealing with hemophilia: the work was just part of the activities at the outpatient clinic.

However dearly the head-nurse may have wanted to describe the clinic as integrated, other actors enforced the definition of the center as a *separate unit*. One of the decisions made in the working group that was formed for the HCC[29] was that a PC was needed for its development. The perception of the head-nurse that the center is based in, and part of an integrated hematology/oncology clinic was challenged by a non-human intervention. In the clinic the nurses worked with 'dumb' terminals that provided access

to the hospital information system (HIS) through the hospital's mainframe computer. The PC was to be placed on the desk where the hemophilia nurse was sitting most of the time, and was to replace the terminal. After having decided on the need for a computer however, it turned out that the network box to which it was to be connected was a dummy: it was merely a box, with no cable leading to it to connect it to the hospital net-work. As a result, the whole ceiling would have to be opened in order to provide such a connection. In a crowded outpatient clinic, this is close to disastrous, and the head-nurse quickly arranged for a room to be allotted to the HCC. Though the head-nurse was trying to factualise her perspective of the center as integrated, the alliance of the PC and the box provided the irrefutable argumentation for obtaining a separate place designated to the HCC.

The discussion on the logistics and registration of the coagulation factor concentrates led to yet another view on what the HCC was. Among participants of the working group, the view became dominant among the internists, the hospital pharmacist and the head-nurse that the position of the hemophilia nurse would have to change. Not only were her tasks concerning registration seen as secondary to a nurse's job – and this in a clinic with a serious lack of nurses – it had also turned out to be costly since registration was not optimal. It was decided that an extra position would be claimed for an assistant-pharmacist to be employed and take over a substantial amount of the nurse's activities. In the period prior to this change I had observed that the nurse's encounters with patients were some of the rare remaining moments of communication between the center and the patients and the activities of running an 'own shop' actually included a lot of 'invisible work'[30] that was valuable for the primary patient care. However, it was no longer feasible to maintain this situation because of the strong opinions against it from powerful actors in the HCC. When it became clear that the activities had to be shifted from the hemophilia nurse to the hospital pharmacy, I pleaded for a reallocation of the time that would become available to a more formalized nurse-patient relationship in the form of a nurse led home-treatment clinic. The head-nurse and the internists-hematologist agreed upon this initiative and before it was actually operating the nurse one morning asked me: "Do you have any appointments today? Because I have my first nurse-led consult today". She said it with a lot of enthusiasm and was hoping I would shift my ethnographic activities to observing this clinic. What it meant to make the HCC work seemed to shift slowly from running an own shop to creating a formally intensified *patient relationship*. The main advantage of this was that now she would not be considered by other nurses to be 'just chatting' with patients, i.e. the invisible work would be made visible. Based on these observations on the different ideas on what it means to make the HCC work, the diffracted range of views of the center can be seen in figure 2.1[31].

The displayed equivocality is not without consequences for me, as a researcher, who entered the setting as a situated yet fuzzy change agent, and is seen as someone who can be aligned with a certain view, but who is also searching for room for interven-

tion in line with pragmatically political aims. As a result of this there was a large array of roles that I was expected – or trying – to play. Besides that, some roles seemed a result of my prolonged stay as an ethnographer. To these various roles and their different origins I will now turn.

Figure 2.1: Views on the HCC
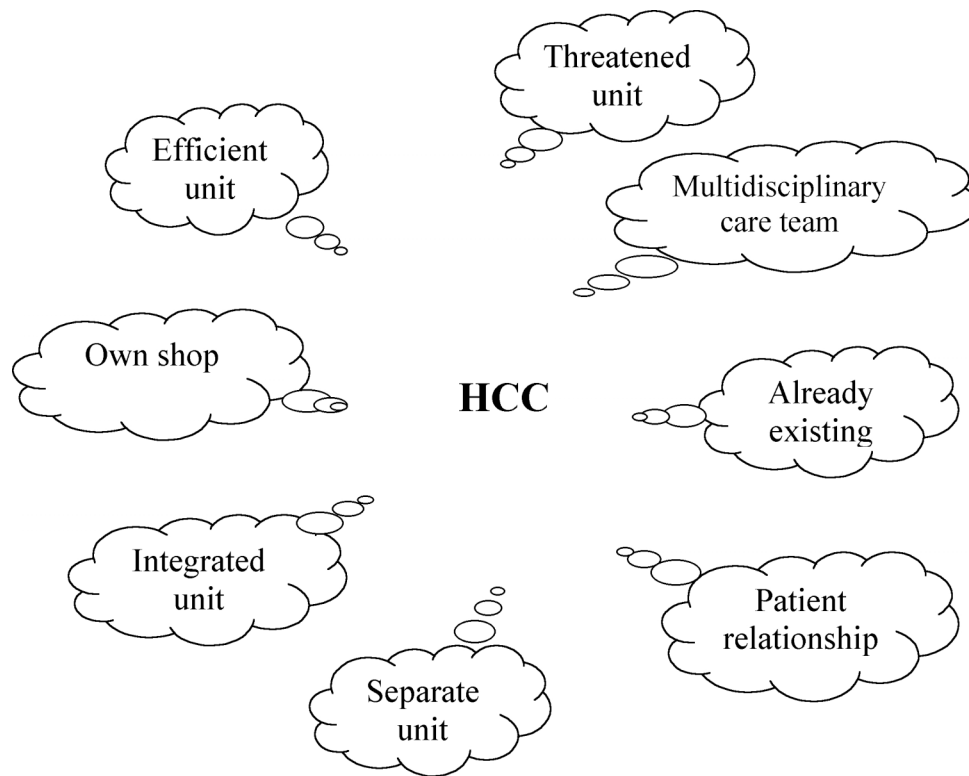
1.4 Clothes Make the Man: get a large wardrobe!

When I entered the research setting, it soon became apparent that the level of flexibility required by me was substantial. Due to the situated ideas of various actors of what the center is, I found that many times roles were being attributed to – or enforced on – me that stemmed from a specific interpretation of the HCC. Also some roles seemed to arise as a result of my presence as an ethnographer. And besides all this, of course, I tried to position myself and adopt roles strategically, seeing if they would enable intervention or alter the site in a way that could facilitate changes that could both 'work' in general, and redesign boundaries in accordance to my politicized insight into the diffracted HCC. For this subtle interventionist work, an instrument that was at my disposal, or rather, that I tried to use was a large wardrobe. This is a well-known ally of an ethnographer facing various groups within one setting[32]. But of course, I could only do so much to divert the attention of my informants from the roles they wished to ascribe me.

At first, I was rather cautious of these different roles, and felt somewhat threatened by the idea that my informants were trying to 'use' me for their various goals. How-

ever, it didn't take long for me to start taking comments on my work and roles being ascribed as valuable sources of information on the setting I was researching. All the more so, since this provided insight into the setting in which I was to act strategically. Had this strategy been based on a preconceived Grand Idea on the way to proceed and intervene, roles being attributed may have posed a threat, but while aiming for ad-hoc intervention as a situated activity the information on the diffracted nature of the site proved an essential prerequisite for identifying acting space. When thus shifting the perspective on the roles that I was asked to play, a stressful situation turned into a rich source of data. The anthropologist Mascerenhas-Keyes states on this issue that: "since stress seems to be a sine qua non of fieldwork (…), rather than escape from it I suggest that we could usefully integrate it into fieldwork methodology" (Mascarenhas-Keyes 1987, pg 189)[33].

1.5 Many Lives in a Hospital

In one of the first weeks of the project the internist-hematologist suggested that I should visit some of the other centers to compare existing organizational practices. He made a phone call to a colleague at the largest HCC in the Netherlands in which he said: "We have a logistic manager employed here, who would like to take a look at the whole logistics of coagulation factors at your place". Though I was quite surprised to be portrayed as an added direct employee rather than an external researcher, this remark made me aware of the positioning taking place in relation to this other center. Also it helped me to realize that the HCC was being perceived as a threatened unit, and that it was important to show that we were doing all we could to get the center organized. This of course had consequences for the space that I perceived to have in order to act on behalf of the center and stressed the need for a concrete result of the project.

A somewhat similar, but more broadly defined role was that of the 'project leader' in the HCC. This was a role that I partly took myself, and that simultaneously was attributed by the internist-hematologist. My choice for this role became apparent just before the first meeting of the project group. Since the aim of this meeting was to present possible directions to pursue organizational change, I had attempted to enhance my credibility by dressing more formally than before. The suit I was wearing was an – by managers well known – ally in the attempt to start an organizational change. As I walked in, the internist-hematologist saw I had dressed more formally, and being quite content his only remark was: "Very good! I will buy you a tie some day". Apparently he wanted to stimulate this development into a more managerial position for me, seeing the need to do much work to survive as a center. Therefore this role was related to his interpretation of the HCC as a threatened unit. Of course, while this managerial role put me in a position with a substantial amount of acting space, it also put me at guard, since it might be conflicting with more subtle ways of intervening and therefore be detrimental to my approach. The responsibility I would have for the outcome of the process would be far beyond my research goals – not to mention my competence. On other occasions the suit

was also a strategic and essential ally. For example when I had to report to the company providing the funding for the research. In a strong alliance with a slick PowerPoint presentation (with the logo of the company embedded in the background of all slides) it helped me to perform competence to this pharmaceutical company[34].

In a very different setting, the head-nurse called me into her office right after a meeting. When I entered she closed the door behind me saying: "So, that door we fully close…". After this, she gave me a reprimand like one can only give to an employee ranked much lower in the hierarchy who has stepped out of line. She had been quite displeased with the tone of something I had said during the meeting, and said she didn't appreciate me being cynical at all. Besides the fact that it was highly puzzling for me to understand what she meant – since I hadn't intended any cynicism during the whole session – it was interesting to be treated as an 'employee' all of a sudden. I took this situation as an opportunity to learn that I posed somewhat of a threat to her view on the HCC as an integrated unit. Since my arrival, the separation of the center from the outpatient clinic had materialized and her action made me realize that this interpretation was seriously restricting my acting space; I would have to be creative in finding ways to keep its representatives on board, while not minimizing my acting space.

A role that I adopted mostly in the early phases of the project was that of 'ignorant eyes and ears'. Since this phase consisted mainly of observing the medical practice, it was important to gain the confidence of the nurses. Therefore, in this phase, substantial modesty was needed. I performed this role by asking many questions, by following the nurses wherever they went, not interrupting them when they were engaged in conversation, and by wearing leisure wear. Being surrounded by healthcare professionals in their white 'uniforms' made any possible sign that clothing might project much more visible, which made me aware of the work I had to do not to stand out, but become part of their reality. This role, and the activity of 'observing', should not be taken as passive and different from interventionist activities. They proved part and parcel of interventions in meetings and when the installation of a PC was carried out, since at many such times the good relationship with the nurses was very helpful for pursuing a change that I perceived to be possible, desirable, pragmatic, and politically sensitive.

As mentioned above, at some point in the project I was carrying out an investigation of financial and procedural consequences of the registration procedure of medication. It had become clear to me that the existing process of ordering and registering coagulation factor concentrates was problematic. The hemophilia nurses took care of the entire process, and since their primary focus was on providing care to patients, erroneous registration was unavoidable. This made the process costly while simultaneously frustrating the primary care process[35]. Though participants of the working group of the HCC agreed with the importance of separating activities for the sake of registration and process-supporting activities[36], they also indicated the pertinence of being able to underline such a point with financial data, and suggested that I would carry out the

investigation to obtain such figures. Though not being equipped with much knowledge of (nor interest for!) accountancy processes, taking up this role seemed a way to realize substantial acting space. A relatively small investment of time could lead to substantial organizational changes if an extra member of staff could be employed with the money that was traced. Therefore, I 'chose' to take up this quite foreign role of 'forensic accountant' – though the 'choice' was highly influenced by not wanting to diminish my position as a 'useful' entity. Realizing that I was facilitating an organizational shift, which was not quite in line with my findings of the importance of the afore mentioned invisible work the nurse carried out while running her 'own shop', made me stress the importance of trying to allot (a part of) the gained time to the nurse led clinic. This was however all I could do, without knowing at that time if this could actually be any kind of an adequate replacement for the informal contacts between patients and the nurse when she was handling the medication. Not taking up this role, however, seemed to jeopardize and marginalize my position substantially.

Where these roles all seemed to emerge from, or at least be related to a specific view on the HCC, a number of roles was also ascribed stemming from other ideas or situations. One such role that was attributed after several months on the site was that of 'adoptive nephew'[37]. The close cooperation with the internist-hematologist over an extended period contributed to this role that became more apparent after a protocol meeting, where a presentation of the HCC project was given to all hematologists of the out-patient clinic. During the discussion I found that I had gained enough insight into the medical aspects of hemophilia to be able to discuss on an equal level with the professionals[38], and after that meeting, the internist-hematologist was quite content with the proceedings. He complimented me in a fatherly manner: "I am really impressed with the medical knowledge you have gained so far". This role may be interpreted as a result of the intense collaboration in this project, and has also been interpreted as being gendered. Waring (2001), has described that her role as a female action researcher led to significantly different and more problematic contact with the actors at her setting than the later introduced young, male IT programmers, who were adopted instantly. Whatever the interpretation, it certainly contributed to the acting space and credit I had.

Based on the observations of the different roles that were ascribed to me, and that I tried to adopt myself, I can draw the inscription of figure 2.2. The relationship between the views on the HCC and the roles that were ascribed becomes apparent when combining figure 2.1 with figure 2.2. With the resulting creation of figure 2.3, I wish to indicate that the roles that were ascribed by actors in this research setting proved highly informative of the interpretations that were present among those involved in the HCC. The remaining role of adoptive nephew did not emerge due to a specific interpretation of the center, and this indicates that there are other factors to be taken into account when studying a setting, such as the gendered nature of relationships and roles. Besides being left behind with a role that does not match any specific interpretation, I

Figure 2.2: Roles ascribed and adopted
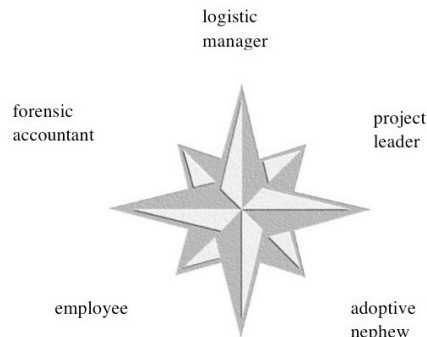
also face certain interpretations that are not accompanied by a role. Reasons for this are varied. In some stories on the HCC I was being aligned in quite an obvious and central way, whereas in others – such as the separate unit – I seemed to be a lot less 'present'. Of course, even the configuration of the computer network and the resultant strengthening of the interpretation of the HCC as a separate unit have consequences for the roles that I am being ascribed or can try to adopt. And therefore it would have been possible to make the inscription more 'neat' with roles matching all interpretations. However, this was not the aim of this exercise. The aim is to show how roles that are being ascribed can be used as findings to gain insight into the different ways in which a site exists from different perspectives, while thereby providing crucial information for identifying room for intervention.

1.6 Discussion: dissection and selection

Centering my realization of the multiplicity of the setting has enabled me to get a feel for the politics of the HCC, for problems that are perceived, for the various expectations of me as a change agent and for the resulting space for intervention. The method of participant-observation has been crucial for obtaining information on the HCC, on the numerous stakes involved, and to intervene subtly by positioning myself in the HCC.

After having shown the hybrid and equivocal reality of the center, I would now like to return to reflecting on the role of the ethnographer, and more importantly for the ethnographer with the intention of engendering situated interventions in sociotechnical design.

The problematique of the idea that it is possible for an ethnographer to enter a site without aligning with one or more of the 'sides', has been discussed extensively amongst scholars within STS[39]. One of the outcomes of this debate is that it is proving highly problematic to try to maintain a 'neutral' position. Stuart Blume describes how his initial: "unwillingness to make an assessment [of whether or not the technology of cochlear implantation for deaf 'worked'] proved

Figure 2.3: Roles and Views on the HCC
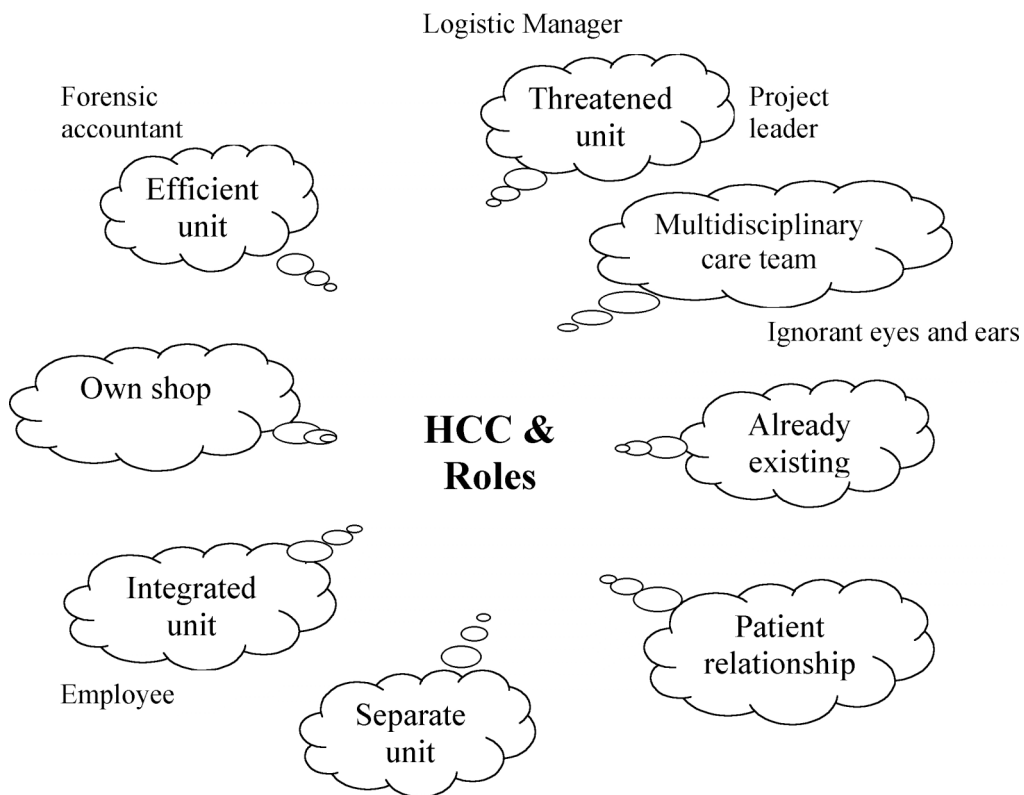
literally impossible to sustain" (Blume 2000, pg 156). If this is the case for an ethnographer who started without interventionist intentions, it should be all the more indicative of normative responsibilities of the intentionally interventionist STS researcher. Any contribution to design that is proposed, will influence the setting, and thereby shift the balance of those actors that are more included and excluded in the design: who is constituted as 'inappropriate/d other'. Realizing this gives the researcher the obligation to become aware of stakes and interpretations that are present or emerging. This does not mean that the ethnographer will be able to disinterestedly 'map' all positions that are 'relevant', but that sensitivity should arise for the diffraction and the possible consequences of change. As studies in STS have indicated: "each merger of actants – humans, artifacts, technologies – create a new entity, whose capacities cannot be fully foreseen" (Berg 1998b, pg 475). This implies that an interventionist ethnographer faces the inevitability of being hoodwinked and tricked by design changes proposed. Though 'better' technology design often seems to refer to the idea that the technology 'fits' onto the work-practice, I have shown in this chapter that what this work-practice is, is opaque and equivocal. At this point it seems appropriate to further theorize the question how to proceed from this acquired complexity in pragmatic yet politically significant ways and how to act upon the insights in the setting and its possibilities for intervention.

Mainly, three options now seem opened up, some more well-trodden than others. First, there is the solution of shunning interventions, when realizing the complexity of the site, and the performativity of any interference in regards to its configuration. But, as we have just seen in the work of Blume, this would actually mean ceasing to do research, for the problem of performativity is not merely one of intentionally interventionist research[40]. Therefore, this solution is actually not an option, especially when realizing that the aim of the research was to operate as a change agent.

The remaining two options both imply creating a new, workable story of the site that is based on modifications of its various interpretations. A first possible way to pursue such a new story is by engaging actors in a confrontation with the various interpretations, in order to let them define the problems and interpretations that they wish to adopt and work on[41]. By means of this approach the aim is to achieve – if not consensus – closure and unification of (coexisting) views. The risk of this method is that it can easily lead to an enactment of positions, rather than challenging them. Feminist studies have made us "reluctant about overly simplistic egalitarian discourses, as they may hide important differences and in practice make space for manipulation" (Markussen 1996, pg 131). Caution is needed not to start seeing the method as an unproblematic solution that obtains its importance from a sublime 'democratic' procedure (Berg 1998b, pg 480). If seen as such, there is every risk that the politics of the setting can be reduced to the positions of the people involved.

In this chapter I have shown how technology at times acted as a constitutive force, with consequences for the configuration of the HCC, and for my position as a change agent. Without the 'trick' played by the combination of network, network box and PC the conceptualization of the center as an integrated unit would not have been questioned to the same extent, and my acting space would have been substantially reduced. This shows that: "[technology] is not just a screen upon which the negotiations between social actors are written out" (ibid. pg 475), and that the tricks it plays are shaping the room for intervention. If the sensitivity for these kinds of interventions is subordinated to the human interpretations and deliberative procedures, this results in a lack of sensitivity for the acting space that emerges because of these changes, and the difficulties in inscribing the outcomes of choices in the setting will be underestimated. Though it seems hard to argue with such 'egalitarian methods' I wish to side with Randi Markussen who stresses the importance to question their functioning in power-differentiated work settings (Markussen 1996, pg 131).

Conceptualizing technology as acting, creative and 'tricky' I can see the act of trying to create new stories as a more strategic enterprise in which a researcher tries to identify which aspects and interpretations in the sociotechnical setting can be combined and allied. Hereby politics as a procedural activity is transformed into the activity of a change agent, i.e.: "immersing oneself in the networks described and searching for what is or can be achieved by new interlockings of artifacts and human work" (Berg 1998, pg

482). Adopting this approach to realize a new story on the setting provides the interventionist researcher with a hybrid collection of aspects, that can be combined, shifted around, and kept for reference when identifying acting space or deciding on an action to be taken. It provides the starting point for, what I would like to call sensitized interventions based upon politicized ethnography. 'Based upon' as used here should not be taken as indicating linearity and a temporal separation. As stated, the intervention and the fieldwork co-exist and -develop. This story will certainly not come out as 'planned' by the interventionist researcher, who – just as any other actor in the setting – is bound to be hoodwinked by the constantly eluding technology. The dilemma of striving for changes, while realizing that they will turn out differently than intended, cannot be solved. Though I perceived the work of the nurse in dealing with patients informally through running her 'own shop' to be important for the quality of the work of the nurse and the care for the patients, I still found myself contributing to the discontinuation of this practice. Though reluctantly, I contributed to the story of the center being an efficient unit, and though attempts were made to ensure a continuation of the patient-nurse relationship in the form of the nurse led clinic, the functioning of this in practice is still to be seen. Without being able to solve this dilemma, it is all the more important to be aware of it, and keep striving for normatively situated interventions - that turn out differently than intended.

Though compatibility of perspectives and positions is of course an important criterion for identifying room for intervention, I have shown it is by no means exclusive. If it would be, this would imply a loss of political pertinence. Yet, the interventions that are being pursued result from a choice – albeit one that is mediated by the research site and the researcher's affordances. Siding with Haraway's plea for explicit situatedness, as opposed to playing the god-trick of claiming to have a view from nowhere (Haraway 1991b, pg 193), I would like to plea for situated interventions based on fieldwork. The positioning this implies can be justified in numerous ways. Of course, it is bounded by possibilities for intervening that seem to emerge, thereby problematizing Haraway's idea of diffraction as an activity to favor those who are excluded from certain knowledges or designs. Similarly it is situated on the grounds of social mechanisms that occur in fieldwork. In the case of the HCC, the close working relationship with the internist-hematologist who instigated the project, would tempt me to be adopt his view on the site and strive to realize it – if only it was clearly identifiable. Another possible choice could stem from an ideological commitment leading to the wish to give voice to a certain (group of) actor(s), such as the hemophilia nurses who seem to be at the bottom of the organizational hierarchy[42]; the 'inappropriate/d others'. This choice would of course bring the mentioned problem of marginalizing oneself by working for the marginalized (if identifiable) to the fore. In this project I had to be quite careful not to be maneuvered into an arguably 'weak' position, which would make it very difficult to materialize any intervention supporting changes that I saw as desirable. Though pragmatism should not be the sole

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leading principle when choosing an intervention, it should certainly be taken as a critical factor, thereby excluding the possibilities for unbridled political activism, but creating space for situated and politically sensitive action.

To conclude, I will give one further example that may be illustrative of how this sensitized intervention materializes in the project. Though I've shown the taking up of roles and my very presence as an interventionist researcher at the site to be interventions, there are also more explicit moments where I chose to act in a slightly more 'traditional' interventionist manner. At one occasion, the future of the hemophilia databases for the care centers in the Netherlands was discussed in a meeting with internists from various HCCs, a representative from the patient association, a software developer from a company involved in the design and a programmer from the hospital IT department. I was also invited to attend this meeting. The point that caused some commotion was whether there should be one national database that all HCCs share, or decentralized databases in all centers. Though the salesperson from the software company tried to stress the convenience of a centralized database, his view was strongly countered by the internists, who claimed that for such a structure trust was lacking among hospitals and care centers. To the obvious discontent of the salesperson, it was stated that there would have to be sixteen databases for sixteen centers that would have to be linked locally to the existing hospital information systems. When this was proposed I decided to intervene by stating that this might prove problematic for smaller HCCs since they would be lacking finances to integrate the systems. Quickly a solution was found in the possibility of providing an Access viewer for the database, which would also enable the use of local databases as stand-alone systems for the smaller HCCs because with this viewer there would not be a need to link it to a hospital information system (HIS)[43]. The final remark from one of the internists of a large HCC that this database without the viewer would have been an appropriate tool to reduce the number of centers from sixteen to twelve, made me realize that this had been a valid intervention on my behalf. I could intervene on the basis of my knowledge of problems patients and healthcare professionals were facing with home-treatment. The distance between the HCCs and patients had increased in both a literal and a metaphorical sense with the introduction of this treatment method (see chapter 2), and, especially for the patient association, the geographical distribution of care centers was an important issue to at least not further increase the physical distance between HCC and the patients. Since the design of the technology posed a threat to some of the smaller centers, it seemed appropriate to intervene on behalf of the patients that are not located close to a large HCC who were about to be constructed as 'others' vis-à-vis the system and thus further marginalized. Without denying the perspective of the health authorities and their wish to reduce the number of HCCs to increase the quality of the provided services, these arguments seemed secondary to the wish of some large centers to increase their number of patients in the competitive times for hemophilia care. If the issue of the amount of centers was to be dis-

cussed, this should be done in a more open and direct way, and with other actors present than by means of this technical design. If I had explicitly defined my role as an observer, who would afterwards intervene, I could not have taken this opportunity to act and shape the technology design on the spot. For this the intentionally ad-hoc nature of the approach was indispensable. Similarly, the period prior to this meeting, in which I had intervened in more subtle ways and had positioned myself more or less strategically, enabled me to act in this 'stronger' way now. Though the intervention was an attempt to make the technology 'better', this was not a naïve, absolute 'better' – it was a situated better for hemophilia patients living at considerable distance from a large HCC. And the reason the intervention could take place, was because the aim of reducing the care centers by means of the database design was seen as inappropriate by various other actors.

1.7 The Fragility of 'Better'

It is important to note here that the sustainability of this situated 'better' might be limited. The perspective of the health authorities on the number of HCCs needed may at other times become more predominant, challenging the position of the small HCCs. In such a situation, the importance of focusing on the political consequences of the database design in relation to the number of centers that are able to work with it would decrease. The alliances that constitute what is 'better' therefore are undoubtedly fragile. Especially in this setting where it is not in any sense obvious who is being marginalized or defined as an 'inappropriate/d other', it remains important to keep assessing which interventions seem suitable. For example, the position of the nurse running an 'own shop' may have initially seemed an important and 'better' aspect of the care provided. However, it proved to be 'better' to transfer the logistics of medication to the hospital pharmacy in the light of the situation concerning personnel in the understaffed outpatient clinic, of the financial consequences of sub-optimal registration, and of the legal problems that might arise when a medication problem would occur without the pharmacy being involved in the distribution of coagulation factor concentrates.

This realization of the frailty of 'better' in this particular case makes a simple 'critical' position problematic. Whereas historically, many researchers within STS have been striving for the improvement of the position of citizens, workers or patients, since they were clearly marginalized[44], the 'others' in this research are not as easily identifiable. The chronic patients have been treating themselves for several years, and have become 'experts' on their treatment. They are also strongly represented by their patient association. This results in a situation in which they are barely influenced by medical professionals. In a talk I had with a patient he stated that "This doctor has just recently joined us". This shows that it is not unproblematic to see hemophilia patients as marginalized. And hemophilia nurses with their primary patient focus are no more 'other' than head-nurses running the clinic and looking after the 'productivity' of the ward to ensure care for all patients.

In this setting in which inappropriate(d)ness is constantly emergent and ambiguous, it becomes unavoidable to reflect upon the problematic position of a researcher claiming to know who is marginalized. A traditional critical approach towards interventionist research with clearly identified 'included' and 'excluded' actors, and political agenda's that seem inherently 'right' do not do justice to the complexity encountered here. Taking the emergent nature of otherness into account, makes the work of the interventionist researcher a pragmatic exercise in balancing the constantly performed and reconstituted 'interests'. Within this methodological setting a researcher is facing the dilemma of continuously assessing the political sensitivity of situated interventions in an emergent landscape of positions, without ever being ensured that the actors that are favored are actually inappropriate/d. On top of this dilemma the tricky nature of a (technological) intervention makes it impossible to ascertain that the intervention will actually benefit those that seem to need support.

These dilemmas similarly apply to the funding structure of this research project. Whereas the critical stance within STS would be highly skeptical towards commercially funded research – especially when it is being done in a medical setting while being financed by a pharmaceutical company – it here seemed to provide me with considerable acting space. I could contribute to the improvement of the working situation of the medical professionals in HCCs that were facing significant difficulties, and that would undoubtedly detriment the quality of the care for hemophilia patients. Meanwhile the company gave us all the freedom to work as we wanted, without directly trying to influence the outcomes or approaches in the project. Their main aim with the grant was to create good will among hemophilia doctors by showing their commitment to improving the organization of hemophilia care. Though the idea that governmentally funded research would be more 'autonomous' may seem quite awkward from an STS perspective, it has proven to be necessary to defend the funding structure of this project to various STS audiences. Until now the project has proved that letting go of ideas on the 'purity' of research funding may facilitate attempts to work for situated 'better' solutions.

As I have tried to show in this chapter, ethnographic fieldwork is a very suitable methodology for obtaining information on the diffracted nature of a site. Especially the reactions to my presence and the roles that were attributed proved highly illustrative and informative for dissecting the HCC. Similarly, the concepts that were introduced from the field of feminist technology studies such as 'situatedness' and 'diffraction' proved instrumental to tell the story as I told it. This combination is leading to politicized ethnography that allows me to take the multiplicity of the setting into account when identifying acting space and working on solutions for perceived problems. It also facilitates continuous awareness of the consequences of the changes that occur in the 'redesign' of the setting and emergent acting space. The result is an interventionist research strategy that abandons 'control' as a useful concept for structuring interventions, and that nurtures situated, continuous, and politically sensitive interventions. It also redefines the idea that

ethnography or user participation inherently lead to 'better' technology, by explicitly arguing for ad-hoc positionings of a change agent in IT development projects that define 'better' as a situated concept. This results in a politically relevant design and development practice, and in the methodological advantage of being highly sensitized to emergent acting space. Though the outcomes of interventions will not cease to elude us, this does not absolve the change agent from the responsibility to keep working towards situated better technologies.

Chapter Two

Embodied Interventions – Interventions on Bodies

Situated experiments in practices of

science and technology studies

and hemophilia care

Many older hemophiliacs look back on childhood years of missed opportunities which have resulted in poor quality jobs and long periods of unemployment. The reasons for this are not difficult to find. Effective treatment with concentrated blood products has not been available for long, and children used to be put to bed for weeks of rest after bleeds (…) Nowadays the outlook for even the most severely affected hemophiliac coming up to school age has never been brighter. The child who is intellectually capable of going on to higher education should have as much chance as an unaffected child of doing so. (Jones 1984, pg. 153).

2.1 Solutions and their problems

This quote, of one of the 'founding fathers' of modern hemophilia treatment, is typical for popular accounts of the impact of technological developments in medicine on the lives of patients. Like for many other chronic diseases, the story on the development of hemophilia treatment is replete with the rhetoric of progress. And in a way this is unsurprising: as in many other cases, the opportunities for patients to participate in activities they would previously be excluded from have improved immensely. Also, their life expectancy has increased while within those lives patients will be facing far less problems with damaged joints due to bleeds.

Though the advances in medical treatment of chronic diseases seem obvious, seeing them as mere improvements in an otherwise static environment poses its own particular problems. As authors from the field of science and technology studies (STS) have observed when researching the development of medical treatment, new forms of care or the introduction of new devices often engender new issues in the sociotechnical interplay of patients, doctors, devices and institutions[45]. From this theoretical perspective, developments in care for (chronic) patients can be seen as *alterations*, rather than mere *solutions*. This affords sensitivity for the issues that newly defined 'patients' and 'care providers' have to face in their transformed care setting.

Analyzing new forms of treatment and their consequences has been a main aim for scientific fields like medical sociology and, more recently, STS. This analytical work has led to detailed studies of the complexities such developments entail for patients and care providers. It has also at times led to critiques of existing care practices, and to suggestions for addressing the problems that were analyzed. However, it has less often resulted in STS researchers getting directly involved in the design and development of these care practices. In this chapter I will explore some of the practical and conceptual issues that occur when STS researchers engage themselves with the *proactive construction of healthcare practices*. By bringing together STS insights and interventionist research, I hope to show how a particular practice – in this case hemophilia care – can be productively reconfigured through entangling it with STS insights and that such entanglements are consequential for STS debates on normativity in STS.

To achieve this aim, I will first describe the emergence of 'interventionist' approaches on the STS research agenda and the different ways 'intervention' is being conceptualized. Following that, I will turn towards a research project where I was actively involved in the construction of a hemophilia care center (HCC) of a Dutch university hospital and unpack what the consequences were of my involvement in this organizational change project. Finally, I will address in which ways the insights from this project may be relevant for the normativity of STS research. I will propose that a situated normative approach is emerging that allows for a reply to the critique of constructivism being 'normatively deficient' without turning towards pre-specified normative agenda's of e.g. social movements, as proposed by authors who refer to themselves as 'critical STS' (Hess 1997).

2.2 STS research and intervention

The history of discussing practices of STS research as 'interventionist' is far from recent. One of the important contributions to this debate is the series of publications exploring the notion of 'capturing' of STS researchers by one side of a controversy (Blume 2000; Collins 1990; Martin, Richards et al. 1991; Scott, Richards et al. 1990). Capturing refers to the situation that studying a controversy symmetrically, i.e. using "the same types of cause [to] explain, say, true and false beliefs" (Bloor 1976)[46], is bound to produce an account which is alternative to the one that draws upon established notions of truth and falsehood. As Steve Woolgar noted already prior to these publications, such an "alternative account will be heard as a comment on the adequacy of the original account" (Woolgar 1983)[47], and therefore "the party with the lower credibility may seize a neutral account because it implicitly levels the playing field" (Hess 1997, pg 161). A major contribution of these publications is that they make it compellingly clear that maintaining a 'neutral' position is simply impossible in the study of controversial practices of technoscience. However, this does not equal saying that 'taking sides' is inevitable[48] and that therefore STS researchers should 'get real' about whose side they are on. Rather, following the analysis of chapter 1, the point is that there will always be an interesting interplay between the positioning of STS researchers and the field they try to engage with.

The notion of 'capturing' was developed in relation to the study of scientific controversies and perhaps as an artifact thereof, it has been conceptualized as the aim of one homogenized 'party' – the underdog – to capture the STS researcher. However, as Brian Martin later pointed out, there may be many cases in which the STS researcher can be seen as both *captured* and *capturing*. Therefore, "the term 'capture' is perhaps the wrong word since it connotes unwillingness on the part of the captured. 'Mutual enrolment' or 'joining forces' are more appropriate descriptions" (Martin 1996, pg 265).

Such willingness of the STS researcher to become part of the controversy studied is further explored by Martin in terms of what he calls 'partisan intervention' and 'open partisanship' (ibid.). He investigates these notions on the basis of his fascinating

involvement in the scientific controversy over the origin of AIDS with the aim "not to argue for intervention as an inherently superior approach (…) [but] to say that it should be recognized as an approach that is useful for certain purposes" (Martin 1996, pg 267). Martin introduces three conceptualizations of 'intervention', being, first a sliding scale from "complete observation at one extreme and complete participation at the other" (ibid., pg 262), which he calls the 'usual' conceptualization. The second is a sliding scale of unobtrusive observation and, what Harry Collins called, 'participant comprehension' (Collins 1984) (and which Collins later conceptualized as 'interactional expertise' (Collins 2004; Giles 2006)) which means that "the social scientist learns about the area by trying, however temporarily, to pass as a competent member or native" (Martin 1996, pg 262). The third scale Martin introduces focuses on the intentions and the purpose of research and conceptualizes intervention as the extremes of aiming at "nondisturbance and major change" (ibid.). According to Martin, the first two notions of 'intervention' are developed by researchers who mainly aim at understanding the practices through partisanship, but his own purpose "by contrast, was at least as much to effect change as to gain under-standing" (ibid. pg 263), which leads him to this third conceptualization.

The development of STS researchers conceptualizing intervention as the aim of changing practices is historically and theoretically situated by Gary Downey and Joseph Dumit (Downey and Dumit 1997b; Downey and Lucena 1997) and by David Hess (Hess 1997; 2001). Downey and Dumit relate their notion of intervention to the "transition taking place in critical intellectual work, from opposing or praising technoscientific prac-tices to intervention, from necessary entrenchment to ongoing participation" (Downey and Dumit 1997b, pg 10). Here intervention is no longer situated in the ethnographic figuration of practices but in "forms of critical participation" (ibid.). They situate the shift from critique and opposition to intervention and participation as part of "a fundamental change taking place in the academy itself" (ibid.)[49]. When exploring interventionist practices of 'hiring in', indicating the willingness of STS researchers to "allow their work to be assessed and evaluated in the theoretical terms current in the field of analysis and intervention" (1997, pg 119) Gary Downey and Juan Lucena make a case for broadening the repertoire of social scientists and "encourage the growth of collaborative relations in academic work and relocate the agonistic politics of rebuttal from a necessity to an option in the everyday practices of academic researchers" (ibid., pg 120).

David Hess situates the turn towards intervention in long-term debates about where and how the normativity of STS researchers should be articulated. Drawing upon Martin's claim that STS has depoliticized its "roots in activist struggles" (Martin 1993)[50] and its base in "radical social movements: radical science, feminism, women's health, civil rights, environmental justice, peace and so on" (Hess 1997, pg 157), Hess links the emergence of interventionist approaches to critiques that constructivist studies provide "no grounds for making a decision about what course of action one ought to take" (Hess 2001, pg 236). He poses that there is a 'second generation' of ethnographically inspired

STS researchers who tend "to be more oriented toward social problems (environmental, class, race, sex, sexuality and colonial)" (ibid.). This move provides such researchers with the normative purchase to "develop ways of intervening in their field sites as citizen-researchers and [to make] (…) their competence applicable to policy problems" (ibid., pg 239). In this sense, interventionist STS is seen by Hess as a combination of the analysis of the "way [practices] might be *better* constructed, with the criteria of 'better' defined explicitly and their contestability openly acknowledged as both epistemological and political" (Hess 2001, pg 240, italics in the original) and the relation to social activism and movements. Hereby the theme of intervention becomes explicitly linked to what critics have called "the normative deficit of STS" (Keulartz, Schermer et al. 2004, pg. 12) and the normativity of STS research is relocated in the connection to the activist roots of STS.

The ties between intervention and activism are further strengthened in a recent proposal for a: "*rapprochement* (…) between the more academic and the more activist wings of STS" (Woodhouse, Hess et al. 2002, pg. 297, italics in the original). When reflecting on the high value many – what the authors call – 'reconstructivist' STS researchers ascribe to explicitly normative components of research, they define this normativity as: "scholars' relatively deliberate efforts to structure inquiry, description, and explanation to serve social purposes" (ibid, pg 298). With the definition of 'reconstructivism' as the: "intention of conducting forefront scholarship aimed in part at helping to inform and deepen public enquiries, deliberations and negotiations concerning the democratic shaping and reshaping of technologies" (ibid., pg. 299), they connect their focus on intervention to grassroots issues and the democratization of the design of technologies.

The conceptualization of interventionist STS research as connected to issues of the proclaimed normative deficit of STS is certainly an interesting one. There are however reasons to believe that intervention and normativity can be brought together *without* linking them to activism, social movements and the democratization of technology. Besides a substantial volume of work that connects intervention to social movements and democratization[51] there is also a growing body of literature that unpacks the ways STS research intervenes in practices and is normatively relevant without connecting it to participatory or activist democratic models[52]. It is to this body of literature that this chapter and thesis wish to contribute.

I propose that though *both groups* of researchers exploring the notion of intervention 'intervene' in the issue of the 'democratic deficit' of STS, the conceptualization of intervention as proposed by 'critical STS' makes it perhaps more fitting for the study of settings in which the stakes seem rather evident, the 'sides' are clearly divided and the normativities involved are somewhat crystallized, i.e. where the issues of the environment, class, race etc. mentioned above by Hess are dominant. Yet it may also be that such unsituated loyalties risk reenacting pre-determined normative positions, rather than

opening them up and do what Hess himself calls "'good ethnographies' [which] frequently interrogate or complexify the taken-for-granted, such as commonsense categories employed by social scientists, policy-makers, activists and scientists" (Hess 2001, pg 239). Critical STS thereby runs the risk of first re-enacting and then critiquing the usual suspects, rather than empirically unpacking, complexifying and re-situating normativities one wants to attach ones loyalties to in particular events.

According to Roland Bal this limitation of the critical STS notion of intervention is partly a consequence on the notion of 'membership' as deployed by Collins and Martin: "The idea of 'membership' too easily misses that there is a lot of heterogeneity within a practice; that we, as all others, have to make choices as to where our priorities lie and what goals we want to pursue" (Bal and Mastboom 2007). This implies that the critical STS notion of intervention is less appropriate for the study of practices where the 'core' of the issue is not clearly articulated (or where it is, and the role of the STS researcher would be to increase complexity) and where all actors are in some sense "working the peripheries of each other" (ibid.).

Another reason for these limitations of the critical notion of intervention may be the strong connection between critical STS and controversy studies. The work on studying controversies partly draws on the assumption that the study of Science and Technology is ideally located in controversial events for this is where the STS researcher gets insights into otherwise disclosed mechanisms. Following this assumption, a concept of intervention that strongly draws on the positions that may be taken within controversies could potentially be equally applicable to less controversial settings. If we however realize that controversies produce *crucially different networks* than those that would be encountered when issues and positions are more complex and multiple, (Bal 1998) this has more far-reaching consequences for a notion of intervention that heavily draws on controversial settings: the critical notion of intervention may then more often be problematic than apposite.

For these reasons, the notion of intervention that I will explore in this chapter, is on the one hand close to the third conceptualization proposed by Brian Martin, i.e. it is dealing with the interplay of developing an understanding of a field while at the same time trying to change it. On the other it proposes a different pathway for locating normativities, i.e., not situating them in social problems as defined outside of the particular practice under study, but rather within the practice the STS researcher tries to 'act with'. I hope to show that this approach to intervention, which I will refer to as 'situated intervention' is an equally strong reply to the critique of the normative deficit of STS, without reducing the space to explore and complexify multiple normativities.

With this theoretical aim in mind, I will now turn to the question *how* situated interventions may come about in practice by analyzing my involvements in the development of the hemophilia care center.

2.3 Reconfigured care, different patients, changed doctors; towards home-treatment of hemophilia

Hemophilia is a bleeding disorder, causing a patient to get bleeds either spontaneously or after intense activities. Bleeds occur due to a deficiency of coagulation factors in the blood, which are responsible for blood clotting. With the development of medication to substitute lacking coagulation factors, the duration of treating a bleed decreased from several days or weeks of hospitalization to injecting this medication with almost immediate results. This development cleared the way for one of the most remarkable events in the history of hemophilia treatment: the change from hospital treatment to home-treatment[53].

Whereas up until the early 1960's patients had to be treated in a hospital by having their joints immobilized and by receiving blood transfusions to allow a bleed to pass or, from 1966 onwards by receiving concentrated blood products such as cryo-precipitate[54], they can at present go through a training in which they are taught to self-diagnose bleeds and administer coagulation factor concentrates at home, either ad hoc or as prophylactic treatment[55]. Since virtually every severe patient undergoes this training, the vast majority of bleeds of hemophilia patients is no longer treated *in* but *under the supervision of* a hemophilia care center.

With the displacement of hemophilia treatment from the hospital to the home- (or work-, or holiday-, etc.) setting, medical professionals had to adjust to their new role of long-distance controllers of care. They witnessed the occurrence of a substantial discrepancy between the treatment they advised and the actual practice of patients treating themselves at home and started to see the issue of 'compliance' or 'adherence' of patients to treatment advices as a key problem of home-treatment[56].

I got involved in this issue when the care providers of a Dutch HCC approached the research group that I am part of[57]. These physicians were facing a major policy change that intended to restructure the organization of hemophilia care in the Netherlands and wanted to 'hire us in' (Downey and Lucena 1997) to assist them with the implementation of this policy change. The minister of health asked hemophilia doctors to indicate what was crucial for assuring the quality of treatment. Doctors proposed having a multidisciplinary care team, a guarantee of providing care 24 hours a day, regular consults with patients (once a year minimum) and a treatment plan for each patient indicating the preferred treatment for the specific, individual patient, per type of injury. The minister then set these requirements as a norm, presenting hemophilia doctors with quite an 'implementation problem' for this new policy (Borst-Eilers 1999). During one of the first meetings the physician who was our main contact in the project, told me that his foremost concern was the situation of home-treatment because, as he put it: "nobody actually knows what's going on there".

Care providers were still responsible for the treatment taking place in the home setting and expressed a serious concern for the risks that follow from under-treatment which include long-term joint damage and – potentially – the death of patients. With the

change to home-treatment, healthcare professionals had done their best to make the patients feel responsible for their own treatment, but in a psychological and legal sense, they still carried their responsibilities as deliverers of care. During a meeting a hematologist told me the tragic story of a patient who was recently brought into the hospital in a critical state. He had bumped his head into his garden house that morning getting on his bicycle when leaving for work. He went back inside to give himself only about a third of the amount of coagulation factor concentrates that was prescribed in his treatment plan for a head-bleed. At work, he became unwell, and by the time he was brought to the hospital, it was too late to save his life. This hematologist also used this example of a preventable and quite clumsy death, to show to his medical students that accidents *can* happen – with drastic consequences – and to stress the weighty task they will face in enhancing compliance. [58]

Besides the obvious problems of under-treatment, doctors and nurses similarly feared the risks of over-treatment since they were constantly maneuvering within a setting of scarcity of medication and funds[59]. The blood-derived medication is dependent on the availability of donor-blood, of which there is a general shortage[60]. Though since the introduction in 1993 of so-called 'copy-DNA' or recombinant coagulation factor concentrates potentially provides unlimited supply of safe medication, this promise has not been redeemed. Recombinant coagulation factor concentrates are not made from human blood, but through DNA manipulation of hamster cells. This reduces the risk for all kinds of infections and supply problems that are implied in using human products. Quite regularly however, pharmaceutical companies announce problems in the production process with the result that their products may be unavailable for several months. Though blood-derived medication with the same effect is generally available, it is risky to make patients switch between products. They may develop an inhibitor to all coagulation factors, which makes treatment largely ineffective, and for young patients who have only used recombinant medication, switching to blood-products means being exposed for the first time to all associated infection risks[61]. Therefore, doctors and nurses have to take strong action in case of a supply problem to at least distribute recombinant products to children and only change the medication of older patients (back) to blood-derived clotting factor.

But even if availability of products is *not* a problem, care providers (and patients!) are still sensitive to the financial aspects of treatment with extremely expensive medication. At various occasions in the project they (as well as patients) stressed the exuberant costs of treatment per patient, per year, being several tenths of thousands of euros. Both doctors and patients compared their treatment to "shooting up a Mercedes [Benz] a year". Though the issue of compliance and limiting over-consumption had been a matter of concern for quite some time, it had become more important as a result of the above mentioned substantial changes in the policy demands that were imposed on the HCC by the Ministry of Health.

2.4 Ways of dealing with non-compliance

Non-compliance has mainly been seen as a *problem per se* in literature on the treatment of chronic diseases. In *Tools of Care*, Dick Willems states that this has resulted in the situation in which: "compliance enhancement has become a basic principle of good medical practice" (Willems 1995, pg. 126). The prevalence of compliance enhancement initiatives, however, is hardly any guarantee for its success. As a recent review of randomized controlled trials (RCTs) of enhancement interventions shows, low adherence with prescribed treatments is seen as: "ubiquitous", and the authors conclude that: "the full benefits of medications cannot be realized at currently achievable levels of adherence; therefore, more studies of innovative approaches to assist patients to follow prescriptions for medications are needed" (McDonald, Garg et al. 2002, pg. 2868). It is rather ironic that this conclusion follows an extensive literature search that has shown that: "even the most effective interventions [to enhance compliance] had modest effects" (McDonald, Garg et al. 2002, pg. 2868). So even though striving for full compliance as an optimal state of treatment has proven extremely problematic[62], it can still be seen as the dominant assumption in medical literature on adherence, with more enhancement tools and maximum compliance as the undisputed goal. This assumption is key for the dominant repertoire on non-compliance that I would like to call the *repertoire of distrust*.

2.4.1 The repertoire of distrust

In compliance literature non-compliance is often analyzed in terms of the 'underlying cognitive mechanisms' causing the 'problem': "Patients *forget* their medication, they perhaps have an unspoken *resistance* against it and *think the disease is over* the moment they don't suffer from it any more"[63] (Willems 2001, pg. 64, italics in the original). In accordance with that, attempts to enhance compliance are often expressed in a terminology that produces an: "atmosphere of unmasking, of distrust and of authority" (Willems 1995, pg. 127). These cognitive explanations result in strategies of improvement of patients' knowledge of their disease, and of their attitude by providing better information on treatment. Information flyers are not the only resource of this repertoire. In the treatment of chronic diseases, treatments plans, medication journals, examinations, diplomas and the signing of contracts by patient and care provider are common interventions focused on improving patients' knowledge of their disease and overcoming cognitive hindrances to being fully compliant. An interesting feature of this repertoire is that it mainly focuses on what I would like to call '*treatment as planned*'; treatment as defined in treatment plans, at a considerable distance from the practices of care delivery. It is this distance in the repertoire of distrust that seems to produce *evidence based failures* for dealing with the issue of compliance. Being familiar with STS critiques of this repertoire of distrust, I took the low success-rates of these compliance enhancement initiatives as a starting point to reflect on the *causes* for this poor track record, for which I turned to on *home-treatment as embodied practice*.

2.4.2 Events in hemophilia home-treatment

In the project at the HCC, there was no need to introduce this empirical turn to practices of home-treatment like I introduce it here in this chapter: I was strongly encouraged by the healthcare professionals of the HCC to study patients at home. From their practical experience that patient and care provider annually negotiate a treatment plan that is sensible for both, while treatment practices deviate substantially[64] from this negotiated plan, they were highly interested to find out *what was happening* with treatment in the homes of patients. On top of that, in the case of hemophilia treatment healthcare professionals hold a somewhat unusual position. The chronic patients are very experienced in dealing with their disease while hemophilia doctors often change the scene: due to its low incidence, hemophilia treatment is concentrated in university medical centers but *scientifically* the development of treatment methods is rather unexciting. For doctors there is therefore not much to gain by specializing in hemophilia care. This leads to a fairly high turnover of care providers, and a more fixed and central position for patients[65]. As one patient described the position of one of the care providers in the HCC "This doctor has just recently joined us". In this setting, researching the practice of home-treatment was seen by healthcare professionals as a welcome experiment that could perhaps help them to alter this balance slightly. Interestingly, the empowerment of doctors is unlikely to be the aim of medical STS that is related to social movements and yet it seemed appropriate in the specificities of this care practice.

Following a route proposed by various STS authors (Akrich, Bessy et al. 1993; Thévenot 1993; Willems 2000), I decided to focus the analysis of present practices of home treatment on the ways in which humans and non-humans share the coordination work that is needed to bring about a particular practice of home-treatment. Further, I followed a call for symmetry in studying both events of non-compliance as well as compliance as phenomena needing further analysis (Willems 2001).

2.5 Situated (ir)rationalities

> P: If you want to get a piercing done, and you want it to work out all right, you will
> have to take a considerable boost of clotting factors. I think that's going too far;
> shooting up €500,-- just for a piercing[66].

An internist from the largest HCC in the Netherlands whom I encountered during the project was rather cynical about the competence of patients to treat themselves. He stated about home treatment that "patients are just doing whatever they like". This statement turned out to be quite wide off the mark when we started observing and interviewing patients at home. One of the first things that became apparent was that those who suffer from a chronic illness spend a relatively small period of time in their role as patient[67]. They have to combine a variety of 'worlds' in which they play various – not necessarily complementary – roles. It was quite obvious that the homes and settings of hemophilia patients are quite different from the previous locus of treatment: a university

hospital. This insight was of course nothing new, and care providers had realized this when home-treatment was instigated. It was therefore embedded in the above-mentioned training program, exam and signing of a contract by the patient. This served the aims of facilitating 'correct' treatment at home and ensuring a clear distribution of liability:

> P: Before I started home-treatment I got some kind of a training in injecting. They checked if I was doing everything in the correct way. It was mainly practical. When you're treating yourself at home, you shouldn't panic. The chance of reactions [to medication] was larger then, but I wasn't suffering too much from that. It was a risk that you took home, though. So you had to be sure you could deal with it. What I remember most were the practical things: whether you put the stuff down neatly and whether your fingers were clean. And of course it was also there to diminish the risk for the doctor as much as possible, because if things went wrong the doctor could point out: 'look, it's not our fault, because we have been telling this for a hundred times'.

Various interventions in the establishment of home-treatment have been mainly geared towards formally distributing legal responsibilities or towards informing and educating patients about their treatment. There is, however, a problem with the temporality and spatiality of these interventions: they are introduced at a particular moment and place while they should have their effect at a later stage in a radically different location. It is this time and space lag and the absence of (a connection to) the intervention in the actual event of treatment that often renders it useless. The absence of a socio-material connection between the actual events of treatment to these initiatives deprives them from their potential to coordinate the various roles hemophilia patients are playing.

Within the repertoire of distrust, the medically situated view on (ir)rationality, and its concurrent disciplining tendencies suppose unknowledgeable patients who are unable to be 'model patients' with full compliance – and who ignorantly harm themselves. We found that patients realize quite well that such 'models' exist but that their deviations from this are often far from arbitrary or resulting from incompetence or cognitive destructive tendencies:

> P: I run my own business, which means that my time is very valuable. And since my health is relatively good, I don't like unnecessary investigations. I want to have a few purposeful things investigated, but not for the sake of research. I've made good agreements with doctor Johnson about that. So, as far as that goes, I might not be their model patient. I'm calm, so in that sense maybe I am, but what they like most is to see everybody every half-year to do all kinds of nice investigations. I've reduced that to once a year. And that's good enough for me, because I told

them I would always come by if something was wrong. Every year I hear the same thing during check-up. I need them for the stuff, and as back up in case something goes wrong.

The 'model' that patients should adhere to, meets strong competition from other worlds in which the patient plays a part and that enact different expectations of patients[68]. These other roles may seriously put the 'alliance' between HCC and patient – that is needed to live the role of hemophiliac – to the test. During the interviews several patients mentioned situations in which the demands of others were perceived to be opposite to the demands of treatment, for example when taking part in their gym class at school, or when a patient felt he should participate in a decathlon that was organized by his neighbors. However, the alliance also, at times, received unexpected support where it could have been fractured:

> P: A few weeks ago, at school, we had to lug a bunch of tables from the first floor downstairs for an exam, and then I will carry them as well. That shouldn't be too much of a problem, but there were a few colleagues who said 'why don't you do the corridor, then we'll do the stairs'. Then I think, yes, they've got a point there.

In this case the role of being a comradely school teacher is about to be in conflict with that of being a hemophiliac, and the school setting together with the obvious urgency of getting things ready for an exam, challenges the durability of the alliance between this patient and the HCC. It has been noted that: "improving the success of a treatment programme not only demands strengthening the alliance between patient and programme, but also between the programme and the patient's relatives and other significant persons" (Willems 1995, pg. 135). This means that persons, in this case colleagues, can help to coordinate the roles and worlds that need to be brought together.

Delegating the construction of alliances to humans may be a fruitful approach in some respects, but solely including humans may also limit their durability. Similarly, defining non-adherence as a 'cognitive problem' ignores the way coordination can be obstructed by socio-*materilites*.

> P: I was still working in an office then. I would take factor VIII that was being kept in the fridge there, with my name on the bottle. When I would get a bleed, I would stay inside the building. They reserved a separate room for me for this purpose. This saved time.

In order for treatment to be carried out in a safe way, it is important that a second person is present to intervene in case of an allergic reaction to medication. This need discords

with the specificities of the workplace: the desire for privacy and the corporate ideal of productivity of labor are afforded at the expense of the safety of hemophilia care.

Symmetrically studying both the mysteries of non-compliance *and* of compliance proved highly fruitful for gaining understanding for the complexity of worlds patients have to coordinate in the practice of hemophilia home treatment. These insights were valuable when experimenting with interventions to change these practices. These experimental interventions could hereby not aim at an uncritical and unspecified enhancement of adherence, but contribute *to targeted forms of coordinating the various worlds patients inhabit in those instances where it seemed to matter most*. These experiments consisted of a range of developments, including the design of a digital version of the log book with data on medication that was administered at home and of a web portal for communication between patients and HCCs. However here I will focus on two rather modest yet effective interventions; the introduction of a small but powerful technological device: a temperature logger and the development of a multi-disciplinary hemophilia consulting hour.

2.6 Experiments in the practice of hemophilia care

As we observed during the study of home treatment, by far the most problematic coordination of the various worlds patients inhabit occurs during holidays. With the introduction and development of coagulation factor concentrates, it has become possible for patients to bring along medication to their holiday destination and carry on their treatment in a place that is even more remote from the hospital than the usual home-treatment setting. Despite this substantial relocation of care, patients are expected to treat themselves on their holiday site as they would do at home or rather, as they would do in the hospital. On top of that they should provide suitable conditions under which medication is stored during transport and stay. And these conditions are quite demanding: in order not to loose its efficacy, coagulation factor concentrates should be kept in a cool place, preferably a vibration-free industrial refrigerator. With the displacement of care to the holiday setting, the norms of professional cooling equipment, the careful chain of transport before the medication arrives in the center[69], and all the safety regulations that a hospital pharmacy has to adhere to are substituted by a portable cool box or a small daypack that is equipped with a cooling compartment and removable cooling elements. This delegation hardly coordinates the worlds of the hemophiliac and the holiday maker, which sometimes leads to serious treatment problems.

> P: I had an ankle bleed over there that lasted almost for a week. In that week I took a lot of medication. Out of four weeks I've been sitting on four different campsites in the same chair all the time. I've shot up 2000 units every day, but it wouldn't pass. We've been looking for a treatment center in the area after a day or three, but it started to improve slowly. Probably the medication didn't work. Possibly they were kept in a warm place. We kept the medication in a separate bag with

cooling elements, but it was over 30º Celsius outside. I think that we should have exchanged them every day, and I must have forgotten. I've been sloppy with that.

I: Could you check afterwards if the temperature had actually been the problem?

P: No, I haven't checked.

The socio-materiality of beaches, campsites, high temperatures, cooling elements and laidback holidaymakers provide strong challenges to the effectiveness of this event of hemophilia care.

In the analysis of practices of hemophilia home-treatment, these tricky treatment events during holidays were further analyzed by first specifying to whom the 'problems' were actually 'problematic'. Of course it could be argued that this state of affairs is only problematic from the position of the hemophilia doctors, while it looks celestial for those propagating the 'autonomy' of patients. Within this repertoire any intervention would be an illegitimate and unfair way of disciplining patients[70]. But even when taking the extreme position that patients should have the 'freedom to die' – which would be the ultimate risk of treatment with ineffective medication – this freedom may have implications for the risk other patients face during treatment. In the case discussed in the quote the patient did not merely use large amounts of factor VIII; the medication was also exposed to high temperatures while the patient did not check if the medication actually lost its efficacy. Since clotting factors that are not used on holidays are returned to the HCC and administered to other patients[71], this means that his 'freedom' actually jeopardized the effectiveness of the treatment of other patients. On these grounds, this seemed a situation in which it would be worth experimenting with an intervention that would enact the world and responsibilities of the hemophiliac in a stronger way, thereby enhancing compliance to the way medication is supposed to be handled.

It was the hematologist who was involved in the project who pointed my attention to a device that might play an important coordinating role here: a TechTemp™ temperature logger that registers temperatures at regular intervals. We started an experiment to see how these loggers could enhance the proper handling of medication. For this they were included in the package that contained the medication, and this package was sealed in a plastic bag. Patients were notified that a temperature logger was included in their holiday pack, and that upon returning unused medication, the temperature to which the products had been exposed would be checked. I wrote a small research protocol for the pilot that included the rule that every time one of the two loggers was available it would be given to the first patient coming for a holiday pack. This experiment had two interesting results. First, several times the medication that was returned had been exposed to temperatures that were unacceptable according to the instructions for use. This came as a surprise to the nurse, since she had actually been unhappy about the fact that every time she had to hand out a logger, this was to a pa-

Datalogger HOTDOG DT1

_ Working range: -40°C...+65°C, waterproof (measuring), 0°C...+50°C (evaluation)

Memory capacity: 16,000 measured values

Time ranges: 2.2/4.4 hours to 500 days

Measurement interval: 2 seconds to 2 hours

tient who she perceived to be very reliable. Her expectations concerning reliability were influenced by both ethnicity and holiday destination: a middle aged native Dutch man, going on a short holiday to France was expected to face a smaller risk than a Moroccan man driving to Morocco for a six week holiday during summer. She now feared that the experiment would fail since nothing would go wrong and no interesting data would be produced. Though we could never assess the appropriateness of her expectation, it was interesting to see that reliable patients were exposing their medication to high temperatures.

Second, the logger, though actually only registering temperature, proved also to be quite an intervention, changing the way patients were handling medication. A particularly 'reliable' patient, who surprised both the nurse and himself by having exposed the medication to excessively high temperatures during his first journey, received the logger some months later when coming for another holiday pack. Upon returning from this second trip, he was quite sure that this time nothing had gone wrong with the medication but actually this second pack had to be thrown out as well. This time it turned out that the medication had been exposed to temperatures that were *too low* – it had been frozen. He placed the medication in his ski box on top of his car on his skiing holiday, also when traveling, and during the night, to ensure a cool environment. Though the result for the medication was the same, in the sense that it had gone to waste, this event indicates that the logger can be a powerful actor. Including it is consequential in the remote landscape of a holiday setting. It proved able to facilitate the coordination of the worlds of strict safety regulations and of the relaxation on holiday through its temperature measurements. Even when medication was exposed to temperatures that had been either too low or too high, this no longer jeopardized the effective treatment for

other patients, thereby confining the risks of inappropriate handling of medication to the individual patient.

Though adding the logger to the holiday event influenced the actions of this patient to a certain extent, it did not prevent the medication from getting disposed. A discussion that now becomes pertinent, is whether the world of the hemophilia patient may be performed in an even stronger way by developing a logger that does not merely register temperatures but that also acts – for example by beeping – on behalf of the HCC when the medication is about to be exposed to a temperature that is either excessively high or low. This could prevent the wasting scarce medication. Whether such an extended coordination mechanism would be too much of a disciplining intervention in the holiday of patients, or can be justified by the risk of treatment with ineffective medication of future patients, is at present unresolved. The argument of scarcity is valid here as well, and it seems that in this particular setting, this stronger intervention would be warranted.

Some tensions that may emerge from this experimental intervention are that in order to actually provide functionalities like alerts we would either have to look for other loggers that are able to do this, or get involved with a redesign of the loggers, which would provide all kinds of other constraints of intervention and design. Also, though the logger may at times be a lifesaver, it may also lead to shifting both responsibility and cost completely to hemophilia patients[72]. When the costs of medication that has gone to waste would be claimed with patients, this could on the one hand be seen as a strong incentive for enhancing compliance, but it would need to be analyzed in the light of strong enactments of self-reliance for hemophilia patients. Patients are for example taught to be self-reliant in survival camps. When discussing this rather counterintuitive practice of doing hazardous activities like *abseilen* with young people with a bleeding disorder, the pediatrician from the HCC did not see any conflict. Rather, she stated, this was an important moment for these young individuals to break out of the overprotective atmosphere that their parents often created for them. I was clearly unable to 'intervene' here since I was unable to articulate the camps as at least partly problematic – even though the camps are sponsored by pharmaceutical companies, who are of course not disinterested in enacting patients as 'self-reliant' and 'certain', especially when these 'selves' are enacted by the practice of prophylactic home-treatment. Similar shifts in responsibility and discipline, combined with availability of products that was previously unthinkable has elsewhere been analyzed in relation to the 'epidemic' of obesity in the US. It has been noted that:

> "[T]he neoliberal shift in personhood from citizen to consumer encourages (over)eating at the same time that neoliberal notions of discipline vilify it. Those who can achieve thinness amidst this plenty are imbued with the rationality and self-discipline of perfect subjects, who in some

sense contribute to the more generalized sense of deservingness that characterizes US culture today" (Guthman and DuPuis 2006, pg 427).

Though such ironic interplays of performing self-reliance at a rather high cost (possibly even financially) are worth further investigating, for now this experiment has proven fruitful in raising questions about which forms of autonomy can be enacted in the case of hemophilia treatment. It also points out which further experiments could be carried out.

The example of the temperature loggers shows that interventions in the coordination of care can fruitfully be combined with the normative sensitivity that is engendered by STS work on compliance and the possible role of small technologies in coordinating complexity in home-treatment practice. But the experiments were not limited to small technological devices. The role of the hemophilia nurse had seemed of exceptional importance during the analysis and therefore seemed to warrant further articulation. Continuous mild interferences in treatment had come to the fore when observing the interactions between hemophilia nurses and patients who came to collect their medication. Though handing out medication could be seen as a routine task that could be carried out by any qualified pharmacy employee the nurses insisted on doing this 'unfitting' work themselves - to the great dissatisfaction of nursing management and other nurses at the ward, who qualified these conversations as "chatting with patients". During the casual exchanges with patients, hemophilia nurses often found out clinically relevant information concerning their situation – such as stress for an exam – and could give treatment advice accordingly. Being sensitized through the publications of various STS scholars (Star and Strauss 1999; Suchman 1995; 2000) to the importance of articulating and accommodating 'invisible work', I realized that this work could be legitimated by providing a formal space for such encounters.

This contributed to installing a multi-disciplinary hemophilia clinic, which included a nurse-led clinic and a clinic for the physiotherapist. This clinic is an example of an intervention that seemed of substantial importance for coordinating and negotiating the worlds of hemophilia patients and other roles. The aim of the consulting hour was not merely to inform or 'educate' patients further, but to formalize the role of the hemophilia nurse in communicating with patients to spot emerging difficulties. Furthermore, by scheduling this clinic parallel to the surgery hours of the hematologist, both cooperation between patients and the hemophilia nurse and between nurse and hematologist were intensified. Here, the threat to the legitimacy of nurses taking rather substantial and non-standardized action in guiding patients did not come from clinicians who were defending their professional autonomy. Doctors, especially those in training, where quite used to the situation where a hemophilia nurse would correct their prescribed treatment since she simply had much more expertise on these matters. Rather, the threat came, perhaps unexpectedly, from colleagues who saw the hemophilia nurses as excessively self-dependent and insufficiently integrated in the totality of the ward, as described in chapter

1. Though the installation of the hemophilia clinic may seem a rather minimal intervention, it was quite consequential for the situated normativity of legitimized nursing work on the ward.

A final advantage of installing this hemophilia surgery hour was that hemophilia patients who used to be seen by various doctors in different surgery hours that were distributed over the week would meet again at least while waiting for the consult with the hematologist, or hemophilia nurse. In the days of hospital treatment, patients also brought issues to the hospital that were relevant for the way they were living their disease. This not only hospitalized the patients but also socialized the hospital, a similar situation has been described as: "'smuggling' patient perspectives and competences into the daily work of the physician" (Willems 2000, pg. 29). Bringing patients and healthcare professionals back in a more structured contact might help to bridge the increase in distance[73] that has arisen between HCC and patients as a result of the development of home-treatment. Bridging this distance may facilitate the shift from mere compliance enhancement to finding ways to coordinate the complex worlds that might collide in treatment practice.

I have tried to further explicate the aims of the clinic as a place to discuss the complexities of coordinating different roles, rather than to merely discuss 'patient issues' to both patients and healthcare professionals by addressing this issue in a talk I gave at the official opening of the HCC. By quoting their statements from the interviews and affirming that it simply cannot be expected that they are 'model patients', I presented the consultancy hour as an opportunity to discuss the complexity they face during home-treatment. This pointed out that conceptualizing 'hiring in' as the "willingness on the part of social researchers to allow their work to be assessed and evaluated in the theoretical terms current in the field" (Downey and Lucena 1997, pg 119) seems to imply a unidirectional consequence for STS researchers. Rather, I would claim that for interventionist research to be different from consultancy there should be a *mutual willingness* and interest of various parties to be inspired and 'contaminated' by each other's practices. On this note I return to the consequences of these events for conceptualizing intervention and normativity in STS research.

2.7 Useful risks of artful contamination

I hope to have show that the experimental interventions in the practice of hemophilia care were strongly related to STS research on compliance and medical practices, to the coordination of worlds patients have to live in and to studies of making work visible. The conceptual and practical critiques on interventions aiming at mere compliance *enhancement* have been an inspiration to experimentally intervene in the *kinds* of compliance that can be enacted in particular treatment events, such as compliance to medication handling in a holiday setting. Considering the complexity people face in combining their 'being patient' with the other roles they play makes full compliance equally unattainable as well as undesirable. This made the experiments that dealt with a par-

ticular (and particularly problematic) issue in hemophilia home-treatment of interest to me as well as to the healthcare professionals of the HCC. By rejecting the notion that compliance is something medical practices should have 'more' or 'less' of, interventions can be assessed on the basis of their contribution to the coordination of the worlds patients inhabit and indicate in which instances stronger compliance enhancement may be worth pursuing. Furthermore, studying the invisible work hemophilia nurses were doing allowed me to articulate this work in the more legitimized setting of a nurse-led clinic.

To this extent, I hope to have shown the interventions to be connected to STS research. This does not mean that any skillful sociologist, engineer or healthcare consultant could not have come up with the same interventions; they may be similarly sensitized to emerging normativities and opportunities for situated compliance enhancement[74]. STS has not delineated unique forms of expertise based on which an intervention can be claimed to be an 'STS™ intervention'. Yet, the interventions in this case were certainly shaped by a figuration of compliance that is crucially different from that within the repertoire of distrust. This shows that STS researchers may not have unique forms of expertise, but certainly have a rather well developed sense for the inter-play of socio-materialities and situated normativities (Law 2004b).

At the outset of this chapter, I proposed to explore a situated normative approach that would be an apt reply to the critique of constructivism being 'normatively deficient' without relocating the normativity of STS in agenda's of social problems, activist move-ments and the democratization of technology. I also proposed that the approach of situated interventions that focuses on complex and emerging normativities would possi-bly be more fruitful for studying practices that would not easily be typified as 'controver-sial'.

In the light of critiques that STS has difficulties to overcome its 'normative deficit' (Keulartz, Schermer et al. 2004) it is rather interesting to observe that the situated interventionist experiments described here seem to make normativity fairly 'easy'. This does not mean interventions are in any way predictable and certain; as Donna Haraway keeps reminding us "[t]here are always more things going on than you thought" (Haraway 2004, pg 332) which makes the nature of any intervention extremely tricky (Haraway 1991a) but an ethnographically inspired analysis of these practices of hemo-philia treatment exactly seemed to facilitate what Hess promotes: it allows one to "'inter-rogate or complexify the taken-for-granted, such as commonsense categories employed by social scientists, policy-makers, activists and scientists" (Hess 2001, pg 239). In this analysis, doctors turn out to be marginalized, nurses not suppressed by clinicians striving for autonomy but by their colleagues and patients self-reliant to such extents that this produces unwarranted risks for patient safety: not quite the usual normative suspects but a set of normativities that clearly facilitates experimental interventions as analyzed above. Normativity was neither found by assessing the democratic involvement

of patients in shaping the care practices, nor in critically assessing the roles of care professionals who were disciplining patients through intrusive devices such as log books. Rather, 'acting with' patients, campsites, doctors, loggers, nurses and hospital clinics the practice of hemophilia home-treatment turned out to be loaded with unexpected normativities to 'act with' as well. The experiments therefore show an interesting way out of the normative deadlock of STS, not by introducing external normativities, but by *relocating normativity in the events of treatment itself*. Intervening in these events thereby becomes a way of *doing normativity*.

Based on the normative complexity encountered and enacted in the case of the HCC I propose a study of intervention and STS that is broader than the focus on activism and democratization. The activist approach has proven fruitful for more controversial cases. It however also runs the risk of *producing* some of the tensions that are encountered in the study of intervention. The "tension between the tendency to immerse oneself in the complexities of ethnographic detail and the tendency to produce an explicit contribution to a research tradition of theoretical models and empirical findings" (Hess 2001, pg 239) is not as vividly encountered in the study of situated interventions; here the only way to come to such explicit contributions is *through* immersing oneself in the normative complexity of practices. Rather than claiming that "[o]ne can maintain a high standard of descriptive analysis while at the same time providing grounds for making prescriptive recommendations" (Hess 2001, pg 240) this approach proposes that it is *only through* high standard analysis that one can find situated grounds for experimental interventions.

Rather than drawing upon rather crystallized normativities of social movements, the approach of situated intervention allows for a position in which normativities of STS researchers are contaminated. Drawing upon Chantal Mouffe's conceptualization of this term, a relation of contamination means that both STS insights and (healthcare) practices under study are entangled and that changes in the domain and normativity of practice changes the identity and normativity of the domain of STS and vice versa (Mouffe 2000, pg. 10). Though exploring such contaminating experiments may prove fruitful for situating interventions, there is always the risk that STS insights get subsumed and any form of the critical edge is lost or that all sensitivity for the complexity of practices is exchanged for "[h]eroic images of scholars as activists without double-bind [which] madden as much as they lure" (Fortun 2001, postscript: 2)[75] – what Downey and Lucena call the "complementary risks of cooptation and social engineering" (Downey and Lucena 1997, pg 120). In this case 'normativity made easy' would certainly overshoot the mark since it would be simply an a-critical stance. Paraphrasing Lucy Suchmans' concept of 'artful integration' (Suchman and Trigg 1992), interventions in the practice of healthcare can be carried out with the aim of coming to *artful contamination*: the way STS scholars are influenced by the practices they act with, without loosing the 'anti-bodies' they keep building up by being part of other practices, be they offices of

hemophilia nurses or meetings of research groups, homes of patients or STS conferences, festive openings of hemophilia care centers or debate with a patient association. Besides drawing upon a repertoire of reading and practicing what David Hess called 'good ethnography', artful contamination is to be developed by moving around. Preventing that the activities of interventionist STS research become sedentary is crucial to minimize the risks of cooptation and social engineering. Maintaining many 'partial connections' (Strathern 1991) to practices of care and practices of (critical) STS prevented in the case of the HCC that I either a-critically adopted the discourse of distrust in relation to compliance or that I saw every compliance enhancement initiative as an unjust intervention in the complex lives of autonomous hemophilia patients. Moving around in care and STS opens up the complexity of both, reclaims normativity from the critics and the ethicists, and allows STS researchers to do normativity as a fruitfully risky business.

Chapter Three

Preventing Implementation

Exploring interventions with standardization in healthcare

3.1 Guidelines, normativities and minding their 'gaps'

Research on standardization of care and clinical guidelines has found itself struggling with ways of bridging what is often referred to as 'the gap' between medical quality as defined in clinical guidelines and the practices of care delivery. Treatment methods and procedures, which have been identified as medically supreme in Randomized Controlled Trials (RCT's) and translated to clinical guidelines, are often not encountered when observing health care work in action. The adherence rate of healthcare professionals to clinical guidelines of approximately 50% (Burstin 1999; Grilli and Lomas 1994)[76] are frequently seen as problematic by health scientists and policy makers alike. Folders with clinical guidelines are often ironically referred to as 'paper tigers': despite their clinical potency, they hardly threaten existing practices of healthcare work.

Such observations about low adherence rates are often coupled to a sense of bewilderment about variability and to pleas for exploring better strategies for implementing aggregated clinical evidence into the messiness of medical practice (e.g. (Cabana, Rand et al. 1999; Freeman and Sweeney 2001). In these quests, integrated care pathways[77] (ICP's) are often presented as potentially fruitful tools for such implementation (Campbell, Hotchkiss et al. 1998). As I will explore in this chapter, this reading of the role of ICP's is an unfortunate one. Whereas pathways originated from the wish to make clinical evidence locally relevant in more dynamic ways, critically scrutinizing *both* the clinical evidence *and* the practices of care delivery, the role pathways are nowadays often ascribed fails to recognize the problematic privileging of aggregated medical knowledge over organizational complexity. Ironically, where ICP's were developed to address the 'implementation problems' that are produced by an epistemic hierarchy of clinical evidence to which practice is to 'adhere', its present conceptualization merely reproduces these problems. The discussion on pathways thereby threatens to shift from one about the critical analysis of care practice and evidence, to one on the problems with 'implementing' ICP's.

Over the last decade, researchers from the field of Science and Technology Studies (STS) displayed an increasing interest in the dynamics of standardization in healthcare and in the issues that emerge when aggregated clinical evidence is being privileged in guideline development and use (Berg 1997; Epstein 1996; Epstein 2003; Lennarson Greer 2002; Timmermans and Berg 2003; Timmermans and Mauck 2005). More recently, such studies have also included the analysis of ICP's which has resulted in pleas for a 'processual understanding' of pathwaying (Pinder, Petchey et al. 2005) rather than one of 'implementing evidence'. In this chapter I will explore the role of studies and research practices by STS scholars for strengthening the processual approach to pathwaying. I will do so by drawing upon research that is on the one hand reflexive about the unintended ways in which STS research is 'interventionist', but that on the other explicitly aims at intervening (cf. Wouters and Beaulieu 2007) in (healthcare) practices due to its framing as contract research. I will therefore explore the

capacities of interventionist STS research to do, what Stefan Timmermans and Marc Berg have called, "politics through standardization" (Timmermans and Berg 2003, pg 216).

Furthermore, I will claim that such studies can function as a empirical test bed for STS research practices that aim at 'unpacking' the notion of 'intervention', in order to explore different ways to engage with an area of research, a theme that I will explore in this chapter and to which I will return in the conclusions of this thesis. Though the topic of 'intervention' is hardly new to the field of STS, where the notion that every research is inherently and inevitably always a form of intervention has been explored since the late 1980's (Ashmore 1989a; 1989b; Ashmore, Mulkay et al. 1989; Collins 1990; Martin, Richards et al. 1991; Scott, Richards et al. 1990; Woolgar 1988; Woolgar and Ashmore 1988) STS experiments explicitly aiming at intervening in (healthcare) practices may provide useful reformulations of the topic and the issues of the normativity of STS research. I will claim that there are striking similarities about the need to stress a processual understanding of pathwaying and developing a situated understanding of the normativity of STS. Both these issues deal with attempts to preempt the privileging of aggregated knowledge – whether normative or clinical – over the complexities of practices. Both try to facilitate a more dynamic interaction between various knowledge practices with different levels of aggregation and detail. And both aim at avoiding the situation in which 'the goods' have been defined outside of the practices to which they are to relate and need to be 'implemented'. Both draw upon a strategy that I call 'preventing implementation'.

In order to explore these issues, I will first analyze how the guideline movement has been actively involved in the creation of 'implementation problems', how care pathways have emerged in relation to this development and how these very pathways are at present involved in the re-creation of the very concerns they were supposed to address.

Second, I will briefly consider some of the critiques that are regularly voiced about the way STS research is said to be normatively deficient. I will question these critiques and point out the way the proposed solutions of 'making choices about normative perspectives' may lead into further problems of implementing those perspectives into practices. I will propose an alternative way of dealing with normativities in STS research.

Third, I will explore the value of experimental social science research practices for the strategy of 'preventing implementation' by analyzing some events in an interventionist research project I was involved in that had the aim of developing standardized care trajectories for a hematology / oncology ward. I will claim that such studies may be of interest for developing standardized care pathways in situated ways, that is, in ways that are strongly related to the interplay of problems patients and care professionals encounter in everyday care practices.

Finally, I will return to the question of what such research practices have to offer for preventing the implementation of normativity in STS research by arguing that what

such studies have to deal with is not their presumed normative deficiency, but their normative surfeit.

3.2 Guidelines, pathways and the re-creation of 'implementation problems'

In 1981 the American College of Cardiology (ACC) (…) began developing clinical practice guidelines to assist in the diagnosis and management of patients with various cardiovascular diseases. (…) Although a number of reports have found that implementing practice guidelines leads to improvements in the quality of care delivered, others have found a discouraging lack of guideline implementation and/or impact. Despite the considerable investment in the development and dissemination of guidelines, many studies suggest that a large proportion of eligible patients do not receive the cardiovascular care recommended in guidelines. There continue to be gaps between ideal goals of evidence-based therapy and practice in treatment in several cardiovascular disease states.

The ACC launched the Guidelines Applied in Practice (GAP) Program (…) Key features include building partnerships, flexibility to allow local adaptation, tools derived directly from the guideline, involvement of caregivers across the continuum of care (i.e., not just cardiologists), involvement of patients, use of champions/opinion leaders, and use of data to change behavior and measure effectiveness of the approach.

http://www.acc.org/qualityandscience/gap/gap_program.htm
(accessed: January 18th, 2007)

The GAP program of the ACC presented above, 'making available' guidelines via ICT systems, developing evidence-based support systems for practices of medical decision-making are but some of the initiatives popping up throughout Western medicine with the aim to improve the 'implementation' and 'dissemination' of guidelines into practice. The Cochrane Collaboration and other databases are set up with the aim of 'opening up' and 'making available' evidence and guidelines to doctors in their various workplaces. ICT that draws upon these guidelines is often attributed the power to "address the quality gap in health care by providing automated decision support to clinicians that integrates guideline knowledge with electronic patient data to present real-time, patient-specific recommendations" (Goldstein, Coleman et al. 2004, pg 368). Yet it is increasingly acknowledged – with a perhaps unintended but rather ironic sense of understatement – that: "technical success in implementing decision support systems *may not translate directly* into system use by clinicians" (ibid., emphasis added).

If the lack of adherence to guidelines by clinicians would be due to inaccessibility of guidelines or a shortage of prompts that aid clinical decision-making, these initiatives might be fruitful. However, the 'solution' of creating guideline databases hardly

addresses the issue of non-use despite availability. Similarly focusing on the strength of ICT-based decision support systems to 'direct' medical work insufficiently addresses the fact that such decision aids are overridden in 49% to 96% of all cases since alerting systems "contain error-producing conditions like low specificity, low sensitivity, unclear information content, unnecessary workflow disruptions, and unsafe and inefficient handling" (Sijs, Aarts et al. 2006, pg 138). Therefore such approaches can be seen as attempts to merely digitize a conceptually problematic solution.

Besides a focus on ICT-driven solutions, the discovery of the 'implementation problem' of clinical guidelines by the healthcare improvement movement has resulted in a strong interest in studying 'factors' that hamper or facilitate their dissemination into medical practice (Grol 2000; Grol and Wensing 2004; Grol, Zwaard et al. 1998; Taylor and Taylor 2004) and to develop rigorously controlled studies to distill these factors – of course preferably by means of the methodological gold standard of the RCT[78]. This line of research seems problematic on two terms: first, many years of implementation research hardly show any changes in the way in which guidelines are integrated with medical practice and second, the lists of factors for success and failure, which are constructed through such studies are becoming ever longer[79], thereby hardly providing any guidance for those actively involved in strengthening the relations between medical practices and medical evidence.

One of the problems with the development of guideline-supporting ICT and with the study of factors that aid implementation, is that they both provide 'solutions' that leave the privileged epistemological status of aggregated medical knowledge untouched; they merely focus on *how* practices of healthcare delivery can be made to 'adhere' with the 'forefront of medical knowledge' and how 'interventions' can be 'implemented' in patient care (Wensing, Wollersheim et al. 2006). However, as Sandra Tanenbaum has pointed out, succinctly summarizing a series of vigorous controversies around standardization of healthcare practices, the agenda of creating Evidence-Based Practice (EBP) is a form of epistemological politics, defining which knowledge and which knowers are to be privileged in both policy arenas and consulting rooms (Tanenbaum 2005, pg 163). 'Solutions' that fail to deal with these tensions of EBP in a creative way and that merely stick to the rhetoric of implementation have therefore proven practically ineffective, politically desensitized and conceptually problematic. On all these grounds, it therefore seems important to search for practices that conceptualize the problems of standardization and various modes of knowledge production in healthcare differently.

One interesting practice in which healthcare improvement practitioners try to entangle and translate both the practices of care delivery *and* clinical evidence is the original approach to the development of integrated care pathways. Though at first developed in the 1980's with the main purpose of allowing hospitals to meet the length of stay parameters imposed by third-party payers in the managed care setting of the USA (Pinder, Petchey et al. 2005, pg 761), pathways have since the middle of the 1990's

gained importance as ways to not merely implement clinical evidence, but to review it in the light of an (equally critical) evaluation of the practice of care delivery for which it is to be made relevant. As Denise Kitchiner, chair of the British National Pathway Association states, such a critical review of both clinical practice and medical evidence:

> allows the development of locally agreed guidelines, which are incorporated into the pathway and provide the standard for future routine patient care. Guidelines are more likely to succeed if they are developed by those who will be using them. (…) Analysis of the causes of variation [which, so the proponents claim, becomes possible and more feasible through locally agreed upon pathways] provides valuable information which can be used to improve clinical practice. It also allows clinicians to evaluate the effectiveness of national guidelines at a local level and to collect observational evidence when randomised trials are impractical or unjustified. (Kitchiner and Bundred 1998, pg 147)

The development of pathways can thus be understood as first, translating practices of healthcare delivery, second, as situating clinical evidence in the specificities of care practices and third as articulating other forms of clinically relevant knowledge than the outcomes of RCT's. This makes their development an interesting site for doing epistemological politics.

Admittedly, such a reading of what Ruth Pinder et al. call "the pathway movement" (Pinder, Petchey et al. 2005, pg 763) is a generous one. It is equally possible to analyze pathway development as simply aiming at "facilitating the introduction into clinical practice of clinical guidelines and systematic, continuing audit" (Campbell, Hotchkiss et al. 1998, pg 133). With its drive of reducing practice variation amongst healthcare practitioners it becomes just another attempt to 'implement' aggregated medical knowledge into the messiness of clinical practice. Pathways and their development have often been: "treated uncritically as helpful (and technically neutral) tools rather than embodied practices for routing patients through the system" (Pinder, Petchey et al. 2005, pg 762-3) thereby exchanging their epistemologically political sensitivity for an "over-rationalist and sometimes evangelical" (ibid. 763) mode of 'modernizing' medical work. This tendency is most obvious in attempts at the beginning of this century to standardize the very practices of developing integrated care pathways. Rather than adopting "a critical and processual understanding of pathways" (ibid.) and their development, the pathway movement has made strong efforts to neutralize the development of care paths, which has resulted in highly detailed manuals that lay out a 32-step methodology for designing and implementing a pathway (Vanhaecht and Sermeus 2002). The ironic consequence of this is that the success of rigidly developed integrated care pathways has become dependent on their 'implementation'. Thereby the history of epistemological

politics that the pathway movement once aimed at refiguring seems to be repeating itself.

It would be an overtly pessimistic and linear reading of the history of pathway development to claim that the processual understanding of pathwaying has been overtaken by the implementation approach. Also at present there are initiatives where pathways are being developed in ways that try to make them an *outcome* of a dynamic process of standardization, rather than a *starting point* that medical practice has to adhere to. But before turning to the analysis of a project that tried to deal with pathways in this manner, let me turn to the potential relevance the discussion on guidelines, pathways and implementation problems may have for issues on the normativity of STS research.

3.3 STS research and overflowing normativities

It may seem somewhat evident that critiques on epistemologically privileging aggregated medical knowledge over local complexities would be consequential for the spatialities where STS researchers situate their own normative claims. One could expect the practices studied to be no less than crucial sites for situating the normativity of STS research. Yet, the stance of many researchers to refuse to "determine what the specific context looks like apart from the interpretation of relevant actors or 'actants'" leads to continuous critiques on what has been termed "the normative deficit of the constructivist approaches to science and technology" (Keulartz, Schermer et al. 2004, pg 12). At regular intervals scholars claim that adding an explicit normative positioning in the "larger issues" provides opportunities "to bridge the apparent gap between the [constructivist] program's descriptive richness and its normative irrelevance" (Hamlett 2003, pg 134). A usual suspect: the gap. But sensitized by the history of guideline development we also may have a feeling for *what is producing* this gap. And indeed, this statement is followed by a claim that STS should "help change the direction of [technological] change into channels more compatible with *normative standards*" (ibid., italics added).

Such critique constructs what I would like to call a 'deficit model of normativity', and draws on the odd assumption that 'real' normativity does not reside in practice and must therefore be created and introduced – perhaps implemented – into practice by (STS) scholars. Practices are seen as facing a deficit of normativity and (STS) researchers may play a role in filling this void.

Michael Lynch has analyzed a similar line of reasoning in relation to work on the public understanding of social science (PUSS) as the 'PUSS deficit model', which he contrasts with what he poses as the 'PUSS surfeit model'. This latter model conceptualizes the role of STS researchers as one of dealing with the widespread distribution and translation of social science knowledge (Lynch 2004) rather than one of bringing 'scientific knowledge' to the public. Lynch further states that attempts to create some epistemic authority for STS researchers at times takes the form of throwing off "'relativism' or

'symmetry' in order to provide some leverage for normative judgments. Sometimes, such proposals are presented as the next 'wave', or a step 'forward', but more often than not they take one step forward and two steps back" (ibid., pg. 9).

Drawing upon the analysis of the implementation problems of guidelines and pathways, it becomes clear that the claims that STS scholars can become authorities on normative standards is more than likely to be just another claim to go 'beyond' while being a step back in disguise. Paraphrasing Lynch, I therefore pose that interventionist STS experiments may be fruitful for proposing the *normative surfeit* model for STS, thereby refiguring the role of the STS researcher as one of dealing with the overflowing normativities encountered in a setting one is engaging with. A model in which the ethics of the STS researcher is situated in the specificities rather than in a form of normativity that is situated outside of the practice one is entangled in. This is of course not an attempt to enact STS researchers as exempt from normative attachments and as merely loyal to local specificity. It is a re-figuration of STS research practices as critically analyzing the normative surfeit encountered rather than transforming their fidelities and attachments into general normative beliefs (Zuiderent-Jerak and Jensen 2007) or moral standards, which make them end up with normative implementation problems. I will return to this issue in the conclusions of this thesis.

In order to explore the interplay of pathway development and the normativity of STS research, I will now turn to the project where I was actively involved in the development of care trajectories.

3.4 Situated standardization for hematology and oncology care

Being part of the department of Health Policy and Management of a university medical center (UMC) gives the often analyzed problem of access[80] by STS researchers to medical practices a very specific twist; one may be invited as a resource for organizing care practices, rather than a time-consuming social scientist with obscure ethnographic tendencies. Because of this organizational position, and as described in chapter 1, the research group I am part of was initially approached by one of the medical professionals of hospital A to participate in setting up a hemophilia care centre. The closing of this project resulted in a new request by management and medical staff to analyze some persistent problems they faced in the hematology / oncology outpatient clinic, which the hemophilia care centre was part of. It was a clear intention right from the start of the project by both the hospital and by our research group that we would not merely carry out an analysis, but also be actively involved in the organizational changes that would take place. In 2003 I therefore started a study of the work and its problems in the out-patient clinic. This was done over a period of three months by combining ethnographic approaches such as participant observation (19 days), semi-structured interviews with resident staff, junior doctors, operational management, research nurses, medical secretaries and medical social workers (23 in total), focus-group project meetings (2 times), interactive presentations to nurses (2 times), hematologists (once), oncologists (once)

and other personnel of the clinic (2 times) and by quantifying problems through analyzing data (for example about the time clinics were running late) from the hospital information system.

This approach was not part of a 'design phase' in which the solutions were thought out, but it was a way to get engaged with the practice. It proved crucial for finding spaces to 'act with' various actants of the ward, such as doctors, the planning module of the hospital information system, nurses, the hospital IT department, doctor's assistants, strategies for working together with hospitals in the region, secretaries, plans for renovating the ward, cluster management, the finance and control department, etc. It was also a time to link the ward up with various practices to which it was *not* yet allied, such as the wards of the children's hospital that had a new way of doing triage of patients 'implemented' by a consultancy company (and that management there was about to 'dismantle'), an oncology ward of another university hospital that had developed a planning system for their treatment centre that was yielding good results, and STS literature and conference talks on standardization.

After this first phase, I wrote a proposal for changes that could be experimented with at the ward. I concluded that amongst the problems I encountered, three important issues were: the strong variability of workload during the week, the absence of a planning system for the treatment centre of the ward, and the plainly overcrowded surgery hours of both hematologists and oncologists. By situating the problems in the system of care delivery, rather than in the individuals, the solutions were framed as sociomaterial interventions in this system. The implied solutions were therefore; reducing variability by shifting surgery hours around to find a better distribution over the week, developing a planning system for the treatment centre to ensure that a critical resource was put centre stage in the planning of activities, and creating space in the surgery hours of the doctors. The aim of this chapter is not to give a complete account of the project and the interventions that were experimented with. It is however worth noting that some definitions of the 'problems' of this ward were explicitly not taken into account in the conclusions of the analysis. One such definition was that in order to prevent the chaos behind the counter where patients made appointments, the tasks should be divided into front- and back-office activities. Either doctors' assistants should carry out front-office activities and thus be available for patients, or back-office activities and could be located in a separate room. This approach was proposed by a unit manager who was inspired by customer relationship management (CRM) as promoted through management journals (e.g. Chase and Tansik 1983). However, ethnographic observations showed that the only way doctors' assistants could manage the peak-loads at the ward was by noticing when a colleague was about to get behind with serving patients and helping him or her. I claimed that separating the activities of doctors' assistants without first addressing the causes of work- and peak-load would have a detrimental effect on the work flow. Historically, STS researchers are not best known as authorities on organizational issues[81], but

it seemed like this statement was legitimized through the ethnographic research and my position at a management institute.

The problems and their solutions that were agreed upon were the outcome of all the interactions that had taken place in the previous phase. When this analysis was accepted, the medical coordinators[82] were positioned 'in the lead' of the project by making them chairs of the working groups for hematology and oncology. These multi-professional groups, consisting further of staff members, nurses, doctor's assistants, research nurses, the management of the secretaries, the operational manager of the ward and me, met once a week to discuss the progress of the project and to work out care trajectories for the large majority of patients. The set up with multi-professional working groups with the medical coordinators as chairs made my role one of 'acting with', which meant that I had to give up some of my freedom to propose interventions and get them accepted, but which also involved a different distribution of the ownership of the project and its interventions; one, which proved crucial both during the project and after its completion.

The analysis was allied to a conceptual approach to standardization of care that is being developed at the department of Health Policy and Management of the Erasmus Medical Center. The aim of this approach is to change healthcare organizations from their unit based organizational structure (outpatient clinic, laboratories, radiology department, clinical departments, etc.) to a process based organization focused on the trajectories groups of patients go through[83]. Conceptually, this approach to standardizing healthcare practice draws upon the process based focus of care pathways, yet moves away from the standardization of trajectories of individual patients and the process of decision making by individual specialists. Rather than trying to standardize individual patient trajectories that have been shown by STS researchers (Berg 1997), medical sociologists (Wiener 2000) and ethnomethodologists (Garfinkel 1967b) to be extremely complex, dynamic and unpredictable, standardization is focused on an *aggregated level*, i.e. at the level of *patient groups* that have to make use of the same resource. On this level it turns out that trajectories display substantial similarities. Whereas individual patient trajectories are inherently unpredictable, analyzing the trajectory for groups of patients makes them predictable and allows for care to be organized accordingly. Even if certain steps cannot be planned for specific patients due to the variability of individual care trajectories, it is possible to assess for a group of patients how often a particular step (for example an emergency CT-scan for oncological patients having a relapse) will occur and make sure the organization is ready to meet this demand (for example by keeping emergency slots available until such a CT-scan needs to be made or through creating direct access to the radiology department). Such capacity can then be assigned on a last minute basis to individual patients.

Traditionally, and for good reasons, STS researchers would be skeptical about a standardization initiative that claims to sweep aside the problems of the complexity of patient trajectories by claiming to address the issue at an aggregate level. Often the politics of aggregation is bound to a claim to serve everyone better, whereas it in fact accomplishes this ambition at a high expense for those marginalized or excluded (Star 1991). Such critiques however have mainly been directed towards what healthcare improvement researchers working on reducing access times of patients to wards have called 'carve out' (Silvester, Lendon et al. 2004), which is the practice of reserving capacity for categories of patients, thereby excluding those patients that do not fit in the category or do not fit the assumed standard. Healthcare improvement researchers working on healthcare logistics and reducing access times share the STS aversion to such forms of standardization. The logistic alternative they propose is to work with 'advanced' or 'direct access' (Murray and Berwick 2003): an approach that does not separate urgent from non-urgent patients to treat the latter earlier at the expense of the former, but tries to undo the extra work the management of such categories involves by treating patients as soon as possible and desirable.

An important principle of this approach of developing standardized care trajectories is that these are no longer the *point of departure* for an organizational change and implementation phase that follows the design phase. They are rather the *outcome* of the project as a whole: it was only apparent how the care trajectories would look when exploring which organizational interventions were feasible. The continuous aim was to avoid making a design of pathways that would then need to be 'implemented', and through which we would have re-created 'implementation problems'. By conceptualizing the care trajectories as an outcome of an experimental change process, it proved possible to prevent both implementation and its problems.

Since this approach was the conceptual starting point of the research, situating solutions in particular patient trajectories was pursued by sketching pathways for all relevant patient groups (see for an example of these flow charts figure 3.1 and 3.2). Their relevance was defined by aiming at a large majority of patients, since the interventions were, in order to prevent the issues of 'carve out' mentioned above, to have consequences not merely for one group of patients, but for all patients of the ward.

Since the hematologists kept a diagnostic registration, we could easily assess that we would need 12 standardized care paths[84] to cover 69% of the patients, which we decided would be a large enough group to seriously impact the work on the ward. Since the oncologists did not keep such a registration, we had to make an estimate for the number of care paths that were needed to cover approximately 80%. This turned out to be possible by developing 6 additional trajectories[85].

To illustrate in which ways the interventions shaped the situated standardized care trajectories, I will now explore some ambiguities that came up in the case of two specific experiments; reducing follow up for hematologists and introducing a nurse practitioner for oncologists.
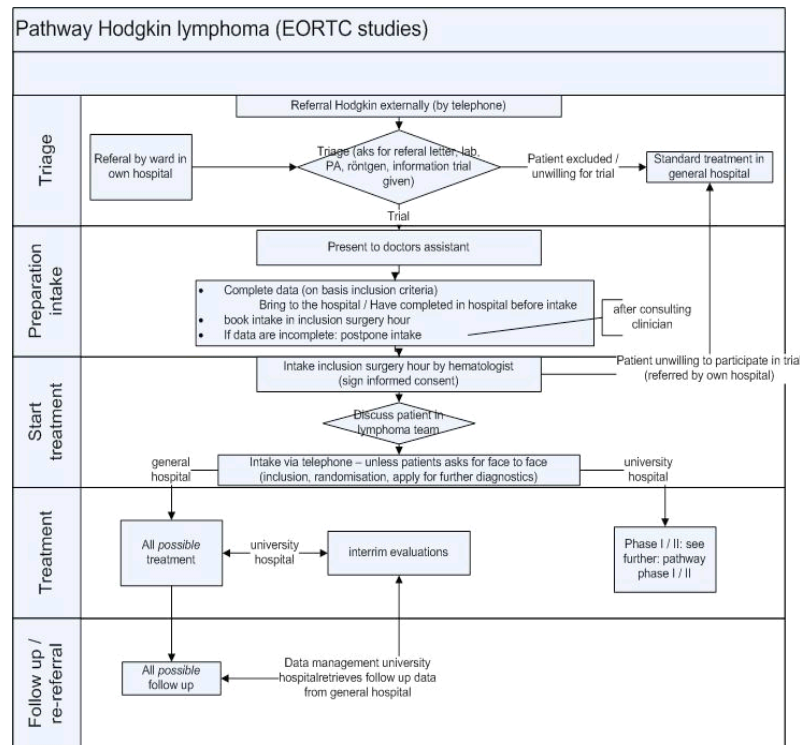

Figure 3.1: Flow chart care trajectory Hodgkin lymphoma

3.5 Integrating planning and care trajectories

Many discussions about the way in which the care trajectories were developed, centered on various versions of the flow charts. They proved to be interesting experimental devices in the delicate process of articulating specific issues. At a certain time different versions of flow charts were used to explicate a difference in practice amongst medical professionals. There was a lively discussion going on among the hematologists about what to do with the late follow up of some forms of treatment. The follow up of lymphoma treatment is life-long and this means many places in the surgery hours of hematologists may be filled with such late follow up. Of course this caused friction in a setting charac-terized by a scarcity of slots in surgery hours. This resulted in the claim of one doctor that: "it's because of this 20% of my surgery hours that I cannot see this patient who is referred with a neck this thick! [*holding hands around her neck at about 10 cm distance from the skin*]". She questioned the idea that the follow up of these patients was really
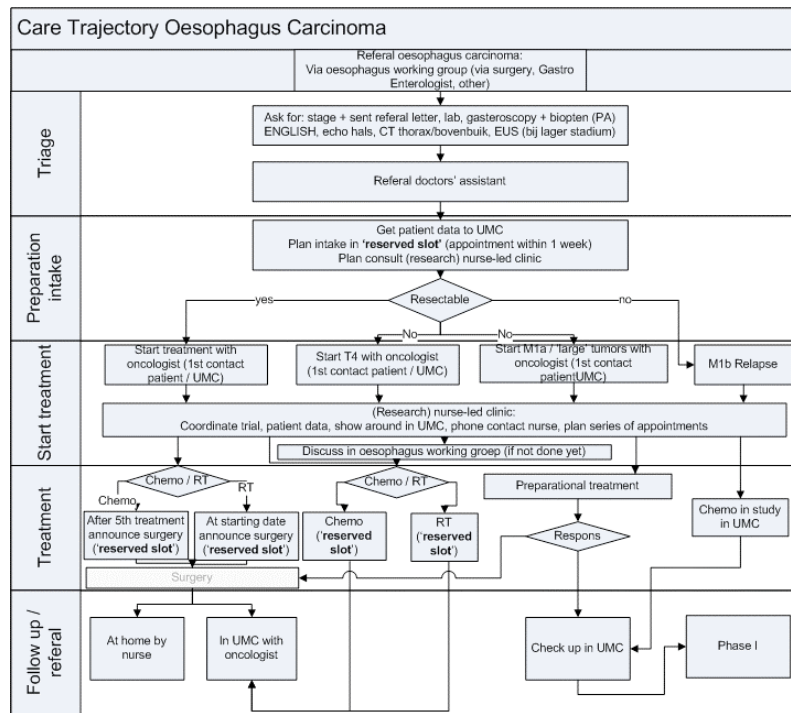
Care Trajectory Oesophagus Carcinoma

	Referal oesophagus carcinoma: Via oesophagus working group (via surgery, Gastro Enterologist, other)
Triage	Ask for: stage + sent referal letter, lab, gasteroscopy + biopten (PA) ENGLISH, echo hals, CT thorax/bovenbuik, EUS (bij lager stadium)
	Referal doctors' assistant
Preparation intake	Get patient data to UMC / Plan intake in **'reserved slot'** (appointment within 1 week) / Plan consult (research) nurse-led clinic
	Resectable — yes / no
Start treatment	Start treatment with oncologist (1st contact patient / UMC) — No / Start T4 with oncologist (1st contact patient / UMC) — No / Start M1a / large tumors with oncologist (1st contact patient UMC) / M1b Relapse
	(Research) nurse-led clinic: Coordinate trial, patient data, show around in UMC, phone contact nurse, plan series of appointments
	Discuss in oesophagus working groep (if not done yet)
Treatment	Chemo / RT — Chemo / RT / Preparational treatment / Chemo in study in UMC
	After 5th treatment announce surgery ('reserved slot') / At starting date announce surgery ('reserved slot') / Chemo ('reserved slot') / RT ('reserved slot') / Respons
	Surgery
Follow up / referal	At home by nurse / In UMC with oncologist / Check up in UMC / Phase I

Figure 3.2: Flow chart care trajectory oesophagus carcinoma

part of her job, since it hindered her to treat patients who were in acute need, as the thick neck indicates highly swollen glands that are typical for severe cases of lymphoma cancer. Since these patients were almost solely tertiary referrals, they had nowhere else to go, as opposed to the patients who came for late follow up. As a solution she agreed with my suggestion that this follow up would go back to the hospital that had initially referred the patients. She stated this was possible since data managers of the university hospital would visit these regional hospitals on a regular basis to ensure completion of research data from the medical records kept there. This practice was already in place for some trials. This way, she claimed, she could see more patients in need of highly specialized care and patients could receive their follow up in a hospital much closer to their place of residence.

However strong the arguments in favor of this change may seem, the head of the department – and the one commissioning the project – held a very different view on the matter. He stated that handing over the late follow up to referring hospitals would jeopardize the success of the university hospital in studying complications in such patients. This he defined as a serious risk to the academic task of the organization, which he saw as undesirable both from the point of view of care delivery and scientific publications. In response, I made two competing schemes of the care trajectories (see figure 3.1 & 3.3). I also calculated how big a percentage of the surgery hours was spent on late follow up of large trials that could potentially be handed over to the referring hospitals. This was approximately 11% of all consultations. The estimate of the hematologist of 20% was
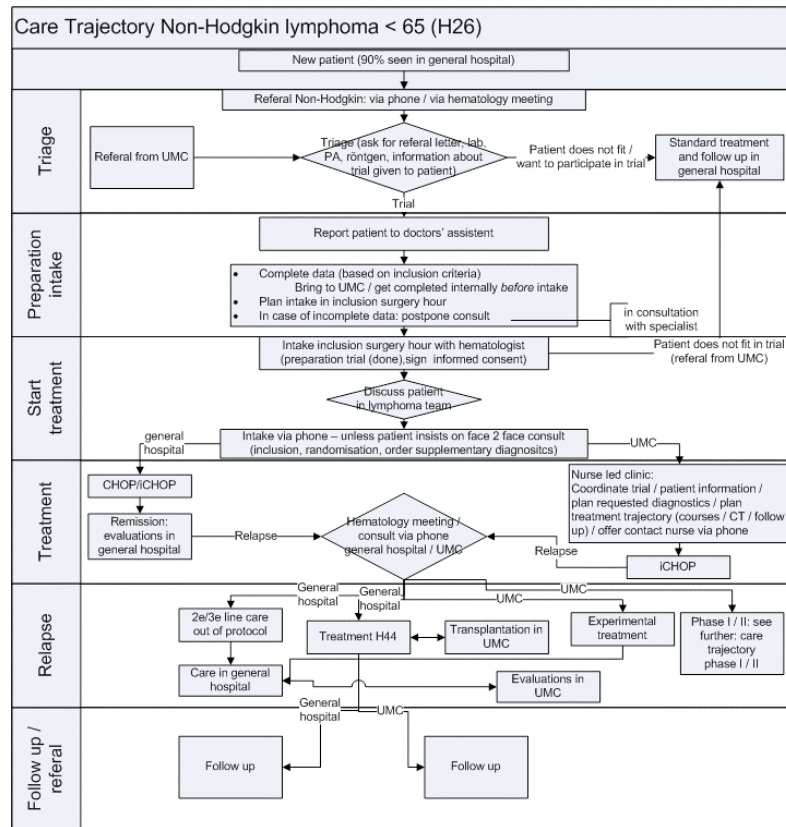
Figure 3.3: Care trajectory non-Hodgkin lymphoma, with follow up both in the general hospital and the university hospital

quite adequate, but to avoid a heated debate she differentiated between patients for whom she was certain that no late complications would be missed and those for whom there were still minor risks.

Finally I calculated how many extra surgery hours would have to be staffed in case the hematologists would decide to consider this part of the treatment as an integral part of their work.

Until then the discussion around this topic was taking place at a relative distance from the practice of care delivery: the medical staff had meetings to decide on their strategy in these matters in the absence of nurses and operational management. This seemed to result in a somewhat content-biased decision that management merely had to 'carry out' rather than be involved in – with all concurrent 'implementation problems'[86]. This practice of decision making – and its organizational consequences of overcrowded surgery hours and stressed personnel – was not easily overcome: neither operational management nor I was welcome at the staff meeting where these issues were discussed. Through the experiment with introducing contradicting flow charts and calculations of the number of patients and the time needed for late follow up in this session, I tried to ally some organizational knowledge with the decision making of the medical

professionals. This did however not lead to anything like more 'rationalized' decision making about late follow up.

When checking afterwards with the doctor who had brought up the issue of the late follow up what the outcome of the meeting was, she said that it led to a brief discussion, but that the real topic of the meeting was actually their boycott of the newly introduced diagnosis related group (DRG) registration. This boycott was a lever to increase the salaries of academic junior doctors, since the hematologists saw all their good young colleagues move out to general and teaching hospitals where the wages were substantially higher. This boycott by university hospitals caused a lot of anxiety for the head of the department who wanted the registration to be complete for budgetary and academic reasons. The tension that arose had dominated the meeting – which made it quite understandable why the hematologists did not want anyone looking over their shoulder in those settings.

Such general staff meetings on strategic issues are quite rare, and perhaps due to the tension that had arisen, the sensitive issue of the late follow up did not reappear on the agenda. However, when interviewing the hematologists at the end of the project, one of them said:

> The discussion about whether the late follow up should be carried out here or in the periphery may not be properly closed – in fact it may never have been brought up for discussion openly – but as a matter of fact most of us now refer those patients back. I and [two of the other hematologists] certainly don't keep those patients for follow up. After a few years we simply send them back. But you cannot do this all at once. You have to announce that about two or three times. If you all of a sudden send them away, they'll be standing on your doorstep after three months with all kinds of complaints. They become far too insecure then

And the hematologist who brought up the issue in the first place stated: "I simply send them back, even though the discussion is not closed. I just want space in my surgery hours".

It is hard to imagine how formalizing this practice in a decision about the design on a standardized care trajectory that would then have to be implemented could have been beneficial here. It would merely have polarized the discussion on a sensitive issue on medical content, whereas the 'guerrilla tactics' with a settlement for what seemed feasible proved more fruitful for addressing the organizational issues of the ward. The problems coming from late follow up were further articulated by introducing an indicator for the return rate[87] per doctor, which entangled the issue of how often a doctor sees a patient with good organizational practice, without explicitly addressing the issue of the late follow up. This resulted in 'sub-standardization' amongst a few of the hematologists who were responsible for a substantial part of the 'production' of the ward.

3.6 Creating care professionals and standardization

One of the more dynamic aspects of the project was the introduction of nurse practitioners in the treatment of oncology patients. This change was proposed due to several reasons. First, the above mentioned efficiency gains were mainly possible for the hematologists since in most cases the oncologists had a much less cooperative relationship with general hospitals, making re-delegation of tasks between various healthcare institutions unfeasible. It therefore seemed that the logistic interventions were less effective and alternative ways to create space in overcrowded clinics were needed. Second, other university centers were showing impressive results with the introduction of nurse practitioners in their outpatient clinics. Several members of the oncology working group attended a presentation in another Dutch university hospital where a nurse practitioner spoke about the substantial reduction of the patient return rate, enthusiastic patients and a level of professional autonomy of qualified nurses that was almost becoming problematic since the oncologists hardly showed their faces any longer, content to leave treatment under the supervision of these 'new professionals'. A third reason also seemed to warrant the intervention, since a high variation in the way individual oncologists treated their patients produced much tension at the ward. Most of the oncologists had up to 18 patients booked in surgery hours that had 12 places (of 20 minutes each) but would still manage to be ready on time. Yet, one of their colleagues had a different schedule. She only had about 8 patients booked in her surgery hours and was still running late at every clinic. There was also substantial variability in the return rate of patients per doctor: the doctors who saw the most patients also reduced the number of times they saw their patients to the amounts prescribed in treatment protocols, whereas the one other doctor asked patients to come for an extra check up in between chemo treatments.

These colleagues were stuck in a real dilemma: although the practice of the one doctor seemed highly patient-centered, its consequences was that her colleagues had *less* time to spare per patient – provided they did not want to increase the admission time to the ward and could not hire new colleagues. This situation had led to a long-lasting conflict which had been addressed in various ways. The medical coordinator had many conversations with his colleague over the years, and the controversy had reached the point where the professor who had the final responsibility for the ward enforced shorter times per patient and a lower return rate for her. The doctor then urged her patients – who were surprised by the change in the way they were being served – to file complaints to the professor about the new policy. Answering these letters eventually became too much of a burden for him and he let go of his demands. After all these attempts, it was now seen that installing a nurse practitioner could somehow reduce her return rate and the time she spent per patient, since large parts of treatment would end up with this new professional. Whilst there had initially been substantial skepticism from the entire medical staff about the re-delegation of their tasks to new professionals, this was one more reason to be in favor of introducing nurse practitioners.

It may come as no surprise that the initiative with nurse practitioners was not much of a success. Using change initiatives to overcome strongly politicized controversies rarely solves the controversy but generally *dis*solves the change initiative (c.f. Buchanan 1997). We spent several sessions sketching the scheme for the tasks of the nurse practitioner in one of the most simple care trajectories: testis carcinoma. There was a clear consensus guideline for the treatment of patients with this disease of which a substantial part is a medically very straightforward late follow up, which cannot be done in general hospitals due to the low incidence rates of the disease. It therefore seemed an ideal case for specifying the tasks of a nurse practitioner and defining the moments at which s/he should contact an oncologist. After standardizing the re-delegation of work, however, we ran into a strong lack of trust between oncology nurses and the oncologist who took most time per patient. Also, the discussion amongst the oncologists further polarized, leading to statements from the opposing oncologist that "psychosocial care is an integral part of treatment that can only be done by a doctor" and from one of her colleagues that what they were discussing here was "monkey medicine", drawing on the metaphor that claims that even a well trained ape could do medical work. All in all, one could say that in the experiment we were unable to make this experimental intervention work since it proved impossible to co-construct problems, solutions and situated standards. The proposal for introducing nurse practitioners was not taken up by cluster management and the net outcome of the experiment was a nice picture (figure 3.4) with no impact.

Realizing that it was not feasible to come to this more formalized re-delegation of tasks to nurse practitioners, it was decided that the project would still pursue the re-distribution of work, but do so in a more modest form through the introduction of a nurse-led clinic for oncology patients, an intervention that had already proven successful in the construction of the hemophilia care center (see chapter 2). This way we tried to create a collaborative connection between medical professionals and nurses. This strategy proved fruitful about three months after the closing of the project. In a 'follow up meeting' of the project nurses and doctors agreed that the former would join the oncology-meetings where patients were being discussed. They also both expressed the wish to further explore the possibilities for delegating more administrative and planning related tasks to nurses. This meant that the care trajectory for oncology patients may soon look substantially different.

3.7 Conclusion: interventions in pathways and in STS

At the introduction of this chapter I proposed two ways in which experimental STS research with standardizing healthcare practices might be interesting; for analyzing how situated standardization can contribute to a more processual understanding of the development and use of care pathways and for exploring the relationships between such experiments and the issue of the normative deficit of STS research.
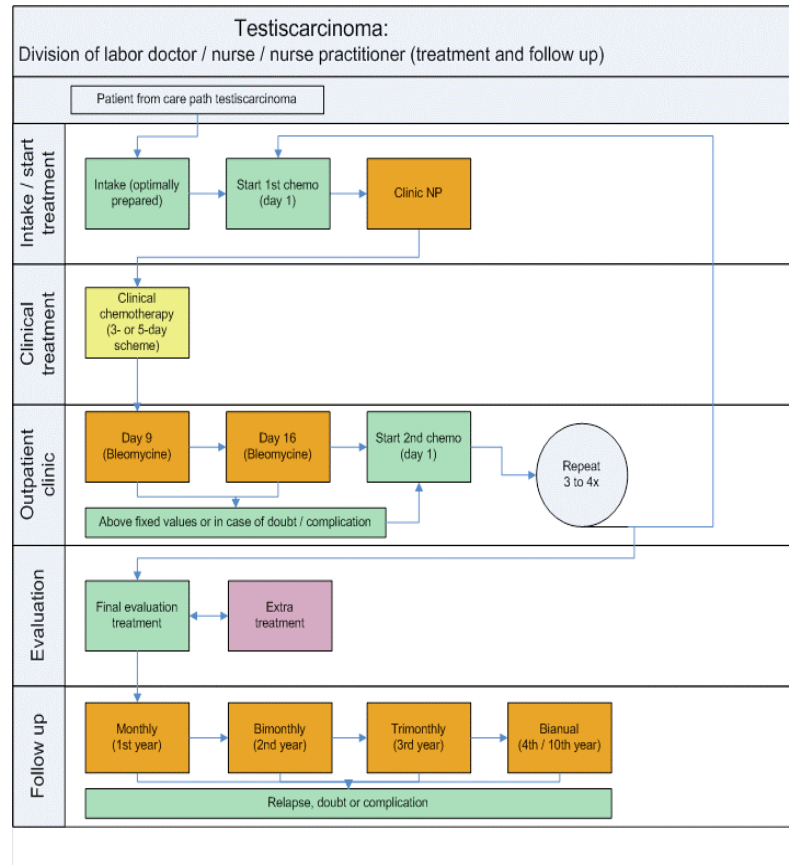
Figure 3.4: re-delegation of tasks to a nurse practitioner in the treatment of testis carcinoma

I hope to have shown that interventionist STS projects may contribute to the creation of situated standardization of care. Rather than 'implementing' guidelines or pathways 'into' medical practice, aggregated medical knowledge is allowed to become, what Timmermans and Mauck call "a scientific rallying point in a comprehensive organizational process of change" (Timmermans and Mauck 2005). The events described above are illustrative of the ways in which standardized care trajectories and the interdependencies of medical work were co-constructed.

The situatedness of interventions in organizational complexity also brings us back to the second point of exploring the normativities of STS research through 'unpacking intervention'. Conceptualizing the unwillingness of many STS researchers to 'get real' about normativities outside the empirical specificity of practices as a 'normative deficit' seems to be somewhat of an absurdity when analyzing the experienced need to be normatively highly specific when exploring situated standardization in the events described above. As the issue of reducing the late follow up showed, it seems an odd thing to claim that such a setting – bursting with multiple normativities – needs an STS researcher with a normative agenda that is defined "apart from the interpretation of relevant actors or 'actants'" (Keulartz, Schermer et al. 2004, pg 12) and that is "more compatible with normative standards" (Hamlett 2003, pg 134). The point is rather that there

is a continuous interplay of competing normative 'standards' that are enacted, marginalized or challenged in the practices STS research engages with. Getting closer to the normative complexity of practices and explicitly involved in them through experimental research practices makes the problem for the normativity of STS research not one of *adding* normative standards, but one of sorting these attachments within overflowing normativities. The resultant normative surfeit model of interventionist STS seems not in need of a translation of situated normativities into moral singularizations and beliefs. Rather, it articulates the value of an *ethics of specificity*[88] for STS research.

Engaging with practices in experimental ways may be one powerful approach for enacting such normative surfeits, be it through drawing flow charts or trying out the consequences of nurse led clinics. In that sense, exploring various modes of intervention in STS research seems just as valuable for articulating the processual approach to pathwaying, as it is for preventing the implementation of normative standards into healthcare practices and STS debates.

Chapter Four

Patients and their Problems

Situated alliances of patient-centred care and pathway development

It is 11:00 a.m. on a morning in May in a hospital in a large city in The Netherlands. This hospital, which we will call 'hospital A', is a university medical centre and we are observing the work at the hematology / oncology outpatient clinic and treatment centre. Most of the patients here are tertiary referrals who can no longer get the care they need in regional hospitals. Patients are referred by hospitals in the region but also by clinics throughout the Netherlands: hospital A is specialized in particular forms of cancer treatment. We are witnessing a common phenomenon at this time in the morning in the treatment centre of the hematology / oncology ward: patients receiving chemotherapy fill all the chairs and there are still many patients waiting for their consultation with their haematologist or oncologist.

At the counter where new appointments are made is a patient from the south of the Netherlands who has to travel about 200 kilometres to get the specialized haematological treatment she needs. Together with her husband, she just came from a visit with the junior doctor who gave her an order-sheet indicating that she requires an appointment for a scan at the radiology department, and also a test of her bone marrow. With this sheet they have returned to the counter and have awaited their turn. Fadila[89], one of the doctors' assistants, is scheduling the requested diagnostics and tries to call a secretary of the radiology department. The secretaries at radiology seem to be very busy and Fadila is put on hold. After holding the line for half an hour, she manages to get through. In this time she couldn't really continue her work at the counter, so the patient records have piled up. This means patients have finished the consultation with their doctor, have come back to the counter for follow up appointments and are waiting for their appointments in the queue or in a seat near the counter.

"Of course you can choose to send patients home, and call them back later to make appointments, but then you shift your work to the afternoon after 2 p.m." Jane, a colleague of Fadila informs me. I realize that they do not consider this to be a real option since at that time there will be new consultations with other patients queuing up.

11:30 a.m.
The patient from the south of the Netherlands hears that her appointment is in a few weeks time, at 8:30 a.m. The husband of this patient (who's doing virtually all the talking since his wife is very tired) indicates that this is quite early if you have to make a three hour journey, and besides, he's not happy that the bone marrow is planned a day before, also at 8:30 a.m. "But a

skeleton is always at 8:30. That can't be arranged differently", Fadila says, "and I've been working on that appointment for half an hour, and the day before they don't have a place for you in the radiology department." The patient and her husband leave being rather taken aback, but soon after they return to the counter. The queue has become quite long, and Fadila is helping the next lady. Other patients, two elderly people, come to the counter to indicate that they are still sitting there and would like to go home. They are completely worn out. The husband of the patient argues: "But if there's no place for the scan on the day before, can't we change the bone marrow then?" Fadila changes this unwillingly.

When the man has left, Fadila says: "That's so annoying, you know, that I'm trying to get rid of this pile of patient records, and than you have a patient like this constantly wanting something else!"

After some time, again the patient and her husband come back. They have called with their own internist in their local hospital, who has indicated that they don't have to come to the university hospital for this particular scan. The husband indicates that they have now made an appointment in their regional hospital for this. Fadila is helping another patient, and her colleague takes over the patient from the south of the Netherlands. But Fadila has to interfere anyway, to explain what has just taken place. Now the patient who was being helped by Fadila gets angry with the patient from the south of Holland: "Well, I'm standing here waiting, and you just jump the queue!" Her husband tries to calm her down.

12:08 p.m. The junior doctor tells Fadila in passing that after all the patient needs to get cytogenesis as well, and that she has to make an appointment for this. She does this on the day following the existing appointment for the bone marrow, and informs the patient, who is still waiting near the counter. The husband asks to change the appointment to the same day as the bone marrow. Fadila does this, and also cancels the appointment with the radiology department. This doesn't take half an hour this time, but still takes a long time.

After the patients have left, and the appointments have all been made, the doctor comes to the counter. He indicates: "well, actually I'm not there when you've made the appointment for the bone marrow, because I'm taking a course then."

4.1 Introduction: Patient-centred pathways

This situation is unfortunately a rather common sight in Western-European outpatient clinics. When presenting this observation to students following a course in healthcare change management at the institute where I work, a healthcare manager among them ironically noted that this way of organizing treatment is: "probably the only thing that is properly standardized in Dutch hospital care."

The observation comes from the 'interventionist' study described in the previous chapter, that I carried out in hospital A between May 2003 and September 2004 at the request of clinicians and management of the outpatient clinic. Their request was to analyze the situation on their outpatient clinic, suggest ways to improve the organization of care and carry out these suggestions together with care professionals and management of the ward, as mentioned in chapter 3. The project that was set up for this was conceptually related to a hospital-wide experiment of creating standardized care trajectories.

Since the early 1950's 'standardization' and 'patient-centred care' have been strongly contrasted in the medical sociological literature[90]. Standardization has been conceptualized as an ally of the 'biomedical model' of medicine that was subjected to critique in order to develop the 'patient-centred' way of care delivery[91]. The strategy of hospital A however was to create patient-centred care through the development of standardized care pathways, thereby making standardization an unusual ally to their general aim. In this chapter I will therefore focus on the question how the concepts of 'standardized care trajectories' and 'patient-centred care' were related in this setting. Which specificities could lead to the pragmatic commensurability of these concepts? How could the dichotomy between standardization and patient-centeredness be refigured? Which kinds of patient-centred care could be enacted through the development of standardized care trajectories? And which kinds of standardization would match which forms of patient-centred care?

To address these issues, I will first elaborate further upon the method of interventionist research that was introduced in the previous chapters. Secondly I will deal with different conceptualizations and practices of the crucial concepts in this analysis: 'patient-centeredness' and 'pathway development'. I will relate common notions on patient-centeredness to the classical debate amongst political scientists on the respective merits of expertocracy and participative democracy. I will then discuss two classic positions in the standardization debate and relate them to situated standardization as introduced in chapter 3. Finally I will tease out the connections between situated standardization to a third form of patient-centred care that is inspired by a third position in the debate on the merits of different democratic models: the pragmatist notion of 'issue politics'. By indicating the way 'situated standardization', 'issue politics' and 'patient-centred care' relate, I hope to show that recent debates within political science and philosophy are helpful for reconfiguring discussions and practices on patient-centred

care and standardization in such a way that *the articulation and settlement of issues* patients, care professionals and organizations face are put centre stage.

4.2 A hybrid methodology of interventionist research

To situate standardization in the specific problems of different care practices and relate them to a conceptualization of what the organization of care could be like, it is crucial to get a thorough understanding of the issues at stake in the care practice under study. In order to formulate and elucidate these we used a hybrid study design combining qualitative and quantitative methods. The outpatient clinic and treatment centre hematology / oncology is a large unit of one of the largest university hospitals in the Netherlands. Annually the outpatient clinic is attended by approximately 1150 new patients who in total come to the clinic some 11000 times for follow up consultations. In the treatment centre chemotherapy is administered some 2100 times per year. Other treatments like blood transfusions etc. are given about 2600 times. We used a case study design for the project where the initial analysis phase lasted three months. Qualitatively, I conducted 23 semi-structured interviews with resident staff, junior doctors, operational management, research nurses, medical secretaries and medical social workers. These interviews lasted for 1 to 1,5 hours and were transcribed and analyzed.

There has been an observed dissimilarity between what people do and their accounts of what they do (Suchman 1995). To counterbalance this limitation of merely working with interview data, I engaged in participant observation, analyzing the interactions taking place behind the counter, in the consulting room, in the treatment centre, in the waiting rooms and in staff meetings. In total this cumulated in 19 days of ethnographic research. Working with this approach allowed me to ask questions to staff while they were performing their daily activities, confront statements from interviews with our observations and get a general feeling for the care practices at the clinic.

Quantitatively, I analyzed to which extent the clinics were running late, how many patients were booked in the agenda's for whom there was not a regular slot available (double bookings or over bookings), whether clinics started on time, whether there was an overall balance between the capacity of the clinics and the number of patients that visit, how many cancellations of clinics by doctors took place and the amount of variability on these parameters for individual doctors. I also quantified the increase in the number of treatments given at the treatment centre over the last years and the distribution of treatments over the various days of the week over the last three months. I did not look at the often relevant 'no show' indicator, since the patients at this ward are so ill that they hardly ever stay away without notification.

I generated these indicators by making use of the hospital information system (HIS) in which agenda's were being 'closed' by the doctors' assistants. This means they registered at what time a clinic had started, when it ended, and any changes that had taken place in the schedule. Such specific data is hardly ever available through a HIS since such items are often not registered. Though a previous manager had introduced

the practice of 'closing' the agenda's, the resultant data had never actually been processed to become meaningful information for organizational or clinical management prior to the project.

The findings[92] were discussed in two focus-group project meetings during the first three months. One of these meetings was held after six weeks, the second after ten weeks. The meetings served both the aims of articulating issues and testing out potential journeys towards their settlement. The meetings were attended by organizational management, doctors who where involved in the project (including those with management responsibilities), and other staff from the clinic. Two interactive presentations were given to nurses at different times, to allow all to attend and give their feedback. The same was done for doctors' assistants. All haematologists and oncologists were informed through interactive presentations at their respective staff meetings. Finally, I also discussed the findings with various professionals in hospital A who were working on similar projects.

After the first phase of the study, I wrote a proposal for possible changes for the ward. When this analysis and its directions for a solution were approved by medical and organizational management, the medical coordinators were positioned 'in the lead' of the project by making them chairs of the working groups for hematology and oncology[93]. These multi-professional groups, consisting of the medical coordinators, staff members, nurses, doctor's assistants, research nurses, the management of the secretaries, the operational manager of the ward and I, met once a week for about ten months to discuss the progress of the project and to sketch out standardized care trajectories for the large majority of patients. These pathways focused on the interventions that were proposed to deal with the issues I identified in the first phase. Those interventions were tested out, altered if needed and then more widely introduced or abandoned, as described in chapter 3.

In the final two months of the project, I evaluated it by again using a hybrid design, interviewing professionals and analyzing data from the HIS (which was much less cumbersome the second time since this was now translated in automatically generated indicators). The results of the project[94] were discussed in the steering group, the maintenance of the pathways handed over to the medical coordinators and the maintenance of the indicators handed over to the quality manager.

4.3 Clandestine forms of patient participation

In the research design, the explicit involvement of patients was not envisioned. This had a number of reasons. One of them was the somewhat sceptical response of doctors to the idea: they rather saw our time dedicated to analyzing the data from the HIS and the ethnographic analysis, since their experience was that even when they felt they were facing substantial organizational problems, they still tended to score well on a patient satisfaction questionnaire – an observation that I shared from previous projects and that is well documented in the medical sociological literature on this topic[95]. During my ethno-

graphic observations I could fully understand why satisfaction questionnaires are so problematic: in a poorly organized health care setting, professionals tend to be prepared to go at any length to provide the treatment their patients require. Patients often value this extra effort highly and translate this into a high satisfaction rate. They are however often not in a position to see in which ways organizational problems *could have been prevented*.

Another reason doctors put forward for not including patients in the study was that we would have to get approval from the medical ethical committee which would delay the project and would prevent actually addressing the problems we could already articulate. I strongly felt this reason was partly used to discard the somewhat touchy subject of patient-involvement but was unable to include e.g. interviews with patients at this stage of the research.

However, during the project patients were still included in three ways. Firstly they were all around. Their interactions with personnel at the clinic was observed during the days of participant observation, they became familiar with and approached me and shared some of their experiences.

Secondly, I met a 'long term patient' on a birthday party. This patient had been treated at the ward for more than ten years. Interestingly, he was an organizational advisor working for a large Dutch consultancy firm. I had a number of private meetings with him to discuss proposed changes and get input from this 'expert patient'. The consultant was able and more than willing to give valuable input both on the level of the organization and the interventions and on issues of change management.

Thirdly, at a later stage of the project, a brief questionnaire was developed for patients from the treatment centre that contained questions about their experiences with treatment. This questionnaire was used to assess the accurateness with which patients were informed about their treatment and included items like:

> *"Have you had any reactions to treatment about the risk of which you were not informed? If so, which reactions."*

On the basis of the patient identification numbers I could see what treatment they had been receiving and found that they were often taken by surprise by reactions that were rather common. Though I was unable to assess whether this meant patients had not been informed or had forgotten, I interpreted the outcomes as an argument in favour of setting up a nurse led clinic providing more time for discussing issues like reactions to treatment.

A question worth exploring is whether this somewhat clandestine participation of patients makes this study any less 'patient-centred'. In order to address this issue, we will first unravel the very concept of patient-centeredness.

4.4 Democratic diffractions of patient-centeredness

As I indicated above, the issue of patient-centeredness has been dominated by its dichotomous origin: in the medical sociological literature patient-centred medicine is generally positioned as a response to the proliferation of evidence based medicine[96]. Proponents of this dichotomy claim that in "the conventional way of doing medicine, often labelled the 'biomedical model' (…) the patient's illness is reduced to a set of sings and symptoms which are investigated and interpreted within a positivist biomedical framework" (Mead and Bower 2000, pg 1088) whereas patient-centred medicine requires a "willingness to become involved in the full range of difficulties patients bring to their doctors, and not just their biomedical problems" (Stewart, Brown et al. 1995)[97]. In this discussion, two noteworthy events occur. First, a rather interesting actor is introduced to the scene: the "patient-centred doctor" (Mead and Bower 2000, pg 1088) who of course makes all *other* doctors seem like rather awkward medical professionals. Second, it is always *patients* who bring difficulties to their doctors rather than focusing on the way the issues patients, doctors and the organization of healthcare articulate, interrelate in a specific configuration.

In the quality of care literature this form of patient-centred medicine has often been directly translated to a plea for the direct involvement of patients in the organization and delivery of their care. Participation of patients is positioned directly opposite of the expertocratic model of the doctor who knows which treatment is good for patients on the basis of her/his training or experience. The adoption by the institute for healthcare improvement (IHI) of the motto "Nothing about me without me" refers to participation as an unproblematic good. In this sense patient-centred care and being a 'good' patient or doctor is conceptualized in the same way as participatory democrats un-problematically conceptualize 'good' citizenship as direct involvement in political processes that affect people's lives. The dichotomous nature of the debate on patient-centred care therefore seems to follow a similar structure as the discussion that is taking place within political science on forms of democracy.

The explicit protagonist of direct democracy, Richard Sclove, concisely formulated the fundamental premise of the participative model for the shaping of our (technological) culture when he states that:

> Insofar as: (1) citizens ought to be empowered to participate in shaping their
> society's basic circumstances and (2) technology profoundly affects and partly
> constitutes those circumstances, it follows that (3) technological design and
> practice should be democratized. (Sclove 1995, pg 3)

Sclove's definition is easily adapted to the issue of patient-centred care by exchanging 'society's' for 'physical', 'technology' for 'medicine' and 'technological' for 'medical'. So conceptually the separation between patient-centred care and EBM strongly resembles

the distinction between participatory democracy on the one hand and expertocracy on the other.

Combining patient-centred care and participation with 'strong' democracy is helpful for seeing some of the potential limitations that may be expected from this conceptualization of patient-centeredness and that are articulated amongst others by researchers with a background in Science and Technology Studies (STS). One of the major difficulties of this notion of patient-centeredness is that it displays little sensitivity for the inherent power relations that are present in the interactions between doctors and patients. Such differences are often obscured through the participative rhetoric (Markussen 1996).

A second problem is that it also performs patients as wanting to be involved, to be fully informed, and as the ones making the choices about the care they are receiving. Such a deliberatively democratic take on patient-hood is rather problematic. It raises questions on the actual desirability of patients being performed as inherently having a 'perspective' (Pols 2005) and being able to not only *choose* but also *bear the responsibility* that results from their active participation for the *consequences* they may suffer (Mol 2006). It thereby seems that participatory approaches denies patients the right to depend – at least partly – on the experience of care providers and also delegate part of the burden of responsibility to professionals. Or as the Dutch philosopher Hans Harbers expresses this critique in a more general sense:

> In emphasizing formal rights to participate, for example, [such a conception of democracy] tends to disregard substantial differences – differences in power as well as differences in expertise (…) [T]he theory of deliberative democracy inclines to deny the human right on political laziness – a right so elegantly accounted for in systems of *indirect, representational* democracy. (Harbers 2003, pg 20, italics in the original)

So the substantial critique on the model of participatory, or 'strong' democracy should make us aware of the conceptual implications for contemporary notions of patient-centeredness. But in the context of this study I was also interested in the question whether or not I would be able to find doctors that relate even remotely to the images of the 'biomedical doctor' and the 'patient-centred doctor'. For by empirically exploring the different types of doctors and the issues they face in providing patients with their care in a system under stress, I could observe to what extend the dichotomy may be productive or problematic. I wondered whether I would actually be able to find a doctor who's practice could be described as: "interrupting the patient's 'voice of the life-world' with response-constraining questions, [while] the doctor's 'voice of medicine' effectively strips away the personal meaning of the illness" (Mead and Bower 2000, pg 1089). Perhaps surprisingly it looked like I found exactly such a doctor in the outpatient clinic in hospital A.

During a clinic I observed, this doctor had 17 patients booked in 12 slots. Many patients had been booked in between which gave him not the 15 minutes per follow up visit that was the norm for this clinic, but reduced this sometimes to 5. During those visits, he welcomed the patients, went through a checklist for their trial with them, physically examined them and at times gave practical advice about ways of dealing with the consequences of treatment. He would for example advise a patient having difficulties with eating because of the treatment of oesophagus carcinoma to adjust his eating habits.

> "just eat toast bread in stead of fresh bread. It's just like when you're going fishing and you make such a nice sticky ball of fresh bread. Or like an hourglass: the sand runs through as long as it's dry, but if you add water to it, it immediately clogs".

During the consultation he was mainly busy with looking for lab results in the HIS, filling out forms, writing in the patient record and meanwhile hardly looked at his patients. When he accompanied a patient who came for the fist time to the treatment centre, he walked too fast and the patient and his wife walked in the wrong direction. He therefore had to return and call them back.

Patients who were getting their treatment already for a longer time seemed to be used to the quick, business like and rather biomedical encounter. When asked: "do you still need anything?", a patient responded "Dexamethasone", immediately realizing that a request for a recipe for cancer medication is an appropriate answer whereas "A talk about problems at home" or "More time to think before starting the next course of treatment" would be inappropriate. Many a times there seemed to be very little space for the voice from the other life-worlds patients inhabit:

> *One of the patients entering is a Croatian man who almost has no voice left – probably due to his oesophagus carcinoma treatment. His wife does all the talking. He indicates he needs more time before his treatment starts. His wife indicates that she went to Croatia for three weeks to let herself be spoiled by her family in her own house, but she came back earlier, because she noticed her husband was not doing well at all.*
> *"Where's the problem?", the doctor asks.*
> *"Mentally. He's just not doing well at all. He was able to prepare for those previous courses of chemotherapy, and then it is working out, but now it was totally unexpected, and then he can't deal with it", she replies*
> *"Yes, but of course we didn't plan it like that", the doctor says. "He just responded well and then we said 'well, lets just continue immediately then'", he says.*
> *While I wonder how 'we' decided this, she replies:*

"But he's having a very hard time. I just can tell. And he can't sleep at night at all, is very afraid. Then I really have to hold his hand tight and caress him on the head. But he says: "Doctor will get very angry when I don't want to continue". But I told him: "Doctor can't get mad, can he?!" Can you?! And he's also very worried about his feet. He still has this strange feeling there. And he's always outside, except when he's sleeping. And then soon he will have to stay inside: he just can't do that! I can tell: I'm already looking at this man for 35 years, unfortunately". She says it lovingly and grabs his arm.

The doctor asks about the tingling sensation in his feet and fingers. Indicating he has already explained this, he once again tells that this is due to damage of the fine nerves as a result of the course of chemotherapy and that this is a side effect that generally disappears, but sometimes stays.

"But if my husband continues to live, like a pathetic little man, that's also not good!" the lady continues.

"No, quality of life matters too", the doctor agrees.

"And he's getting so forgetful: he forgets his keys and all. He never used to do that!", she further explains.

"Well, that can't be due to treatment", the doctor replies.

He proposes that he gets a time out for one week, also because the values in his blood at present don't allow a new course of treatment. But he also indicates that he can't wait for another two months: "Then I don't have a clue of what I'm doing anymore".

I find the visit rather confronting. There is so little space for the quite realistic fear, doubts and worries of this patient and his wife. And how can the doctor be so sure that the forgetfulness is not due to treatment? – though perhaps in a psychosomatic sense.

When the doctor comes back he says to me: "It's a pretty bizarre couple. He used to booze it up and was a real potentate. And she's taking charge a bit now. I notice because they have been visiting me since…" he looks in the electronic record "since 1998 already".

At first sight it seemed as if we had been able to identify a doctor as described in the literature on patient-centeredness as a representative of the 'biomedical model'. However, it would have been too easy to make a caricature of this doctor without knowing what he actually knows about the 'life-world' of his patients. It turned out that there was more to his knowledge of his patients than mere ethnographic observation of the clinic would reveal. And because of his quick way of seeing patients there was the possibility of seeing many patients in a short time – due to which the admission time of the clinic

could stay within one week and he contributes to a system that is patient-centred in the sense of having short admission times for severely ill patients.

The second quest was to identify a 'patient-centred doctor' in this clinic, and once again I seemed to be lucky. There was one oncologist, as briefly introduced in chapter 3, who took all the time her patients required – up to 45 minutes for a consultation that was planned to last 15. Observing her clinic was a very different experience. She fully displayed the "willingness to become involved in the full range of difficulties patients bring to their doctors, and not just their biomedical problems" (Stewart, Brown et al. 1995), truly following the definition of the patient-centred approach. She was willing to discuss any problem that a patient encountered and defined nothing as being beyond her scope. One of the patients for example had difficulties deciding whether or not to book a holiday because she did not know whether the course of treatment would be postponed. This doctor would go into the details of explaining that a last-minute booking would perhaps be most suitable in this situation, and explained which websites were offering such holidays at the best rates.

Though this seemed to be the most amazing care that an oncologist could provide to patients, it did mean that patients had to wait long hours in the waiting room before she would have time for them. Often patients who were scheduled later in the morning or afternoon called in advance to hear how much she was behind schedule this time so they could adjust their time of arrival.

Her 'patient-centred' approach also meant doctors' assistants could either not go for lunch, or had extra work during the afternoon sessions that was piled up from the morning. If she had her clinic in the afternoon they could either not go home in time, or leave behind a pile of records of patients needing appointments for the morning crew who would need to call those patients.

But the problems seemed more substantial than just these extra waits for patients and postponed lunch breaks for staff. It was interesting to observe that this doctor indicated from the start of the project that she had no time for an interview. She disdained my invitation for it, stating she was spending her precious time on patient care. When mentioning this to the medical manager of oncology he got highly irritated, walked into the secretariat and summoned the secretary to make an appointment for this oncologist for the interview.

As expected she was late for the interview but at least she did come. However, in the first sentences it became apparent that she would not be cooperating readily. When introducing the project and the aims of improving the organization of care at the hematology/oncology ward she snappishly replied:

"And 'putting patients centre stage'[98], where does that fit in?!"
TZJ: "You're still missing that?"
"I don't know, I don't see it"
TZJ: "What do you mean, you don't see it?"

"Well, where do you see it?!"

TZJ: "Well, where you should start seeing it, in this project is when patients who now have to wait for a very long time to get their diagnostic trajectory organized will be helped in a much smoother way".

Etcetera… A skilled intervention of this interviewee; rather than allowing the interviewer to let her do the talking, she took over the interview and forced the interviewer to justify his good intentions. However, these intentions were obviously not convincing. Soon she interrupted again, pointed at the tape recorder and said:

One more thing, what will happen with those tapes? Who will have access to them?

I later found out that her position had been under serious stress. Complaints from her colleagues about the clinics that always ran late had reached the medical management, which had resulted in some organizational interventions, as described in the previous chapter. This oncologist was given a strict maximum of seven patients she could see per clinic – while others had twelve slots and were actually seeing up to eighteen patients. As a consequence, those patients that did not fit her schedule any longer were booked with other doctors. This was highly inefficient, according to her, as she explained during the interview:

We have to be able to treat our patients properly, our own patients, and not ad hoc from one to the next doctor which makes you lose grip and leads to things to just going wrong. That is not in the interest of patients, nor in our interest. It seems like you're being relieved but it gives twice as much work, because this other doctor sees the patient once between things, but he does not have the story and the policy in his head. And sometimes things are not done in a proper way then, or you miss certain things. It is just not in the interest of the course of chemotherapy. And afterwards I get all these things to be arranged on my desk, all the phone calls of things that are not correct. So finally, if you just would have taken a bit more time during the surgery hour, you would have been finished much earlier.

When indicating the possibilities for having a nurse practitioner take over substantial parts of treatment and improving the cooperation with this professional and with other colleagues through re-installing a weekly oncology meeting she stated:

Well, but of course it is… we can do it without a doctor. I see people from the community hospitals who say: "I've seen the doctor at the beginning and at the end of the chemotherapy and besides that I haven't seen him." So it's possible. I guess it can work out fine with all these nurse practitioners, but I'm used to intervening a bit and small complaints can easily be steered away

from. And that's why I see people briefly [before each time they get treatment] (...) And an oncology meeting doesn't cover everything and I think it shouldn't: that would only take more time. I thought we were working on solutions?! To improve things?!...

Only later it became clear that there was more to her critique than mainly the issue of the inefficiencies that were introduced by treating patients with a team of professionals. A nurse of the treatment centre could clarify some other reasons for the wish of this doctor to be the sole professional treating these patients. The nurse criticized the fact that this oncologist would overrule the biomedical limits that had been set to the treatment of patients in oncology trials and expressed the difficulties she faced when treating patients that were under the care of this doctor. Right after a disturbing event at the treatment centre where a patient had received treatment in a way that caused great suffering, she shared that she couldn't face the 'stress schemes' this oncologist was working with any longer. The rigid trial protocols clearly indicate after how many 'reactions' a patient has to stop the course of chemotherapy. When the treatment of the patient has to be stopped more than a certain number of times due to reactions of the patient, the course has to be terminated. However, this oncologist worked with her own additional stress schemes for the instances in which a patient was having reactions. The main exception was that she introduced having additional breaks of about half an hour after which the course was re-started. The nurse indicated that she felt she was forcing patients through treatment that was no longer bearable for them. Ironically, the full focus of the individual wishes of patients at times made a complete turnabout into a situation in which patients were *under the complete control* of this oncologist. The patient-centred repertoire provided unprecedented space for a medicalization of her patients that was much more substantial than the biomedical model would ever permit.

The way this doctor was reacting to proposed interventions for multi-professional cooperation like a weekly oncology meeting, the introduction of nurse practitioners, letting her patients be seen by colleagues and, later, the introduction of a nurse-led clinic were not merely attempts to prevent the segmentation of integrated care but also endeavours to prevent any form of inter-professional audit of the care that is delivered. This indicates that by focussing primarily on patient-centred care as situated in the inter-personal encounter between two human beings – a doctor and a patient – other possible issues of delivering highly complex patient-centred care are easily overlooked. What may at first sight look very sympathetic and patient-centred can in practice turn out to be highly coercive (Silverman 1987). This is the type of consequence of power relations in healthcare that we have been warned for above by STS critics of participative democratic approaches.

As we saw in chapter 3, at the end of the day this oncologist successfully resisted attempts to change her practice of 'patient-centred care'. Patients noticed that she was having less time for them and that they were often referred to colleagues.

Some of them told her that they were surprised about this change of policy. She then encouraged them to file an official complaint to the medical professor of the ward, since they were no longer receiving the quality of care they experienced before and were victimized to an efficiency move. As a result this professor spent a substantial amount of time answering those complaints and decided to release the imposed sanction.

Of course this is a rather extreme case of how patient-centeredness at the level of individual patients is not merely limiting, it also at times excessively empowers care professionals to use patients as puppets on a string. Within a healthcare setting, 'playing the patient card' is a powerful strategy. When patient trajectories are unique and patients should be treated by the organization as individuals, all kinds of inter-professional checks are bound to be weak. The risk of 'patient-centred care' empowering doctors in unprecedented ways is a phenomenon that is insufficiently documented in the medical sociological literature.

Before analyzing how the dichotomy of patient-centred care versus EBM can tentatively be refigured, I will now turn to an analysis of different forms of standardization and their relations to an intertwinement of personal, organizational and professional issues.

4.5 Dynamic processes of standardization

As proposed in the previous chapter, the intervention of developing pathways for the hematology/oncology clinic is far from original: the development of all kinds of integrated care pathways (ICPs) has been very much *en vogue* over the last few years (Pinder, Petchey et al. 2005). Proponents tend to ascribe almost mythical powers to care pathways. If spread is an indicator of succes, then pathways are surely succesful. For example, Kitchiner and Bundred claim that "[t]he rapid increase in the use of pathways supports the recognition that they can provide a powerful tool to facilitate the implementation of locally agreed multidisciplinary guidelines to promote effective clinical care" (Kitchiner and Bundred 1998). The strong claims by proponents that such standardization of healthcare practices can provide impressive increases in efficiency (Evans III 1997), effectiveness (Berdick and Humphries 1994) and patient- and professional satisfaction (Ford and Fottler 2000), supports recent policy developments which: "include the drive to standardise professional performance in an era troubled by revelations of professional misconduct post-Shipman, and the shift from professional discretion and variability to a more rules-based, audited practice" (Pinder, Petchey et al. 2005). The ICP movement thereby increasingly position pathways as 'rationalizing techniques' (Berg 1997) reducing 'practice variation'. In relation to the challenges that Western healthcare systems are said to be facing of an aging population, the increase of chronic diseases and the growing complexity of medical treatments (Committee on Quality of Health Care in America 2001) the lack of empirically robust evidence of the effectiveness of ICPs hardly seems to reduce the faith expressed in their transformative powers. And since the solution the ICP movement takes as a starting point is the development of Integrated

Care Pathways, most of the analytic and practical focus is on the methods needed for creating pathways and on ICT that supports their implementation and management[99] - though it is of course quite ironic that the zealots of EBM have hardly managed to assess the efficacy of their own instruments in accordance to their own requirements of 'evidence'.

The conceptual configuration of being perplexed about levels of practice variation, claiming the need to standardize care, and promoting the role of ICT as implementer of this 'solution' seems to be a recurring trope in the history of healthcare quality improvement (Berg 1997). However, it has also proven empirically problematic and bound to be subjected to severe conceptual critique.

Traditionally, it is this kind of standardization that critics hold responsible for creating "assembly-line medicine" (Ritzer 1992, pg 43) of which it is feared that simple, economically interesting care trajectories are standardized to a great extent at the expense of other forms of care – if only because it seems hardly imaginable that this same detailed ICP methodology is applied to all patient groups that need hospital treatment. It is the kind of development that, according to George Ritzer, will ultimately lead to the "dehumanization and depersonalization of medical practice" and is seen as part of the drive for efficiency as an ultimate and unquestioned goal of our society that Ritzer so whole-heartedly critiques through his McDonaldization thesis.

As analyzed in the previous chapter, both practically and analytically there seem to be severe limitations to the way in which the ICP movement increasingly seems to conceptualize the role care pathways play in the transformation of care[100]. If however, we follow the definition of situated standardization as introduced in chapter 3, and focus on the actual changes in medical practice as a result of standardization and on the perceivable renegotiations of orders and autonomies that come with the standards, this may change the value of pathways from "Taylorist devices for standardizing care and treating each individual in precisely the same way" to "means of affording individualistic treatment, while simultaneously creating organizational efficiency by 'tayloring' the organisation to the patient (rather than the other way round)" (Pinder, Petchey et al. 2005). This changes the focus from pathways as implementation techniques of standardized and evidence based medicine to processual learning devices for inter-professional quality improvement. What becomes important through this shift is no longer the pathway but the 'pathwaying' and this opens up new spaces for situating the activity of standardizing care practices and "do politics through standardization" (Timmermans and Berg 2003, pg 216). It is this form of pathwaying that I would like to propose as a practice of situating standardization in specific issues that follow from the analysis of the complexity of a care practice.

4.6 Patient-centred pathwaying as issue politics

The re-location of standardization in the actual issues that are faced in the practice of care delivery is a move that corresponds with a recent development of the re-appraisal

of the role issues play in articulating publics in political theory. The most important source of this focus on issues is the work of the American pragmatist philosopher John Dewey. In his classic work *The Public and its Problems* (Dewey 1927) he claims that "when consequences concern a large number, a number so mediately [sic] involved that a person cannot really prefigure how they are to be affected, that number is constituted a public" (Dewey 1927, pg 53). This statement is of interest here since it implies that in cases where issues are too complex for any actor to fully deal with them, publics are implicated in and articulated through those very issues. A public than becomes what Noortje Marres, drawing on Dewey's premise, calls "a community of strangers, or perhaps more appropriately, (…) a community of strange things" (Marres 2005, pg 58) that cannot be known a priori to the articulation of the issue. This re-conceptualization of the public as not existing *in abstracto*, but as only coming about through issues in which it is implicated, has consequences for the solutions that seem suitable for the settlement of those issues. Rather than proposing referenda, citizen's panels and other proce-duralist ways for dealing with problems, the articulation of issues becomes relevant since it is only through the issue that it becomes clear who and what is implicated (Latour 2005).

For our analysis of the reconfiguration of patient-centred care and standardiza-tion, the consequences of this redefinition are that it cannot be known on beforehand who is implicated in a particular issue in a healthcare setting. The relevance of proce-duralist approaches like involving client boards or having patients participate in the redesign of their care therefore has to be judged in the specificities of their setting. Patients may be attached to an issue only as subjects or victims (e.g. in the case of a project on the prevention on decubitus ulcers or post-operative wound infections) or as fully implicated publics (e.g. in the case of the speed of redesigned care trajectories that may allow patients to hear about their diagnosis from their oncologists on the same day as their first visit which may actually be too soon for anyone to cope with the perhaps dramatic diagnosis) which has substantial consequences for the way they would be involved in their settlement.

A consequence of this shift is that the IHI slogan "Nothing about me without me" becomes problematic because it does not take the articulation of *issues* as a starting point, but the articulation of *publics*. A serious risk of this approach is that many issues that are relevant to healthcare professionals and organizations, which may have serious consequences for the care patients get, are insufficiently addressed. Another conse-quence is that the narrow definition of patient-centred care as regarding the interaction between an individual doctor and an individual patient seems to shift away the focus from the many issues that complex healthcare settings are facing. Not only are issues of a more professional or organizational kind externalized to the notion of patient-centeredness; related issues of inter-professional checks that are to ensure the content

of medical treatment may even be positioned *counter* to the pursuit of making healthcare patient-centred.

Moreover, the present definition of patient-centred care and its translation to participative practices for healthcare improvement threatens to obscure many issues that cause great suffering for patients and care professionals alike. I hope to have shown that experiments with situated standardization, that focus on the articulation and settlement of issues, can refigure the ways care can be made patient-centred in more substantial and material ways. Pathwaying then truly becomes a dynamic form of doing issue politics.

Chapter Five

Competition in the Wild

Emerging figurations of healthcare markets

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In 1999 the Atrium Medical Centre, a large teaching hospital in the hills of the south of the Netherlands, jumped on the bandwagon of innovating joint replacement services by introducing a 'joint care' trajectory for their patients receiving a new hip or knee. Clustering patients in groups of five led to a group-dynamics where patients were inspired by each other's recovery process. Combined with an improved intramural coordination, the length of stay of these patients at the Atrium MC was reduced from an average of 18 days to about 6 days: a dramatic result both in terms of service levels, discomfort for patients and hospital costs.

In May 2005 a nearby clinic, the Maasland Hospital, which offers a similar joint care trajectory, announced that it had developed a new care arrangement for joint replacements called '*Healing Hills*', in which patients don't spent all their recovery time in the hospital, but are quickly transferred to a luxurious hotel in the area, Chateau St Gerlach (figure 5.1) to allow them to recover in the pleasant surroundings of the Limburg hills through which "The highest quality of care and the hospitality of Limburg"[101] are brought together. This arrangement was developed in cooperation with one of the smaller health insurance companies in the region, who was preparing itself for the opening up of the health insurance market on January 1st 2006 by creating an image of combining top clinical care with the typical southern Dutch *savoir vivre*.

The announcement received substantial local press coverage, and although managers and doctors of the Atrium MC laughed the 'innovation' off as "mere window dressing", they did recognize the potential consequences of this stunt on their image, and realized something had to be done.

On a service level, it was hardly possible to compete with the care that the Maasland hospital was offering. But on an economic level the Atrium MC figured they could become a far more interesting partner for the insurance companies, since the trajectory they could be offering might be substantially cheaper while of better medical quality. This was interesting since on January 1st 2005, a new financing system was introduced for Dutch hospital care, a type of DRG system, in which the price of about

Figure 5.1: Chateau St Gerlach

10% of all treatments has been made freely negotiable between hospitals and insurance companies[102]. Hip and knee replacements are within those 10% which made a sharp price vital for the upcoming round of negotiations. The management of the Atrium MC decided, together with their orthopaedic surgeons, to have a close look at their joint care trajectory and through an improvement project realized they could further reduce the length of stay to about 4,5 days for a total hip and to 3,5 days for a total knee replacement. They also figured they could expand their inclusion criteria due to which not merely 50% of the patients needing a new hip or knee could be treated in this way, but at least 80%. They made a business case for this redesigned joint care trajectory in which they brought together the financial gains of the proposed changes and the investments needed to realize the medical improvements that resulted in the shorter length of stay. Through this they realized that they could reduce their costs per patient with about € 700,--, leading to a total net increase of profit of about € 600.000,--[103] based on their present revenue per patient and production.

During the annual negotiation with CZ, the largest insurance company that has a market share of roughly 70% in this southern region, the CEO of the Atrium MC took a considerable risk: he put the business case on the table and showed not merely the gains of this redesigned trajectory, but even the total cost price for the Atrium. The insurance company appreciated his openness and reached an agreement in which the Atrium MC became the 'preferred partner' for knee and hip replacements in this region, and was allowed to expand their 'production' for this type of care. CZ would send a letter to all their clients that in case of a knee or hip replacement the Atrium MC is the place to be and CZ would support and attend the festive opening of their centre for elective treatment that would take place some months after the negotiations. They decided on a price that allowed the Atrium MC to have a reasonable profit and that still was substantially lower than that of the neighbouring hospitals.

The director was satisfied about this 'golden deal'; the risk he took by putting all his cards on the table seemed to have paid off. But the quality manager still had a major concern: the business case was still based on *proposed* changes and not on a realized result. Though it may be easy to sell this product at such a sharp price, she knew that it would be no sinecure to actualize the improved care process. She wondered whether the deal that was made would be helpful in realizing the changes that were needed, or whether the orthopaedic department would have a financial deficit next year.

5.1 Dynamic relationships between market mechanisms and healthcare delivery

Concerns about the relationship between healthcare delivery and market mechanisms have a longstanding history. Even the founding father of economics and the most iconic promoter of the 'free market', Adam Smith, argued in *The Wealth of Nations* that the invisible hand would display some imperfections when left to reign in healthcare. The trust patients should be able to have in their doctors and the importance for medical professionals to afford a solid education, would sit uneasily with a doctors' income at a

relatively low market value. Doctors wages therefore had to be protected through restricted admission to the medical profession (Smith 1776 (2000), chapter X)[104].

Some 230 years later, exploring and reconfiguring those very limitations of free market mechanisms in healthcare has become one of the main tasks for health economists. Following the founding father of health economics, Kenneth Arrow, who posed that "when the market fails to achieve an optimal state, society will, to some extent at least, recognize the gap and nonmarket [sic] social institutions will arise attempting to bridge it" (Arrow 1963, pg 947)[105], health economists have focused on the study and development of those very institutions.

In the light of the case shown above, it seems like claiming that markets can still be kept away from the healthcare domain (Godlee 2006) or that "healthcare is not a market" (Palm 2005) seems at best to be fruitless attempts to intervene in a political debate through what discursive analysts call 'factual reporting' (Edwards and Potter 1992)[106]. At worst it is somewhat of an empirical absurdity that leaves crucial questions about the specificities of the role of market mechanisms in healthcare improvement unaddressed. Yet this is exactly the structure of the present discourse on marketization in healthcare: a clear division between the protagonists of healthcare markets who claim that the efficient market hypothesis is similarly applicable to healthcare as it is to e.g. financial markets, and its critics who claim that the managerialization of healthcare is ruining the actual work professionals are carrying out. Ironically, these positions both leave the questions unaddressed on *how* market mechanisms in healthcare are made to work, what the 'others' of newly created market 'orders' are (Berg and Timmermans 2000), and what potential alternative figurations of market mechanisms could be. These issues are thereby largely left to health economists. This gives this particular branch of science an under-challenged position which is equally overlooked by those promoting the managerialization of all kinds of social services which has become known as 'new public management' (Pollit and Bouckaert 2000) and to critics of consumerism and choice in healthcare.

In recent years, the social study of markets has experienced challenging theoretical developments through the work of Michel Callon (Barry and Slater 2002b; Callon 1998a; 1998b; 1998c; 1999; Callon, Méadel et al. 2002; Callon and Muniesa 2005) in the direction of what is called "the performativity of economics" (MacKenzie and Millo 2003). Following the early work from Actor-network theory (ANT) about how scientific facts are not 'discovered' but enacted through *hybrid collectifs* (Callon and Law 1995) in the construction of which scientists play a crucial role (Callon 1986; Latour 1987; Latour and Woolgar 1986 [1979]), Callon has turned towards the ways in which economics is not merely discovering existing external market laws but is actively involved in bringing those laws into being. This empirical turn reconfigures the unit of analysis for economists and economic sociologists from the study of market laws *or* market practices to the ways in which markets are performed through the activities of economists. It opens up the

ways in which markets are enacted to empirical scrutinizing and creates "an abundance of ways of *seeing* economic markets" (Barry and Slater 2002b, pg 291, italics in the original). It also is highly consequential for the roles students of emerging markets play in their construction. As Callon puts it:

> The market is no longer that cold, implacable and impersonal monster which imposes its laws and procedures while extending them ever further. It is a many-sided, diversified, evolving device which the social sciences as well as the actors themselves contribute to reconfigure. (Callon 1998b, pg 51)

The study of the emergence of choice, consumerism and marketization in *healthcare* markets seems so passionately polarized that even the most vigorous proponents of the empirical analysis of medical practices, tend to take a priori sides pro or contra 'the market'.[107] Callon reminds us however that "it would be a mistake to be simply opposed to markets or to marketization" (Barry and Slater 2002a, pg 186). Through studying the performativity of economics Callon rather creates important normative acting space that has so long been reserved for economists and which is of both substantial conceptual and practical value. I therefore wish to explore in this chapter how the work of Callon relates to the experimental development of healthcare markets in the Netherlands. I will claim that the notion of the performativity of markets opens up the construction of markets to a multitude of actors who were analytically and practically excluded previously, like economic sociologists, anthropologists and researchers from the field of Science and Technology Studies (STS). On the basis of an interventionist STS project on the construction of healthcare (market) practices, I will pose that the involvement of such researchers in the construction of market laws may however be a less controlled and more risky process than suggested by Callon.

I will indicate that though Callon creates important normative spaces, he overlooks the complexity of ways in which mechanisms of perhaps carefully constructed markets display a multiplicity of consequences. The construction of (healthcare) markets is not an isolated project, but is entangled in what Laurent Thévenot calls "conventions (…) [which are] involved in the collective creation of 'forms of the probable'" (Thévenot 2002, pg 70). Relations may on the one hand be shaped through situated practices and local situations, but are simultaneously influenced by historically shaped 'investment in forms' (Thévenot 1984). Such investments are related to the creation of certain formats of information (Thévenot 2001, pg 407) which allow for specific forms of comparability and, therefore, probability. Examples of such forms are 'statistical probability', which requires a very different format of information than 'evidence based on proximity to a prototype' or 'law like probability' which requires objects in a series or 'plausibility anchored in proximity', involving localized and personalized things (ibid.). According to Thévenot, these types of probability afford different critiques and justifications and "sustain orders of 'worth' which people refer to in disputes and which have to meet certain political and moral requirements" (ibid. 409).

So where the story on emerging healthcare markets is on the one hand about the enactment of calculative agents through "the equipment and devices which give his/her actions a shape" (Callon 1999, pg 191), as Callon would propose, it is on the other a story on the ways in which information is formatted through calculative spaces and is thereby related to and shaped by earlier investments into particular forms of market laws that allow for particular forms of justifications. In this sense the 'opening up of healthcare markets' to social scientists will prove to be situated in 'forms of the probable' that are (also) shaped outside of practices of healthcare marketization and outside of the present moment. In a comment to the work of ANT scholars like Latour and Callon, Thévenot states that:

> "[t]he notion of network is very compelling because of its power to embrace in its description a potential list of entities which is much broader than the one offered by models of action and practice. But this notion tends to overlook the heterogeneity of links for the benefit of a unified picture of interconnected entities" (Thévenot 2001, pg 408)

The notion of 'forms of the probable' tries to deal with this lack of sensitivity for heterogeneity that depends on historic investments and on the historic enactment of forms of equivalences. Thereby this concept is highly consequential for the normative acting space for the experimental interventions of social scientists which are no longer acting in isolation of e.g. economization as an order of worth being related to the heavy investments into the forms of financial calculability.

I will propose that as long as the study of multiple ways of performing laws of markets ascribes special agential talents to materialities and sciences like economics, without paying attention to the historical investments that entangle certain interventions to habits, patterns, and specific forms of justification, this provides important conceptual and practical limitations for both more critical and more action-oriented research activities. As stated by MacKenzie and Millo, leaving the understanding of the historically specific situatedness out of the study of markets could lead to "quite mistaken conclusions about performativity" (MacKenzie and Millo 2003, pg 111). I will indicate that broadening Callonistic studies of the construction of (healthcare) markets by adding sensitivity to the 'forms of the probable' may be fruitful for overcoming the somewhat excessive present focus on the opportunities for STS scholars to experiment with shaping laws of healthcare markets in different ways. This may be helpful to sensitize social scientists for the risky journey they embark upon when getting actively engaged in the construction of (healthcare) markets.

In order to do this I will first point out the way in which the performativity of economics for economic practice relates to common notions in the study of markets. I will second point out some misreadings of Callon's contributions which help to seize the value of his contribution. I will third articulate some limitations of this approach and,

fourth, relate them to an interventionist research project in the present emergence of a Dutch healthcare market. Fifth, I will elaborate on the fragile connection between materialities of markets and market practices. I will conclude with proposing some conceptual changes that seem to be fruitful for the analysis of and involvement in the construction of markets.

5.2 Homo economicus or homo sociologicus

Students of markets have traditionally been divided into at least two camps.[108] The first is that of "'orthodox', rational, neoclassical (…) economics" (MacKenzie 2004, pg 303). It claims that market mechanisms work since all available information is processed by a fully rational, gain-driven *homo economicus* who makes choices in his or her own best interest. This implies rational agents who "are characterized by very specific and highly demanding competencies: they are calculating, know and pursue their own interest, and take informed decisions" (Callon 1999, pg 183). Neoclassical economics has been critiqued by economic sociologists and anthropologists for being mainly interested in the study of the abstractions of the market – its 'laws' – while insufficiently studying the empirical complexity of market*places* (Callon 1998b, pg 1). Rather than proposing a *homo economicus*, this second position proposes a *homo sociologicus* who acts in fundamentally different ways than that proposed by neoclassical economics. Had they not strayed from their initial unit of analysis, the econo*my*, economists had uncovered "empirical evidence that contemporary exchange rarely if ever works according to the laws of the market" (Miller 2002, pg 218).

By claiming that market laws are ideological models that economists try to model the world after, rather than an "empirical core to economic activity" (Miller 2002, pg 219), economic anthropologists brutally separate the 'modelled reality', the illusory product of economists, from the 'real reality', to which anthropologists claim special access[109]. Even if the domains of economic theory and economic activity are at times more interactive "it will be because the economists (…) are gaining such considerable power that they can transform the world to fit their theories" (Miller 2002, pg 229). So according to some economic anthropologists market laws either *should not* work in economic practice and if they *do*, it is because economists violate some pristine practice through acts of power. For this very reason Callon critiques this second position since "saying that economics has failed by neglecting to develop a theory of real markets and their multiple modes of functioning, amounts to admitting that there does exist a thing – the economy – which a science – economics – has taken as its object of analysis" (Callon 1998b, pg 2).

6.3 How economics performs markets and may be getting company

The third position, that Callon proposes, is radically different. It maintains that economics does not simply *study* the economy; it is actively involved in performing, shaping and formatting economic practices through the framing of calculative agencies. As often quoted, Callon states that:

"Yes, *homo economicus* really does exist. Of course, he exists in the form of many species and his lineage is multiple and ramified. But if he exists he is obviously not be found [sic] in a natural state – this expression has little meaning. He is formatted, framed and equipped with prostheses which help him in his calculations and which are, for the most part, produced by economics" (Callon 1998b, pg 51)

The crucial difference between this conceptualization of *homo economicus* and that of economic anthropologists is that the reality performed by economics is not a violation of the pure state of *home sociologicus* as this last does likewise not exist in and of itself but is the product of similar, albeit sociological or anthropological, prostheses. And like *homo economicus* exists once it is performed through spaces of calculability, similarly economic goods, or rather, products are only found as "the outcome of a double process of dis-entanglement and entanglement" (Barry and Slater 2002b, pg 292). For calculations to be performed both "the agents and goods involved in these calculations must be disentangled and framed" (Callon 1998b, 16) which means that a clear and distinct boundary needs to be created between what will be seen as within the space of calculation and what is outside of it. Economists have introduced the concept of 'externalities' to indicate what needs to be kept outside of the frame and what is within the boundaries. Only after this process of framing in which the order of "entities, states of the world, possible actions and expected outcomes of these actions" (Callon 1998b, 19) is established, it becomes possible to conclude calculation and perform a market transaction. Since this framing involves the mobilization and inclusion of elements which are only momentarily singularized but are inevitably implied in other framings, total framing is impossible.

The notion of the embeddedness of the economy in economics enables the study of the specificities of particular market configurations and the ways in which these might be configured differently. By opening up the construction of markets to empirical scrutiny, students of markets can start articulating an important issue that "neoclassical economists and economic sociologists alike seem to neglect [which is] the important question of the costs and investments of bringing calculative agencies into existence" (Tryggestad 2005, pg 590). Enabling the articulation of the issue of *cui bono* (Star 1991, pg 43), is one of the most substantial achievements of the empirical turns researchers from the field of Science and Technology Studies (STS) have made in the study of scientific facts and technology development. The earlier empirical turns are consequential for the present study of market laws: "the connections between techno-sciences and economic markets make both the orientation of technological developments and the organization of the markets more central and disputable" (Barry and Slater 2002b, pg 287). The focus on the performativity of economics opens up the normative conceptualization of "markets as political issues" (Barry and Slater 2002b, pg 287) which can either be studied critically or can be reconfigured actively through "experimenting

with new configurations" (Barry and Slater 2002b, 288). And it is exactly this experimenting with new configurations that is largely left to economists, when other social scientists either argue for or against markets. Exploring the situated normativities within those economical experimentations creates room for alternative instrumentations.

5.4 Sociological and economical readings of Callon

As argued above, the radical consequences of this move on the performativity of economics are easily overlooked by economic sociologists. The critique most substantively voiced by economic sociologists is that Callon may claim to focus on the constructed nature of *homo economicus*, but in his work he ends up "treating the economic model of the market as though it were core to actual economies rather than a projection of economists" (Miller 2002, pg 219). This criticism mainly springs from the fear that the moral agenda of economic sociologists of showing the reductionism implied in the belief in rational choice would be jeopardized (Barry and Slater 2002b, 292). It is the polemic relationship between economic sociologists and their object of analysis that makes Callon's refusal to conform to their notion of the market as *embedded* in and thereby separated from cultures highly suspicious. Hereby Miller overlooks that taking *homo economicus* seriously does not equal taking her/him at face value. It is exactly through taking the cumbersome work of economists seriously that Callon diffracts what *homo economicus* is, thereby allowing for economic ambiguity.

Besides economic sociologists, market economists may have a similar misreading of Callon. It could easily be stated that Callon's claims are in fact nothing new for economists. Or at least for health economists, for in the domain of healthcare the issue that markets cannot exist *in abstracto* but need to be enacted through infrastructures has been considered factual information since the work of Adam Smith and the analysis of Kenneth Arrow. In this way, Callon's claims are in fact nothing new for economists and are merely exploring the political economics of what Marx called 'commodification'. The difference between the claims of Callon about materialities and markets and the appreciation for market infrastructure within health economics and policy scientists are however substantial. The importance of market infrastructures is for example appreciated in a recent paper by Helderman, Schut et al. (Helderman, Schut et al. 2005). They state that market-oriented healthcare reform in the Netherlands has known three phases: first (1988-1994) there was a phase where there were serious challenges to etatist health policy plans by market-oriented policy programs. However, when it came to "decision making and *implementation*, the market-oriented program soon lost its impetus because it was technically too complex" (Helderman, Schut et al. 2005, pg 189, emphasis added). During the revival period of the etatist approach (1994-2000) "the government also persevered in creating the *technical and institutional preconditions* for regulated competition" (Helderman, Schut et al. 2005). When finally the market-oriented program revived (2001-present) in a 2001 reform plan, the odds for the

success of regulated competition had increased substantially "due to the technical and institutional adjustments that have taken place" (Helderman, Schut et al. 2005).

Their observation that "workable competition cannot be introduced overnight but requires prolonged investment in developing adequate systems of risk adjustment, consumer information and product classification" is quite commensurable to Callon's work on the ways in which economists are actively implied in *making markets work*. However, they leave the more radical normative acting space for discussing *what* this 'working regulated competition' *is* untouched since they maintain a distinction between an *infrastructure* that is created (consumer information, risk adjustment mechanisms, etc) and a *superstructure* that is implemented (the notion of regulated competition). This is all the more surprising since the specificities of the ways in which markets are performed through particular 'infrastructures' are evident in their study of the case of Dutch healthcare reform. One of the robust entanglements of the Dutch health system, is its politically and legally secured 'right of receiving care' the eroding of which can, according to one of the authors, only be balanced through the "duty of redistribution" of income and, in case of rising healthcare expenditure, ever increasing solidarity-transfers (Schut 2003, 16). Such spaces of calculation that enable the levelling of income effects or that enact the adjustment of insurance risks for the market of healthcare insurance policies (Ven and Ellis 2000) do not merely allow for the 'implementation' of 'regulated competition' but perform what health market mechanisms are in very specific ways. Since the authors do not problematize the consequences of the singularization of 'regulated competition', practices of 'ontological politics' (Mol 1999) are rendered invisible under the neutral heading of 'implementation' – as critiqued in chapter 3.

So one of the most radical points of Callon's study of markets is the way in which materialities are not merely infrastructure that are required for the implementation of market laws that economists study: both economics and materialities are agents performing market laws in particular ways. And, the claim is, so could others. How they could be doing this, is unfortunately an under-explored issue. I will now turn to the case on the development of a particular performance of healthcare marketization, in which I was actively involved as, one could say, one of the "[i]nnovative actors [who] are experimenting with new configurations" (Barry and Slater 2002b, pg 288) of healthcare markets.

5.5 Healthcare improvement and marketization: the case of Better Faster

In November 2003 the Dutch Ministry of Health, Welfare and Sport and the Dutch Hospital Association launched a large improvement initiative called 'Better Faster'. The initiative was presented as giving an impulse to the quality, safety and efficiency of the hospital care sector. It was also widely perceived as an attempt to point out the willingness of the Ministry to invest in quality in a time of dramatic changes in health policy. The initiative came at a time of a broad policy enterprise of creating 'regulated competition' for Dutch healthcare. In the following two years the Ministry was switching its

payment structure to a Diagnosis Related Groups (DRG) based system, was commencing the above mentioned competition for the price for a certain percentage of DRGs, and was introducing a new health insurance law which gave insurance companies a leg up for becoming ever more powerful players in negotiating healthcare quality and price. The aims of the improvement initiative largely resonated with the aims of the changes in the policy structure. The main assumption of the initiative is that healthcare delivery can

> "often be done faster or better. Faster, because care must be available when it is needed. Better, because it needs to be as safe, efficient and patient-friendly as possible. That is why we need to be more open about how we use both human and financial resources. We need to make it easier to compare the performance of care providers. So they need to work on the basis of clear norms and protocols. And good practice needs to be applied faster. After all, care providers have a lot to learn from each other". (www.snellerbeter.nl/english)

Through a range of activities, the initiative had to "prepare the hospital sector for the new care system" (ibid.).

The Better Faster initiative consists of three so called 'pillars': first, there is a set of activities aimed at increasing awareness of good practices, partly through an online 'best practice' database and partly through 'ambassadors' from large business firms who give their view on for example safety, logistics, or accountability in healthcare[110]. Second in January 2004 the Dutch Healthcare Inspectorate introduced a set of performance indicators for hospital care which was to be extended and improved over the coming years. Third a quality, innovation and efficiency collaborative was started in October 2004 with different 'Breakthrough projects'[111] ranging from the prevention of post-operative wound infections, prevention of decubitus wound ulcers, operation theatre efficiency, medication safety, blame free reporting, instant access to outpatient clinics, care process redesign for oncology care and elective surgery and a leadership project. For this third pillar there are national working conferences on each subject for the improvement teams from participating hospitals and each hospital receives substantial support through an advisor who spends several days a week supporting the various projects and advises cluster management and hospital board[112]. The collaborative was set up in three groups of eight hospitals, each hospital being included for two years at a stretch and each group starting one year after the previous one. These three pillars are supposed to strengthen each other to encourage various actors to compete for efficiency and high quality:

> "The aim is to help parties in the field improve their performance, starting with hospital and primary health care, where there is plenty of room for improvement. The programme does not only target care providers, since it is important for as many parties as possible to benefit from the activities being implemented under its aegis. It will help insurers, for instance, to see who is and who isn't adopting proven good practice". (ibid.)

This makes the intervention of Better Faster highly layered, with benchmarking as an approach to classify differences between hospitals, performance indicators to create a monitoring and accountability practice and the collaborative improvement program to achieve substantial improvements in the domains of patient safety and patient logistics.

Following the radical constructivist (Hagendijk 1996) study of the ways in which markets are performed, the Better Faster initiative does of course much more than merely preparing the care sector for the new care system; it is actively involved in performing healthcare as a market of a particular kind; a market where a reduction of price can go hand in hand with an increase of quality and patient-centeredness. The assumption that competition in healthcare is about increasing value (Porter and Olmsted Teisberg 2004) rather than about starting a price war, was widely distributed throughout the initiative. It was stressed that e.g. reducing the number of blood transfusions administered is both a patient safety issue and a major cost saving instrument, reducing the poorly funded inpatient days through the reduction of decubitus wound ulcers is both a way of making care patient-centred (according to the definition I introduced in chapter 4) and a cost saving well worth the investment in preventive mattresses (Manna, Steinbusch et al. 2006) and, as shown at the case that started this chapter, that a thoroughly redesigned care process will provide more timely care of higher quality at a lower cost.

The department of Health, Policy and Management of the Erasmus University Medical Centre is heavily involved in the second and third pillar of the Better Faster initiative. Researchers from this institute were responsible for the development of the set of indicators, following a highly experimental and pragmatic strategy in a debate on performance indicators that had long been dominated by scientistic issues of validation and accuracy[113]. The institute was also one of the three consortium partners running the third pillar, the other two being the Dutch Institute for Healthcare Improvement and the Dutch Order of Medical Specialists. The institute also happens to be the place where I work and I ended up becoming project leader of the process redesign project and hospital advisor for the aforementioned Atrium MC.

The care process redesign project is one of the places where the notion that creating patient-centred, high quality care is a 'business strategy' was most prominently situated. It is especially when looking at an entire trajectory patients go through, rather than e.g. the efficiency of individual organizational units, that the often uncoordinated steps which prove harmful to both patients and the hospital organization become visible. In one of the care process redesign projects in one of the participating hospitals this soon became apparent. In a multi-disciplinary group that was focusing on the care for patients with colon and rectum carcinoma and that was chaired by a medical specialist it was found that often patients where receiving colonoscopies more often than medically necessary in their diagnostic trajectory. Even when a gastroenterologist had performed the colonoscopy and had diagnosed the patient with cancer of the colon, a surgeon

would perform the same colonoscopy with a slightly different instrument. When discussing this finding in the project group, the surgeon indicated that the gastroenterologist did not register the distance between the anus and the tumour with sufficient accuracy even though this was crucial knowledge for the surgeon in deciding on a procedure: when the tumour was situated in the last 12-15cm of the large intestine, it was a case of rectum carcinoma which needed to be treated with a combination of radiation therapy and resection. When situated elsewhere it was a case of colon carcinoma where radiation therapy was not needed. Since the gastroenterologist was not aware of the importance of this information and therefore produced unreliable data, and since not treating rectum carcinoma with radiation therapy reduced the survival rate of these patients substantially, surgeons had started to perform their own colonoscopy with the sole aim of defining the exact position of the tumour. The meeting led to a change in the practice of gastroenterologists who started registering the location with more precision, which resulted in the removal of this double diagnostics. The result was an improvement of patient-centeredness since patients did not have to undergo highly unpleasant diagnostics more than medically needed, an increase of the safety for patients since colonoscopies can be a source of various contaminations, an enhanced effectiveness since treating the cancer did not need to be postponed till after the second colonoscopy, and an improved efficiency since costly diagnostic tests and valuable time of doctors were no longer wasted.

This is perhaps a moving case of healthcare improvement. The issue here is however *how* this instance of the performance of healthcare improvement as a business strategy was achieved. According to Callon:

> "[t]he weakness of sociology and anthropology [and, one could add, of most STS!] when they come to analyse economic activities is precisely their reluctance to do the same jobs as economics. Economists are able to tell how it is possible to calculate profits and so on, but sociologists do not provide these kinds of tools (…) [we should] devise our own tools, like the economists, but tools that will endow economics agents with the capacity to experiment with different forms of markets organization" (Barry and Slater 2002b, pg 300-301).

Within the collaborative we realized from the start that we needed to be able to provide such tools for calculating project gains and potential profits. Therefore, the care process redesign project created a space of calculability for the throughput time of patient trajectories. The two generic goals of the project where a decrease of throughput time whith 40-90% and a decrease of length of stay with 30%, while teams were encouraged to formulate care process specific goals on quality, efficiency and patient-centeredness domains since these could not be defined on a generic level for the many different kinds of patient trajectories that were involved. In order to know whether the fixed aims were being achieved *and* as a crucial intervention in the improvement projects, measuring throughput times became crucial. We therefore introduced a measurement tool which

would frame the steps patients go through as trajectories and which would generate run charts on the basis of that data (see figure 5.2)[114].

This measurement tool was performing care trajectories in particular ways. First, by separating the trajectory in various phases like 'admission time to outpatient clinic', 'diagnostic trajectory', and 'length of stay', specific problems in the organization of care were articulated. Second, through displaying both median and average of each indicator, it was rendered visible whether the process of a certain group of patients was highly variable or rather similar. Third, by adding an indicator like 'number of visits prior to treatment' we articulated the problem of many different visits that perhaps could be combined or, as in the case of the double colonoscopies, removed. The notion that gains could be realized through reducing the number of steps in the process was further supported through flow charts that each team made of the process they were working on (see figure 5.3). Combining these charts with the calculated waiting time for each individual step or phase in the process created an entanglement between quality of care, throughput time and the number of activities. Through positioning care professionals in the lead of the project teams, we also entangled them as those performing crucial data on throughput and as the innovators redesigning the care processes. In successful cases enthused doctors started creating their own devices, using the relatively simple features of excel to e.g. perform the inter doctor variability for certain forms of care. When presenting on a national working conference the different steps patients with the same disease would go through in their hospital, a vascular surgeon reported on stage in front of nearly 200 colleagues from sixteen different hospitals, that he and his fellow surgeons had found no medically valid explanation for the differences in their practices.
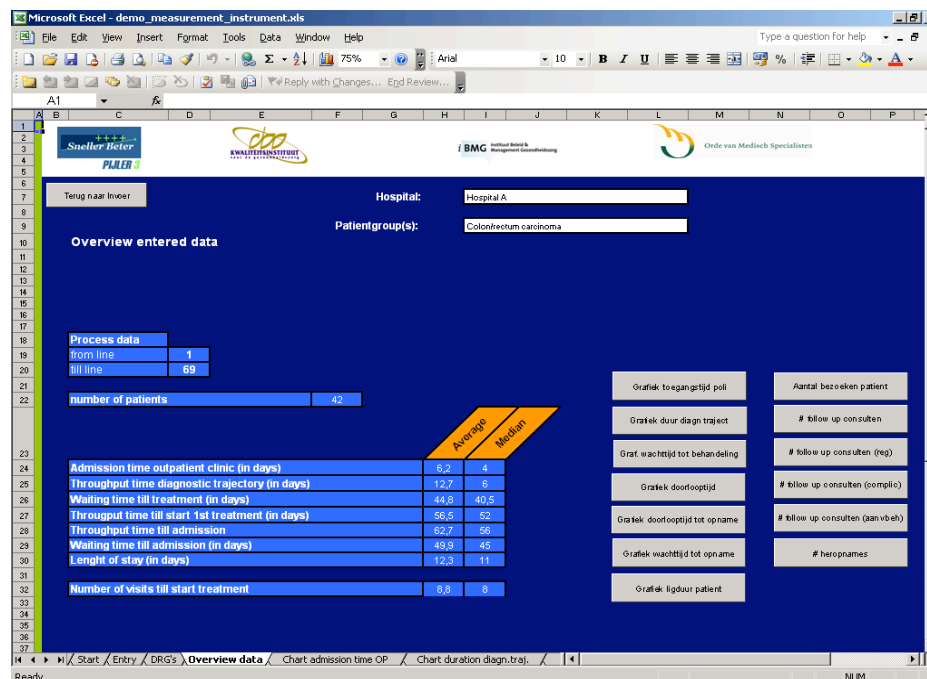

Figure 5.2: measurement instrument process redesign

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The development of these tools that performed the delivery of healthcare as processual rather than divided in separate episodes and disciplines was crucial for the entanglement of professionals in the improvement agenda. We however still had to perform the difference between current and desired processes as financially interesting, thereby framing quality improvement as a core business strategy for the Better Faster hospitals. Though Callon claims that "the idea of market organization as an open field of reflection and experimentation is making progress" (Barry and Slater 2002b, pg 299) he also states that the monopolization of the analysis of economic laws by economists who "perform the idea of pure markets, governed by natural laws" (ibid.) seriously impedes the emergence of collective learning processes. We however experienced none of this monopolizing and the cooperation with health economists and financial analysts in hospitals was extremely fruitful for the development of business cases (Leatherman, Berwick et al. 2003) of redesigned care trajectories[115].

The claim that "economists, by profession, tend to think in terms of a tug of war between the private sector and public sector" (Barry and Slater 2002b, 299) which would restrict the possibility of experimenting with an array of organizational forms with different normative consequences, is certainly not applicable to health economists. As stated, healthcare has always had somewhat of a *status aparte* in discussions on the 'free' market. It could even be assumed that the very notion of economists monopolizing discussions about potential market forms is mainly being performed through the distance economic sociology, anthropology *and* Callon seem to have taken from economics. Studies of the engagement of STS researchers with other scientific practices showed different disciplines to be "far from unified and in fact highly contested internally (…[with]) the strongest critique (…) com[ing] from within the discipline" (Kember 2003, pg 176). Paraphrasing Sarah Kember I would propose that the social study of markets requires a stance that does not singularize 'economics' by remaining distant from it, but that sees economics as an opportunity rather than merely a problem (Kember 2003, pg ix). For the project team of the care process redesign project, this allowed us to play a role of "engaging strategically with the differences within [economics]" (Kember 2002, pg 638) rather than one of "rehearsing endless critiques of conventional economics and often in a vain attempt, a delusion, that [we] might convince economists" (Barry and Slater 2002b, pg 301).

Our team received substantial help from some of the participating hospitals and from health economists at the department of health policy and management. For the development of a business case for the redesigned care trajectories in individual hospitals, the input of their financial department proved invaluable. They were carrying out calculations of cost prices per step in the process as part of the introduction of the DRG based funding system. Through combining these with our tool we developed a business case where 'the cost of poor quality' was rendered visible (see figure 5.4). In the case of
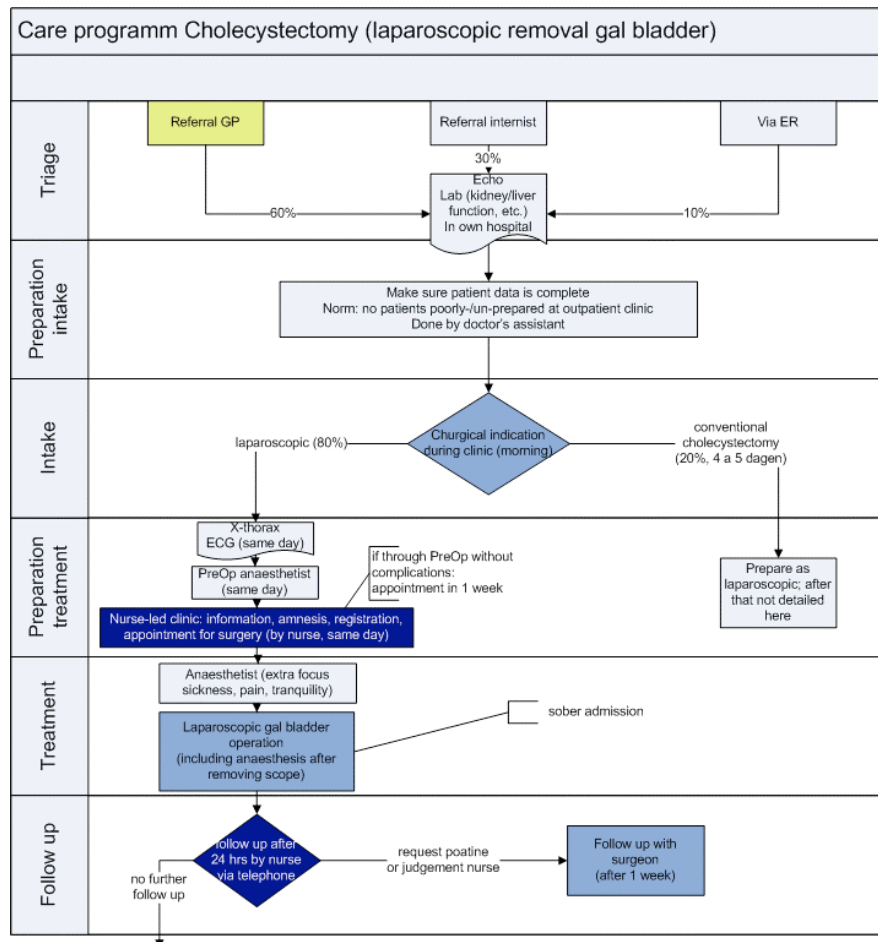
Figure 5.3: flow chart laparoscopic gal bladder

patients with colon or rectum carcinoma this resulted in a difference in one of the partici-pating hospitals of approximately € 950,-- per patient on a total cost prize of less than € 5.500,--

The development of these calculative devices proved highly consequential. The approach was adopted amongst others in the Atrium MC and soon after the first results came in, a board member presented the results of the redesign projects in both qualita-tive and financial terms to his management team in a presentation with the telling title *Returning to the essence; Top quality care with maximal profit.* This session resulted in the management embracing the redesign of care processes as their core strategy for the coming two years, aiming at having redesigned the care for at least 50% of their patients within that time. This same director also presented the gains and resulting strategy at a national working conference. The approach was incorporated in a report (Manna, Steinbusch et al. 2006) health economists and sociologists of the department of health policy and management published and distributed to all other Better Faster hospitals. The consequences also came back in an interesting discussion I witnessed between this director and a location manager (of one of the three hospital's locations) about appoint-

ing new nursing personnel for elective surgery. After having presented the business case on small surgical procedures like the laparoscopic removal of gal bladders, the director stated that the location manager could simply submit a proposal for extra nursing staff since he had a perfectly worked out business case to cover such an investment. "Just hand it in to me and I'll pass it through the board meeting next week without any problems", he stated. "But I don't need to", the location manager replied. "I'm exactly showing that I can cover for the investment of extra nursing time through the gains we realize by improving the process. And then I still have nursing time left to spare!". This was a rather extreme example of the refiguration of economic discussions in a hospital setting with a board member stating he could approve a claim for extra personnel and a manager refusing the offer[116].

fin.code	activity	profile baseline				desired process	
		frequency	price/unit	costs		frequency	costs
190011	Intake visit internist/GE	1,00	€ 33,15	€ 33,15		1,00	€ 33,15
411000	Return visit internist/GE	2,21	€ 26,52	€ 58,61		0,50	€ 13,26
190011	Intake visit surgeon	1,00	€ 30,19	€ 30,19		1,00	€ 30,19
411000	Return visit surgeon	0,69	€ 24,15	€ 16,66		0,10	€ 2,42
190011	Intake visit cardiology	0,17	€ 27,21	€ 4,63		0,17	€ 4,63
411000	Return visit cardiology	0,17	€ 21,77	€ 3,70		0,17	€ 3,70
	Pre-Op	1,07					
190035	Day treatment	1,02	€ 151,92	€ 154,96		1,00	€ 151,92
34686	Colonoscopy	0,89	€ 253,01	€ 225,18		1,00	€ 253,01
34690	Sigmoidscopy	0,22	€ 204,90	€ 45,08		0,05	€ 10,25
39876	Rectoscopy	0,46	€ 125,60	€ 57,78		0,00	
50501	Biopt (PA)	1,06	€ 42,94	€ 45,52		1,06	€ 45,52
87511	X-colon	0,30	€ 148,00	€ 44,40		0,15	€ 22,20
85002	X-thorax	1,02	€ 43,44	€ 44,31		1,00	€ 43,44
87090	MRI Abdomen	0,44	€ 278,84	€ 122,69		0,66	€ 184,03
87070	Echo stomach organs	0,80	€ 92,30	€ 73,84		0,66	€ 60,92
39494	Echo heart	0,09	€ 53,00	€ 4,77		0,09	€ 4,77
87042	CT abdomen	0,06	€ 235,12	€ 14,11		0,00	
07-_-_	Lab			€ 102,38			€ 102,38
34738	Colon resection	0,60	€ 1.542,00	€ 925,20		0,60	€ 925,20
35024	Anterior resection	0,35	€ 2.057,00	€ 719,95		0,35	€ 719,95
34732	Total colectomy	0,05	€ 2.814,00	€ 140,70		0,05	€ 140,70
	Inpatient						
190204	Inpatient days	12,30	€ 206,04	€ 2.534,29		7,00	€ 1.442,28
			Total: hard euro's	€ 5.402,08		Total: soft euro's	€ 4.193,91

Figure 5.4: business case colon/rectum carcinoma

With all usual reservations, it could be said that we seemed to be somewhat successful in performing the healthcare market as competing on value rather than merely on price. Through a dynamic process of creating collective calculative devices quality improvements and financial gains were entangled and health professionals and their (historically obvious) fear of budget cuts were dis-entangled. The redesign project team, doctors, Excel run charts, health economists at the department, care process flow charts, financial analysts of the hospital, DRG pricing systems, healthcare management etcetera were drawn together in the creation of a hybrid forum that performed an alter-

native market that had nothing to do with healthcare *adhering* to market laws but with actively configuring a specific kind of market in this healthcare setting. Where Callon states that "[i]f we accept that there is nothing which could happen without being framed, the role of the sociology and anthropology of economies is precisely to design tools and to provide actors with such tools" (Barry and Slater 2002b, pg 300), I would claim that the "performative activities of the social sciences" (ibid.) go even further. Besides the provision of other actors with new tools, STS researchers can claim a more substantive position through their active involvement in performing markets.

But of course such an interventionist STS approach to performing markets comes with theoretical consequences. An issue that is puzzling about the way market laws were being enacted is that where Callon ascribes a crucial role to the construction of calcula-tive collective devices, there seemed to be a more dynamic relationship between market activity and the availability and functioning of materialities.

5.6 Fragile devices, robust markets

According to Callon, the most important asset of Actor-network theory is that "ANT is based on no stable theory of the actor; rather it assumes the *radical indeterminacy* of the actor" (Callon 1999, pg 181), italics in the original). The main advantage of this point of ANT is that it opens up the social sciences to non-humans. It becomes possible to show the importance of technologies in performing the laws of the markets in specific ways. Through the spaces of calculation that are created in the interaction of Excel spread-sheets and run charts, project meetings and hospital information systems, quality collaboratives and hospital board rooms, market laws in healthcare can be performed in such ways that the viable vision for hospitals in the New Health Economy is to focus on optimally adding value. Following the strategy of 'drawing things together' (Latour 1990a) to create the entanglements and dis-entanglements, seemed to produce the calculative collective devices that were just fit for the job of creating a value law in marketized healthcare.

It was interesting to experience how relatively easy it was to reconfigure the notion of a cost-saving-based healthcare market into a value-driven one where other items than financial profit were articulated and entangled with costs in the space of cal-culation. It sure did not happen without effort, but how come it was feasible to perform this shift through creating such a space of calculation? The creation of calculative devices hardly seems to provide an answer here since the entanglements were often very loose and ambiguous. Many actors were jumpy and tricked the others in the space of calculation. Where insurance companies were framed as a key player in the perfor-mance of a value driven healthcare market, purchasing care that offered best value for money, there emerged huge differences between the various entanglements of the purchasing and marketing departments in some major insurers. Where purchasers were trying to get the best value deals with preferred providers, marketing pursued a strategy of stressing maximum choice for clients through having contracted all hospitals. Also the

measurement tools which seemed such faithful allies acted quite tricky at times, which could have raised the question whether they were actually 'working'. This is however not what actually happened. Rather, the 'working' of the tools was never questioned, despite the fact that they were severely unreliable.

This point became pertinent during a series of interviews conducted with two types of participants: the program managers of each hospital who were in charge of all projects in their location and the care process redesign internal advisors, generally having a background in quality management[117]. Those interviews were held after the first year of the project in all eight hospitals of the first Better Faster group.

Getting the teams started with using the measurement instrument was not the smoothest episode in the care process redesign project. Though hospitals and teams were generally content with the tool we provided for them in generating care process data, this hardly made their job less cumbersome. The production of outcomes and run charts was based on immense amounts of invisible work (Star and Strauss 1999) in hospital IT departments, the offices of quality coordinators, and the wards and clinics where the processes were taking place. Apologetic emails started flowing in once the deadline for delivering the baseline measurements had passed, medical professionals told me they were embarrassed that their IT systems were unable to produce the requested data and though virtually all projects managed to submit their measurements at the end of the day, they often had to make substantial investments of time and other resources to be able to do so. As one quality manager put it:

> [Generating data] has often been hand work. That even went as far as having an intern sitting with a stopwatch in the consulting room. Some things have just been tallied, measured. People were making lists. It hasn't been picked up as a normal part of the primary process.

In another hospital they measured by going through the paper-based patient records retrospectively and then introduced inserts for the later measurements to prevent having to go through the entire medical record to keep track of the trajectory:

> That was a hell of a job, after which you only have covered twenty patients and that than leads to an immense discussion. "I know that patient and there was this and that reason why it took so long". And now the continuous measurement, with the inserts, I just don't find that feasible. It just doesn't work. Period!

Despite all that handwork, the results often were far from complete. Many items that are needed for enacting trajectories in stead of mere events are not registered since the health market is still largely based on a pay-per-activity basis. This means activities are registered since they are reimbursed, but crucial steps in the care trajectory that are not accompanied by a chargeable activity are hard to trace. As one quality manager stated:

> Your most important measurement is still: when was the diagnosis finalized? And you just can't trace that back anywhere. The most probable moment is when

there is a visit with the doctor after lots of diagnostics. It just makes it really complicated. The only advantage is that the oncologists simply know their patients by heart, can name them and those files you just dig up, you can browse through them and thereby measure the results.

It will come as no surprise that program managers where in a hopeful mood about ICT developments in reducing this extra work. The goal of the Better Faster collaborative after all is to spread results and approaches throughout the hospital, and they could simply not see their employees merely generating measurements all day long:

> Now the art is to get those measurements ensured in the standing organization and make it a part of the work-process of that standing organization. And also a bit better than how we did the baseline measurements: we'll need to automate that. More handwork doesn't make anybody happy. I will not tolerate that our care coordinators will be merely walking around here on the wards making lists. They should be able to get this data on their screens in a very easy way.

However, also the ICT initiatives that had started in some hospitals proved demanding and far from easy solutions.

> Last year we hired someone at Planning & Control who started working on the system to see what we can get out of it. What will have to be registered at the point of care if you want to be able to subtract the data later on? You can generate some things from the system, but for the rest you simply have to dive into the patient records. And this person developed some methodologies to get reasonably reliable figures that were structurally argued against, because there will always will be differences [with the data from the paper-based records]. The question then becomes: how big can that difference be? What time can be invested in relation to the reliability of data? You just have to find a way in that.

In another hospital, attempts to make dashboards for redesigned care processes took many months and hours of ICT consultancy to realize. Some hospitals realized this demand would increase rather than decrease in the coming years and try to take this into account in their budget approvals.

> We did give a boost to our ICT strategy which should be focusing more on that but this will not always be in sync with the questions which come popping up from the projects.

Interestingly, the hard-won successful entanglement of some actors like financial IT systems and departments tended to produce the *dis*-entanglements of other actors who were crucial for the construction of a value-driven healthcare market:

> We really learned a lot from developing those business cases. It cost us huge amounts of energy, but we get an immediate return on investment for that the moment we start measuring. It was a major pain but I'm happy we did it in the end.

What caused most of the work? Why was it so hard to develop those business cases?

Perception, as far as I can tell. Professionals wondered: are you in it for the money or for the quality? It gave the scent of budget cutting.

After many years of budget cutting and financial targets, many doctors, nurses and ward managers were at guard for a project that was so warmly embraced by senior management and board. In some hospitals this development of enhanced managerial interest and the withdrawal of clinical interest was countervailed by specifying the financial gains for doctors and in some cases, where these could not be made visible, agreements were made to share hospital profits with doctors – even when these were employed by the hospital. Also, some hospitals entangled medical professionals by funding the time doctors were putting into the improvement programs separately, despite the fact that they should be profiting from the improvements as well. As one program manager put it:

> That's just how it works in society: "you're willing to put money in it so I guess it's important".

So the process of creating this space of calculation was far from unproblematic. Figures that were dearly needed to sustain the claim that process improvements were attained and were financially relevant, were absent, incomplete or at best generated through huge investments of time, energy and money. The entanglement of crucial actors threatened previous attainments in drawing things together. The issue of whether the devices we introduced 'worked' seemed highly contestable. Interestingly, they proved most valuable boundary objects, attaining different levels of validity in different settings. Where data could be highly contested in the setting of a project meeting with medical specialists, nurses, managers and consultants, that same data became 'harder' when being discussed in a project review with the board of directors, and yet harder on a national presentation by a board member for an audience of colleagues. The messy practices of generating indicators hardly seemed to affect the appreciation for the approach of entangling costs and qualities. This process of what Latour and Woolgar (Latour and Woolgar 1986 [1979]) have called purification prevented critique to the measurement tools. Rather it reinforced "an important 'looseness of fit' between the political economy of measurement systems in the form of policy demands for accuracy and control, and their instrumental features" (Power 2004, pg 769).

> This simply means providing care, what we're doing here is running a business. And we're rapidly improving that (…) You've got lots of indicators, that you can all start measuring. But the point is of course to get those indicators that give you the quickest overview in how the process is running. (…) I actually only want to see the deviations. I'm not really interested in the figure; I want to see whether the light is green, red or yellow. How does it look? I want to see the overviews of departments, but I really want that people in those departments become aware that they'll have to work on this. This also applies to our ward managers. They are

directly present in the care process. When I drop by at the ward they should, in a way, when I ask them: how many patients are waiting for discharge here? They should be able to say: zero, four, three, like that. Or on quality: how many patients are having pain-score x? When I ask people now they are not aware, they don't know. They all do their best, they are all doing a good job, but they are just not working on that. Though that is something that can really tell you something about how things are going in the hospital. How many O.R. cancellations are there in the hospital? That's telling for how the process behind that is organized.

Ironically, the expectations higher management had of the usefulness of such indicators in simple dashboards seemed inversely proportional with the success of their teams and ICT departments in generating indicators with relative ease. The issue of the performance of value driven health markets despite the absence of reliable materialities that articulate laws of healthcare markets in unequivocal ways therefore poses a theoretical puzzle that is hard to solve within Callon's approach. I will therefore conclude with some reflections on what this experiment with the development of laws of Dutch healthcare markets has to offer for the social studies of markets.

5.7 Economists and materialities as the right stuff? Historicity, probability and the sociology of markets

Callon's claim that "it is impossible to think of markets and their dynamics without taking into account the materiality of markets and the role of technological devices" (Barry and Slater 2002b, pg 285) certainly has proven of value for opening up the way in which sociologists have been studying markets and have been relating to the experimental shaping of market laws. The focus on materialities does however at times seem to relinquish ANTs highly praised indeterminacy of the actor for a privileged agential status of material tools and of economic scientists constructing them.

In the story based on Garcia's (Garcia 1986) study of the transformation of the table strawberry market in the French Solonge region, Callon seems to produce an actor who's strength can be compared to Latour's heavily critiqued enactment of Pasteur (Latour 1988):

> "In the construction of the strawberry market, a young counselor of the Regional Chamber of Agriculture played a central part. The remarkable thing is that his action was largely inspired by his training in economics received at university and his knowledge of neoclassical theory. The project, which he managed to launch through his alliances and skills, can be summed up in a single sentence: the construction of a real market on the pure model of perfect competition proposed in economic handbooks (…) [I]t is no coincidence that the economic practices of the strawberry producers of Solonge correspond to those in economic theory. This economic theory served as a frame of reference to create each element of the market" (Callon 1999, pg 191-192)

However seductive this explanation is we are reminded by early critics of ANT (Amsterdamska 1993; Bloor 1999a; 1999b) not to overstate the agential strength of (economic) scientists since they are acting in splendid *nor* historic isolation. Callon's account however does not situate this counsellor in a wider range of practices that probably were crucial for allowing this Solonge strawberry market to emerge.

In order to understand the successful construction of strawberry markets and the performance of healthcare value markets despite the at best questionable functioning of the tools to enact its calculability it is relevant here to focus on what Luc Boltanski and Laurent Thévenot call 'regimes of justification' (Boltansky and Thévenot 1991). Such regimes and their strength are relevant when analyzing the concepts STS scholars and economic anthropologists bring into play when trying to articulate the 'other' of economic 'orders'. Concepts mentioned above by Tryggestad like "costs and investments" and the "*cui bono*" issue of Star are strongly related to "market worth" (Thévenot 2002, pg 63). Capturing the others of marketization in a kind of 'political economy' indicates the strength of economization when social scientists and others make justifications.

The involvement of STS researchers in performing market laws is situated in what Svein Hammer, following Michel Foucault[118], calls "[t]he interaction between *technologies of government* (concrete techniques, calculations, procedures, programs, etc) and *governing rationalities* (more abstract processes of reasoning, conceptualization, discussion, etc)" (Hammer 2006, pg 5, italics in the original). Such governing rationalities, or 'logics' (Thévenot 2002) of economics are historically specific and are strongly linked to other practices of marketization in what was once called the 'public' sector. The arguable successes of transforming practices of e.g. postal services, tele-communications and the energy sector from heavily regulated systems into mail-, telecom- and energy markets is now consequential for the strength that market logics have in healthcare. The marketization of other 'public' sectors has locally been far from unproblematic and has always required much work for the creation of calculative spaces to be even remotely successful. Yet, collectively these market practices attain a 'robustness' that cannot be reduced to either of these practices[119]. Furthermore, they are shaped by and contribute to the "collective creation of 'forms of the probable'" (Thévenot 2002, pg 70) of 'public' goods being translated to financially priced and ranked items.

In this sense the enthusiasm that Callon may inspire for the involvement of STS researchers in performing and re-configuring markets should rather be tempered through an understanding of a *dual meaning of such 're-configuration'*: on the one hand this entails a process of *figuring anew* healthcare market practices through drawing together heterogeneous agencies, and on the other it will produce the *repeating of figurations* that are existent in healthcare and other practices through the strength of probable market regimes that follow out of an investment in forms. There is therefore all likelihood that though in various participating hospitals the price for treating cancer of the colon was reduced through improvements in the process for patients suffering from this disease,

this will quickly translate into a maximum price for treating such illness with hospitals focusing mainly on shortening length of stay without making the necessary improvements in their care process thus performing a healthcare market that is driven by a price war. This is the kind of 'justification' (Boltansky and Thévenot 1991) which the form of comparison on price may have made probable.

Another noteworthy instance of the ways in which STS researchers are tricked by the 'forms of the probable' comes to light when comparing two versions of an article on the second pillar of the Better Faster collaborative. In an early version of their paper on the development of indicators for the Dutch Healthcare Inspectorate Berg, Meijerink et al. indicate their intentions with their strategy for the experimental introduction of such a space of calculation:

> [O]ur 'feasibility first' philosophy emphasized that our aim was to start a process of self-improvement, of increased attention to accountability and the legitimacy of the public's question for transparency. It was not a 'ranking' we were after, nor an attempt to provide a flawless and transparent map of the hospital landscape. Such an attempt could only have invoked debates about the accuracy of map [sic], and the injustice of some of the representational techniques selected. Rather, we opted for a deliberately rough and multi-interpretable map, leaving the hospitals free to add explanatory markings and legenda, and work from there. From such a map, no simple overall rankings could be made, but many more or less interpretative comparisons between individual hospitals or scores would be possible. (Berg, Meijerink et al. 2004, pg 15).

In the published version of their article this paragraph has largely remained untouched. It is however no longer the ending of their discussion, but it is followed by the following paragraph:

> This strategy has proven powerful. The Inspectorate received little true opposition to the request for the indicators, and hospitals were fully responsible for the publication of their own information. *When the national news paper did rank the hospitals*, public discussions mostly turned to the as yet rather incomplete data as delivered by the hospitals, and about the ranking method used by the newspaper. (Berg, Meijerink et al. 2005, pg 70, emphasis added).

By the time their paper has been published, their aim of not providing simple rankings had been overtaken by one of the largest Dutch newspapers which provided *exactly such rankings*, which are now published on an annual basis. Opposed to what is suggested by Berg et al. the mere existence of these rankings was of course highly consequential for hospitals, which became clear during the kick off meeting of the quality collaborative. This meeting coincided with the first newspaper publication of the ranking

on the basis of the performance indicators. Some participants were quite upset about this. As one of the quality managers indicated:

> Together we are in the earliest stages of building these indicators and all of a sudden we are comparing it! (…) This publication in the [newspaper] was initiated by Better Faster. It is a bit too much of a coincidence to have [the kick off meeting and the first publication of the ranking] on the same day (…) Those colleagues of yours just shouldn't mess with us like that!

One of the senior managers of the participating hospital that was ranked the lowest spent a large part of the day glued to his cell phone in the corridors of the hotel where the kick off meeting was held, explaining to journalists of the local newspaper why he was at some fancy national meeting while it was 'shown' that his hospital was a mess. Local media reporting on the ranking of a hospital display little sensitivity for the far from reliable production of these indicators and to the ecology in which the information becomes knowledge (Berg and Goorman 1999; Brown and Duguid 2000; Star 1995). What was left for this manager to do was to indicate that the reason he was at the Better Faster meeting was exactly to improve the quality of the hospital. During the first year of the Better Faster collaborative this hospital certainly did not excel on all aspects. However, they managed to strategically focus on such improvement issues which counted most as a result of which they mounted the charts to one of the highest positions in the second year of publication. Once again this indicated that "[w]hat's measured is what matters" (Bevan and Hood 2006).

It could be stated that providing a public space of calculability while expecting calculation by actors other than the Inspectorate not to take place displays little sensitivity to the probability of ranking that is enacted through the production of healthcare performance indicators[120]. Once such consequences are realized, it is of course the question to what extent STS researchers are able to actively shape laws of markets differently or to what extend their initiatives need to be in line with prevailing and probable governance logics to be successful.

To prevent that creating financial calculability becomes too restrictive for enacting the multiplicity of the "orders of worth" (Thévenot 2002, 61) in healthcare, a sensitivity for prevailing regimes is indispensable. Hospitals, healthcare insurance companies and regulatory bodies all deal with such multiplicity and can even be seen as "compromising device[s]" (Thévenot 2001, pg 411) entangling a plurality of worlds and worth's. Insurance companies like the one presented in the opening case to this chapter have a long tradition of discussing both price and quality with hospital directors and doctors. They distribute 'care innovation funds' on an annual basis and hardly reduce negotiations to financial outcomes alone. Since such regimes of quality improvement are equally present and institutionalized, this enhances the chances for the creation of a value-driven healthcare market. Yet, the strength of the order of worth of financial economization may prove such a probable form that the entanglement of price and other

worthwhile aspects of healthcare practices is jeopardized. Such a market regime which privileges financial calculability over other forms of legitimate evaluation (Thévenot 2002, 61) has become highly common for other 'competitive public services' which may contribute to the silencing of a more diverse set of consequences (Dewey 1927) in laws of healthcare markets as well.

Including the strength of regimes of economization in relation to other orders of worth in the analysis of doing ontological politics through enacting specific (healthcare) markets refigures the role of actors to which Callon attributes a privileged agential status: economic scientists and the "equipment and devices which give his/her actions a shape" (Callon 1999, pg 191). In this sense it becomes possible to display relations between various contemporary market practices in and outside of healthcare and the consequences they have for the mobilization of possible futures, promises and expectations (Borup, Brown et al. 2006; Brown and Michael 2003) for newly emerging markets in spite of their far from optimally functioning materialities. Such relations will be highly consequential for emerging (healthcare) markets and this broadened understanding may prove invaluable for sociologists, anthropologists and STS researchers exploring the frictions within (health) economics and getting actively engaged in performing specific (healthcare) laws that afford plurality of orders of worth. Not only can they be aware of other practices which they can entangle, they will also become more sensitized to the tricky and complex field they enter where their experimental configurations of markets may enact market laws in ways they were exactly trying to prevent. This sensitivity is much needed in what I, paraphrasing Edwin Hutchins (Hutchins 1995), would like to call interventionist studies of 'competition in the wild'.

Conclusion

Loyalties, Betrayals and the Ethics of Specificity

© Simon Kneebone, Yoland Wadsworth and Teun Zuiderent-Jerak. [121]

"Ethics has much to learn from modern technology studies,
in which the intimate intertwinement of technology and society
is exposed in minute detail"
(Keulartz, Schermer et al. 2004, pg 12)

"[P]eople in general know where they are
because they know that they (their ideas) have come
from somewhere else now necessarily 'forgotten'"
(Strathern 1991, pg 55)

When Elizabeth Costello, the main character in the novel of the same name by J.M. Coetzee (Coetzee 2003), is standing in front of 'the Gate', she is asked by the gate-keeper to write up a statement about what she beliefs in. In her first attempt, she claims a dispensation from the condition to enter, by composing a statement that says:

> "I am a writer, a trader in fictions. I maintain beliefs only provisionally: fixed beliefs would stand in my way. I change beliefs as I change my habitation or my clothes, according to my needs. On these grounds – professional, vocational – I request exemption from a rule of which I now hear for the first time, namely that every petitioner at the gate should hold to one or more beliefs".

Unsurprisingly, the request is not granted. The gatekeeper drops the sheet of paper on the floor and hands her a new sheet saying: "What you believe".

Her second attempt is slightly more successful. It passes the gatekeeper and she gets to appear in front of a team of judges for whom she has to defend her declaration of belief. She claims:

> "I am a writer, and what I write is what I hear. I am a secretary of the invisible, one of many secretaries over the ages. That is my calling: dictation secretary. It is not for me to interrogate, to judge what is given me. I merely write down the words and test them, test their soundness, to make sure I have heard right. Before I can pass on I am required to state my beliefs. I reply: a good secretary should have no beliefs. It is inappropriate to the function. A secretary should merely be in readiness, waiting for the call. In my work a belief is a resistance, an obstacle. I try to empty myself of resistances".

When questioned by one of the judges who states "Without believes we are not human", she claims that she is not bereft of all belief, "I have beliefs but I do not believe in them. They are not important enough to believe in. My heart is not in them. My heart and my sense of duty". Her heart and tests are insufficient grounds to grant here entrance through the gate – perhaps they are insufficiently disembodied – so she has to make a third attempt.

This time she claims to believe in what is there, regardless of whether she believes in it or not. She believes in the frogs that appeared in her childhood when the rains came back to the Australian land she grew up in. She believes in the river that the frogs live in. "I believe in what does not bother to believe in me". When confronted by a judge with the contradiction with her second declaration, she claims that her present 'she' is a different one then the one 'she' was then. Both are real and neither is. "I am an other". When they give up on her, she states "I am not confused". "Yes, you are not confused. But who is it who is not confused?", her judges ask, before first starting to giggle and then losing all dignity and bursting out in a roaring laughter.

When later that day she meets the gatekeeper, she shares that it didn't go all that well. She asks if she stands any chance to make it through the gate. He states: "We all stand a chance". "But as a writer", she insists, "what kind of a chance do I stand as a writer, with the specific problems of a writer, the specific fidelities". The gatekeeper says it's not up to him to decide on this. But when she asks if they meet many people like her, in her situation, he finally looks up from his work and says: "All the time. We see people like you all the time".

For many STS researchers, the problem that Elizabeth Costello runs into sounds highly familiar. Their stubborn unwillingness to separate what they believe in from the situated-ness in which something seemed worth caring for is at times confronted with settings which preclude such ethical flexibility. There seem to be continuous requests for 'getting real' about the normativity of interventionist agenda's in academic, policy and hospital settings (Bal, Hendriks et al. 2004), where part of these agenda's is exactly to do ontological politics by ethnographically elucidating the normative complexity of sites and situating oneself in ad hoc ways, as illustrated in chapter 1 of this thesis. Normativities may be rightly tested at the time, but are not important enough to believe in.

Such fidelity to specificity is challenged in different ways in different settings and to analyze these differences is important for empirically scrutinizing the potential of inter-ventionist experiments within STS. As described in chapter 2, the situated normativity of practices of home treatment in hemophilia care was that it proved important to enhance compliance through situated interventions. The combination of patients dealing with scarce medication that required careful handling in order to be effective, the redistribu-tion of medication to other patients when coagulation factor concentrates came back from holiday sites and the somewhat unusual position hemophilia doctors who are often visitors to a steady group of chronic patients, seemed to justify attempts to improve adherence to treatment. Experimenting with compliance enhancing devices like tem-perature loggers therefore seemed to be appropriate to perhaps alter this balance slightly. This however raised substantial criticism in some academic settings where this act was seen as 'disciplining patients'. Similar issues were raised by critics at confer-ences when I posed situated standardization as in some cases contributing to the

specific enactment of patient-centeredness, a point I made in chapter 4. Medical sociologists stated that I was being subsumed to or had 'gone native' in quality improvement agenda's. At the same time hospitals participating in the Better Faster collaborative asked for an overview of the steps they had to go through in their process redesign projects and the interventions that would allow them to 'implement best practices', which would exactly prevent the kind of learning experience that would enable hospitals to situate standardization in the specific issues they articulated. The process redesign team managed to translate the highly problematic agenda of best practice implementation by introducing an 'intervention database' which allowed participants in projects to see which interventions were tried out in any of the other 35 projects in other hospitals. The database allowed them to see what they were doing, but gave such minimal information that the teams could actually only make use of it when contacting the team member of the other hospital who was responsible for that project. In this sense we could keep our fidelity to the specificity of *why* a practice is 'best', rather than getting lost in an implementation agenda – with all its corresponding problems described in chapter 3. Though some participants appreciated the approach we followed here, others challenged this fidelity by stating that the integrated care pathway (ICP) approach was much easier to 'apply' since it provided 32 steps that should be followed.

Other STS researchers who engaged with practices in more interventionist ways experienced similar issues. One of the more vivid recent example of the way 'fidelities' of STS researchers were refigured as 'beliefs', is the case where the epistemic authority of STS was literally 'put on trial'. In the legal case of the *People v. Hyatt* (2001) the acceptability of an STS 'expert', Simon Cole, testifying on the scientific credibility and admissibility of forensic fingerprinting evidence was himself subjected to an admissibility hearing (Lynch and Cole 2005). In this case Cole ended up being refused admission as an expert on fingerprinting and in an oft-quoted ruling, the judge stated that: "what Dr Cole offered here is 'junk science'" (Lynch and Cole 2005, 292). The analysis by Lynch and Cole of this not unequivocally successful case of intervening in legal practices offers interesting space for further reflection on the issues of intervention and STS presented in this thesis.

Two matters seemed to seriously limit the acting space for Cole; first there was his asymmetrical move to claim epistemic authority as an STS scholar about the credibility of fingerprinting through his deconstruction[122] of its scientific reliability. This of course resulted in an ironic 'constructivism based truth claim' within the tensions of which it became hard for Cole to manoeuvre. Just as issues on the 'truth' about climate change have shown that it is questionable "to what extent (…) such a constructivist stance leave[s] room for speaking truth to power" (Demeritt 2006, pg 458), it proved problematic for a constructivist to try to speak truth to law. Rather than following recent asymmetrical pleas for STS researchers claiming 'expertise on expertise' (Collins and Evans 2002), Lynch and Cole conclude that a less problematic authority is to be

expected from "immersion in the subject matter" (Lynch and Cole 2005, 297) that one is dealing with.

Second the setting of a court is strongly enacting dichotomies and its actors are continuously doing 'boundary work' (Gieryn 1983) enacting true/false, scientific/ unscientific, admissible/not-admissible, guilty/not-guilty couplets[123]. The point here is not to claim that such dichotomies are problematic per se and tune in on what Casper Bruun Jensen has rightly called "a mainstreaming of the dissolution of the dualism" (Jensen 2004, pg xii)[124]. The issue is rather that there seem to be specificities to the ecologies in which experimental interventions can evolve. Different settings grant experiments of different sorts with other dualisms and other possibilities to dissolve them. The cases presented in this thesis and those of Cole and Costello articulate the question under which circumstances interventionist experiments can occur and what their specificities are. This is an issue worth reflecting upon when exploring the acting spaces of iSTS.

Ecologies of intervention[125] – socioinstitutional histories

When comparing the challenges Cole faced with her own practices of engagement with her field of study, Randi Markussen remarked that "it seems easier to ascribe rhetorical authority to STS within information technology studies and computer science than within the social science field of public understanding and law" (Markussen and Olesen 2007). She relates this phenomenon to the long-standing and quite productive connection between sociotechnical approaches of studying ICT and information systems development in Denmark. Since such a relation is not there to the same extent for Cole to draw upon,[126] his situation is quite a bit more precarious. This implies that histories of 'acting with' configure the acting space for present practices of iSTS and such a sensi-tivity for ecologies of intervention and their histories, their conventions and routines (Thévenot 2002) may be useful for reflecting upon some of the limitations for experi-menting in different technoscientific practices.

In a similar comparison, Steve Brown notes that the acting space for STS researchers in management practices seems to differ from such space in many scientific practices: though "[s]cientists and managers are equally involved in the provisional production of order, not least through the deployment of calculative means (…) managers seem to need management scholars (for whatever reasons) in a way that scientists do not appear to need STS scholars (perhaps yet)" (Brown 2004, pg 3-4). This existing relation between management studies and business can become productive since there at times seems to be a "direct and fairly compelling affinity between the work [of] management scholars and STS'ers" (Brown 2004, pg 5). The absence of such a clearly articulated productive relationship makes Cole's experiment more problematic and the setting of a court hardly seems to be a place to open up such acting space.

The cases presented in this thesis are situated in practices of health manage-ment and health policy. This is a field that the Department of Health Policy and Management where I am professionally based has been co-constructing for many years.

These historic relations between the department and Dutch healthcare institutions and the present involvement of many colleagues in healthcare improvement projects make that healthcare professionals and institutions tend to see the department as a resource for thinking and acting with them. As elaborated in chapter 1 and 3, this has consequences for the ways in which spaces for intervention can be created - 'intervention' is often even expected by healthcare professionals - and for the way in which the issue of 'access' that often poses problems in ethnographic studies (Winthereik, de Bont et al. 2002) is reconfigured substantially. This institutional setting with its many connections to healthcare practice has proven consequential for the rhetorical authority I could claim as an STS researcher. The point here however is not to claim that there are organizational domains and institutional settings in which access and space for intervention is unproblematic. Interestingly, in case of the Better Faster collaborative objections to interventionist practices were raised by commercial healthcare consultancy agencies. One of the founders of one such a firm protested to the Ministry of Health and stated that the government funded quality collaborative was creating 'market imperfections' for the healthcare market this ministry was trying to construct and – not unimportantly for their own commercial aims – also spoiled the healthcare consultancy market. This issue was resolved by including a small number of consultants from this firm into the collaborative, thereby giving them a piece of the pie. This did however further increase the already stunning complexity of this program. Alternatively, as the Better Faster program was intended to be a 'quality improvement collaborative' for which an outside institution (NIVEL) was hired to do the evaluation, the directorate of the program especially warned me and my colleagues from the department of Health Policy and Management that our work was not to be seen as research, separating this from the advisory roles we were supposed to take and thereby reinforcing boundaries rampant in the (bio)medical sector. This once again shows that practices of engaging with fields are not merely a pratice of 'sorting once attachments' (Jensen 2007) but also, as I indicated in chapter 1, of 'getting once attachments sorted'.

Ecologies of intervention – teaching as/and intervention

The acting space for iSTS is also constantly cultivated through the teaching programs that are offered to (future) healthcare managers and policy makers. The courses that staff from the STS-inspired research group teaches on medical technology, knowledge management, healthcare governance and healthcare change management would of course not generally be qualified as STS courses but they have been heavily infected by this field and by (somewhat) related fields like critical management and organization studies. Through such courses there is a continuous production of partial connections between practices of STS and healthcare management practices that may result in future opportunities for further methodological and theoretical experimentation and will contribute to what Mike Lynch has called "a 'public understanding [of social science]' that is already bursting at the seams" (Lynch 2004, pg 6). That the creation of such surfeits is

fruitful became clear when one of the oncologists specialized in palliative care stated during the project at the hematology / oncology ward that she was interested in our project since she was quite fed up with medical sociologists who she encountered in her medical training who refrained from entering the normative complexity she was trying to maneuver on a daily basis.

> Then you have someone like Anne-Mei The [referring to (The 1999; The, Hak et al. 2000)] who comes and tells me that I don't communicate sufficiently and unequivocally with patients about the inevitability of their dying. Well, it's interesting, but it's nothing I'm not already aware of: that's what I'm trying to deal with all the time! But she doesn't tell me what we can do to create the time I would like to have to talk with my patients in a more calm and clear way.

This was an interesting instance of knowledge translation, since Anne-Mei The does more than state that doctors do not take the time they should take for patients. The mainly focuses on instances where even when patients and doctors do communicate, oncologists can be enthused about a 'good response' to palliative treatment, while patients mistakenly but understandably take this as a sign that there may be hope for their survival (The, Hak et al. 2000). But at the same time this oncologist in the project points exactly to an uncomfortable feeling about the absence of organizational complexity in The's analysis that is highly familiar to an iSTS researcher. Where the approach of situated standardization is exactly aiming at the entanglements of organizational specificity and the content of care that is being delivered as described in chapters 3 and 4, The's focus on communication seems to leave the materialities in which those interactions are situated untouched. The abundance (and critical appraisal) of medical anthropological insights in this setting lead to shared interests between this oncologist and myself that proved productive when experimenting with the introduction of nurse practitioners and a re-delegation of work from oncologists to such 'new professionals'. This oncologist was interested in this experiment because it would allow her to overcome (her reading) of The's diagnosis by generating more time for patients with whom she wanted to communicate in a less hasty way.

The issue of teaching and/as intervening has been most present in business environments. As Steve Brown notes about this: "through the reflexive loop of the MBA, management studies is simultaneously researching and educating its object of study" (Brown 2004, pg 7). The relatively modest position of STS in legal departments may perhaps be part of the reason why in practices of law there is still an ecology in which experimental STS interventions like in the case of Cole may hardly survive. On the one hand this may be taken as a plea for maximizing interventionist spaces by intensifying STS teaching for e.g. medical professionals, but on the other it may also be worth exploring the range of consequences such translated courses may have for the other practices of STS. One of such quite different consequences of teaching STS courses

has been observed in the Danish context of health ICT development. Signe Vikkelsø had to do quite some translation work when she was invited to a meeting with an IT manager of a hospital who stated that "he was very interested in doing a 'proactive ANT'"[127] (Vikkelsø 2007), and this while she was actually more interested in "a more 'traditional STS-study' of the [electronic medical record] at work" (ibid.).

The issue of teaching as/and intervening seems to point to an area of research that is worth exploring further. The relation between the creation of spaces for experimental STS interventions and e.g. practices of medical training programs would be interesting here. Such research should not merely focus on the fruitful interactions that may be prepared, but should similarly articulate how the role of STS researchers is restricted for doing research that is not of immediate 'use' for (healthcare) professionals. When actors in hospitals start asking for 'doing proactive ANT', it may become harder for STS researchers to legitimize more analytically distanced research practices. Some other scientific domains, like business administration or e.g. health economics, seem to have less of a problem with the 'fit' between their teaching programs and their other forms of acting with practices. Stans van Egmond describes how the teaching programs on health, policy and management are seen by health economists to play a crucial role in their involvement in creating regulated competition in Dutch healthcare (Egmond submitted). She quotes Wynand van de Ven, professor of health economics, who stated in an interview with her that:

> Let's not forget the importance of the education we offer. Each year we deliver about fifty students, in twenty years. That makes about one thousand people working in health care, for the Government, for insurance companies, for advisory boards that have been educated about regulated competition and are very familiar with it. As far as I know we've been the only country so consistent in this. (ibid., pg 10)

So the discovery of the relevance of courses in STS as an intervention in various fields is preceded by many fields realizing the value of their teaching programs. However, STS teaching programs seem to create spaces for intervention just as well as they seem to backfire. To analyze the specificities of such interactions I will now turn towards the consequences of the reflexive relation STS has with the fields it tries to engage with.

Ecologies of intervention – practices of mutual betrayal

The complexity of consequences of teaching STS point out that though receptive ecologies of interventionist research practices may be highly relevant for emerging spaces of 'acting with', they are not leading to any kind of unproblematic 'fit' between STS insights and the networks iSTS is engaging with. The gesture of STS of "finding variability and heterogeneity in what appears to be formally and monolithically structured" (Brown 2004,

pg 6) rather tends to result in a potentially productive process of the 'mutual betrayal' of STS and its subject matter. Brown has referred to this practice as:

> "not simply a critical relation, but (…) the insistence that for a relationship to be possible at all it is necessary to add a little noise, that the relationship can only proceed if the taken for granted assumptions which structure the object [with which STS engages] are routinely violated" (Brown 2004, 7)

Conceptualizing intervention as a form of betrayal of various both theoretical and empirical subject matters has certainly been fruitful in the cases analyzed in this thesis. Assumptions about ethnography leading to 'better' design of (ICT for) work practices were betrayed and translated into ethnography as a way of elucidating the normative multiplicity of a site, as discussed in chapter 1. In chapter 2, a starting point of seeing non-adherence by patients to treatment plans as a problem, which was an important problem according to those issuing the project, was violated and refigured in materialities that enacted actors in the complexity of their practices of home-treatment or providing oncology or hematology care. Health economists who were conceptualized as merely 'implementing' regulated competition were tricked into the opening up of the ontological politics of creating healthcare markets in chapter 5. But as Cole and Costello remind us such betrayal is not reserved for STS; there is a continuous back and forth interplay of betrayals and fidelities in sometimes intended and often unexpected ways. The case of the development of situated standardization for the hematology / oncology ward provides some telling instances.

My expertise in this project was fuzzily configured as both practical and analytical. It was therefore that ethnographic research – what Talese called 'the art of hanging around' – was conceived as 'useful' since it had to lead to a clearly defined and shared problem space. One of the specific figurations was that the project was aiming at creating a calm and 'do-able' (work)place for doctors, nurses, doctors' assistants and patients. A requirement for this was that the number of patients this ward cared for would cease growing. Improvements were not to result in taking more patients on but to having more time available for the population presently in their care. However, when looking into why the reduction of the overruns of the clinics was not fully realized after one year, I found out that there had been an increase of 'production' of 8%. When discussing this with one of the haematologists who had been heavily involved in defining the problem space he said, with a non-innocent smile: "But that's good, isn't it?!". The aim of refiguring conceptualizations of 'patient-centred care' through situated standardization, as described in chapter 4, and for creating a workplace that was more liveable for doctor's assistants and nurses who were working extremely hard for a substantially different salary then their medically trained colleagues, were certainly betrayed by the academic and professional ambitions of this doctor. The aims of the project had hereby been strongly translated, despite attempts to constitute them as immutable mobiles (Latour 1987) through their quantification. This observation does not imply that the betrayal of

our intended aims stemmed from this doctor having a 'hidden agenda' that he strategically pursued. It rather points out that this outcome, though not aimed at, certainly was acceptable and beneficial to some actors in this setting. Since the chief of the department, who had the final responsibility for both this project and for the way the ward was run, also was inclined to support increases in production for financial and academic reasons, it proved impossible for me to re-articulate the issue of the increase of production as a *problem* for the ward. Following the conclusion of chapter 5, where I argued that it is of importance to be sensitive to "forms of the probable" (Thévenot 2002) that may influence certain outcomes of interventions, this observation shows that the regime of efficiency that is strongly enacted through utilization charts as management information and formalized in management targets for such wards, proved influential on the acceptability of unforeseen outcomes.

So where the back and forthing of fidelities and betrayals may at times result in creative tensions, there are continuous uncertainties about ending up in either of the extremes of being externalized to the field one tries to act with – e.g. through the ruling of a judge – or of getting subsumed by the normativities of a practice and finding one was tricked into pursuing agendas that were not part of the problem space ones loyalties were connected to. Though having stressed in chapter 2 the need for iSTS researchers to develop what I, betraying both Lucy Suchman and Chantal Mouffe, call 'artful contamination', Cole, Costello and some instances in the cases analyzed in this thesis indicate that this practice is full of uncertainties. Where in some chapters of this thesis I have referred to specific instances of such uncertainties as 'risks', I would here, in the somewhat more general setting of this conclusion, like to follow – albeit for different reasons – Michel Callon's claim that "the notion of risk is a counterproductive one" (Barry and Slater 2002b, 289). Callon proposes the notion of uncertainty (Callon, Lascoumes et al. 2001) since 'risk' would be too indicative and would preclude social scientists to "give room to actors and let them choose the repertoires of the debates" (Barry and Slater 2002b, 289). My objections to this separation between 'social scientists' and 'actors' should be evident by now. I rather would argue that the notion of risk has to be used with extreme caution since it may enact strong conservatisms for STS researchers with clarity about 'proper' and 'inappropriate' levels of acting with. Through amongst others it's entanglements with environmental issues, 'risk' often has a strong negative connotations, indicating problems rather than its business like connotation of 'taking a risk' and potentially getting substantial rewards. Due to this connotation, conceptualizing 'getting subsumed' as a 'risk' produces a very different epistemological status for STS knowledge than typifying such instances as potential opportunities for 'getting artfully contaminated by' interesting actors about what seductive situated normativities are. This allows for more empirically interesting betrayals of a priori normative stances which can be analyzed for their consequences and be seen as 'artful' or 'harmful' only in their situatedness.

Ecologies of intervention – distance and heterogeneity

This brings me to another issue for the formation of ecologies of intervention; the question of interactions between distances and homogeneities. Since experimental STS interventions are always operating across various separate domains a difficulty is that such practices may be seen as "a two leg match, if you like, where the first game is always played 'away'" (Brown 2004, pg 2). Clearly, the case of Cole can be typified as such an 'away match' with the 'other' of fingerprinting identification having a mass of cheering hooligans in the form of judges, public prosecutors and many verdicts in which their expertise has lead to the successful articulation of guilty/not-guilty demarcations. However, such competitive renderings of action oriented research practices may be producing a distance that performs the 'others' to act with as excessively homogeneous. Marilyn Strathern has compellingly argued that "the question of complexity seems (…) a simple matter of scale" (Strathern 1991, pg xiii). A legal court, an assignment to come clean about ones beliefs, and the competitive metaphor of the sports match therefore do not take advantage of Strathern's notion of "increasable complication" (Strathern 1991, pg xiv) that may pose a more fruitful ecology for iSTS. In chapter 2 and 5 I have followed Sarah Kember's adage to try to get closer to medical practices, "engaging strategically with the differences within [them]" (Kember 2002, pg 638). Such closeness will increase complexity which may be productive for finding frictions within what seems to be a homogeneous practice from a distance. This normativity of scale and the practice of getting closer to fields to act with are in line with critics of critique. As Bruno Latour stated: "The question was never to get *away* from facts but *closer* to them, not fighting empiricism but, on the contrary, renewing empiricism" (Latour 2004, pg 231).

Though normative acting space has shown to increase in the cases in this thesis and in the work of Kember, the observations about the ecologies in which such interventionist practices occur indicate that such closeness is not something that can simply be pursued and attained, as a simple reading of Strathern may indicate, but is highly dependent on existing partial connections between STS researchers and their subject matter. Within such ecologies it will however do STS researchers good to question metaphors and approaches that singularize both their field and the field they want to act with. As I have indicated in chapter 5, claiming that healthcare is not a market but an area of care would easily turn interactions with health economists into an 'away match'. As shown in the analysis of the construction of healthcare laws of markets this would exclude STS researchers from the material and discursive involvement in the ontological politics that is taking place under the veil of 'implementing regulated competition'.

Ecologies of intervention – messy epistemic authorities

The issue of which epistemic authority one is ascribed, one chooses, or one translates and the way in which this relates to the multiplicity of a site of ethnographic research has been scrutinized in chapter 1. I have shown that the interplay of adopting, translating and denying roles can be highly informative for elucidating this very multiplicity, making

stressful situations a methodological asset to the ethnographic researcher (Mascarenhas-Keyes 1987). Similar issues about the ways in which different settings are consequential for the epistemic authority a researcher can adopt or ends up with are addressed by Lynch and Cole in (Lynch and Cole 2005), by Markussen in (Markussen and Olesen 2007) and by Bal, Hendriks and Bijker in (Bal, Hendriks et al. 2004). Such authorities have proven consequential for the ways in which ecologies of intervention are configured in various ways. Elsewhere Casper Bruun Jensen and I have claimed that:

> "epistemic authorities, which are acquired or adopted in particular research projects effect opportunities for developing other research strategies – for example they may diminish focus on the 'others' that are created in particular 'new orders'. Consequently such 'others' may be conveniently forgotten since they no longer are needed for maintaining authority and may even come to appear as a hindrance for the interventions that are explored" (Zuiderent-Jerak and Jensen 2006, pg 3)

The forms of epistemic authority STS researchers end up with therefore may figure their accountabilities within the interventions in such ways that they produce a reduction of space for analyzing the consequences of their interventions. This need of course not be the case: as I have shown in chapter 1, certain settings may allow for substantial fuzziness about ones roles and epistemic authority. Yet, as Cole's experiences show, there are other settings where the space for refiguring ones epistemic authority may be strongly singularized by strong agencies like the ruling of a judge. Realizing with Donna Haraway that "[t]here are always more things going on than you thought" (Haraway 2004, pg 332)[128] it seems crucial for practices of iSTS to maximize the resistance different ecologies afford to the singularization of roles and authorities. Where the consequences of merely 'being there' for ethnographically inspired interventionist research practices have been explored (Hartswood, Procter et al. 2000) there is insufficient attention for the consequences of practices of being *not* there in particular situations. As stated above, the process redesign team was not there when they were asked to come up with simple steps that would allow for the implementation of best practice care processes. The elusiveness of what it then was that we *were* doing was needed to not loose hospitals that had heavily vested interests in the development of integrated care pathways.

Sociomaterial politics, increasable complexity and the ethics of specificity

In the introduction to this thesis, I have expressed my discomfort with STS authors restricting themselves to the exploration of mainly discursive interventions in practices. Taking the radical indeterminacy of the actor and its consequence of appreciating material agency seriously, I have unpacked some of the ways in which ontological politics can be located in the sociomaterial refigurations of (medical) practices. By contrasting the cases in this thesis with some other accounts of experimental interventions and STS I have also explored how different ecologies perform the acting space for

iSTS in different ways. The aim of this was to enhance the sensitivity for practices of connecting fidelities to and betrayals of different subject matters of STS. In the empirical chapters of this thesis, I have emphasized the strategies of 'finding frictions within practices', pursuing 'fuzzy relations' between doing fieldwork and intervening, 'preventing implementation' of clinical guidelines, and 'opening up' seemingly singular notions like 'regulated competition' in healthcare by indicating the performativity of economics. In this conclusion I have argued for the interplay of fidelities and betrayals, contaminations and translations as a potentially fruitful conceptualization of artful contamination and *doing normativity*. Such involvements in building the formal result in a situation where STS researchers have two subject matters to betray: the traditional 'subject' of study and the conceptual starting points of STS. Neither is singularized and free from the uncertainties of being tricked into building a formal that was unforeseen. In the conclusions of chapter 5 I have therefore indicated the importance of being aware of potential 'forms of the probable' that prevail in the practices one engages with. Though it may at times be productive to conceptualize the uncertainties as risky, it has also proven valuable to think of them as opportunities for increasing normative complexity. In this sense the betrayals of some normativities of 'critical STS' has lead to more situated normativities.

The critique of disciplining patients into treatment regimes through compliance enhancing materialities was betrayed for enhancing the agency of 'marginalized doctors' and medication safety standards. The critique of Evidence Based Medicine as violating professional decision making was betrayed articulating issues care professionals and patients face that led to situating standardization. The critique of the performativities of practices of marketization and choice in healthcare was betrayed for the involvement in constructing healthcare competition as a value-driven market. These situated normativities in experimental cases of iSTS make STS researchers highly similar to Elizabeth Costello who is standing in front of the Gate. Keulartz et al. formulate the normatively situated stance of STS researchers as the refusal of "[r]adical constructivists (…) [to] determine what the specific context looks like apart from the interpretation of relevant actors or 'actants'". They also conclude that this stance has resulted in "the normative deficit of the constructivist approaches to science and technology" (Keulartz, Schermer et al. 2004, pg 12). Relating the unwillingness to 'get real' about normativities outside the empirical specificity of practices to a 'normative deficit' however seems to be somewhat of an absurdity when analyzing the absolute need to be normatively specific in the three cases presented in this thesis. Getting closer to the normative complexity of practices and explicitly involved in the interplay of fidelities and betrayals, the conceptualization of iSTS as dealing with issues of, paraphrasing Lynch, a *normative surfeit* seems more appropriate. The normative surfeit model of interventionist STS is not in need of a translation of situated normativities into moral singularizations and beliefs. Rather, it articulates the value or an *ethics of specificity* for (i)STS research. Relocating normativity in

practices of which the multiplicity is ethnographically performed does not repair the old problem of moral ambiguity or prevent issues of the tragic (Nussbaum 2001 [1986]). The radical contingency of all claims and their tricky nature (Haraway 1991b) will lead to new betrayals that may produce fruitful refigurations but that may also reveal great suffering. When engaging in practices of issue politics through iSTS it will therefore remain crucial to articulate spaces for the empirical analysis of the complexity of consequences of such interventions. Stronger rhetorical authorities of iSTS researcher may however preclude exactly this space for studying such consequences. So while it will always remain an empirical question whether STS has taken an unwarranted risk or has productively engaged with uncertainties, STS researchers may end up in a position where this question can neither be articulate or addressed.

This thesis is a case of the articulation of the issues of iSTS it order to explore what its consequences are for practices of care delivery and of STS research. Just as such a pragmatic focus on the role of issues in articulating publics has proven invaluable for the reconfiguration of discussions on democratic deficits in political science and STS (Marres 2005), putting issues patients and care professionals face centre stage when situating standardization of healthcare practices has resulted in a conceptualization of STS as dealing with a normative surfeit. In this sense experimental interventions in healthcare practices have allowed me to relocate the normativity of STS in a form of Deweyan issue politics (Dewey 1927). When our fidelities and betrayals are not dealt with in practices, in their embodiments of doing research in practice, rather than of practice (Mol 2002), we may end up in the situation of Cole and Costello, who are asked to betray their situated normativities in singularized beliefs and epistemic positions, and will result in STS being accused of being normatively deficient. Conceptualizing the situated normativities of interventions in terms of the uncertain interplay of loyalties and betrayals brought to and encountered in the experiment, we might be in the company of many who are involved in engaging with the surfeit of normativities in healthcare and other practices. After all, the Gatekeeper sees people like Elizabeth Costello all the time.

Notes

[1] Which of course says nothing about the actual time it takes to arrive at ones destination, which may be dependent on road quality, congestion, indication of directions, unequivocal street names and road signs, means of transportation, yellow cabs breaking down, cows on the road, moment of presence (e.g. independence day or Diwali) etc.

[2] Again, this says nothing about the duration of the journey or the amount of steel nerves required to arrive in the first place. Any foreigner who attempted to get anywhere driving via the *Arc de Triomphe* in Paris may prefer the friendly chaos of Ahmedabad traffic or the clarity of finding one's way in New York!

[3] A contribution that has proven invaluable in the last decades to argue against the development of fully standardized electronic medical records that seemed to provide new and unprecedented opportunities for disciplining the use of the medical record by care professionals. See (Berg 1997) This argumentation will continue to prove its value in future practices of standardizing healthcare work through new ICT initiatives and through the development of care pathways.

[4] A point many EBM researchers and policy makers are of course well aware of and which is leading to the development of e.g. practical clinical trials and the inclusion of patients in guideline development (cf. chapter 3).

[5] See for a somewhat absurd attempt to secure neutrality through the separation of the politics and methodology of doing STS (Collins 1990) and for a suitable critique (Martin, Richards et al. 1991).

[6] Which is not the same as stating that doing STS 'has politics'. As the contribution of Collins to the discussion nicely illustrates, the tendency of STS researchers to claim that things 'have politics' without haven fist been defined and enacted as political in nature entails what Noortje Marres calls "a strangely naturalist understanding of politics" (Marres 2005, pg 29).

[7] A notion further explored in (Mol 1999; 2002).

[8] Such pleas were also a critique to calls for 'democratizing' technoscientific developments. I will deal with the relationship between such democratization initiatives and experimental interventions with the co-construction of practices in chapters 1 and 4. They were strengthened by what I would like to call a position of 'critiquing critique' (Latour 2004), an position I deal with in chapter 2.

[9] I am indebted to Maggie Mort for bringing this point forward.

[10] I am indebted to Emilie Gomart for this formulation and for extended and challenging discussions on the issue of intervention and STS.

[11] Quoted in: (Anon. 2001).

[12] See, among many others, (Toffler 1981), for an example of work in the long tradition of techno-utopian writing.

[13] Quoted in: (Hess 1992, pg 4).

[14] Concepts that have been framed for this are for example "hybrid collectives" (Callon and Law 1995), "actor-networks" (Latour 1987) and "sociotechnical ensembles" (Bijker 1995).

[15] See for example (Brown and Duguid 2000), particularly chapter 4, and (Suchman 1999).

[16] For example (Hughes, O'Brien et al. 2000), (Lloyd 2000), (Hartswood, Procter et al. 2000; Hartswood, Procter et al. 2003).

[17] This critique is of course not generically applicable to CSCW researchers, who often have an explicitly political agenda when trying to develop IT for specific categories of employees – preferably shop-floor workers. However, it is relevant for the authors that I will discuss in this

chapter. And they are the ones not merely signaling the problems concerning the question on how to bring together ethnographic findings and IT design, but also trying to develop approaches to deal with this issue.

[18] The discussion on this point is somewhat beyond the scope of this chapter, but briefly it can be stated that by means of increased 'rigor' the aim is to enhance the 'control' of projects (Avison, Baskerville et al. 2001, pg 38). This should be obtained through "determine[d] control structures in the early stages of the project" (ibid. p. 40), and this would be a requirement for the ability to 'manage' projects. This whole approach is rather opposite to the intentional fuzziness that I will prove to be highly valuable – both conceptually and practically – for interventionist research in the remainder of this chapter. The idea that 'control' is an appropriate and fruitful managerial requirement or strategy is highly contested. See for a thorough critique (Ciborra 2001b).

[19] Though I am certainly aware of the explicit political discussions on the positioning of research within the Scandinavian PD / Cooperative Design tradition, it is beyond the scope of this chapter to give an account of the way a reflexive and politically sensitive approach towards ethnographic interventionist research relates to the Scandinavian tradition. For this I would like to refer to Markussen (1996) who gives a historically sound and conceptually interesting positioning of the common ground and differences between them.

[20] See for some classics (Bijker 1995), (Latour 1996).

[21] Hemophilia is a hereditary bleeding disorder that is treated by administering clotting factors intravenously.

[22] Of whom it is worth noting that they are based at various computer science departments.

[23] This point has been made in many STS and IS articles. For an excellent example, see (Monteiro and Hepsø 2001).

[24] This comment is a direct critique of PD approaches that have a tendency to hide the interests and interventions of designers behind a discourse of 'supporting user-interests'.

[25] Needing to consist at least of a hematologist, medical social worker, orthopedic surgeon, medical psychologist, physiotherapist, rehabilitation doctor and oral surgeon (Jones 1991).

[26] A risk identified by Downey and Dumit (1997b, pg 27). Whilst they don't perceive this to pose a substantial threat to an established scholar as Donna Haraway, they all the more stress the danger for the less established researcher.

[27] By far the largest HCC in The Netherlands, and the only center already living up to the majority of the demands.

[28] Hemophiliacs treat themselves intravenously with coagulation factor concentrates. The use of medication is always a sensitive issue, since the medication is extremely costly and scarce, and since the patients are largely responsible for diagnosing and treating their own bleeds.

[29] Forming this group itself was a constitutive and interventionist activity, since it brought together some of the people involved in the HCC, thereby rendering it all the more tangible.

[30] A concept that, according to Blomberg et al. (1996) should be a focal point in studies of ethnographically informed technology design.

[31] Note that the inscription might make it seem as if the positions are equal in size and strength. I wish to stress here that equivalence is a highly inappropriate concept for describing the views, since they are constantly being performed and altered.

[32] See for an interesting account of the way dress was used in order to deal with different groups in an anthropological study in Goa, (Mascarenhas-Keyes 1987, pg 182-183).

[33] On turning fieldwork problems into research data, see also the contribution of Ross Winthereik, de Bont and Berg (2002).

[34] For the consequences of this type of funding, see the Discussion.

[35] For an analysis of the problematic nature of integrating registration for secondary purposes in the primary care process, see (Lei 1991).

[36] An important distinction suggested by (Kluiver and Nibbering 2001).

[37] A role that has also been observed in an action research project by (Waring 2001).

[38] Note that hemophilia is a rare disease with only some 1500 patients in The Netherlands, and that for most hematologists their knowledge of treating such patients is rather basic.

[39] See, for this debate, (Scott, Richards et al. 1990) and the reaction from (Collins 1990).

[40] For a collection of studies dealing with the inherently interventionist nature of anthropological work, see (Downey and Dumit 1997a).

[41] See, for a method to obtain this unification (Checkland and Holwell 1998), especially chapter 6.

[42] Though, as Berg rightly states, it is much more interesting to see how the processes of codevelopment of tools and practices lead to unforeseen configurations that "transform the very *nature* of the issues at stake (…) [Therefore] we should focus more on how the very meaning of 'hierarchies' is being transformed rather than discussing whether hierarchy is becoming less or more pronounced" (Berg 1998b, pg 478, italics in the original)).

[43] Though this would increase the chances of the database being used in small HCCs lacking the funds to establish links to the HIS, a resultant disadvantage of this solution is that, of course, patient data would have to be entered twice; both in the HIS, and in the hemophilia database.

[44] This position has been identified as 'critical STS' on which Hess states that its diversity and anarchy: "insure the vitality of dissent that is at the core of *democratic* research" (1997, pg 157, italics added).

[45] See for example: (Berg 1997; Callon and Rabeharisoa 2004; Dodier 1998; Gomart 2002; Mol 2002; Pasveer 1992; Ploeg 2001; Willems 1995).

[46] Quoted in (Martin 1996, pg 266).

[47] Qouted in (Hess 1997, pg 161).

[48] I want to thank Brian Martin for pointing out this way in which captivity is sometimes wrongly understood.

[49] They do not elaborate extensively on this remark but it seems they are making a point that relates to the 'Mode 2' and 'Triple Helix' discussions (Etzkowitz and Leydesdorff 2000; Gibbons, Limoges et al. 1994), which are beyond the scope of this chapter as well.

[50] Quoted in (Hess 2001, pg 236).

[51] See e.g. various contributions to (Downey and Dumit 1997a), and (Campbell and Eubanks 2004; Woodhouse and Patton 2004). I would like to thank David Hess for pointing out some of these core texts.

[52] See e.g. various contributions to the workshops organized by Steve Woolgar and colleagues in 2004 and 2005: (Woolgar, Coopmans et al. 2005; Woolgar, Neyland et al. 2004) the contributions to (Zuiderent-Jerak and Jensen 2007), i.e. (Bal and Mastboom 2007; Jensen 2007; Markussen and Olesen 2007; Mesman 2007; Vikkelsø 2007; Zuiderent-Jerak 2007) ,and (Wouters and Beaulieu 2007).

[53] A change that only took place in Western Europe, North America and Australia, for in other regions there is not enough supply of coagulation factor concentrates to treat patients in this manner at all.

[54] A substance with a high concentrate of coagulation factors obtained by freezing and melting blood plasma.

[55] Prophylactic treatment is the treatment given to keep the coagulation factor in the blood on a high enough level to prevent bleeds.

[56] Though beyond the scope of this chapter, it would be interesting to investigate compliance when treatment was mainly situated in the hospital. One would expect that 'full compliance' would be equally absent.

[57] This group was at the time called: Research on IT in Healthcare practice and Management (RITHM), and focused on the sociotechnical study of information technology and organizational change in healthcare. The reason they could approach us was that they had an offer of one of the pharmaceutical companies producing coagulation factor concentrates to finance research into the changes needed for hemophilia care centers. This fund was labeled by the company as 'goodwill money' that, so they claimed, would otherwise be "spent on flyers".

[58] In all the empirical material presented, patients are referred to as 'he'. This is neither a sign of sexist language nor of some bizarre selection of interviewees. Hemophilia patients are all male: women can only be so-called 'carriers' of the disease.

[59] It is worth noting here that *what* over- or under-consumption exactly is, is highly subjected to debate. This can be seen by looking at the international discussion on differences in national treatment policies (Steen Carlsson, Hojgard et al. 2003).

[60] On a global scale, there is such shortage of medication that about 80% of the patients receives no treatment with coagulation factor concentrates or even blood transfusions at all (Mannucci 2003).

[61] Though blood-products are thoroughly screened to decrease contamination risks, the dangers of spreading unknown or 'new' diseases can never be fully precluded. In the 1980s, many patients with hemophiliac where infected with HIV. There is also a very high rate of hepatitis infections among hemophiliacs. This makes patients extremely wary for being exposed to 'new' diseases such as Von Creutzveld Jacobs Disease (vCJD).

[62] Not merely because it is very hard to achieve, nor just because there often is substantial medical debate about *what* patients should comply to, but also because historically it can be argued that balancing the activities of a care provider prescribing only with "approximate accuracy" and patients complying with "only modest fidelity" has enabled mankind to: "survive bleeding, cupping, leeches, mustard plasters, turpentine stupes, and Panalba" ((Charney 1975) quoted in (Willems 1995, pg. 134). Limited compliance may similarly have been a life-saver for various hemophilia patients who during the distribution of HIV infected blood products in the 1980's.

[63] Translated by the author. Original: "patienten *vergeten* hun medicijnen, ze hebben er een misschien onuitgesproken *weerstand* tegen en *denken* dat de *ziekte over* is zo gauw ze er geen last meer van hebben".

[64] Since they were very keen on having a quantification of this 'substantial deviation', I called in a colleague from my institute who analyzed the data that patients entered in their treatment journal, and that the hemophilia nurse typed into a database using SPSS software. Interestingly, these data had not been analyzed before. The outcome showed that patients *with similar treatment plans* had *highly individual treatment patterns*. These findings were discussed with both healthcare professionals and patients.

[65] This strong position for patients was further enacted by a very strong and influential patient association, the Dutch Association of Hemophilia Patients. With a membership rate of about 95% of Dutch hemophilia patients, they could act (and were seen) as a very strong agent.

[66] The quotes that are used come from interviews with patients of one of the Dutch HCC's. These interviews were carried out by Gezieneke Aris, for which I am very grateful to her. I've translated the quotes that I use into English and slightly edited them for sake of readability. 'P' stands for patient, and in later quotes 'I' for interviewer.

[67] Cf. (Conrad 1985) quoted in (Willems 1995, pg. 135) and (Houten 2000).

[68] It is important to stress here that *what* this 'model patient' is within the HCC is similarly equivocal.

[69] With pharmaceutical companies like Aventis Behring claiming on their website (www.aventisbehring.co.uk) that they have their own fleet of transportation vehicles, because delivering the medication following first class safety regulations is not to be outsourced: it is part of their core competence.

[70] Though this critique may sound like a bit of a straw man argumentation, this is exactly the critique I received when presenting this material on an STS forum. The question that was critically raised was: "But aren't you just disciplining the patients?!".

[71] A practice that is actually not in line with the Dutch laws for pharmacies but that can be found in all HCC's because of the high costs and scarcity of the clotting factors.

[72] I want to thank David Hess for pointing out these tensions.

[73] 'Distance' is to be taken here is a metaphorical sense. This is worth mentioning, because the physical distance between patients and HCC's is a hot topic amongst the patient association, HCC's and the Ministry of Health, who have to find a balance between the standards a HCC should live up to, and the need for a geographic distribution of centers.

[74] I thank Brian Martin for pointing this out.

[75] Quoted in (Hess 2001).

[76] Both cited in (Timmermans and Mauck 2005).

[77] Also known as care pathways, coordinated care pathways, critical (care) pathways, anticipated recovery pathways or care maps (Pinder, Petchey et al. 2005, pg 777).

[78] See e.g. (Grol and Grimshaw 1999; Roila 2004).

[79] An interesting parallel can be drawn here with the study of factors of ICT implementation in healthcare. In a recent study, an international group of medical informatics researchers reported to have found "[a] total of 110 success factors and 27 failure criteria (…) distributed on categories like functional, organizational, behavioral, technical, managerial, political, cultural, legal, strategy, economy, education and user acceptance (…) All success factors and failure criteria were considered relevant by the Delphi expert panel. There is no small set of relevant factors or indicators, but success or failure of a Health ICT depends on a large set of issues" (Bender, Ammenwerth et al. 2006, pg 125). Though their conclusion almost leads them to a conceptualization of the implementation process as 'mess' (Law 2004a), they do not question the usefulness of the study of 'factors'.

[80] E.g. (Winthereik, de Bont et al. 2002).

[81] However, as Dan Neyland rightly noted when commenting this chapter, one may question how long such a position of non-expertise can be maintaine once more and more STS researchers have positions in business scools, are involved in ever more practical forms of organizational

research and are called upon to act with other actors in very practical ways. The erosion of the stance of non-expertise is interestingly explored by (Vikkelsø 2007)

[82] These are doctors who are responsible for managing the medical part of the work on the ward. They are the medical part of the dual management, the 'organizational' part being covered by an operational manager.

[83] For a further elaboration of this approach, see (Berg, Schellekens et al. 2005).

[84] Being: Hodgkin lymphoma, Non-Hodgkin lymphoma < 65, Non-Hodgkin lymphoma > 65, Recurring follicular Non-Hodgkin lymphoma, Chronic lymphatic leukemia general, Chronic lymphatic leukemia campath, Multiple myeloma < 65, Multiple myeloma > 65, Haemostasis, Thrombosis, Hemophilia, Phase I/II trials.

[85] Being: Testis carcinoma, Bladder carcinoma, Colon carcinoma, Oesophagus carcinoma, Ovary carcinoma and Phase I trials.

[86] Of course I'm not implying here that operational managers or nurses should take final decisions on where which care is given. What they *could* however bring in, is the organizational consequence of the decision: *if* it is decided on medical grounds that late follow up is a core task of this department, *then* you will have to spent more time doing surgery hours, hiring more staff or reducing the number of patients treated in the department. Of course these later options would be hampered by budgetary considerations.

[87] The ratio of patients coming for the first time to patients coming for another time.

[88] I would like to thank Casper Bruun Jensen for bringing this concept into our discussions.

[89] The names in the excerpts have been changed.

[90] Some classic examples from various decades being (Friedson 1960; Parsons 1951; Strauss, Fagerhaugh et al. 1997).

[91] This distinction is made amongst others in (Mead and Bower 2000, pg 1088) and in (Benzing 2000).

[92] We will not discuss these here in detail, but we showed that clinics of haematologists were running late on average by almost 35% and that junior doctors held extra clinics that added up to 39% of the total of the clinics capacity merely to deal with the number of patients.

[93] Medical coordinators are doctors who are responsible for managing the medical part of the work on the ward. They are part of the dual management, the 'organizational' part being covered by an operational manager. In all our experiments we have found it is crucial that the medical professionals chair the projects. This means they carry the final responsibility for the project but does *not* mean they also have to *manage* the project. We have found it fruitful to make a distinction between chair and project manager, the latter being either a researcher or – preferably – a member of staff or management.

[94] Again, this is not the place to deal with those in detail, but some results were that the clinics were running late with about 24 minutes (reduction of 53%) while the total number of new patients had increased with 8%.

[95] See for an interesting analysis of the limitations of patient satisfaction questionnaires: (Edwards, Staniszweska et al. 2004).

[96] See e.g.: (Benzing 2000; May, Rapley et al. 2006; Mead and Bower 2000).

[97] Quoted in (Mead and Bower 2000).

[98] She referred to the slogan hospital A uses which claims to put patients centre stage.

[99] See e.g. (Sermeus, Hoy et al. 1997).

[100] For a compelling and more general analysis of ways in which formalities or 'governing by abstraction' has been unproductively polarized in a pure planning approach or romantic notions of the 'real world' (Stinchcombe 2001).

[101] Broos, CEO of the hospital group in the press release on the 2nd of May 2005.

[102] The remaining 90% being financed through a system of budgeting and fixed prices per treatment.

[103] It may come as no surprise that the figures are fictitious. They are however fairly close to reality.

[104] Referred to in (Schut 2003).

[105] Quoted in (Schut 2003).

[106] See for an interesting study of persuasion through factual reporting and its relation to Actor-network theory, (Elgaard Jensen submitted).

[107] Amongst researchers from the field of Science and Technology Studies (STS) this has resulted in the odd situation that authors, who are equally used to propagating the study of complexity and situated normativity when discussing e.g. standardization in healthcare, take rather extreme sides in the debate on healthcare markets. On the one hand there is someone like Annemarie Mol who, despite having coined the term 'praxiography' (Mol 2002), states that on issues of marketization in healthcare she is "convinced that we should expect little improvements [in healthcare] through an increased emphasis on choice" (Mol 2006, pg 9), whereas on the other there is someone like Marc Berg who has become an almost prophetic proponent of marketization and regulated competition as an unproblematic solution for achieving "right incentives for high-quality, affordable care" (Berg 2006).

[108] Of course, this neat split is an immense simplification, as the field of economics (even of the rational choice type) is far from homogeneous, and the split is used by social scientists (like me) as a rhetorical devise. I will return to this issue below.

[109] A distinction which is crucial for many anthropological takes on markets, such as Millers work on Virtualism. See for a sharp discussion of the difference of this take on the study of markets and the approach proposed by Callon, (Holm 2003).

[110] Resulting in claims of e.g. Rein Willems, the CEO of Shell Royal Dutch Oil that their motto "You work safely or you don't work here at all" is equally applicable to the healthcare sector which should have a safety management system up and running within a few years, (Shell-Nederland 2004), and Peter Bakker, the CEO of TPG, a large logistics firm that includes the recently privatized Dutch postal service claiming that "2,5 billion euros" could be saved in the hospital sector through logistic improvements, (TPG 2004).

[111] See for an elaboration of the concept of breakthrough collaboratives (Cretin, Shortell et al. 2004; Leatherman 2002; Øvretveit, Bate et al. 2002; Wagner, Glasgow et al. 2001; Wilson, Berwick et al. 2003).

[112] Interestingly, this choice of the ministry was challenged by existing healthcare consultancy companies who claimed that investing in quality through assigning advisors to hospitals and allowing them to participate in the collaborative without having to pay for it was a form of 'market contamination'.

[113] See for an account of their construction (Berg, Meijerink et al. 2005). I will return to this pillar in the last section of this chapter.

[114] Our Excel expert being Jeroen Wien of the Dutch Institute for Healthcare Improvement. I'm very grateful to his expertise and enthusiasm for developing such tools.

[115] That such monopolizing would be practically unfeasible becomes clear when thinking of the involvement of sociology on framing the market through e.g. the notion of Risk Society (Beck 1992) which has had a strong influence on the emergence of an industry of risk management (Barry and Slater 2002b, pg 289).

[116] The point here is of course not that process improvements always lead to financial gains, as sometimes introducing a clinically relevant improvement introduces an increase of costs. The point here would be that also financial costs and quality gains can be entangled in a calculative space which creates both a separation and a relation between them, and allows them to be taken into account in relation to each other. By articulating the delivery of care as a process, it often proved possible to entangle such various elements that issues previously seen as costs could now be seen as investments. A nurse led clinic for patients undergoing elective surgical interventions like laparoscopic gallbladder surgery would be seen as a mere cost when conceptualizing care delivery as individual interventions. Entangling the various steps in the concept of the care process refigured such a clinic as an investment with a gain at a later stage in the process since patients were better informed and often did not need to return to the hospital after surgery for a follow up visit.

[117] All interviews accept the one with the Atrium MC were carried out by the author and by Marije Stoffer. Participants of the Atrium MC were interviewed by Marc Rouppe van der Voort and Marije Stoffer. I am grateful to them for their contribution.

[118] Cf. (Foucault 1991) and (Lemke 2002).

[119] This also implies that the dubious 'working' of healthcare markets may in future be un-problematically used for the marketization of e.g. education.

[120] Or perhaps it displayed substantial sensitivity to such probability. As the quality manager commented, when reading an earlier version of this chapter, his comments were not based on suspicion alone; they were based on what he called a "situated suspicion" based on the double role the department of Health Policy and Management and the Dutch Healthcare Quality Institute played in both Better Faster pillars. Whether this coincidence was accidental or intended is of course not at stake here; the issue is that social scientists may want to be aware of the forms of the probable that they are bound to get entangled with.

[121] Idea for cartoon taken from (Kneebone and Wadsworth 1998).

[122] Steve Brown proposes the more elegant concept of "producing variability from apparent stability" as an alternative for 'deconstruction' (Brown 2004, pg 7), which I, for reasons of textual economy, will abstain from using.

[123] See for an interesting study of boundary work between credible and noncredible expertise in legal environments (Bal 2005).

[124] In his novel Rondo Veneziano, the Dutch novelist Gerrit Krol relates such dichotomous tendencies to the external symmetry of mobile living organisms (most humans and most animals). He proposes the contrast with the more capricious forms of immobile forms of life (e.g. trees) as a productive metaphor to refigure such dichotomies (Krol 2005 [2004]).

[125] Paraphrasing, of course, (Star 1995).

[126] But see the work of Sheila Jasanoff, amongst others, in this field, i.e. (Jasanoff 1995).

[127] For another interesting analysis of the relevance of STS teaching practices and ICT consultancy in Denmark, see (Gad 2006).

[128] Quoted in (Markussen and Olesen 2007).

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Summary

This thesis discusses and relates two particular questions. The first more empirical question deals with innovative ways of organizing hospital care. Through the analysis of a series of cases in which care trajectories were 'redesigned', the relations between standardization of healthcare practices and complexities in patient care are explored. This relationship has often been analyzed in rather binary terms. Either practice variation is seen as the problem and medical practice needs to be rigorously standardized to make it 'evidence based' *or* standards and evidence are the problem, violating complexities of healthcare practices and turning them into 'assembly line medicine'. I show how both these approaches to the relation between standardization and complexities are problematic. Attempts to 'rationalize' medical practice on the basis of aggregate medical knowledge separate the standard and the care practices it is to become relevant for. This creates 'implementation problems' and often painful marginalizations of other forms of knowledge and practice. Critiques of standardization on the other hand tend to result in an awkward conservatism: they privilege a fascination for complexity over sensitivity for problems that follow from the way sociotechnical arrangements currently 'work'. In addition, they tend to be extremely limited in perceiving how this practice could also 'work' differently. Both these approaches to studying complexities and standardization therefore fail to contribute to situated improvements in healthcare practices. These are nevertheless dearly needed to prevent substantial suffering for both patients and medical professionals.

In this thesis I explore the relationship between complexities and standardizations in a less dichotomous way. I pose the question what formalities and standards actually do in healthcare practices and in which different ways standardization can be 'done'. This opens up the debate on standardization in healthcare to empirical explorations in which attempts to standardize certain aspects of care are not inherently opposed to e.g. making care patient-centered. It rather raises the question which ways of 'doing standardization' enable which forms of 'doing patient-centered care'. Through empirically exploring processes of standardizing care trajectories in hospitals, I propose an experimental approach of standardization that is situated in particular issues relevant in the healthcare setting one engages with. Rather than starting with a medical standard that is 'implemented' into healthcare practices this approach starts with articulating specific problems that patients and care professionals face and uses these to come to *situated standardization*.

The second more theoretical question of this book deals with the consequences of the experimental and direct involvement of researchers from the field of science and technology studies (STS) in care innovation initiatives. Recent pleas for social scientists to

'get real' and 'become useful' for care practices have led to the accusation that more analytical, constructivist fields like STS are 'normatively deficient'. Though good at describing complexities and problems in (care) practices, students of science and technology are said to provide insufficient normative and practical leverage for providing solutions for the complexities they describe. This perceived 'normative deficit' has led to proposals to connect STS research to explicit normative agendas like political activism, social movements and the democratization of technology. Such pleas often end up re-enacting pre-determined normative positions that are then 'added' to a practice. Un-situated normative 'standards' are thereby proposed that STS researchers are to bring to their research site, rather than situating normativities in the complexities of their research settings. In this book I propose a radically different approach to the normative deficit of constructivist social sciences. In the empirical cases of creating situated standardization of care practices, the last thing that was needed was a pre-defined normative agenda. Experimenting and 'intervening' in these care practices performs a situation in which social scientists do not struggle with a normative *deficit* in their research but rather with overflowing normativities: a normative *surfeit*. Instead of turning ones' normative fidelities into normative beliefs by aligning STS research to explicit ethical agendas, situating normativities in the specificities of a care practice allows STS researchers to come to an *ethics of specificity*. This ethics of specificity builds on the heterogeneous normativities in care practices without privileging one over the other a priori. Rather, the ethics of specificity is linked to the formation of issues in healthcare settings.

The way these two central issues of standardization in healthcare and normativity in interventionist research are addressed in this book follows a similar logic. Both standardization and normativity are situated in the particularities of practices for which they are to become relevant. Studying standardization of healthcare and the normativity of STS research in a situated way prevents that ethics or standards are defined outside of the practice for which they should be consequential. They therefore need not be 'implemented' after design: rather such an implementation phase with all concurrent 'implementation problems' is to be avoided. This book therefore draws upon a strategy of *preventing implementation* of both normativity in research and standards in healthcare.

The questions in this thesis are explored through the analysis of three cases. In each case, I was actively involved in developing standardized care trajectories for hospital care. These cases were all characterized by co-constructing healthcare practices while constantly creating partial connections between those practices and STS research. I therefore refer to this type of research as 'interventionist Science and Technology Studies' (iSTS). 'Intervention' may of course be seen as a highly layered concept that, following the performativity of researchers in enacting worlds, can to some extent never

be avoided. Posing its counterpart – non-interventionist social science – possible implies a naïve yet not harmless conceptualization of scientific practice. 'Intervention' is certainly not introduced here to re-iterate a descriptive/useful dichotomous understanding of the social sciences. It is proposed to indicate the explicit aim of these research projects to change the care practices under study. Further, it is maintained because of the potentially productive tensions it raises in a medical setting. When social scientists study the work of healthcare professionals, 'intervention' is generally reserved for the objects of study. The notion of intervention in relation to STS research therefore reclaims some of the ideas about 'where the action is' from the field of medicine.

The first case in this thesis concerns the development of a hemophilia care centre at a Dutch university hospital. The second case is a project on the development of standardized care pathways in a large hematology/oncology ward. The third case involves the development of such pathways for sixteen hospitals in a national quality collaborative improvement program for hospital care. All these settings were researched by carrying out participant observations of care settings and by interviewing professionals and at times patients about the care practice in which they were implied. It also consisted of focus group meetings about organizational change proposals, steering group sessions and project reviews about the development of projects and analyzing data from hospital information systems about issues like the time clinics were running late, throughput times for patient trajectories and length of stay of patients in the hospitals.

In chapter 1 I focus on methodological issues in the relationship between ethnographically inspired analyses of work practices and the complex potential this engenders for intervention. Whereas ethnography has been identified as an important method for developing situated solutions for specific workplaces by neighboring fields like participatory design, action research and computer supported cooperative work, its political pertinence and fuzzy practice have been underexposed. I challenge the oft-encountered notion that ethnography leads to 'better' material interventions. In this context 'better' is often seen as 'more appropriate for a workplace'. However, fieldwork in the construction of a hemophilia care centre (HCC) of a Dutch university hospital shows that what this workplace is, and therefore what materiality is desired, is equivocal. I also show that 'doing fieldwork' cannot be separated from 'informing design' or 'intervening'. 'Intervention' is a subtle, layered concept and a continuous activity. Based on these insights I develop the iSTS approach as being geared towards interweaving fieldwork and informing the design of material interventions in an intentionally ad-hoc and non-sequential way. This articulation of iSTS sensitizes the fieldworker to the located and strategic multiplicity of a site, to the data that can be found in roles and epistemic authorities that are being ascribed by various actors resulting from their 'view from somewhere', and to the

acting space that is constantly emerging and changing in an iSTS project. I claim that the approach can lead to sensitized interventions situated in politicized ethnography.

In chapter 2 I discuss the notion of 'intervention' as it has historically developed in STS. Intervention has become attached in 'critical STS' to normative agenda's of social activism and I show that, though this is one way of addressing the criticism that constructivism is 'normatively deficient', this critique can be rebutted through interventionist research without embracing activism as a strategy. Drawing on the same case of being involved in the development of the HCC, I indicate how the practice of hemophilia home-treatment benefits from STS insights on the issue of compliance and making 'invisible work' visible. Non-compliance has often been conceptualized as a problem per se in the quality of care literature, resulting in a plethora of equally unsuccessful compliance enhancement initiatives and cognitive interventions. STS researchers have questioned the aim of full compliance, realizing patients have to live in many different worlds simultaneously – worlds which at times may challenge their role of being a 'patient'. By shifting their focus from trying to understand irrational non-compliance to the study of achieving compliance in practice they have indicated interesting acting space for situating compliance enhancement initiatives in the complexity of the live-worlds of patients. I explore the interventions this insight has led to and relate them to the possible gains for iSTS to *do normativity* through practices of *artful contamination* of research practices. I claim this move to be of value for overcoming the normative deficit STS has been accused of and propose iSTS research as a fruitfully risky business.

Chapter 3 deals with the study of compliance by clinicians to prescribed guidelines. Following a very similar rhetorical structure as the compliance debate about the actions of patients critiqued in chapter 2, the low adherence rates of healthcare professionals to clinical guidelines is often seen as highly problematic by health scientists and policy makers. However, as in the debate on patient adherence, the common 'solutions' to improve the success rate of implementation initiatives tend to leave the epistemological status of aggregated medical knowledge untouched. Such initiatives therefore tend to be practically cumbersome, politically desensitized and conceptually problematic. I analyze the experimental interventions with standardization of medical care practices in a second case, a healthcare improvement project at a hematology / oncology outpatient clinic of a university hospital. I will show that this iSTS project is a form of doing politics through standardization. Rather than following the above mentioned extremes of striving for the full rationalization of medical practice, or of celebrating complexity that boycotts being standardized, I articulate the value of iSTS experiments *and* of much early work from the integrated pathway movement to come to situated standardization of healthcare practices. Through finding frictions within discussions on evidence based practice and amplifying those, this chapter articulates a 'processual' approach to 'pathwaying'.

In chapter 4 the same case of iSTS at the hematology/oncology outpatient clinic and treatment centre is explored to intervene in discussions on the relation between standardization and patient-centeredness. In the medical sociological literature, 'standardization' and 'patient-centered care' have been positioned as perfect conceptual opposites. In this chapter I explore the specificities of this opposition, their limitations, and in which sense a re-conceptualization of both concepts could lead to their pragmatic commensurability. Drawing empirically upon the development of patient-centered care trajectories and conceptually on the pragmatist philosophical work of John Dewey and his reappraisal of issues in democratic theory, I indicate that recent debates within political science are helpful for reconfiguring discussions and practices on patient-centered care and standardization. Through putting the issues patients, care professionals and organizations face centre stage in the process of 'pathwaying' healthcare, situated standardization can be attained which is addressing the initial problems the pathway movement was focusing on, but that have been subsumed by implementation agendas of pathwaying. In discussions and practices of standardizing healthcare, there is a need for such a reappraisal of a processual approach that focuses on issue-articulation. Such a reappraisal can lead to care pathways that make care patient-centered in more substantial and material ways.

Chapter 5 deals with the possibilities for iSTS in enacting emerging healthcare markets. The social study of markets has experienced challenging theoretical developments, particularly through the work of Michel Callon on 'the performativity of economics' – the notion that economics is not 'discovering' market laws but is actively involved in the creation of the laws of the markets. This notion has opened up the construction of markets to many previously excluded actors, for if economist shape laws of markets through shaping materialities of markets, why would social scientists exclude themselves from this process? However, Callon's focus on the role of materialities in performing spaces of calculation and the role of economics in creating materialities easily leads to over enthusiasm for active engagement by social scientists. Drawing on the third case of the development of situated standardization through process redesign in a national healthcare quality collaborative, I analyze the possibilities for STS researchers to enact healthcare markets as value- rather than cost-saving-driven. I pose that iSTS involvements in the construction of market laws may however be more risky than suggested by Callon. Since markets can 'work' despite the absence of well functioning materialities it is important to sensitize the interventions by STS researchers for prevailing market regimes and market practices to what Laurent Thévenot calls 'forms of the probable'. Sensitivity for such forms is of importance since they are highly consequential for the acting space of social scientists in performing markets.

In the conclusion I return to the main questions in this book. Exploring some 'ecologies of intervention' I show that the active involvement of STS researchers is helpful for finding frictions within medical practices and for elucidating normative complexity. This complexity is not a paralyzing outcome that problematizes normative interventions, enacting the 'normative deficit' that STS research has been accused of. Rather it opens up stale normativities that have too easily assumed who are marginalized and who are centralized. Following the work of Michael Lynch on the surfeit of public understanding of social science, I similarly claim that there is a normative surfeit, rather than a deficit to be dealt with in (interventionist) STS research. iSTS proves fruitful to elucidate this normative complexity and allows for the productive interplay of the normative loyalties of STS researchers and their selective and situated betrayal that at times seems needed in research practices. Such interplays between loyalties and their betrayals is crucial for coming to an ethics of specificity.

Samenvatting

In dit proefschrift staan twee vragen centraal. De eerste, meer empirische vraag, betreft het innoveren van primaire processen in zorgorganisaties. Aan de hand van een analyse van een reeks casussen waarin zorgprocessen zijn 'herontworpen', verken ik wat de verhouding is tussen standaardisering van zorgpraktijken en de complexiteit van patiëntenzorg. Deze relatie is vaak onderzocht in termen van uitersten: ofwel ziet men praktijkvariatie als het probleem en grondige standaardisering van medisch werk als oplossing die medisch werk 'evidence-based' maakt; ofwel ziet men de standaarden zelf als het probleem, omdat zij onvoldoende rekening houden met complexiteiten uit zorg-praktijken en zorgverlening reduceren tot lopendebandwerk. Ik laat zien hoe beide manieren om deze relatie tussen standaardisering en complexiteiten te leggen proble-matisch zijn. Wie probeert medisch werk te 'rationaliseren' op basis van geaggregeerde, van hun specificiteit ontdane, zuiver medische kennis, brengt een onderscheid aan tussen de standaard en de zorgpraktijk waarvoor deze relevant moet worden. Enerzijds ontstaan hierdoor 'implementatieproblemen', anderzijds worden hierdoor vormen van zorgverlening en kennis die niet in de standaard zijn opgenomen, op veelal pijnlijke wijze gemarginaliseerd. Tegelijkertijd leidt kritiek op standaardisering vaak tot een opmerkelijk soort behoudendheid: fascinatie voor complexiteiten gaat in dit geval ten koste van gevoeligheid voor problemen die volgen uit de manier waarop sociotechnische praktijken nu werken. Bovendien blijken deze kritieken vaak buitengewoon beperkt in hun vermo-gen om te analyseren hoe een praktijk ook *anders* zou kunnen werken. Geen van beide manieren om de relatie tussen complexiteiten en standaardisering te bestuderen kan hierdoor als een bijdrage worden gezien aan het gesitueerd verbeteren van zorg-praktijken. Om vermijdbaar lijden voor zowel patiënten als zorgverleners tot een mini-mum terug te brengen, zijn zulke verbeteringen echter hard nodig.

Ik volg in dit proefschrift een andere weg. Ik verken de relatie tussen complexi-teiten en standaardisering niet als een dichotomie, maar ik stel de vraag wat formalise-ringen en standaarden feitelijk doen in zorgpraktijken en op welke verschillende wijzen men standaardisering tot stand kan brengen. Langs deze weg ontstaat er in het debat over standaardisering van zorgwerk ruimte voor een empirische analyse waarin pogingen om bepaalde aspecten van zorg te standaardiseren niet per definitie tegenge-steld zijn aan bijvoorbeeld het komen tot patiëntgerichte zorg. Een vraag die hieruit voortvloeit is welke manieren van standaardisering, welke vormen van patiëntgerichte zorg mogelijk maken. Door een empirische verkenning van initiatieven om zorg-processen in ziekenhuizen te standaardiseren, ontwikkel ik een experimentele aanpak van standaardisering rondom specifieke kwesties die van belang zijn in zorgpraktijken. In plaats van te vertrekken vanuit een medische richtlijn die 'geïmplementeerd' wordt in

een zorgpraktijk, begint deze aanpak met het articuleren van bepaalde problemen die patiënten en zorgprofessionals dagelijks tegenkomen om vandaar uit tot *gesitueerde standaardisering* te komen.

De tweede, meer theoretische vraag in dit proefschrift, betreft de gevolgen van een experimentele en directe betrokkenheid van onderzoekers uit het wetenschaps- en techniekonderzoek bij initiatieven om zorgverlening te vernieuwen. Recente pleidooien voor 'nuttig' en 'bruikbaar' sociaal-wetenschappelijk onderzoek hebben tot de beschuldiging geleid dat meer analytische, constructivistische wetenschapsgebieden zoals het wetenschaps- en techniekonderzoek zouden lijden aan een 'normatief tekort'. Wetenschapsonderzoekers zouden volgens deze opvatting wellicht goed in staat zijn om complexiteiten en problemen in (zorg)praktijken te beschrijven, maar zij zouden tekort schieten in het aanreiken van voldoende normatieve en praktisch toepasbare handvatten om de praktijken die zij beschrijven ook te verbeteren. Deze veronderstelling van een 'normatief tekort' heeft tot het voorstel geleid om het wetenschapsonderzoek te koppelen aan duidelijk vastgestelde normatieve agenda's, zoals politiek activisme, sociale emancipatie en de democratisering van technologie. Hiermee worden vooraf ingenomen normatieve posities bevestigd om vervolgens te worden 'toegevoegd' aan praktijken. Dit creëert niet-gesitueerde normatieve 'standaarden' die wetenschapsonderzoekers opleggen aan hun object van analyse, in plaats van normativiteiten te situeren in de complexiteiten die zij aantreffen en articuleren. In dit proefschrift stel ik de vraag of wetenschapsonderzoekers niet op een volledig tegengestelde manier weerwoord kunnen bieden aan de opvatting dat er in de constructivistische sociale wetenschappen sprake zou zijn van een normatief tekort. Aan de hand van de empirische casussen van het vormgeven van gesitueerde standaardisering van zorgpraktijken, laat ik zien dat het laatste waarop zowel de onderzochte praktijken als de onderzoeker zaten te wachten, een vooraf vastgestelde normatieve agenda was. Door te experimenteren met en te 'interveniëren' in deze zorgpraktijken, ontstaat een situatie waarin het probleem van sociale wetenschappers niet zit in het normatieve *tekort* in hun onderzoek maar veeleer in de overdadige normativiteiten: een *normatieve overvloed*. Wie het wetenschaps-onderzoek verbindt met van tevoren ingenomen ethische standpunten, zet loyaliteit aan bepaalde normatieve posities om in een normatief 'geloof'; het situeren van normativiteiten in de specificiteiten van een zorgpraktijk daarentegen stelt wetenschapsonderzoekers in staat te komen tot een *ethiek van de specificiteit*. Deze ethiek van de specificiteit bouwt voort op de normativiteiten uit zorgpraktijken zonder op voorhand al een normatieve stelling in te nemen. Het gaat hierbij dus niet om het introduceren van normatieve opvattingen in zorgpraktijken maar om het vormgeven van kwesties die volgen uit de praktijken die onderzocht worden.

Deze twee vragen; die over standaardisering van zorgpraktijken enerzijds en die van normativiteiten in interveniërend onderzoek anderzijds, worden in dit proefschrift volgens eenzelfde logica behandeld. Zowel standaardisering als normativiteit worden gesitueerd in de praktijken waarvoor ze van waarde moeten zijn. Wie elk van beide vragen gesitueerd onderzoekt, voorkomt daarmee dat er een ethiek of standaard wordt vastgesteld buiten de praktijk waarvoor ze relevant behoort te zijn. Er zal dus ook geen sprake kunnen zijn van een ontwerpfase die gevolgd wordt door een implementatiefase: een centrale bevinding is dat een dergelijke implementatiefase met alle bijbehorende 'implementatieproblemen' juist ten enen male voorkomen dient te worden. Ik streef daarmee in dit proefschrift naar een aanpak van het *voorkomen van implementatie* van zowel normativiteit in onderzoek als van standaarden in de gezondheidszorg.

De centrale vragen in dit proefschrift worden verkend aan de hand van een analyse van drie casussen. In elk van deze casussen was ik rechtstreeks betrokken bij het ontwikkelen van gestandaardiseerde zorgprogramma's voor ziekenhuiszorg. De casussen worden gekenmerkt door een co-constructie van gezondheidszorgpraktijken terwijl ik telkens gedeeltelijke relaties heb gelegd tussen deze praktijken en het wetenschapsonderzoek. Ik noem dit soort onderzoek daarom 'interveniërend wetenschaps- en techniekonderzoek'. 'Interveniëren' kan natuurlijk gezien worden als een buitengewoon gelaagd concept en kan, bezien vanuit de performativiteit van onderzoekspraktijken in het vormgeven van werelden, tot op zekere hoogte nooit voorkomen worden. De tegenhanger van 'interveniërend onderzoek' – niet-interveniërend onderzoek – voor mogelijk houden, gaat uit van een naïef doch niet onschuldig wetenschapsbeeld. 'Interventie' dient er in dit proefschrift zeker niet toe om onderscheid te maken tussen de 'beschrijvende' en de 'toegepaste en bruikbare' vormen van sociale wetenschap. Ik gebruik het begrip 'interventie' om aan te geven dat deze onderzoeksprojecten expliciet ten doel hadden om de zorgpraktijken die ze bestudeerden ook te veranderen. Daarnaast houd ik ook vast aan dit concept vanwege de wellicht productieve spanning die het oproept in een medische setting. Wanneer sociale wetenschappers het werk van zorgprofessionals bestuderen, dan zijn de 'interventies' meestal voorbehouden aan het object van onderzoek. Door interventie te koppelen aan wetenschapsonderzoek wint dit onderzoek in discussies over de vraag 'waar handelen plaatsvindt' een deel van het terrein terug van de geneeskunde.

De casussen in dit proefschrift betreffen achtereenvolgens: 1) de ontwikkeling van een hemofilie behandelcentrum in een Nederlands academisch ziekenhuis, 2) de ontwikkeling van gestandaardiseerde zorgprogramma's voor een grote polikliniek hematologie / oncologie, en 3) de ontwikkeling van dergelijke zorgprogramma's in zestien ziekenhuizen binnen een landelijk verbeterprogramma voor de ziekenhuiszorg. Al deze casussen zijn onderzocht door het uitvoeren van participerende observaties en inter-

views met professionals en soms ook met patiënten over de zorgpraktijken waar zij mee te maken hadden. Daarnaast bestond het onderzoek uit focusgroepbijeenkomsten over organisatorische voorstellen tot verandering, stuurgroepbijeenkomsten en *project reviews* over de voortgang van projecten, en uit analyses van gegevens uit ziekenhuis-informatiesystemen over zaken als de uitloop van spreekuren, doorlooptijden van patiëntentrajecten en ligduur van patiënten.

In hoofdstuk 1 richt ik mij op methodologische vragen over de relatie tussen door etno-grafie geïnspireerde analyses van werkpraktijken en de complexe mogelijkheden die deze bieden voor interventie. Hoewel etnografie binnen aanpalende wetenschaps-gebieden als *participatory design*, actieonderzoek en *computer supported cooperative work* bekend staat als een belangrijke methode om tot gesitueerde oplossingen te komen voor specifieke werkpraktijken, is zowel haar politieke relevantie als haar ondui-delijke praktijk onvoldoende belicht. Ik stel de veelvoorkomende notie ter discussie dat etnografie leidt tot 'betere' materiële interventies. In die notie staat 'beter' immers meestal voor 'geschikter voor deze werkplek'. Aan de hand van veldwerk bij de totstand-koming van een hemofilie behandelcentrum in een Nederlands academisch ziekenhuis, laat ik echter zien dat er meer dan één antwoord te geven valt op de vraag wat een werkpraktijk *is*, en welke materiële interventies afhankelijk daarvan gewenst zijn. Ook laat ik zien dat het 'doen van veldwerk' niet gescheiden kan worden van het 'informeren van ontwerp' of van 'interveniëren'. Zoals gezegd is 'interveniëren' een subtiele, gelaagde en doorlopende activiteit. Op basis van deze inzichten ontwikkel ik een aanpak van interveniërend wetenschaps- en techniekonderzoek; hierbij hecht ik er belang aan het doen van veldwerk te vervlechten met het informeren van het ontwerp van materiële interventies. Dit proces verloopt daarmee bewust ad-hoc en niet stapsgewijs. Deze onderzoeksaanpak maakt de veldwerker gevoelig voor de gesitueerde en strategische meerduidigheid van een werkpraktijk. Ook stelt zij onderzoekers in staat het toeschrijven van rollen en epistemologische autoriteiten door actoren uit die praktijk om te zetten in onderzoeksgegevens: actoren schrijven deze rollen toe aan de onderzoeker vanuit hun specifieke positie en kijk op wat een werkpraktijk is en zou moeten zijn. Tenslotte maakt deze aanpak onderzoekers gevoelig voor de handelingsruimte die telkens ontstaat en verandert in een dergelijk project. Ik stel dat deze aanpak kan leiden tot interventies die gevoelig zijn voor de meerduidigheid van werkpraktijken en die gesitueerd zijn in een gepolitiseerde etnografische praktijk.

In hoofdstuk 2 bespreek ik het begrip 'interventie' door te kijken naar de historische ontwikkeling van dit begrip binnen het wetenschapsonderzoek. Interventie is binnen de 'kritische wetenschapsstudies' verknoopt geraakt met activistische normatieve agenda's. Ik laat zien dat dit slechts één manier is om de kritiek te pareren dat constructivistisch onderzoek 'normatief tekortschiet'. Deze kritiek kan ook worden weerlegd zonder dat

wetenschapsonderzoekers hun werk verbinden met activistische onderzoeksagenda's. Op basis van dezelfde casus van mijn betrokkenheid bij de totstandkoming van het hemofilie behandelcentrum, geef ik aan hoe de praktijk van thuisbehandeling van hemofilie kan profiteren van wetenschapssociologische inzichten in kwesties betreffende therapietrouw. Therapieontrouw is in de literatuur over kwaliteit van zorg vaak voorgesteld als een probleem op zichzelf. Die voorstelling van zaken heeft geleid tot een stortvloed aan initiatieven en voornamelijk cognitieve interventies om therapietrouw te vergroten, die in de praktijk vaak weinig effect blijken te sorteren. Wetenschapsonderzoekers en medisch sociologen hebben zich gerealiseerd dat patiënten in vele verschillende werelden tegelijkertijd moeten leven en in deze werelden sterk uiteenlopende rollen spelen. Sommige van deze werelden en rollen maken het mensen soms haast onmogelijk om de rol van 'patiënt' te vervullen. Vanuit dit besef hebben deze onderzoekers het doel van volledige therapietrouw ter discussie gesteld. Door hun aandacht te richten op de vraag hoe therapietrouw in de praktijk soms *wel* bereikt wordt, in plaats van zich te verbazen over 'irrationele' therapieontrouw, hebben zij interessante handelingsruimte gecreëerd om therapietrouw vergrotende initiatieven te situeren in de complexiteit van de leefwerelden van patiënten. Ik verken de interventies die uit dit inzicht voortkomen in een empirische analyse van het thuisgebruik van stollingsmiddelen door hemofiliepatiënten. Dit leidt tot een exploratie van de mogelijke voordelen voor wetenschapsonderzoekers om *normativiteit te doen* door middel van praktijken van *vaardige besmetting* van hun eigen normatieve aannames door hun onderzoekspraktijken. Ik stel dat deze aanpak van waarde is voor het voorkomen van het normatieve tekort waarvan het wetenschapsonderzoek is beticht en draag interveniërend wetenschapsonderzoek voor als een riskante, maar vruchtbare onderneming.

Hoofdstuk 3 gaat over het onderzoek naar de 'therapietrouw' van medici zelf aan voorgeschreven richtlijnen. In eenzelfde retorische structuur als ik in hoofdstuk 2 signaleerde in de discussie over het handelen van patiënten, wordt door gezondheidswetenschappers en beleidsmakers in de discussie over het naleven van richtlijnen vaak de lage 'therapietrouw' van zorgprofessionals als groot probleem gezien. En net als bij het debat over therapietrouw van patiënten, stellen de voorgestelde 'oplossingen' om praktijkvariatie te verkleinen de epistemologische status van geaggregeerde medische kennis niet ter discussie. Zulke initiatieven blijken daardoor veelal praktisch omslachtig, politiek onvoldoende gevoelig en conceptueel gezien problematisch. In een tweede casus, over een verbeterproject op een polikliniek hematologie / oncologie van een academisch ziekenhuis, onderzoek ik experimentele interventies in standaardisering van zorgpraktijken. Ik laat zien dat dit interveniërende wetenschapsonderzoeksproject een vorm is van het bedrijven van politiek door middel van standaardisering. In plaats van de hierboven vermelde extremen na te streven van ofwel het volledig rationaliseren van zorgpraktijken ofwel het toejuichen van complexiteiten die niet te standaardiseren

zouden zijn, richt ik me op de waarde van interveniërende onderzoeksprojecten voor het realiseren van gesitueerde standaardisering van zorgpraktijken. Door interne spanningen op te zoeken binnen discussies over *evidence based practice* en door deze te versterken, kom ik in dit hoofdstuk uit op een 'procesmatige' aanpak van het maken van zorgprogramma's. Hierbij zijn deze programma's geen vertrekpunt voor organisatie-verandering, maar een uitkomst van een dynamisch proces van zorgprogrammering.

In hoofdstuk 4 verken ik dezelfde casus van interveniërend wetenschapsonderzoek op de polikliniek en dagbehandeling hematologie / oncologie, ditmaal met als doel te inter-veniëren in discussies over de relatie tussen standaardisering en patiëntgerichtheid. In de medisch-sociologische literatuur worden 'standaardisering' en 'patiëntgerichtheid' steevast als exact tegengestelde concepten gezien. In dit hoofdstuk verken ik de specifi-citeiten van deze tegenstelling, hun beperkingen en de vraag in hoeverre een andere invulling van beide concepten zou kunnen bijdragen aan hun pragmatische verenigbaar-heid. Door in empirisch opzicht gebruik te maken van de ontwikkeling van patiënt-gerichte zorgprogrammering en in theoretisch opzicht te werken met het pragmatisch-filosofische werk van John Dewey en zijn herwaardering van de aandacht voor kwesties in democratische praktijken, geef ik aan dat recente discussies binnen de politieke wetenschappen van belang zijn om discussies over en praktijken van patiëntgerichtheid en standaardisering anders te voeren. Door de kwesties waarmee patiënten, zorg-professionals en organisaties geconfronteerd worden, centraal te stellen in het proces van het 'programmeren' van zorg, kunnen wetenschapsonderzoekers gesitueerde stan-daardisering creëren. Hierbij articuleren ze een insteek van de ontwikkeling van zorg-paden die aanvankelijk ook centraal stond in de zorgpaden beweging maar die steeds marginaler is geworden doordat zorgpaden als 'producten' worden gezien die 'geïmple-menteerd' moeten worden, zoals beschreven in hoofdstuk 3. In discussies en praktijken van standaardisering van zorgwerk, is een procesmatige aanpak van zorg-programmering die zich concentreert op kwesties die spelen in zorgorganisaties toe aan een herwaardering. Zij kan immers leiden tot zorgprogramma's waarbij zorg op meer substantiële en materiële wijze patiëntgericht wordt.

Hoofdstuk 5 gaat over de mogelijkheden voor het interveniërend wetenschaps- en tech-niekonderzoek om bij te dragen aan de totstandkoming van zorgmarkten. De sociologie van markten maakt spannende theoretische ontwikkelingen door, met name dankzij het werk van Michel Callon over de 'performativiteit van de economische wetenschap' – het besef dat economen geen marktwetten 'ontdekken' maar zelf actief betrokken zijn bij de vormgeving van deze 'wetmatigheden'. Dit concept heeft de vormgeving van markten toegankelijk gemaakt voor veel voorheen buitengesloten actoren; immers, als economen marktwetten vormgeven in de materialiteit van marktpraktijken, dan is er geen reden voor sociale wetenschappers om zichzelf uit te sluiten van dit proces van vormgeving.

Met name voor wetenschaps- en techniekonderzoekers is hier volgens Callon een schone taak weggelegd, vanwege hun kennis over het vormgeven van zulke materialiteiten. Ik laat echter zien dat de aandacht van Callon voor de rol van materialiteiten bij het vormgeven van 'calculatieruimten' en voor de rol van de economische wetenschap bij het vormgeven van deze materialiteiten, bijgedragen heeft aan een overdreven enthousiasme voor de rechtstreekse betrokkenheid van wetenschapsonderzoekers bij het vormgeven van marktwetten. Op basis van een derde casus over de ontwikkeling van gesitueerde standaardisering door middel van procesherinrichting binnen een landelijk verbeterprogramma, analyseer ik de mogelijkheden voor het vormgeven van zorgmarkten die over het coördineren van verschillende waarden gaan en niet alleen inzetten op kostenbesparing. Ik stel vast dat de betrokkenheid van interveniërende wetenschapsonderzoekers bij de vormgeving van marktwetten wellicht riskanter is dan Callon voorstelt. Uit de casus blijkt namelijk dat markten kunnen 'werken' ondanks de afwezigheid van goed functionerende materialiteiten. Dit inzicht tempert het optimisme om markten vorm te geven op manieren die afwijken van reeds bestaande marktregimes en van wat Laurent Thévenot 'waarschijnlijkheidsvormen' noemt. Gevoeligheid voor deze vormen is van buitengewoon groot belang voor de handelingsruimte van sociale wetenschappers bij het vormgeven van markten.

In de conclusie keer ik terug naar de centrale vragen die ik in de inleiding opwierp. Door enkele 'ecologieën van interventies' te verkennen, geef ik aan dat betrokkenheid van wetenschapsonderzoekers kan bijdragen aan het ontwarren van spanningen binnen zorgpraktijken. Interveniërend wetenschapsonderzoek is hierdoor in staat de normatieve complexiteit van zulke praktijken te ontrafelen. Deze complexiteit is geen verlammende uitkomst van het onderzoek en zij maakt normatieve interventies dan ook niet kansloos. In plaats van te resulteren in het 'normatieve tekort' waarvan het wetenschapsonderzoek zo vaak is beschuldigd, breekt zij vastgeroeste normativiteiten open waardoor wordt voorkomen dat wetenschapsonderzoekers al te makkelijk vooraf aannemen wie er gemarginaliseerd is en wiens positie centraal gesteld wordt. In navolging van het werk van Michael Lynch over de overvloed aan algemene wetenschappelijk kennis, stel ik dat (interveniërend) wetenschaps- en techniekonderzoek met name het hoofd moet zien te bieden aan een overvloed aan normativiteit, in plaats van aan een normatief tekort. Interveniërend wetenschapsonderzoek blijkt niet alleen van belang om deze normatieve complexiteit bloot te leggen; ook brengt zij een productieve wisselwerking op gang tussen normatieve loyaliteiten van wetenschapsonderzoekers en het gesitueerde 'verraad' van deze loyaliteiten dat in onderzoekspraktijken soms nodig blijkt. Dit samenspel van loyaliteiten en hun verraad blijkt onmisbaar om tot een ethiek van de specificiteit te komen.

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It is impossible to duly acknowledge all those who have contributed to this thesis, and this is what I will do here. Acknowledgements tend to address that writing a thesis is a lonely process – a loneliness that was from time to time interrupted by those who are being acknowledged. The only real complaint I could have about the process of writing this thesis is a constant *lack* of loneliness. Exploring 'intervention' in STS research provided continuous contacts with actors and colleagues to 'reflect with' and 'act with'.

I feel very fortunate that many of these contacts were with Marc Berg. It is a rare privilege to be supervised by one of your favorite scholars, and the opportunity to work with Marc ensured that the years I worked on this thesis were very valuable. The times we worked together in many projects in Dutch hospitals and engaged in discussions on the different ways in which the social sciences and care practices can relate to each other, have been among the most inspiring professional experiences I have had. His feedback, always being generous, merciless, humorous and pretty close to instant – no matter how pressing his other obligations and even after he had largely 'left' academia – has been crucial for this thesis and for my development as a researcher.

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During the years of carrying out the research for this thesis, I have been part of two very stimulating research groups: the science and technology studies (STS) medical IT group called *Research on IT in Healthcare practice and Management* (RITHM) and later the *Healthcare Governance* section. RITHM was a treat. Brit Ross Winthereik and Irma van der Ploeg, your critical and always productive reflections on my projects and approach have been no less than crucial. Antoinette de Bont, Stans van Egmond, Arjen Stoop, Samantha Adams, Jos Aarts, Bert Huisman, Habib Pirnejad and Zahra Niazkhani: many thanks for interesting discussions and for being great colleagues.

The merger of RITHM with the policy researchers in Healthcare Governance shows how stimulating and fruitful it can be to bring together researchers with not necessarily similar empirical domains but with shared interests in empirical and

About the author

Teun Zuiderent-Jerak was born in Amsterdam on June 1st 1975. In 1993 he completed his secondary university preparatory school (VWO) at the Montessori Lyceum Amsterdam. From 1994 till 1999 he studied Arts and Sciences at the University of Maastricht, the Netherlands, where he specialized in the Science and Technology Studies program *Technological Culture* and which he completed with a Master of Arts degree. He also participated in the international program European Studies of Society Science and Technology (ESST) at the University of Maastricht and Roskilde University, Denmark, which he completed in 1999 with his second Master of Arts degree.

From 1999 to 2000 he studied Pali (an ancient Indian language) and Vipassana meditation at the Vipassana Research Institute in Igatpuri, India, which he combined with doing voluntary work. After completing the Pali diploma course, he returned to the Netherlands and started working at the department of Health Policy and Management as a Research Fellow.

Since 2001 he has carried out various research and organizational change projects. He was project manager for setting up a hemophilia care center of a large university hospital, project manager of 'Working Differently', a reorganization project at a large hematology / oncology ward, and project leader of the process redesign project in the *Better Faster* quality collaborative for improving hospital care delivery. During this last project he was responsible for around 40 improvement projects in 16 hospitals which all focussed on reducing the throughput time and length of stay for oncology and elective patients. Furthermore, he was an advisor to the Atrium MC (a large teaching hospital) during the two years this hospital was part of the *Better Faster* collaborative.

Additionally, he has participated in the departmental teaching program by teaching courses on medical technology and since 2005 by coordinating a course on (critical perspectives on) change management in healthcare for students of the Health Sciences Bachelor program.

Teun Zuiderent-Jerak has published articles in the academic journals *Scandinavian Journal of Information Systems, Human-Computer Interaction* and *Science as Culture*. He has also co-edited a special issue of *Science as Culture* on *Unpacking 'Intervention' in Science and Technology Studies*.

Currently he is a researcher in the project evaluating the *Care for Better* quality improvement collaborative for innovating care for the elderly, the handicapped and in home care. He also is principal investigator in the evaluation research on the integrated development and implementation of innovations in care for the elderly. These projects focus on the interrelations between innovation, quality improvement and the construction of markets in healthcare.