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Guest Editorial

The Shaping of Patient 2.0: Exploring Agencies, Technologies and Discourses in New Healthcare Practices

This special issue investigates the idea of a Patient 2.0 in a distinctly open and exploratory manner. We find that the term 'Patient 2.0' is multi-layered and difficult to define unequivocally, and therefore generative and thought-provoking. What does it mean to be a Patient 2.0? What are the specificities and novelties of the so-called Patient 2.0? What expectations, strategies, and practices does this imply? How does Patient 2.0 come into being, and what are the consequences? What can we learn by studying Patient 2.0?

These questions are central to this special issue, and they emerge from an underlying concern for, and fascination with, a term that may indeed refer to something new 'in the world,' but which may also help us identify an emerging figure or person. Are we witnessing the birth of a new kind of patient, or is the term merely a buzzword, a fancy way of referring to traditional patients? This issue takes up the challenge implicit in these questions, and attempts to adopt Patient 2.0 as a *significant* term for those concerned with current trends in healthcare systems. In line with the exploratory nature of the issue, we do not provide a fixed definition of the term; rather, the issue is devoted to an exploration of the notion and its various dimensions and implications, and suggests different ways to conceive and consider

Patient 2.0, thus fleshing it out with both empirical material and analytical frames.

The term 'Patient 2.0' is obviously akin to concepts such as Web 2.0, Health 2.0, and Medicine 2.0 (Bos, Marsh, Carroll, Gupta, & Rees, 2008; Eysenbach, 2001, 2008; Rochman, 2010), and it suggests a kind of upgrade or enhancement of the 1.0 version. The concept of Web 2.0 was suggested at the beginning of the millennium in relation to a new model of content generation and circulation on the Internet which, through new web technologies and social platforms, began to be driven to a far greater extent by users enabled not only to access and consume information, but also to produce and share it. This model has rapidly conquered various areas of everyday life, and is also unavoidably opening up new opportunities and raising new issues in relation to health, the delivery of health services, and the meaning itself of being afflicted by a disease. Informed by science & technology studies, our interest is in the *transformative* aspects relative to Patient 2.0 that may be linked, though not exclusively, with (internet) technology. Indeed, it is our intention to avoid reducing the evocative power of Patient 2.0 merely to the tools and technology that may be used, and we suggest that interest in Patient 2.0 is more broadly concerned with the proactive, interactive, and multifaceted nature of individuals engaged in their own health conditions. Indeed, it is not only technological interests that seem to be converging on and aligning around the patient, but also political,

economic, organizational, social, and ethical issues. The special issue focuses on *Patient 2.0*, and not on *Health 2.0* or *Medicine 2.0*. This is because we find that the concrete, situated actions of people engaged in the mundane daily activities of an individual with a health issue provide a unique perspective from which to consider the broader transformations in and around healthcare systems, whilst the other labels stimulate reflections on more general and broader tendencies that remain unanchored to the lived experience of people struggling with a disease.

Background to the Issue

This special issue is the outcome of a lengthy process that began in 2009 with the preparations for a track at the EASST conference in Trento, Italy 2010. In the call for papers, we asked potential contributors to observe the healthcare domain through the “intriguing lens” of *Patient 2.0*. The aim of the call was to stimulate wide-ranging conceptual and empirical reflections on the enactment of patients through *engagement with/enrolment through technologies*. Contributions ranged from the conceptualization of *Patient 2.0* to the design of health technologies and services, and from the role of online patient communities to issues of governance. The richness of the presentations made during the conference obliged us to pursue an open, investigative approach in the call for papers for this special issue. Fifteen full papers were submitted. The review process was guided by two primary concerns: firstly the ‘intrinsic’ soundness of a contribution, and secondly its ‘innovative qualities’ in terms of opening new perspectives on the concept. Following a stimulating and rewarding review process, the issue includes five articles. We would like to thank all the presenters at the conference track, and all the contributors to the special issue, for

allowing us to engage in demanding and thought-provoking work from which we have learned an immense amount.

Healthcare Systems in Transformation

Healthcare systems in many Western countries are undergoing profound changes that pose considerable challenges for policy- and decision-makers, healthcare professionals, patients, and citizens. The healthcare sector constitutes one of the greatest fiscal burdens in society. Spending is steadily increasing due to a range of factors: the elderly component of the population is increasing; novel medical technologies are continuously being developed and introduced; treatment is becoming ever more sophisticated and specialized; and the disease pattern of the population is changing. Today, chronic diseases constitute the primary challenge for the healthcare sector, and treatment of these diseases is fundamentally different from the episodic and acute treatment for which much of the healthcare sector was initially designed. We are witnessing a structural redesign in the delivery of health services, moving from ‘management and care’ to ‘treatment and cure’ (Gerhardt, 1989), with increasing attention being paid to outpatient care, prevention, and wellness (Geissbuhler, 2011). Coincidentally, we have seen an immense proliferation in the past decade of both internet technologies and the availability of relatively affordable and easy-to-use medical devices marketed for patients and laypeople. There thus seems to be a market-driven rebalancing of the patient-doctor relationship in terms of the technologies available, and this can also be observed in the field of computer sciences, where traditional ‘medical informatics’ have been coupled with the relative novel ‘consumer health informatics’ (Eysenbach, 2000; Bakker et al., 2005). We should, however, be cautious about

considering novel health technologies to be simply solutions to problems. As Brown and Webster (2004) have argued, these technologies have profound and unexplored consequences for people's lives as well as for medical encounters, and they come with a range of more or less obvious social and ethical consequences. In this issue, for instance, Bruni and Rizzi (2013) consider how medical encounters are changing or may change as a consequence of the engagement by individuals (with chronic conditions) in self-care and self-monitoring practices. In what follows, we discuss some of the general concerns and issues that have stimulated our engagement with the concept. These concerns are somewhat broad and general, the idea being to cultivate a basis for multiple and possibly divergent forms of reasoning around the concept, not to take unequivocal positions on Patient 2.0. Accordingly, we discuss some of the consequences of Patient 2.0 and the appraisals and criticisms that we consider to be central to the concept.

The (All-too-obvious) Cyborgian Quality of Patient 2.0

By combining the word "patient" with the version marker "2.0", the term makes obvious reference to the cyborgian quality of our contemporary condition, as suggested by Donna J. Haraway (1991). In this sense, Patient 2.0 suggests a version of the patient as a human actor wired into a network of external health infrastructures and internal miniaturized devices, intermingled with institutions, organizations and social groups. This reference also reaffirms the apparently proactive and generative nature of the patient as an agent producing data, information, knowledge, and contents to be shared on a variety of platforms and in different settings. Movements such as *Quantified Self* (Swan, 2009; Lupton, 2013) and patient communities such as

Patientslikeme.com (Wicks et al., 2010), or the growing network of biohacker labs (Ledford, 2010) are good examples of this tendency. But the term is cyborgian in another sense: just like all the other "2.0's", Patient 2.0 evokes both a state of being and a process of becoming, something that we are already experiencing but which is also an emerging phenomenon whose consequences are yet to be realized and experienced. Haraway's cyborg analysis of the OncoMouse (1996) is informative in regard to Patient 2.0. The OncoMouse is a highly controversial and contradictory because, Haraway shows, it is simultaneously an animal, a techno-scientific product, and a breast cancer-curing device. Arguably, Patient 2.0 is equally heterogeneous. This notion concerns a) the active, autonomous, and technologically capable patient; b) involvement in organizational optimization and health care budgets; c) patient education and developing markets for self-monitoring technologies; d) knowledge creation as well as f) it challenges established forms of research and knowledge. Partly fact and partly fiction, Patient 2.0 appears to act as a key rhetorical device in a series of current narratives, discourses, and concerns. Bjørn and Markussen's contribution in this issue (2013) employs Haraway's figure of the cyborg along with Braidotti and Balsamo's conceptualisations in an analysis of implanted heart defibrillators. The authors shed light on how these novel technologies are promoted and advertised, and they untangle the technological infrastructures involved in the treatment of patients with these implants, thus illustrating what a Patient 2.0 might be, and the related expectations and implications.

Different Settings for Care: Patient 2.0's Different Ways of Knowing

Patient 2.0 raises issues of a future of reorganized healthcare practices in

which the technologically empowered and autonomous citizen engages in new forms of participation, collaboration, and self-management. It thereby contributes to reconfiguring and re-articulating the delivery of health services, as well as traditional interdependencies. In this transforming context, a critique has been brought against medical science and biomedical perspectives being paternalistic, rationalist, and arguably unable to appreciate a holistic view of the patient. In this sense, Patient 2.0 can be seen as a reproof to medical science for being patriarchal, alienating and objectifying (Leder, 1998), and of medical settings as constraining the ability to look at bodies and disease in different ways.

Indeed, competences, skills and expertise are produced *in the wild*, and they enable patients to ground, integrate, supplement (Storni, 2013), or even dispute (Arksey & Sloper, 1999) established medical knowledge and practices. As such, Patients 2.0 may potentially lead to the creation of new ways of knowing, dealing, and treating disease (Arksey, 1994; Nettleton & Burrows, 2003). From this perspective, Patients 2.0 can be seen to be renegotiating the terms and perspectives on which empowerment and participation may be based, thus challenging the traditional distribution of authority in the healthcare system (Epstein, 2008; Callon, Lascoumes & Barthe, 2009). Recent studies confirm this, and although concerns about the production and proliferation of 'non-authoritative' knowledge have been raised, especially in medical science, clinical knowledge, treatment practices, research agendas, and health policies are potentially affected by more or less informal networks of patients and the "research in the wild" that they produce (Rabeharisoa & Callon, 2002; Callon & Rabeharisoa, 2003). This is further linked to recent studies of personal health information management carried out in households. These show

that laypeople collect, organize, and use information for purposes that are neither anticipated nor desired by healthcare personnel (Moen & Brennan 2005; Aarhus & Ballegaard, 2010; Piras & Zanutto, 2010; Storni, 2010; Danholt & Langstrup, 2012). Jeanette Pols's (2013) contribution to this issue is concerned with how medical and patient knowledge intervenes and interacts, and how we might further a different kind of patient engagement. Interestingly, Pols describes the mundane daily production, appropriation and accommodation of health knowledge in the practice of patients in their domestic settings. She thereby contributes to our knowledge of everyday (self-)care practices and how these differ from institutional ones.

Patient 2.0 and Biopolitics

Another important and somewhat critical perspective on Patient 2.0 may emerge when Patient 2.0 is considered as a powerful, yet subtle, extension of biopolitics. Based on Michel Foucault's (1991) earlier work and the work of followers such as Nicolas Rose and Peter Miller, one might consider Patient 2.0 to be the discursive and material construction of a healthy, active, and self-caring subject. Indeed, patients and their domestic environments may be seen as subjects and spaces that are remotely monitored and territorialized by the medical regime as an instance of biopower. From this perspective, the medical regime imposes patient participation as a means to an end, and the logic and knowledge of medical science are diffused into the lives and homes of patients, so that they can be governed. The contribution to this issue by Langstrup, Iversen, Vind, and Erstad (2013) focuses on telemedicine, but their study is more closely concerned with how the home location is transformed in and by telemedical practices. They consider the processes of emplacement

and place-making that emerges with the use of telemedical technologies, and how it relates to the idea of Patient 2.0. Their article thus contributes to an understanding of what Williams (2002) called changing geographies of care.

Biopower occurs not through punishment, but 'softly', and at a distance (Rose & Miller, 1992; Rose, 2006) or, as Mitchell Dean (2010) argues, through incentives and moralization and by creating desires and needs through markets where subjects can act as free autonomous actors able to choose from among different goods (see also Mol, 2008; Foucault, 2009). The dispersion of medical technologies and practices in the form of smartphone applications, Electronic Health Records (EHR) and Personal Health Records (PHR), medical diagnostic devices, web-based platforms and services, and telemedicine makes this kind of analysis apparent. Storni and Bannon (2011) discuss how the encounter between healthcare infrastructures and patient empowerment may create a paradox: patients supposedly empowered and able to take care of themselves through a form of delegation ultimately find themselves enrolled in the larger, and more traditional, healthcare infrastructures at another level. This inclusion operates as a silent exclusion of their perspective through the imposition of a biomedical language and a specific way of looking at things.

The Body of Work Forming the Background to the Special Issue

Healthcare has received a great deal of attention over the years in the STS field (see, for example, Berg, 1997a,b; Berg & Mol, 1998; Bowker & Star, 2000; Lehoux, 2006). In addition, the number of studies of patients has increased in recent decades, especially in relation to chronic disease (Mol, 2008), less known conditions and information

technology (see, for instance, Lehoux, 2006; Wathen, Wyatt & Harris, 2008). A systematic review of these works would be beyond the scope of this editorial. However, we would like to point out some of the contributions that we consider to have been formative for the special issue. These rest on an empirical, relational, and constructivist analysis of the mutual co-construction of human, technological, and material agency that we believe to be central when discussing a Patient 2.0. An important body of work by actor-network theory-inspired scholars such as Marc Berg and Annemarie Mol has provided in-depth ethnographic analysis of medical *practices*. These studies have challenged the idea of medical science and practice as coherent and homogenous, as well as the notion of the body and disease as coherent and singular (Berg, 1997a; Law & Mol, 2002; Brown & Webster, 2004). Because they are concerned with the performative aspects of medical practices, these contributions have done for medical science what early science studies did for natural sciences in the laboratory (Barnes, 1974; Collins, 1974; Fleck, 1979; Latour & Woolgar, 1979; Knorr Cetina, 1981; Latour, 1987; Pickering, 1995). They have shown the contingent, complex, and 'messy' aspects of medicine (and science), and provided more detailed accounts of medical practices, while also appreciating the careful, meticulous, competent work required by and carried out in these practices. In conjunction with this type of work, we also find contributions concerned with the emergence of patient groups and organizations and their ability to challenge and transform existing medical research and practices of great importance (see Epstein, 2009). Scholars such as Callon and Rabeharisoa (2003) have been concerned with the democratic aspect of an engagement between lay and expert knowledge, and how to facilitate and further it (cf. Jeanette Pols, 2013). Similarly, Akrich (2010) has studied the emergence of activist

health groups in on-line communities, and how they form epistemic communities that affect medical research and policy. Studies of patients outside clinical settings and the management of chronic disease and care practices in everyday life exhibit the complexities, ambiguities, and competences that emerge in the lives of the chronically ill. These studies have also contributed to the field of STS through ethnographically-grounded analysis (Charmaz, 1993; Mol, Moser, & Pols, 2010; Danholt, 2013; Danholt & Langstrup, 2012; Storni, 2013). In addition, scholars such as Berg, Timmermans, Winthereik, and Vikkelsø have considered the technologically mediated aspects of medical practices and the role played by technology in medicine and care (Berg, 1997a,b; Berg & Timmermans, 2000; Berg & Toussaint, 2003; Vikkelsø, 2005; Winthereik & Vikkelsø, 2005; Jensen, 2010). In this regard, the contribution in this issue by Bruni and Rizzi (2013) focuses on how the involvement of the patient as a data provider for the healthcare professional through the use of self-monitoring technologies in relation to the treatment of diabetes is by no means just a simple matter of transmitting data. Instead, the authors show how a concern with validating and assessing the data provided by the patient becomes a key activity in clinical practice. This study, together with the others cited above, contributes to acknowledgment of the symmetrical relationship between technological and human agency, and the more or less obvious ways in which new technologies transform care and work practices in medicine. Finally, the works of Oudshoorn (2008) and Mort and colleagues (2003) expand on this point by showing how telemedicine transforms care, the roles of patients and healthcare professionals, and the competences they achieve by performing 'invisible work' (Star & Strauss, 1999).

Patient – Particular, Situated, Qualitative

As noted above, our choice focuses on Patient 2.0 rather than Health 2.0 or Medicine 2.0. These latter concepts are generally used to present allegedly grandiose transformations in healthcare along with the promises of technologically-driven changes, and the future that we shall all be experiencing soon. Contrary to this, our interest is in the concrete, situated actions of people engaged in the mundane daily activities of being an individual with a health condition.

This also has methodological ramifications, since it encourages us to be attentive to how *specific* people with *specific* problems act and live. This seemingly microsocial engagement does not suggest that there are no broad societal forces at work, or that they are of no consequence for the concrete, situated actions of specific people. On the contrary, it is about insisting on *localizing* actions and actors as argued in actor network theory, which implies a concern with how supposedly 'broad, general, and macrosocial' tendencies and forces are in fact translated into concrete situations and lives, and how they come to matter (Latour, 2004, 2005; Tsing, 2005). This tension between the individual level and macrosocietal trends is well represented in the 'Patient 2.0' label, which expresses both the singularity (patient) and the relationality (2.0) of the lived experience.

The field of STS teaches us to be sceptical of deterministic accounts, and to be attentive to the translational and creative outcomes of everyday practices where seemingly trivial issues such as carrying a self-measuring technology requires careful adjustments to make it compatible with the surrounding social world (Piras & Zanutto, 2013). Any technology, fact, concept, symbol, or discourse is always in the hands of its user, so that it will be transformed

in and through its employment (Latour, 1987; Brown, 2002; Serres, 2007). In this issue, Nielsen and Jensen (2013) provide thoughtful insight into how technologies and concepts are transported between different sites. They analyse the history of the *Stanford Chronic Disease Self-Management Program* and how it travels globally. They consider the frictions that arise when this programme is introduced into contexts other than those within which it was developed, specifically in the context of the Danish healthcare system. The authors reflect on the ramifications of the movement and reception of these 'global' programmes in relation to the concept of Patient 2.0. In this analysis, and in line with STS, we can see how the social and the technical are intimately intertwined, and how they shape each other performatively. Accordingly, they reaffirm how patients and the tools and technologies they use come to be 'together' in a specific space and time.

As mentioned at the outset, the aim of this issue is to explore the Patient 2.0 concept and to acknowledge it as a consequential actor in contemporary society. We believe it provides nuanced and thought-provoking accounts of the ramifications of the concept and what it might mean to be a Patient 2.0. We feel that the issue makes explicit some of the challenges, possibilities, problems, pleasures, and suffering involved in being a patient entangled in technological and organizational infrastructures. The main contributions of the issue, in our opinion, consist in detailed insights into the concrete practices of patients who encounter emerging technological and organizational infrastructures in which the specific expectations of the patient are inscribed (Akrich, 1992). The issue thereby enables us to juxtapose and reflect on these expectations and their practical consequences. We believe the issue provides Patient 2.0 with the accounts it deserves, providing the concept with a complex,

heterogeneous, discursive, and material 'body': a body of mixed components, and of difficulties, potentialities, promises, pain, and suffering. Multifaceted and complex accounts of this nature constitute more careful effective guides for thinking and acting than do univocal and simple ones. While the explorative character of this special issue invites its readers into a new area of study, it also points to the need for further research. Therefore, we would like to close this editorial by pointing to one topic we find particularly important in future research into Patient 2.0, namely online communities and social networks as well as the use of mobile and ubiquitous technologies in relation to health care practices.

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We would like to offer many thanks to all those who helped us with the process of crafting this special issue, and especially all the "invisible workers" that made it possible. Many of the participants at the Trento 2010 EASST track volunteered to review the manuscripts, and other colleagues joined them in this process. We are grateful to all of them for their commitment, their thorough reading, and their detailed comments on the works. The articles in this special issue have benefited from them greatly, and we hope that their work also proved useful for the authors of the manuscripts that we had to turn down. Last but not least, we thank Sampsa Hyysalo and the editorial board of *Science & Technology Studies*, particularly Estrid Sørensen and Jörg Niewöhner, who acted as the journal editors in the last part of the process.

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Cyborg Heart: The Affective Apparatus of Bodily Production of ICD Patients

Pernille Bjørn and Randi Markussen

We argue that a cyborg approach both emphasizes the complexity in treating patients with implantable cardioverter defibrillators (ICDs) attached to home monitoring devices, and makes it possible to decipher modern perspectives in the notion of 'Patient 2.0' and other representations of patients. We attempt to open up the notion of Patient 2.0 exemplified by ICD patients by drawing on the cyborg idea as developed by Donna Haraway as well as her understanding of science and the body as an apparatus of bodily production. We include the feminists Rosi Braidotti, Anne Balsamo, Geoff Bowker, and Leigh Star in discussing the cyborg, its infrastructures and affective potentials. We analyse modern imaginaries of remote monitoring as they are portrayed on the websites of the two largest manufacturers of ICD technologies, and based on an analysis of the apparatus of bodily production involved when patients visit a hospital to have their illness monitored we propose the analytical device cyborg heart to capture an affective apparatus of bodily production in the clinic and the idea of an enlarged sense of community as opposed to modern imaginaries of patient empowerment. Finally we discuss how the device cyborg heart differs from the notion logic of care.

Keywords: cyborg, patient, healthcare

Life is beyond pleasure and pain – it is a process of becoming, of stretching the boundaries of endurance. There is nothing self-evident or automatic about life. It is not a habit, though it can become an addiction. One has to 'jump-start' into life each and every day; the electromagnetic charge needs to be renewed constantly. There is nothing natural or given about it. (Braidotti, 2006: 211)

Introduction

In 1982 Ridley Scott released his film *Blade Runner*, based on Philip K. Dick's book *Do Androids Dream of Electric Sheep?* (Dick, 1968). The film's futuristic image suggests that androids are stronger and more capable than humans. Androids could only be told apart from humans by the use of advanced equipment to detect feelings and emotions through their eyes, and the most advanced

androids were not even aware that they were not human, since they were given false memories of non-existent childhoods. The portrayal of androids in *Blade Runner* calls into question what it means to be human or machine. The ambiguity of several characters urges us to ask, what does it mean to live in a time dominated by scientific and technological imaginaries (Balsamo, 1997)? Although the characters in *Blade Runner* are science fiction, the question remains highly relevant in order to appreciate what 'Patient 2.0' is about?

'Patient 2.0' is a modern term. 'Patient' literally means suffering, and refers to people who are affected by the action of others, i.e. medical institutions, doctors etc. The digits '2.0' refer to a new version of a web-based information infrastructure. Following the modern idea of progress the implied suggestion seems to be that '2.0' possesses the potential to empower/emancipate patients by offering them more opportunities of participating in their own treatment. Emancipation literally means, 'to come out from under the hand of' (Lerner, 1986: 237). Thus '2.0' denotes not only new, but *better* than '1.0' in the sense that the patient potentially becomes less dependent on other people and gain more freedom. The idea is not that the patient becomes 'more patient' as the numbers go up, or 'more entangled' in the infrastructure as the science fiction imaginary suggests. It reads as a modern human centred term rather than a post human term.

We investigate controversies regarding human versus post-human perspectives through a cyborg lens and focus on patients with an implantable cardioverter defibrillator (ICD) hooked up to a remote monitoring system. These patients are literally cyborgs as beings relying on a cybernetic 'command, control and communication' mechanism the phenomenon that Haraway took as

starting point in her cyborg configuration. (Haraway, 1991: 150). The ICD device is a small, battery-powered electrical impulse generator programmed to detect cardiac arrhythmia and correct it by delivering a shock of electricity. It is implanted under the skin. The device appeared in the US in 1980 and in Denmark in 1989. More and more people are under treatment, both those surviving severe heart problems and heart attacks. Increasingly ICD are also used prophylactic (Køber et al., 2006). ICD patients appear as any human in the society, as it is invisible for others how they embody complex contemporary human-machine relations. One needs 'blade runners' so to speak, doctors with advanced equipment to tell the difference.

Haraway's cyborg figuration (1991: 149) builds on a blurring of key modern distinctions, such as human versus machine, organic versus inorganic, and natural versus artificial, which contemporary scientific approaches in biology as well as communication sciences have brought about (Haraway, 1991: 149). The approach differs from sciences operating on essential categories of the human, the organism, the machine etc. and challenges distinctions between what belongs to nature and what belongs to culture. Those distinctions 'implode' when sciences work by 'translating the world into a problem of coding and information processing,' relying on command, control, and communication mechanisms that connect humans and machines. Mind, body, and technologies are 'on very intimate terms' (Haraway, 1991: 165).

Looking into the ICD device infrastructures, we are curious to learn how sciences and stakeholders imagine and manage ICD patients and what kind of realities they help bring about. The cyborg approach invites us to include popular

images of ICD patients, as well as the practices implicated in their treatment.

In what follows, we explore how ICD patients are imagined in the public space of the Internet from the perspectives of two of the largest ICD technology manufacturers. In addition, we move to a heart clinic at a university hospital to decipher the knowledge production in the treatment of the patients, the infrastructures and the involvement of the patients in the collaboration. Subsequently, we bring the various theoretical as well as empirical images together to discuss differences between modern and cyborg approaches in understanding patients and their ethical implications.

We embark on this journey, by going fifty years back in history and look at the genealogy of the term cyborg in order to emphasize Haraway's vision and its implication for making sense of ICD patients and open up the notion 'Patient 2.0'.

Cyborgs for Earthly Survival

When Donna Haraway coined the term *cyborg* in the early 1980s, she was unaware of its former use in another field (Markussen et al., 2000: 10). The term first appeared in 1960 in connection to experiments in the field of medical cybernetics (Kline, 2009: 333). Engaged in bioastronautics, Manfred Clynes and Nathan Kline introduced the term as an abbreviation for 'cybernetic organism' (Clynes & Kline, 1960). They built on Norbert Wiener's definition of cybernetics as the entire field of control and communication theory, whether in the machine or the animal. The term was meant to indicate a literal fusion of human/animal and machine, as in the laboratory mouse they experimented with by implanting an osmotic pump. The researchers used the pump to inject drugs at a rate controlled

by biological feedback and monitored the effects.

The goal was to develop drugs and devices that would make it possible for a human to adapt to an extraterrestrial environment through what they called a 'participant evolution.' They imagined that scientists had a great role to play in making evolution progress much quicker than a 'natural evolution' was able to bring about. Paradoxically, the idea was to free astronauts from a cumbersome artificial environment that imitated worldly conditions in order for them to survive in outer space. According to the historian Ronald Kline (2009), even though those cyborg ideas involved serious interventions into the human body, such as artificial organs, hypothermia, drugs, sensory deprivation, and cardiovascular models, Clynes and Kline thought of the changes as strictly related to extraterrestrial survival conditions, without impinging on the human in his or her earthly habitat: 'Cyborgs would be humans with some organs only temporarily altered or replaced by mechanical devices. On returning to earth, the devices would be removed and normal body functions restored' (Kline, 2009: 342).

Haraway's cyborg vision in 'Cyborg Manifesto' (Haraway, 1990) differs radically from those ideas, both in terms of the perception of the body and of the authority of science. Despite their ambitions about fusions of human and machine, Clynes and Kline's cyborg imagery implies that an 'organic' body can be extraordinarily manipulated without losing its characteristics or being marked. Haraway's vision is cleared of the innocence as well as the anthropocentrism that characterizes the early cyborg imagery. A distinction between a natural and a participant evolution is irrelevant when it no longer makes sense to speak of nature in the singular and as a base on which cultures build. In addition,

her vision of science is very different from the heroic and anthropocentric idea of a science and scientists who transcend earthly conditions. Haraway's slogan 'Cyborgs for earthly survival' does away with the dualist distinction between extraterrestrial and terrestrial survival and the idea of a heroic masculine science that overcomes the shortcomings of the body in space. Her catchphrase stresses immanence: Cyborgs are we, earthly creatures in a world increasingly marked by cybernetic communication technologies and scientific imageries. ICD patients stand out as an apparent example. The cyborg figuration emphasizes that they are indeed unique, yet at the same time, we as contemporary subjects are connected in an enlarged sense of a sociomaterial community.

The cyborg invites us to take a closer look at how a body comes into being and to question entrenched ideas about an organic body as opposed to an artificial one. Alluding to Simone de Beauvoir's famous statement, 'one is not born a woman' (Beauvoir, 1952), Haraway argues that the same is true for organisms. She offers the term 'the apparatus of bodily production' to capture the generation of bodies and other scientific objects in scientific knowledge production (Haraway, 1984: 200). Nature does not work as 'raw material' for science, and the body is not a blank page for social and scientific inscriptions, a passive object of knowledge, not unlike the imagery we saw in the early cyborg discourse. Haraway states:

'I wish to translate the ideological dimensions of 'facticity' and 'the organic' into a cumbersome entity called a 'material-semiotic actor.' This unwieldy term is intended to highlight the object of knowledge as an active, meaning-generating axis of the apparatus of bodily production, without *ever*

implying immediate presence of such objects or, what is the same thing, their final or unique determination of what can count as objective knowledge at a particular historical juncture. (...) Bodies as objects of knowledge are material-semiotic nodes. Their *boundaries* materialize in social interaction. Boundaries are drawn by mapping practices; 'objects' do not pre-exist as such. Objects are boundary projects. But boundaries shift from within; boundaries are very tricky. What boundaries provisionally contain remains generative, productive of meanings and bodies' (Haraway, 1991: 201f).

Scientific representations do not mirror nor control a passive reality, but act as interventions in a dynamic reality in Haraway's pragmatic material and relational approach. Whether cyborg indicates analogies or literal human-machine fusions is not important in her pragmatic and nonrepresentational context. 'The cyborg is text, machine, body, and metaphor – all theorized and engaged in practice in terms of communication' (Haraway, 1991: 212). Haraway's cyborg figuration has been widely explored in feminist, cultural and science studies of contemporary culture and sociotechnical practices. The feminist philosopher Rosi Braidotti describes the cyborg as a 'connection-making entity, a figure of interrelationality, receptivity and global communication' (Braidotti, 2006b: 200). The figuration invites us to rethink the unity of human beings by suggesting an enlarged sense of community as an ethical implication. Braidotti introduces a noncognitive idea of understanding (Braidotti 2008: 184ff) and emphasizes affectivity and endurance as opposed to rationality as a positive force that fulfils a subject's capacity for interaction and freedom, no matter the position (Braidotti,

2006a: 148). She argues that an ethics of sustainability that does not have the human at the centre encourages an enlarged sense of community.

In her influential study 'Technologies of the Gendered Body. Reading Cyborg Women,' another feminist scholar, Anne Balsamo, understands the cyborg as a hybrid with asymmetrical boundaries:

Every cyborg image constructs an implicit opposition between machine and human, at once repressing similarities and highlighting distinctions. In this way it defines the meaning of both the term 'human' and the term 'artificial.' Signs of human-ness and, alternatively, signs of machine-ness function not only as markers of the 'essences' of the dual natures of the hybrid, but also signs of the inviolable opposition between humans and machines. But because the cyborg embodies both 'natures' simultaneously, the resulting hybrid is neither purely human nor purely machine. The distribution of its dual dispositions is never simply symmetrical, and the proximity of each to the other and the combination of dissimilar parts produces a hybrid often unrecognizable as any familiar personage. (Balsamo, 1997)

Balsamo underlines the contradictory elements in the figuration as well as the inability to reduce a hybrid figure to either of its components. In addition, Balsamo shows how the material body is a critical symbolic resource for cultural expression, at the same time as its symbolic form is constructed in interaction with material bodies. Furthermore, she argues that fictional narratives and images serve as cognitive maps of cultural arrangements (Balsamo, 1997:159ff). In line with Haraway, she urges us to take fictional and popular

cultural representations of the body as seriously as scientific representations and, just as importantly, to study how scientific and medical practices impact our lives.

Infrastructural inversion is a way to explore the cyborg figuration (Bowker & Star, 2002: 34). Infrastructural inversion emphasizes the non-neutral effects of technologies, especially technological infrastructures. Infrastructural inversion 'means recognizing the depths of interdependence of technical networks and standards on the one hand and the real work of politics and knowledge production on the other' (Bowker & Star, 2002: 34). An ICD patient may appear as an individual with an implant; the inversion points to the infrastructure that the person depends on, in this case an array of interdependent, non-neutral technical networks and standards, as well as the politics and knowledge production, without which neither person nor device would survive. According to Star, the cyborg *is*, in a sense, the relationship between standardized technologies/infrastructures and local experience; the cyborg is between, yet in relationship with, the categories (Star, 1991: 39).

We want to focus on the tensions in the cyborg figuration between standardized medical-device technologies and how they are implicated in local events of patients and healthcare practitioners and experiences in manners where none of them can be reduced to the other. How we define objects and draw their boundaries have consequences. How are we to understand the role of science when we take into account the complex infrastructures involved in surviving as ICD patients?

Access to 'ICD Patients'

We approach the case of 'ICD patients' by studying the manufacturers' visions and the hospital practices involved in home

monitoring of ICD patients. The market for ICD implantations with the capability for remote monitoring of the ICD patients' conditions is dominated by two medical device manufacturers, who design, build, and maintain the medical devices and the technical infrastructures required: Medtronic and Biotronik. *Medtronic* is an American-founded company established in 1949, today a multinational company specializing in disease management technologies including ICDs. In 2002 they created the Medtronic Carelink Network; today 250,000 patients at nearly 24 clinics in 20 countries are connected to Carelink (Medtronic.com). *Biotronik* is a European-founded company established in 1963 specializing in pacemakers and ICD manufacturing. In 2000, Biotronik introduced their remote home monitoring system, which is used in 3500 clinics across more than 55 countries (www.biotronik.de).

To examine the manufacturers' perspective on ICD implants, patients, and infrastructures, we searched the two websites for all information about the ICD remote monitoring devices directed at patients written in English. The two websites explain remote monitoring differently. The Biotronik website presents several short videos portraying the patient as well as the healthcare professionals in relation to the ICD device and the remote monitoring. The Medtronic website portrays the patient in terms of patient stories presented as narratives as well as pictures. We made the videos and the stories the centre of analysis. Despite the differences across the websites, the patients are characterized in similar ways.

Studying the hospital practices around monitoring of ICD we observed the work practices within a heart clinic at a Danish university hospital. Approximately half of the heart failure patient population in Denmark (3000 patients) have ICD

implants and the number is increasing, with approximately 700 new patients each year (Anonymous, 2012). The clinic specializes in medical device implantations, which includes ICDs. The heart clinic employs mostly physicians and bioanalysts, who assist with implantation as well as monitoring of ICDs. The medical device representatives are also present in the clinic. They are typically former heart clinic employees, who have been recruited by the manufacturing company. We focus on the practices involved when patients with ICDs come in for a check-up at the heart clinic.

Following Haraway (1990), Braidotti (2006), Balsamo (1997), and Bowker and Star (2002), the ubiquity of science and technology in society, so well-illustrated by ICD patients subjected to remote monitoring, makes it relevant to examine images of science outside laboratories and, in the case of medicine, in hospitals and medical practices. Especially with the expansion of the Internet, companies have an opportunity to address many groups, in our case patients, their families and the public, as well as relevant professional groups.

The Manufacturer's Imaginary: The Patient in the Middle of Nowhere

Our first stop in order to explore a cyborg approach is the manufacturer's imaginary and cognitive mapping of their relation to ICD patients, as represented in their website. Modern sciences, technosciences, rely heavily on research and development in private and global companies, and ICDs are no exception. Investigating the manufacturers' perspectives on the patients, we find that Biotronik explains the idea behind the ICD technology inventions as 'products that would work as close to nature as possible' (ref: <http://www.biotronik.de/>). The image of getting close to

nature presumably indicates that the device makes life less painful and complicated for patients. But even though 'nature' appears as a self-explanatory stable standard in their design approach, the nature they are getting close to is described in a specific scientific language. We learn how Biotronik Research & Development created a feature for the ICD called 'closed loop stimulation,' which integrates 'the pacemaker into the body's natural regulatory system. This allowed it [the ICD] to react to the patient's changing physical and related mental activity' (ref: <http://www.biotronik.de/>).

It is clear from these quotes that 'nature' figures as a system and as an ideal, in some respects similar to the cybernetic ideas put forth by Clynes and Kline (1960). The idea of the body as 'a natural regulatory system' belongs to a specific scientific language. It is at the same time a description that allows for implementing the technology, as nature, the body, is described in a language the technology can understand. The ICD is based on the idea that it can be smoothly integrated into the bodily functions, not only physically but also mentally.

Metaphors in sciences and in other fields work by making two subjects interact, in this case the subject 'nature' and the subject 'regulatory system' (Black 1979 (1954)). The meanings of the two subjects interact with one another and create similarities. The idea that 'nature' is a 'regulatory system' has

apparently worked so well that our idea of 'nature' and how it works is shaped by the idea of a regulatory system, just as the idea of a regulatory system is shaped by its use in describing nature. Why some metaphors in science work more effectively than others is an interesting question (Fox Keller, 1988). It turns out that cybernetic metaphors constituted a resource for a number of quite different biological agendas from the 1950s (Fox Keller, 2002: 149). The rhetorical use of the idea of 'getting close to nature' in the ICD manufacturer's communication bears witness to the success of mapping nature cognitively in this manner.

Let us take a closer look at how Biotronik envisions ICD home monitoring.

Figure 1 contains pictures from a Biotronik movie portraying ICD patients and what home monitoring implies. The first picture presents a white, middle-aged, middle-class man fishing in a small boat, completely on his own amid beautiful, natural scenery – a calm lake surrounded by mountains and trees. He is immersed in the wild, enjoying what seems to be his leisure or perhaps retirement time; the natural scenery acts as a symbol of personal freedom, of being outside social or other constraints. Home seems to be where the heart is, so to speak. Similarly, the 'universal' nuclear family appears when, at one point in the movie, he comes ashore and is met by his wife and younger child, a boy.



Figure 1. Screenshots from the Biotronik patient movie on home monitoring, www.biotronik.de, June 2011.

The ‘front stage’ in this imaginary presents the patient as an ordinary person, able to enjoy life, free to move without any ties nor cumbersome connections and wires. The following clips in the movie (see also Figure 1) reveal the backstage and part of the infrastructure involved in making the image possible. We see the two options ICD patients have for home monitoring devices: Bedside version and the mobile version, which resembles an old-fashioned cell phone. It is then revealed that the man in the boat is wearing the mobile monitor on his belt while fishing. We see how data is transmitted continually, indicated in the movie by ‘rings of transmission.’ Then we watch a male physician sitting in his office monitoring his computer screen, where the data from the patient apparently ends up. We also see how the physician takes the telephone and calls the patient, presumably to inform him about his condition.

These pictures from the movie convey the impression that home monitoring is easy for the patient and that the patient is free to live his life as if he were independent and self-contained. Easiness is an important argument in innovation and design (Markussen, 1995: 158). It is usually the life of the ‘receiver’—the user, the customer, the client, or the patient—that is portrayed in those terms. In contrast to the patient, science and the manufacturers are depicted as service apparatuses, constantly available to monitor the patient’s data, and continually in control and ready to contact the patient if they detect something the patient needs to know. Implicitly, it also shows that the free and easy life comes with a price, which can be described in the shape of the monitoring device and the data sent to the physician. The patient’s body seems to work primarily as ‘raw material for humanization’ (Haraway, 1991: 198), and monitoring the heart is all about scientific and clinical data and data transmission—numbers, graphs, etc. Also, the image of

the patient’s involvement in the monitoring practice during remote monitoring is presented as ‘all without the slightest patient interaction’ (Biotronik.de). In this perfect world patient interaction is not viewed as desirable, but should be minimized.

Now shifting to the other ICD manufacturing company, Medtronic, we find similar imaginaries. Medtronic presents their home monitoring devices as:

Convenience – The Monitor is easy to use. With the simple, one-touch monitor, you transmit device information over a standard analogue phone line. If you have an implanted heart device with Conexus Automatic Monitoring, your information may be sent automatically while you sleep. **Peace of mind** – People who use Monitoring report a sense of reassurance knowing their doctor has access to important information about their heart health. If you feel symptoms, your clinic may ask you to send information so your doctor can review your condition. If your device has the Conexus feature, alert notifications may be sent directly to your clinic as defined by your doctor. (<http://www.medtronic.com/patients/heart-failure/living-with-a-device/carelink/carelink-network/index.htm>, emphasis added)

In this description, the material-semiotic actors involved in the apparatus of bodily production belong to science and technology. The design of the device seems to be created with the aim of ‘leaving out the patient’ as much as possible. The patient’s freedom and peace of mind are described as effects of not knowing or being involved as a material-semiotic actor. The special feature, ‘Conexus,’ makes it possible for the device to send all the required information while the patient is sleeping, where sleeping seems to be equated with not feeling anything. The boundaries around the object are drawn in

a manner that leaves out the dependency in the relation between patient and physician. It shows that the infrastructure involved in making monitoring at a distance possible is portrayed primarily from the perspective of the physician, in the transmission of data ready for interpretation and sense-making. Peace of mind comes not only with the price of the connections and wires, but also in surrendering to the power of the physician, and freedom from feeling their own symptoms and body. Freedom may even translate into loneliness, had the nuclear family picture in the Biotronik movie not referred to a myth of eternal happiness.

To summarize: the manufacturers' perspectives delegate power and authority to themselves and the sciences involved, and downplay uncertainty, lack of control, endurance and sensations on behalf of both themselves and the patients. The cyborg lens allows us to point to the ideal which structures those subject images, the ideal of a free-standing, individual human subject, and implicitly, even paradoxically, of science and scientific progress as guarantors of this ideal. It may come as no surprise that the websites are made up of recognizable and well-known, not to say banal and trivial, stereotypes. It is remarkable, however, that the cognitive mapping of those new technologies are primarily understood in a manner that nurtures ideas of one nature, uncontested scientific authority as well as a middle class nuclear family. We will return to this after a visit to the university hospital in order to explore the scientific practices the patients are involved in in this context.

The Clinic: Inverting the Infrastructure and Discovering an Enlarged Sense of Community

The public-funded heart clinic we visited implants ICD devices in the patients and conduct device follow-up visits as well as

home monitoring. But, even as we enter a public hospital, we do not leave the workspace of private companies, since the device representatives are also working in the heart clinic assisting the healthcare professionals. The boundaries between the public and the private have been reworked and reconfigured (Haraway, 1991: 151). Medical device companies play a crucial part in the apparatus of bodily production of ICD patients. A representative from the manufacturer is involved in the implantation; at an observation in the heart clinic we learned that during the implantation this privately-paid person has the authority to make the patient's heart stop under controlled circumstances to ensure that the device works. In practice, this means that when a patient is sedated for surgery, one of the people assisting the procedure is a vendor representative with the overall responsibility to make sure that the technical device works. The apparatus of bodily production of ICD patients thus includes the public /private infrastructure of healthcare professionals.

Besides providing the device itself and assisting with the surgical procedure of inserting the device, the medical device manufacturers also provide geographically distributed global monitoring of the heart. When an ICD is inserted into a body, the ICD data are sent through the technical infrastructure and stored on servers in Europe to communicate updates to the heart clinic. There is a connection between the flesh and muscles and the wires measuring and monitoring the heart inside the body of the patient. Muscle vibrations are refigured as ICD data, a coding that makes particular mappings and measurements possible, and reconfigures the heart in specific ways. There is a wireless connection between the device in the body and the telemonitoring system, located as a mobile device on the patient or as an item at the bedside. This

telemonitoring system is then connected to the device manufacturer, as well as to the heart clinic using the telephone network. Thus, the connection is established and maintained by the telecommunication companies, but is in fact handled by the patients and their families in relation to the device manufacturer. These various entities act invisibly and regularly for this particular apparatus of bodily production to survive. Telecommunication, family, devices, monitoring technologies etc. are all part of the apparatus of bodily production of ICD patients.

In addition, the telemonitoring system acts as a strong material-semiotic actor. It automatically assesses the ICD data that the patients regularly send to the Heart Center. The assessment can be tricky and is therefore further controlled by other important actors, the healthcare professionals. Even though device follow-up can be done by telemonitoring, co-located meetings (where the patient travels to the hospital) are still important. In some cases patients travel far (like in Greenland while being treated at Copenhagen University hospital in Denmark) to receive device follow-up. ICD patients are also connected to local hospitals, and this local hospital manages the main examinations and treatments. Therefore, device follow-up at the heart clinic focuses primarily on the device. However, investigating devices implanted in people includes concerns for the general condition of the patient; it is not merely informing the healthcare professionals about the device. Possible interventions based on the interpretation of ICD data concern not only re-programming the device, but also changing the medication, which requires cooperation with the local hospital.

If one looks for the typical ICD patient, a visit to a clinic will quickly convince you that it is impossible to characterize ICD patients

through means other than 'patients carrying an ICD'. ICD patients might be senior citizens, children as young as 3 years of age, elite athletes in their 20s, blue-collar workers in their 30s, clerks, CEOs, mothers, fathers, the un-employed, university students, etc.

In the following we will study an ICD patient's (in this case an elderly woman) follow-up visit to the heart clinic, which takes place once every three or six months. Elsewhere we have given a more detailed description of the practice (Andersen et al., 2010). In this context, we will focus on the cyborg heart as a scientific object and how the bioanalysts and cardiologists make sense of data, and work together with the patient. The imaginary from the manufacturers' websites conveyed the perspective that physicians immediately knew how to decipher and control their data and the objects they were working with. However, we found in the clinic that cyborg hearts are boundary projects, and boundaries are enacted in the practices where they come together (Haraway, 1991: 201ff). One needs to make sense of data by diagnosing the patient's body directly or indirectly through instruments and technologies (Hogle, 2008: 842).

How to render a body visible and legible is the topic in *Medical Talk and Medical Work* (Atkinson, 1995). Atkinson quotes a study of the use of echocardiography that showed how doctors in the beginning tended to diagnose the unusual as abnormal, which resulted in a proliferation of minor heart diseases:

In practice then echocardiography has not resolved the problem of uncertainty. It requires interpretation of a complex moving image according to sometimes uncertain professional criteria. The image is recognised as being operator dependent, rapid advance in the technology means constant changes in tech-

niques and there is seldom evidence from autopsy or operation to substantiate the diagnosis of disease in the well patient. (Atkinson, 1995: 64 quoting Daly 1989: 104)

When the bioanalysts and cardiologists in the clinic are browsing through the information they receive on their screens, they are faced with similar problems of uncertainty in investigating curves and graphs in order to examine the values of the data – are they stable or not?

An elderly woman is being examined. The bioanalyst asks the patient: 'Please let me know how you feel, and what kind of medication you take?' (...) The patient holds the 'stick' (reader) near the heart. 'When was this?' (...) There are marks—February 9th, April 20th, and April 29th.' The patient says that she had not felt anything. She cannot remember these dates. But at some point the patient remembers: 'Uhh, by the way, I did wake up screaming with a nightmare a few weeks ago, but I did not feel much.' (...) The bioanalyst (...) explains: '(...) They were all during the night; maybe that's why you did not notice. Maybe you had some bad dreams?' There is a conversation between the cardiologist and the bioanalyst—they stand around the machine placed on a low table near the patient. (...) On the screen of the machine they can 'see' the device history. 'Can we do anything to measure these?' asks the cardiologist. After many examinations and discussions (...) they summarize: 'Well, we can say that the machine works as it's supposed to; however, the question remains: should we do anything?' (...) (Observation notes, May 2009)

The conversation is based on joint efforts to make sense of the numbers. It illustrates how boundaries are questioned in such a way that *both* data *and* the experiences of the patient are being problematized. A shock does not exclude the experience of a nightmare. In addition, bad dreams are playing a role in how the bioanalyst make sense of the data from the device. The healthcare practitioners use the information provided by the patient's experience and mental state to test the data. The bioanalyst also explained that even if the device data looked 'good' and did not give rise to any concerns from the point of the device, if the patient had concerns based on experience, they would re-examine the patient and the data and perhaps make an intervention.

The process of data interpretation during telemonitoring is similar. When the bioanalysts and cardiologists in the clinic are browsing through the information they receive on their screens, they are faced with problems of ambiguity in investigating curves and graphs in order to examine the values of the data: Are they stable or not? Are they correct? Sorting out which data deserve to be discussed with the 'additional source of information', namely the patient present in 'flesh and blood,' is a crucial node when enacting the boundaries of the *object* created and the reconfiguration of the further treatment of the patient. This is in contrast to the situation with the woman patient on the manufacturers' website, where the physician easily distinguishes between a dream and a shock initiated by the device and provides a ready-made answer to her question.

Making a body legible involves uncertainties. In cases where the patient seems to feel good but the data are critical, they would not hesitate to define the object of knowledge differently and make an intervention. Adding affective material-semiotic actors, such as the patient's

sensations and experiences and the sensibility of the practitioners, improves the protocol and the quality of the decisions. The episode demonstrates the qualities that Rosi Braidotti's version of the cyborg emphasizes: Affectivity, connection-making, interrelationality, receptivity, and an enlarged sense of community that does not have the human at the centre. Obviously the patients need the medical practitioners' input in the treatment they are subjected to. But the episode reveals that information about the patients' experiences are crucial in the medical practitioners' reading of computer data. Even if the patients may believe that the computer-based data are more objective and hesitate to bring in their own sensations and experiences, the practitioners try to convince the patients that they need their personal affective input and evidence in order to make sense of the data in the best way. This tension between computerized standardized data and experience – the patients as well as the practitioners' ability to make sense of sources of information – is precisely what Leigh Star captures in describing the cyborg as something between, yet in relationship to, standardized technologies /infrastructures and local experience (Star, 1991: 39).

Science and technology has critically been described as 'a culture of no culture' (Trawick, 1992), as if it were governed by rationality beyond social constraints yet worked as an empowering force, an image in line with Clynes and Kline's (1960) ideas as well as the manufacturers' imaginaries. We suggest *cyborg heart* as an analytical device that describes an affective apparatus of bodily production and captures how 'mind, body and technologies are on very intimate terms' specifically in surviving as ICD patients (Haraway, 1991: 165). Patients are not addressed as rational actors accountable for their intentional behaviour, and science and the medical practitioners

are not the only source of authority. Patients are encouraged to recall bodily affects, such as nightmares and dreams, in order to localize things in the past that the data show might have triggered jolts of electricity, things that might have left other material-semiotic traces, such as dreams. Activities occurring while the patient is asleep are not considered irrelevant because they are beyond the subject's rational reach. An enlarged sense of community does not refer to the inclusion of patients as rational subjects as the modern idea of 'Patient 2.0' could suggest, just as the infrastructure does not work as a neutral substrate on which human interactions and interpretations take place. As an analytical device cyborg heart exemplifies an enlarged sense of community, based on affectivity, endurance and connection-making, an image in contrast to the idyllic nuclear family we found in the manufacturers' imaginary and to the idea of the empowered Patient 2.0. Cyborg heart urges us to pay attention to the material and semiotic interconnections and interdependencies we are involved in, as patients as well as in any other capacity.

Cyborg Heart

Donna Haraway's Manifesto co-opted the cyborg figure and took it from the utopian space in cybernetics and dystopian universes in science fiction to the everyday lives of organisms and people on a global scale: Cyborgs for earthly survival. The idea of reconfigurations of materialities, textualities and subjectivities replaced the technological determinism situated within the idea of a progressive development of a rational world, or it's opposite a dystopian nightmare. As an analytic device cyborg heart uncovers modern ideas of subjectivity and technology in the images of science and medicine represented on the websites of ICD manufacturers, and in the idea of

'Patient 2.0' These modern imaginaries bear a resemblance to what Annemarie Mol has termed the 'patient as customer' (Mol, 2008: 14). According to Mol this ideal is based on a logic of choice, and celebrates the notion that making the right choices is the core activity of chronically ill patients. In our case the patient is portrayed as being served by healthcare professionals who are remotely monitoring them, which indicates that selecting the right device on the market, and relying on the professionals involved in monitoring it, will enable you to live a 'normal' life as if you did not suffer from a condition. The concept 'logic of choice' underlines that this imaginary not only belongs to banal advertisements, but has important political effects in promoting a market approach to healthcare.

The manufacturers' imaginary provides freedom for the patient by hiding her or his dependency, at the same time as technologies extend the power of the doctor and the manufacturing company. The home monitoring device is designed to reduce connections, so, for example, the information from the patient's heart is automatically transmitted to the physician. The inscribed user identity envisions a person, who is not involved in her or his treatment, but leaves it to the professionals to make sense of the data and manage her or his condition (Akrich & Latour, 1992: 259). In contrast we discovered in the clinic that the *object* created during monitoring of the illness is not simply data as provided by the technology device. Instead, the *object* of concern during medical monitoring practices includes the patient in mind and body, a *cyborg heart*, with all its complexities.

The 'Patient 2.0' idea differs from the manufacturers' imaginary primarily by turning the perspective on technologies and expertise 'upside down'. The idea embodies the ideal of an empowered patient, and emphasizes that patients should be involved

in their own treatment in an active and rational manner, seeking information about their disease, and engaging themselves actively in monitoring their condition at home. The technology is seen as enabling the patient to be *less* dependent on science and medical authorities. Technological development guarantees progress particularly on behalf of the patient: Yesterday we had infrastructure 1.0, today 2.0, and in the future maybe an even more advanced 3.0.

Cyborg heart configures patients, sciences as well as medical practitioners, companies and technologies very differently. It relates to Annemarie Mol idea of a 'logic of care', an interactive, open-ended process that is attuned to the difficulties of living with a chronic condition and which offers support to patients (Mol, 2008: 25). It shares with Mol the idea that identity is multiple as well as corporeal; neither patients nor scientists are idealised; nor are they seen as stable and unambiguous categories that interact with each other. It underlines the relations and interdependences among human as well as nonhuman entities in constituting an affective apparatus of bodily production. The empirical insights from our cyborg analysis of the work in the clinic highlights the entanglement of elements in making medical decisions such as re-programming the device, performing a new surgery, or changing the medication. The data derive from many sources, numbers on the screen, as well as the patients' sense-making of bodily and emotional sensations. As we saw in the example, 'bad numbers' in combination with 'good interpretations' meant that the medical personnel decided not to intervene. Conversely, if the numbers are 'good,' but the patient feels 'bad,' they will probably intervene. This extraordinary collaboration is captured in the idea of the *cyborg heart* based upon affectivity rather than rationality, an enlarged sense of

community that does not have the human at the centre. We prefer cyborg heart to a logic of care, as the genealogy of care underlines the idea of a liberal definition of the individual and of a human intentional subject.

We can – still – learn from the way the androids in *Blade Runner* question what is human and what is machine. We argue that ICD patients with their cyborg hearts are best understood as an extended community with ethical implications, as in the slogan: Cyborgs for earthly survival: survival on earth, and survival of the earth.

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Looking for Data in Diabetes Healthcare: Patient 2.0 and the Re-engineering of Clinical Encounters¹

Attila Bruni and Carlo Rizzi

Diabetes is an interesting example of a healthcare sector where patients are responsible for producing and aggregating data about themselves, even if only for reporting details of their consultancies with specialists. This is valuable information because it orients the medical action taken on a specific patient and acts as the basis for aggregate-level investigations, and for new therapies and diagnostic procedures. The reliability, truthfulness, and accuracy of such information is therefore of crucial importance for healthcare practitioners; accordingly, being able to count on 'empowered' patients is the best way to obtain reliable, detailed, and updated data. Drawing on the results of a broader research project on diabetes services in Italy, the paper wants to address an essential feature of Patient 2.0: his/her being part of a network of fragmented practices and information and, at the same time, his/her becoming the main point of convergence of clinical information, tools and practices. In doing so, we will underline the re-engineering of clinical encounters and the additional work required to a whole network of actors (doctors, nurses and the patient him/herself) in order to orchestrate data and information.

Keywords: diabetology, distributed and fragmented practice, doctor-patient interaction

Introduction

In the contemporary logic and rhetoric of patient empowerment, self-management and the delegation of a series of tasks and measurements traditionally associated with medical and nursing work constitute one of the most evident forms of the endeavour 'to enlist' (or involve) ordinary citizens in the management and organization of healthcare services. This alters the role of the doctor, who from someone who makes diagnoses and prescribes therapies

becomes a 'life manager' (Carricaburu & Ménoret, 2005) who intervenes in the everyday behaviour of his/her patients. But it also alters the role of the patient, who becomes, amongst other things, the convergence point of important medical information, technologies and practices, a steward of his/her own information (Halamka et al., 2008). Patients are responsible for producing and aggregating data about themselves, even only for reporting details of their consultancies with specialists. This is valuable information

because it orients the medical action taken on a specific patient and acts as the basis for aggregate-level investigations, and for new therapies and diagnostic procedures. The reliability, truthfulness, and accuracy of such information is therefore of crucial importance for healthcare practitioners; accordingly, being able to count on 'empowered' patients is the best way to obtain reliable, detailed, and updated data.

Drawing on the results of a broader research on diabetes services in Italy, the paper wants to address what we claim to be an essential feature of Patient 2.0: his/her being part of a network of fragmented practices and information and, at the same time, his/her becoming the main point of convergence of clinical information, tools and practices. In doing so, we will also underline the additional work required to a whole network of actors (doctors, nurses and the patient him/herself) in order to orchestrate data and information, an often overlooked issue in optimistic versions of the re-engineering of clinical encounters (May, 2007).

The medical sector has not been chosen at random. Diabetes is an interesting example of a healthcare sector where patient empowerment has become prominent: self-management is seen as a key determinant of health outcomes and there is scientific evidence for its importance in regard to treatment efficacy and the quality of diabetes care (Heisler et al., 2003). Indeed, people with diabetes are required not only to shape a therapeutic plan but also to develop competences, together with a certain kind of commitment, in self-monitoring their glycaemia levels. In this regard, we shall also see that technological objects and artifacts are constitutive (Garfinkel, 1967) elements of self-monitoring and of doctor/patient encounters, so that clinical relations can be conceived as a materially heterogeneous, fragmented, and distributed practice.

The conceptual framework of our analysis consists of the diversified body of analysis that has developed at the interface between Science and Technology Studies (STS) and the contemporary sociology of medicine (Berg, 1997; Berg & Mol 1998; Mol, 2002; Timmermans & Berg, 2003), the essential features of which will be outlined in the next section.

Medicine, Technology and the Re-engineering of Clinical Relations

Opening the black box of medicine, STS have led to frame medical knowledge and practice as a process of aligning and mobilizing heterogeneous elements (data, laboratory tests, doctors, patient, healthcare structures, policy decisions). In medical practice, scientific knowledge and technologies dictate clinical criteria, diagnostic techniques, and therapeutic options, while being transformed in their turn. Not by chance, the initial study of 'medical practice as technology' (Casper & Berg, 1995) has evolved over the years into study of the 'practice of medical technology' (Timmermans & Berg, 2003), thereby further demonstrating that medicine has acquired the features of a technology in itself (Elston, 1997).

It can be stated in particular that research has divided between two trajectories, which, though interrelated, have different nuances: a) the role of diverse tools (software, guidelines, protocols) in the 'rationalization' of medical work (Berg, 1997; Timmermans & Berg, 2004). Focusing on the use and alternation of instruments makes it possible to show how they embody different configurations of what 'medical practice' is, what 'science' is, and what constitutes 'rational' medical knowledge. The most general process is the one whereby medical practice and instruments reciprocally construct each

other: the development of instruments is inextricably bound up with the emergence of (and competition from) new forms of medical rationality, just as a new instrument establishes the boundaries between what is 'rational' and medical practice itself. To summarize, protocols, clinical guidelines and decision-support technologies are the means by which medical knowledge and its exercise are rationalized (Berg et al., 2000; Moreira, 2005).

- b) the processes of relational materialism and heterogeneous engineering (Law, 1987, 1994) that embody medical practice. In evident continuity with an actor-network theory approach (Callon, 1986; Latour, 2005), technologies, drugs, organizational devices, and infrastructures are all seen as elements embedded in a heterogeneous network of relations with other instruments, practices, groups of actors, and types of professional expertise. From this perspective, the body and subjectivity can be seen as the effects of a network of heterogeneous materials (skin, bones, enzymes, cells, clothes, machines, and so on) – an ordering process catalogued as a 'person' (Law, 1994: 33). The different branches of medicine, in fact, each with its techniques of inquiry and consolidated knowledge, contribute to constructing different medical representations of the body (Berg & Mol, 1998; Mol, 2002; Berg & Akrich, 2004). In other words, if a body 'holds together', this depends not on some type of coherence internal to the body (which precedes the knowledge produced about that body), but on the fact that the different coordination strategies adopted have been able to re-assemble and align a multiplicity of versions of reality (Mol & Law, 2002: 10).

But how do these processes re-engineer clinical relations? Various researches have

sought to highlight the main shifts occurring, focusing for example on the introduction of electronic patient records, telemedicine services and, more in general, the plethora of new medical technologies and the ways in which they act in healthcare systems and practices (Lock, Young & Cambrosio, 2000; Brown & Webster, 2004; Hyysalo, 2010). Carl May, in particular, argues that doctor-patient relationship is no longer a dyadic and 'private' encounter, but a 'corporate' one. In fact, contemporary medical technologies, together with technocratic management interventions, re-engineers clinical encounters, 'as systems and practices become increasingly oriented around the collection, collation and distribution of evidence and information about individual clinical histories and epidemiology' (May, 2007: 35). Moreover, the doctor-patient encounter takes place in a much more complex and dispersed organizational network, where 'the doctor' is just one of the many organizational interfaces patients encounter. Because of protocols and clinical guidelines, doctors themselves inhabit an increasingly governed terrain, so that also the assumption of the doctor-centred clinical autonomy is partially displaced (May, 2007).

An exhaustive survey of this ramified corpus of studies would fall outside the scope of this article. Before describing our research, however, there is a study that should be briefly recalled, both because it introduces the case examined in what follows, and because of its analytical standpoint, which resembles the one that we adopt.

In an outstanding article on the 'body-we-do', Mol and Law consider the case of hypoglycaemia and glycaemic control:

So how is hypoglycaemia done? A first important mode is, indeed, by knowing it. Knowing is a practice: it only

becomes possible to talk about 'a blood sugar level below 3.5 mmol/l' if someone's skin is pricked, a blood sample is taken, and its sugar level is measured. This used to happen in the laboratory. A technician would puncture a vein, collect some blood in a small tube, insert it in a machine and read the outcome. This still happens, but it has been joined by another measurement practice. Since the necessary machinery has been miniaturized, people with diabetes can now carry it round with them and measure their own blood sugar levels. They prick a finger-tip and squeeze a drop of blood onto a measurement stick. The stick is put into a slot in the machine and within a few seconds a number is displayed. (...) Pricking the finger may hurt, the number may take some while to appear - and so on. (...) But measuring your blood sugar level is also difficult in a management meeting (...) or if you are shopping in town with your friends; or if you are teaching a class of children. Nevertheless, it is possible to measure one's blood sugar level in a clean kitchen or in the bathroom - that is, in a location in which circumstances are as well tamed as in a laboratory. In this way hypoglycaemia may be enacted as a blood sugar level below 3.5 mmol/l. (Mol & Law, 2004: 45)

We thus see how it is possible to frame hypoglycaemia as a materially heterogeneous practice that involves bodies, texts, machines, organizational devices, and other socio-material processes in its performance. This idea will serve as the background to almost all the research examples that we present below, together with the idea that medical knowledge (and practice) is distributed, fragmented and shared between (Bruni et al., 2007):

- the patient, who brings knowledge about his/her body and sensations to the consultancy;
- the doctor, who translates the patient's subjective knowledge into elements of 'scientific' knowledge through its conversion into medical terminology and a narration of the patient's state of health;
- the medical community, within which the various participants learn the systematic use of medical vocabulary and application of a professional vision (Goodwin, 1994);
- the organizational rules and medical protocols, which based on segmentation of the therapy and intervention processes into a sequence of micro-actions;
- the technologies and the objects that participate in the activity and constitute its setting.

In light of the idea of medicine as a materially fragmented and distributed practice, we shall show the ecology of actors, relations, artifacts, knowledges and situated practices involved in diabetes check-up encounters, focusing in particular on the additional work required to doctors and nurses in order to 'check-up' not only the patient, but also the data s/he brings with her/him.

Methodology and Research Context

The research was conducted in 2009 at four diabetology services located in various parts of Italy (north and islands). Access to the field has been facilitated by personal relations of one of the two authors with a few diabetologists, together with a previous professional collaboration he had with the Italian Association of Diabetologists. Although present in clinical encounters, the diabetologists agreed not to reveal the identity of the researcher to patients and

to 'secure' ethical aspects by making all the data anonymous.

At each centre the observation lasted for an entire working week, following doctors and nurses involved in patients' clinical examinations and taking the form of a 'focused ethnography' (Knoblauch, 2005): short-term field visits; data/analysis intensity; audio recording; focus on selected activities; continuous coding; and sequential analysis of notes and transcripts.

The observation covered a total of 141 clinical examinations among check-ups in doctors' surgeries and in the diabetology department. Free and semi-structured interviews were conducted with 22 of the 30 subjects (doctors and/or nurses) encountered at the diabetology centres. Then examined was the use of diagnostic instruments (such as the glucometer to check glycaemia levels), together with the common documents (such as clinical reports and laboratory test results) patients carry with them.

It should be borne in mind that diabetes mellitus is a complex chronic disease: the toxicity caused by the high level of glucose in the blood affects various organs and parts of the body (heart, limbs, eyes, nervous system), for which reason it is not always possible to identify a major lesion to a specific organ. This requires the systemic and synergic management of the patient, with the involvement of different medical specialities and diagnostic-therapeutic technologies.

In this process, a diabetes patient is required not only to shape a therapeutic plan, but also to pay attention to habits and lifestyle and develop competences in self-monitoring glycaemia levels. The glucometer and the glycaemia logbook are the main instruments involved in patient disease self-management².

In the sections that follow, we shall look closely at the use of both these tools and

the practical meanings that they assume in managing a patient's disease, analysing two particular activities that take place during a check-up: inspecting the paperwork, and verifying the relations among patient, tools, and his/her lifestyle.

Check-up Patient 2.0: Re-engineering Clinical Encounters

The periodic check-ups conducted on people with diabetes consist largely in the collection (by the doctors and/or nurses) of the data brought by the patient. The objective for the diabetology team is to update the patient's clinical record with new data and to compare these with the previous ones.

It may therefore seem that the task of doctors and nurses is merely to gather/compare data so to have an updated dataset from which to draw information on the patient and his/her specific case. Management of the clinical encounter, however, is much more complex than this, because it also involves a series of activities performed to gain a picture which is broader than that performed by data and medical technologies.

Inspecting the Paperwork, Reassembling the Network

An activity often performed by nurses (as in other situations of complex diseases/therapies) consists in ensuring that the patients' paperwork is 'in order'. In the waiting room, the nurses check the 'completeness' (as they used to say) of the patients: that is, whether they have brought their medical reports, test results, and any other documentation that may furnish information necessary for the evaluation and adjustment of the glycaemic control. In fact, medical reports, test results, data, and information may be missing for various

reasons. The most common are that patients are more or less cooperative, and therefore take (or do not take) the tests and check-ups in time for the next diabetological examination; or that patients, even if cooperative, have been prevented by circumstances to have the required tests taken (e.g., when specialist examinations prior the date of the appointment with the diabetologist).

Other reasons are due to the action of specialist. It often happens, in fact, that the diabetologist interviews a patient (and, if need be, the person accompanying him/her) to understand what has happened during examinations by other specialists. In short, the diabetologist scrutinize the information that s/he receives from the patient, how it has been produced, who has participated in its production (practitioners, relatives, diagnostic instruments), what other points of view and knowledge have been added or lost in the process.

Inspecting the paperwork is therefore not the mere collection of information to update the patient's clinical record. Its purpose is to reconstruct the dynamics in which particular recommendations, prescriptions, suggestions, and so on, have been made. Provided as an example is a case where a specialist (cardiologist) requests suspension of one of the therapies prescribed by the diabetologist. The reason for the request is not immediately clear to the diabetologist, who therefore asks for further information:

Doctor: Sorry, but I haven't quite understood what happened during the examination, why... you see, it's written here that I should stop the therapy.

[The doctor reads out the cardiologist's recommendations]

Patient: I don't know.

[The doctor turns to the patient's daughter, who has accompanied him]

D: Were you there during the examination?

Patient's daughter: No, my mother went, but she told me that it was a young doctor, not the chief consultant we usually go to.

D: Wasn't Doctor [name] there? Who was it?

[the examination report has been stamped with the name of the chief consultant, but the initials are indecipherable].

Daughter: I don't remember if my mother told me, but I can ring her if you want.

D: No no, it's not important...[turns to the patient]...but can you remember what he said?

P: He told me that I'm really not right, he looked at the analyses, first they did an electrocardiogram and then...

[his daughter shows the electrocardiogram trace]

D: But do you remember why he told you that you weren't all right? It's not that he's written very much, and I'm beginning to think that the person who examined you didn't look very carefully, because for me you're not so bad, though not extremely well, which is normal in cases like yours, let's say... anyway, I don't see the reason for stopping this therapy... unless he asked for some clinical tests to be done and temporary suspension of the therapy... do you remember if he said something like that?

P: Well, he said that I should come back so that the chief consultant can see me.

D: When?

P: In a month.

D: Did he give you any other tests to do?

P: Yes...the twenty-four hour test.

D: It's not written here...he forgot to write it. So I think he wants to do a check...All right, so I'll suspend this [drug], but be sure to call me if you feel that something's wrong.

It is not rare for specialists to omit information from clinical reports (due to carelessness or for some other reason), thus delegating to patients the task of bringing such information to other clinical contexts. Whence derives the importance of another figure, that of the ‘companion,’ who can help reconstruct what happened during the specialist examination. Not coincidentally, in the above example, one of the first questions that the diabetologist asks the patient’s daughter is whether she was present at the last specialist examination and the fact that there had been a change of companion emerges as a potential cause of the loss of important information (to the point that the patient’s daughter offers to telephone her mother, who had been present during the specialist examination).

Therefore, the different ‘papers’ that the patient brings to an appointment are not always (by their nature) exhaustive, but require additional work by the diabetologist: reconstruction of the situation in which the data have been produced and interpretation of the logic behind them. Far from a purely rational model of approaching problems, doctors and nurses are accustomed to weighing up data, distinguishing between ‘old’ and ‘new’, between data produced by ‘us’ (the diabetology team) and by ‘others’ (general practitioners or specialists who have examined the patient), as well as between the recommendations of an experienced doctor and those of a novice. Here we see emerging the bricolage work doctors and nurses are accustomed to in order to keep up clinical data coherently³ and ‘sort things out’ (Bowker and Star, 1999), as well as the situated logic they seem referring to in order to plan future actions.

The diabetology team is particularly interested in understanding the nature of anomalies among values – as when there is a mismatch between the glycate values⁴ and the glycaemic pattern recorded by the

patient. In the following example, the patient is relatively young (under 40 years old) and was diagnosed as diabetic only a few years ago. The nurse notices the mismatch and alerts the diabetologist:

Nurse: Doctor, there’s something here that doesn’t match.

Doctor: What?

N: See, the glycaemic pattern in the logbook is good, but the glycate doesn’t correspond to the average.

D: Did you do the test with his glucometer [i.e. whether comparison has been made between the patient’s and the clinic’s glucometer to verify whether the values coincide].

N: Yes, we did that... and it was in order.

D: How long have you had diabetes?

P: I was diagnosed with it three years ago.

D: How are the test results?

Nurse: Good.

[the nurse hands the test results, the logbook and other sheets of paper to the doctor]

D: Yes, not bad...how have you been feeling lately?

P: Not bad, I’d say good, at times I get a bit tired.

D: What’s your job?

[the doctor begins to enter the data into an electronic clinical record]

P: I work at the Post Office.

D: Are you always indoors? Do you do any sport, or at least go for walks...do you take exercise?

P: Yes, at the office...well, yes, I sometimes exercise, but I don’t do any sports.

D: Have you been to the dietician lately?

P: No, but I’ve kept to the diet prescribed some time ago.

D: Right...where’s the ferritin? You need to keep check on it...do you eat lots of legumes and red meat?

[the diabetologist enters the patient's electronic record and looks at his family anamnesis]

P: Yes, I like them a lot and the dietician told that they're good for you...I also eat vegetables, like tomatoes and stuff with vitamins.

D: I'm beginning to understand...listen, the problem is your iron intake, go back to the dietician after these tests and get him to look carefully at the diet you're following.

[the diabetologist stops entering data into the computer, and then write a request for a series of laboratory tests on the clinical report]

D: You need to do some blood tests... have there been cases of iron deficiency or excess in your family?

P: My father has had problems, but I don't know exactly...

D: Can you find out?

P: Yes, my mother will know for sure.

D: Well if you could find out, so next time we'll add it to your profile...in the meantime we'll do this iron test and check out your liver. For now we'll leave it like this...I can see from the logbook that things are going well...even if the glycate is no use today, the rest of the values are fine. Carry on like this, then let us have the information from the laboratory and your mother as soon as possible.

The nurse directs the doctor's attention to the discrepancy between the glycate level and the glycaemic pattern, stressing that the body's response does not match the values recorded. The first doubt raised by the doctor concerns the patient's glucometer, but the nurse has already compared glucometers and can confirm that the instrument used by the patient is reliable. Moreover, there seems to be no doubt concerning the truthfulness of the logbook and/or the patient's capacities: he shows

himself to be competent and cooperative, and his logbook is accordingly judged to be reliable. The diabetologist then follows up on an intuition. He notices that the value showing the concentration of iron in the patient's blood (the ferritin) is missing from the laboratory test results. He then obtains further information from the patient about his iron intake and looks for additional data in the family anamnesis (present in the electronic patient record). Still lacking reliable data for a diagnosis, he asks the patient to take some tests; have his diet reassessed by the dietician; and consult a non-clinical source (his mother) to ascertain any family problems with iron intake.

In both these situation, the purpose of inspecting the paperwork is to collate fragmented data and items of knowledge: the clinical reports and laboratory test results; the information accumulated about the patient; the knowledge of the patient himself; that of his family members; that of other specialists; as well as that of the diabetologist and the nurses. From a material point of view, this collation work requires the doctor to move among artifacts of different kinds and technical complexity (the electronic clinical record; the glucometer; laboratory test results; the patient's logbook), distributing his action among the different elements at his disposal (as when he removes his gaze from the computer screen to write a request for laboratory tests on the patient's clinical report). Moreover, note that these same artifacts are in the hands of patients: it is them who use the glucometer, who write the logbook and who brings into medical encounters tests results and specialists' recommendations.

In this process, we can see how check-up encounters are constructed through a network of heterogeneous actors, elements and bodies of knowledge, where the patient becomes the main point of convergence of clinical information, tools and practices.

Clinical encounters therefore also interweaves with verification of the relation among patient and instruments.

Verifying the Relationship among Patients and Instruments

The main technology available to patients to attain and maintain a good state of health is the glucometer, a device that measures the concentration of glucose in the blood. However precise, the glucometer may be subject to anomalies and malfunctions, for which reason (as also seen in the previous episode) one of the first things that doctors and nurses do when they notice discrepancies in a patient's data is to compare the glucometer used by the patient with that of the clinic (in order to ensure that it is working properly).

Together with the glucometer, comes the glycaemia logbook where patients have to take note of their glycemetic values. If the logbook is not regularly and properly compiled, the work done by the glucometer becomes useless.

Although very different from a technical point of view, the two artifacts are essential to each other and so is their correct 'maintenance'. In most of the cases, patients are perfectly aware of this, but nevertheless they sometimes try to delegate to one of these two artifacts the demonstration of the impossibility of carrying on self-monitoring:

Doctor: Why have you stopped recording the glycaemia?

Patient: The machine doesn't work, it's not my fault.

D: Why doesn't it work? Let me have a look at it...have you got it with you?

P: Certainly, here it is [takes the glucometer out of her bag]... here it is, see? I turn it on and it flashes like this.

[the doctor looks at the glucometer's display panel]

D: Listen Mr [surname], how long have you been using this model?

P: Since when you gave it to me!

D: When was that?

P: Just over a year ago.

D: And this has never happened before? [the doctor points to a symbol in the lower-right part of the glucometer display] You see this symbol here...?

P: Yes...

D: The symbol is saying that the strips that you're using have expired...that's why the glucometer is flashing, because it knows that the strips are no good, so it won't let you do the tests unless you use new strips... You've done too few tests in the past months...and you can see it...if I count how many results you've written here [pointing at the glycaemia logbook] and then if I count how many strips are left, I can immediately see that you've actually done at most half of the tests written down. Let's be clear about this: you have diabetes, I know how to keep it under control, but if you're not serious about checking it, I can't do anything. Giving me fake data doesn't help me to help you, using the glucometer like this doesn't help either of us... these strips expired a month ago, you've got one month of strips left over... more than thirty tests which haven't been done... and you have the good fortune of not using insulin and having to do only a few tests... but if you carry on like this, there's the risk of insulin dependency and four tests a day... is that what you want?

[The patient is silent]

D: I'll let you have some more strips, but you must use them as I've told you. I'll also get the nurse to explain clearly what the [glucometer's] symbols mean, so that the next time you won't be stopped by a trivial notification like this...

The glucometer automatically verifies expiry of the strips, so that one month before the expiry date, a message appears on the display panel to warn the user that the strips are about to expire. After that date, an error message appears, and it is no longer possible to perform tests. The doctor is somehow sure that in one year this occasion must have happened before and that the patient should be able to understand that there is something wrong with the glucometer, but it is in the logbook that he finds the confirmation of his suspicions (checking the number of strips together with the number of tests written). It is clearly one of those well known situations in which the 'thing' to be repaired is the user rather than the machine or, better, the relationship between the user and the machine (Orr, 1996; Suchman et al., 1999). In fact, when the diabetologist realizes that the problem is not a malfunctioning of the device but the patient's reluctance to its use, he shifts the discourse from the disease to individual responsibility (for instance, by telling the patient that incorrect glycaemia measurements may make the disease worse). In these cases, the disease becomes a property ('*you have diabetes...*'), whose state and progress partially depend on individual behaviour. In this sense, the doctor is not simply telling the patient how to use (correctly) the glucometer, but begin morally lecturing him, stressing the central role he, the patient, plays in the treatment of his condition ('*I know how to keep it under control, but if you're not serious about checking it, I can't do anything. Giving me fake data doesn't help me to help you, using the glucometer like this doesn't help either of us*').

This kind of moralizing comes into play every time doctors and/or nurses envisage the risk of examining 'fake data.' Sometimes patients refer to the (supposed) malfunctioning of the glucometer, but at

other times they try to stack the logbook, in order to avoid reproaches for their conduct (and inaccurate production of data), as in the following example:

Nurse: Mr [surname], already here?

Patient: Why? Isn't it my day?

N: Well, we saw you just a while ago, what's happened?

P: My glycaemia. isn't right...I told my GP...

N: ...and he sent you here. I see...can you show me what you've brought?

P: What do you want...it's nothing more than a month and a half ago.

N: Okay, but can I see the logbook?

P: Whatever you want, here it is!

[The patient takes the logbook out of his shoulder bag and hands it to the nurse. The nurse looks at it]

N: I can't understand much from your logbook...You don't seem to have written it up properly.

[The nurse notes the presence of suspiciously 'round' numbers in the logbook, and a linear trend in the glycaemia levels, as well as invariably the same colour of ink and apparently 'continuous' writing. All of this suggests that the glycaemia logbook has not been used properly, and that it has probably been compiled a posteriori, before going to the doctor. The nurse shakes the diary as if to say that the data are fake, and turns to the patient]

P: What's all this about the logbook, it's me you should worry about!

Nurse: That's what we're doing, and as best as we can, but we can't help you if you don't help us. [...] It's you who has to carry out the treatment...we can help you with it, but you must get on with it.

P: Yes, all right, we'll see what the doctor says.

N: In the meantime I'll tell you what you need to do...you've got to keep close

check on your glycaemia, measure the values correctly and transcribe them, so that you can adjust the dose and follow the diet better...

A peculiar professional vision (paying attention the colour of the ink, the type of hand-writing, the invariably 'round' glycaemia values) permits the nurse to understand that the patient has not kept the logbook appropriately. Treating it as a form to be compiled prior to the examination and thus avoid reproach, here the patient uses the logbook as a legitimizing tool. In a quite paradoxical way, it is like if he recognizes the relevance of the logbook and, at the same time, dismisses it with his conduct. In this way, even more paradoxically, the main tool ought to be a reference point for detailed information translates in an additional source of unreliable data and interferences. This is due to the fact that the logbook is the main linkage between everyday self-management and medical practice and patients (in order to be 'accountable') need to show the doctor they act responsibly. Thus, filling out the notebook, not just living healthy, becomes a primary concern for people with diabetes⁵.

As in the previous example, the nurse takes further action to repair the relationship between the patient and its logbook, mainly adopting the same kind of moralizing practice we have seen deployed by the doctor before. Interestingly, she uses more or less the same words as him⁶ (*'we can't help you if you don't help us. [...] It's you who has to carry out the treatment... we can help you with it, but you must get on with it'*), signalling the typicality of patient's behaviour, as well as of clinicians' response.

We can see here the glucometer and the logbook as expressions of both the process of delegating (Latour, 1992) bits and pieces of activities to non-human actors and the stretching out (Nicolini, 2007) of medical

practices in space and time. What is peculiar here, by the way, is that, once in the hands of the patient, the glucometer and the logbook become occasions for a further delegation and stretching out. That is, the delegation to the glucometer of the impossibility of carrying on self-monitoring and the stretching out of the logbook in terms of a legitimizing instrument of individual accountability.

Moreover, however much doctors and nurses remind patients that they must make correct use of technologies and medicines, blunting the effects of habit or the so-called 'hunger effect' requires further work, as emphasised by a diabetologist specialized in the dietary education of patients:

For the insulin therapy to be effective, it's necessary to organize an educational programme based not only on CHO counting⁷ but also on the development of specific algorithms for adjustment of the insulin dose so as to off-set possible hyper or hypo-glycaemic episodes. This science (so to speak) sometimes suffers from patients' habits, especially when they assess the glycaemic index in relation to portions. If they are in the habit of using household measures, rather than more accurate ones like scales...with the ingredients measured uncooked...there's certainly no lack of personal interpretations of the glycaemic load. In fact, there are cases of people who, even though they've taken the course (...) keep on getting the quantities very wrong...a spoonful, a handful, or a glassful are always much more than the normal. I don't know if they do it on purpose or because they're hungry, but sometimes the portions are almost double. Habit leads them astray in the calculation.

This comment shows that correct management of the therapy mobilizes not only the glucometer but also other scientific instruments (such as an algorithm for counting carbohydrates), which are in their turn associated with further 'domestic' instruments (scales, for instance). This interplay of associations produces a delicate balance between self-monitoring and glycaemic control: patient's habits in counting are not always associated with the precision required by correct exercise of the scientific practice related to carbohydrates schemas and prescriptions, so that they may jeopardize (upstream) the accuracy of the calculations made (downstream). And also weaken the alignment of self-care instruments that support the Patient 2.0 and contribute to the re-engineering of clinical encounters.

Conclusions

Focusing on check-up encounters in diabetology, in this article we have sought to show an essential feature of Patient 2.0 That is, his/her being part of a network of fragmented practices and information and, at the same time, his/her becoming the main point of convergence of clinical information, tools and practices.

'We can't help you, if you don't help us,' doctors and nurses used to say in many occasions, in order to recall patients' attention on the importance of their collaboration for the assessment of the therapy. Note that this is something that goes beyond the issue of patients compliance: the expectation is not simply that the patient will responsibly follow doctor's indications, but that s/he will actively engage in the production of core reliable data. From this point of view, trying to transform patients in 'stewards of their own information' (Halamka et al., 2008), Patient 2.0 is supposed to be a diagnostic agent in him/herself.

This may imply the use of medical instruments such as the glucometer and artifacts such as the glycaemia logbook, the relationship with other clinicians and/or the support of family members⁸. All these elements materialize around two main activities characterizing clinical encounters in diabetology: inspecting the paperwork and verifying the relations between patients and instruments. Here, it takes place an evaluation of the reliability and the accuracy of the data brought by the patient, together with a delicate work aimed at linking fragmented and contextual items of knowledge together and, eventually, moralizing the conduct of the patient. This is so, because data are performative (Bowker, 1994; Mort and Smith, 2009): they account for the situation of the patient and compel doctors to take further action. Not only, in the case of Patient 2.0 they also account for patients' behaviour (in private), their willingness to collaborate and their skills regarding the use of medical technologies (as seen in particular in occasion of the verification of the relation among patients and instruments).

In other words, in the case of Patient 2.0 data 'overflows': they are not merely about the patient's clinical condition but they become significant also in terms of patient's capability, responsibility, virtues and habits⁹. We see here how the 'interactivity' which characterizes Patient 2.0 leads to a paradox: patient empowerment also implies empowerment of the doctors and other healthcare practitioners, who besides making diagnoses and prescribing therapies, must now decipher (and make clearly accountable) the process of production and use of the data patients bring to clinical examinations. In this sense, Patient 2.0 is not necessary an enhanced patient, but the effect of the constant, invisible work (Corbin & Strauss, 1994) made by doctors and nurses in order to keep coherently together bits and pieces of information.

Finally, the constant reference to technological objects and artifacts of various kinds is constitutive of both Patient 2.0 and the re-engineering of check-up encounters. From this point of view, it is peculiar how sometimes clinical encounters focus on the way these (mainly, the glucometer and the glycaemia logbook) are 'administered' by patients. This means also that Patient 2.0 is supposed to be able to develop medical and technical expertise, so to 'help' instruments to work correctly.

Consequently, in the case of Patient 2.0 clinical encounters are *de facto* re-engineered:

- the production of reliable data is highly dependent on the patient;
- medical tools and technologies are in the hands of the patient;
- doctors and patients are equally caught in the web of production, management and administration of data and technologies.

Patient 2.0 inspires further investigation regarding the shifting of accountability for the production and management of clinical data, together with deepening the understanding of the hidden and additional work required to a whole network of actors (doctors, nurses and the patient him/herself) in order to orchestrate the overflowing of data and information.

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- 5 Again, here we thank an anonymous reviewer for having highlighted this.
- 6 These episodes were recorded in two different centres.
- 7 CHO counting is a practice taught to patients involving calculation of carbohydrate intake.
- 8 As nicely noted by an anonymous reviewer, referring to a different medical context, Levinson (2010) has underlined how techniques of documentation can translate a macro discourse into a local practice.
- 9 For the last time, we thank an anonymous reviewer for having suggested this.

Notes

- 1 This article is the result of a collaborative effort by the two authors. If, however, for academic reasons, individual responsibility must be assigned, Attila Bruni wrote section 1 and the Conclusions; Carlo Rizzi wrote the Introduction and section 2. Section 3 was written jointly by the two authors.
- 2 The former is a diagnostic tool measuring the concentration of glucose in the blood; the latter is a form of medical report compiled by the patient.
- 3 We are grateful to an anonymous reviewer for this nice suggestion.
- 4 Glycated haemoglobin is an indicator of the average level of glycaemia in the previous 2-3 months. This average reveals whether and to what extent the patient has maintained good metabolic compensation. This value is part of the 'glycaemic target' which the patient must achieve and keep below a certain threshold.

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The Virtual Clinical Encounter: Emplacing Patient 2.0 in Emerging Care Infrastructures

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Telemedical devices such as the Patient Suitcase for treating chronic heart failure patients at home have been suggested to foster new and empowered patients. In this paper we analyse to what extent the 'virtual clinical encounters' taking place through the Patient Suitcase can be said to have such effects. We find that new skills are developed for all actors involved and that the work involved in the consultation is largely shared, but the normative claims of an independent and self-managing 'Patient 2.0' are difficult to support. Rather than seeing this as a dismissal of the transformative effects of telemedicine, we will suggest the need to decentre the attention from the individual and include the place-making efforts and effects involved in emplacing telemedicine in the home. The technology does not move work, knowledge and power from one actor in the clinical encounter to another – rather it redistributes and transforms it among more actors and more places demanding continuous sharing of work, development of new skills and involvement of distant and at times unruly actors. This may provide more sober accounts of the ways in which telemedicine has implications for the kinds of patients we may find in contemporary healthcare and awareness of the more ambiguous relations between self, place and other in emerging care infrastructures.

Keywords: telemedicine, patient 2.0, the virtual clinical encounter

Introduction: The Patient Suitcase

Your suitcase is your own. It contains belongings that you need while travelling to maintain your looks, your routines, your identity. It allows you to go elsewhere; with a suitcase you don't have to either choose to stay at home or leave everything behind. The Patient Suitcase, however, is not for the travelling of people – quite the opposite. It is a telemedical device that allows the patient

with chronic heart failure to stay at home rather than having to visit the hospital for regular check-ups. What travels is not the person using the suitcase – rather it is the foreign places of the healthcare system, which travel into the home of the patient through the suitcase. And it is the data generated about the body, which travels from the home to the clinic. Through the web-cam and screen of the suitcase the patient and a health care professional

can meet for virtual consultation. This arrangement, as many other telemedical devices developed and implemented in recent years, is to support, at a distance, the treatment of the patient with a chronic illness. Where the conventional suitcase is supposed to help the owner to stay unchanged, the patient suitcase is supposed to change the patient into a particular kind of patient: a knowledgeable, self-caring, self-managing patient. A patient 2.0.

In the call for this special issue this hope for technologies' transformative power for the kinds of patients we might meet in the healthcare system is framed with this reference to 'Patient 2.0'. This figure may, as the call also suggests, first and foremost be seen as an imaginary endowed with various normative expectations as to the effect of Information and Communication Technologies (ICT) for the increased, legitimate and productive participation of patients in treatment and knowledge production in healthcare. As in the case of the 'Web 2.0' concept there is a strong focus on the user-involving aspects of ICT and its effect on the redistribution of power and agency among those participating in a particular arena. Patients in actual medical practices introducing telemedicine may not be directly confronted with the normative visions for a technology-induced transformation of their role as patients. But the technologies, which they are asked to use at home, are indeed inscribed with some of these visions (Akrich, 1992).

In this paper we want to explore how elderly patients engage with telemedicine at home and discuss how they may be said to become particular kinds of patients. Analysing data from an interview-study on the use of the Patient Suitcase among people with chronic heart failure, we want to discuss how issues of space, role and agency must be rethought with the emergence of new kinds of spaces for clinical encounters,

such as the virtual encounter. How do such encounters taking place in the home fit the normative visions related to telemedicine and by extension to the notion of 'Patient 2.0'? Drawing on recent work on tele(health)care in Science and Technology Studies (Mort, Finch & May, 2009; Roberts, Mort & Milligan, 2012; Oudshoorn, 2008; Oudshoorn, 2012; Pols & Moser, 2009; Langstrup & Winthereik, 2010), Computer Supported Cooperative Work (Christensen & Grönvall, 2011; Aarhus & Ballegaard, 2010; Fitzpatrick & Ellingsen, 2012) and Human Geography (de Certeau, 1984; Tuan, 1999) we will argue, that this body of research challenges the notion of 'Patient 2.0' in two ways: first, when these telemedical arrangements are studied as socio-technical infrastructures (Star, 1999) that redistribute agency among human and non-human elements, the agency of the patients seem highly contingent on the arrangement in question and their durability. It is thus difficult to argue that patient *per se* become more independent from using telemedicine. Rather, patients and professionals share work. How they do this is specific to the technologies (Willems, 1995; 2000; Mol, 2000) and sites (López & Sánchez-Criado, 2009; Schillmeyer & Domenech, 2010). Second, directing our attention towards the way in which the Patient Suitcase is *emplaced* within the home as a meaningful place (Tuan, 1999) it becomes clear, that focusing on *the* Patient 2.0 – here the patient with heart failure – may make us overlook the central transformations implied with telemedicine – namely those that have to do with the emergence of new and potentially contentious spaces of care. Decentring the clinical encounter implied with telemedicine and similar technologies also demands a decentring of the notion of Patient 2.0: Rather than being an individual characterized by increased autonomy and knowledge it might be better understood

as a particular ambiguous relation between self, place and other.

Telemedicine and the Clinical Encounter: Patient 2.0 in Place

Telemedicine and telecare are increasingly becoming central nodes in the health care structures being weaved in Denmark and other Western welfare states. The visions in Denmark are clear: Policy makers portray telemedicine as having the potential to simultaneously improve quality of treatment of primarily chronic diseases and lowering costs, because patients can be discharged from the hospital earlier – or not admitted at all (Danish Regions, 2010). Patient advocacies also believe telemedicine to be a way towards patient-centred care by involving patients and their individual needs to a greater extent (Danish Patients, 2010). Thus, by enrolling the home and the patients and framing both as yet unharnessed resources, in policy documents, telemedicine is portrayed as a revolutionary way of treating patients, which has the potential to replace other forms of treatment and communication in the healthcare system. Most notably, the clinical encounter where doctor and patient meet in the institutional setting of the clinic or hospital will be avoided, or it will be relocated by webcams or on-line communication to the privacy of the patient's home environment. Through such 'virtual clinical encounters' and equipped with online 'tools of care' (Willems, 1995) the traditional, passive patient will – or so it is expected – in consequence be substituted by a new and more empowered, knowledgeable and self-caring patient (Kendall, 2001; Bos et al., 2008).

But how is it that some have come to consider the specificities of the clinical encounter in medicine as something which has effects on what a patient might be? Here

we have to look at not just the practices of medicine, but more so the sociology of medicine and its direct impact on policies and practices. Sociological interest in the relations between the clinical encounter and individual notions of self were at the centre of Parsons seminal work on the patient role (Parsons, 1951). Parsons suggested the patient role to be a role with a central function in the overall social structure. The doctor was seen as a legitimate agent of this structure, authorized through his socially sanctioned role to relieve the patient of his or her responsibilities related to other functions in the structure (as a worker, a parent, a citizen) while they were inflicted with disease. The patient is given a different role – the sick role – through the dyadic interaction taking place in the privatized space of the clinical encounter. Carl May has suggested (2007; 2010) that the primacy of the clinical encounter as a privatized, proximal relation as found in the Parsonian account, still frames our understanding of the clinical encounter in the sociological literature broadly. Even within the comprehensive critique of the notion of 'the sick role' and the asymmetries of power it entails, which has been at the centre of medical sociology during the last 30 years, the clinical encounter has generally been addressed as an individuated relation between the health professional and the patient (May, 2007; 2010); one in which power and knowledge flow in a lineal manner, shaping the roles and identities of the actors involved – most often in an asymmetrical way (Lupton, 1994). The critique being raised towards Parsons and towards the practices of medicine found to disempower rather than relieve the patient, foreshadows current suggestions in relation to telemedicine that a more empowered patient may come out of the transformation of the clinical encounter through technology. Thus, among proponents as well as critics

of telemedicine there seems to be a shared focus on which changes telemedicine might bring to a patient's role – or agency – in the doctor-patient relationship. Do we empower the patient by allowing for a more symmetrical relationship (e.g. Ball & Lillis, 2001)? Or do we lose the uniquely dyadic, personalized relationship between patient and professional when using online consultations (Evans, 1993)? These questions of doctor-patient dynamics seem obvious to examine in their own right. But concurrently with the increasing distribution of the health care system which blurs the established distinction between on- and offline care, scholars have pointed to a need for refocusing our analytical gaze towards the chronic care infrastructures (Langstrup, 2013; see also Star, 1999) or corporate ecologies of care (May, 2010: 135) allowing for information, treatment, and bodies to be distributed and coordinated. Clinical encounters then, May (2007; 2010) argues, are to be understood as sites of work and not only in terms of a relationship between doctor and patient, but just as much in terms of *who* and *what* (else) is taking part in them and *where* these encounters take place. The notion of place is of importance here, not as a stable spatial container of social activity, but as the ongoing making of meaningful spaces (e.g. Tuan, 1999; de Certeau, 1984). The home (as well as the clinic, for that matter) may be seen as one such accomplishment of 'ongoing and mediated interaction between self, other and place' (Gorman-Murray & Downing, 2007: 5). Strategically including the home as a site of work raises questions as to the implications for place-making – or more specifically how actors manage the relations between self, other and place as virtual clinical encounters unfold in their home. We should in other words decentre our analysis of the transformations implied by telemedicine from the focus on the

change in patient role alone. The '2.0' next to the noun 'patient' in 'Patient 2.0' should always already imply this decentring as it more than hints at the infrastructures making new clinical encounters take place. However, at least in the vision related to telemedicine, all attention seems to rest on the patient in isolation and little attention is being given to the sociotechnical care infrastructure including specificities of technologies, spaces and other human actors. In recent studies from the overlapping fields of Computer Supported Cooperative Work (CSCW) and Science and Technology Studies (STS) some help is to be found: CSCW has a long tradition for analysing the cooperative work practices distributed spatially and temporally as a consequence of information technology (e.g. Schmidt & Bannon, 1992; Vikkelsø, 2005), and recently a number of studies have addressed the issues of telemedicine and IT-supported home care in terms of new collaborative practices involving a more diverse collective of actors thus posing new challenges to design and use (Christensen & Grönvall, 2011; Aarhus & Ballegaard, 2010; Fitzpatrick & Ellingsen, 2012). Within STS Roberts, Milligan and Mort (2012) have pointed out the increased involvement of telecare-workers, who monitor the data submitted by telecare technology and take calls from the citizens having these technologies installed in their homes (see also Oudshoorn, 2008). Lopéz and Sánchez-Criado (2009) have shown how telecare technology promotes a particular spatialization of care, in which the home is cast as a safe haven and autonomous space for elderly citizens. However, when analysing specific telecare arrangements in Catalonia, Spain, they find that the boundaries between public and private, between the autonomous and the collective are not given even in the context of the home and that such boundaries continuously are negotiated and redrawn in

relation to the introduction of telehomecare (Lopéz & Sánchez-Criado, 2009). These and other studies draw attention to the active role that technologies and spaces (see also Schillmeyer & Domenech, 2010) play in telemedical arrangements. Drawing on these insights, we are interested in looking at the establishment of virtual clinical encounters, their emplacement in patients' homes and in the relations found there as well as the implications for re-configuring actors and spaces in the larger ecology of care.

Context and Methods

The research for this article was carried out in 2010 in connection with but independent of a larger clinical study on the use of a telemedical technology, the Patient Suitcase, for chronic heart-failure patients: The Tele-heart Failure project (Telehjertesvigtsprojektet, 2009). The clinical study consisted of two sub-studies: sub-study 1 focusing on treatment outcomes for newly diagnosed patients with chronic heart failure and sub-study 2 focusing on early discharge from hospital of known chronic heart failure patients (Telehjertesvigtsprojektet, 2009). The telemedical patients were in both instances compared to a group of chronic heart patients receiving conventional treatment. The qualitative study reported in this paper consists mainly of interviews with patients and health professionals involved in the Tele-heart Failure project. Patients were recruited from both sub-study groups by the health professionals responsible for the clinical study by asking whether the participants would be interested in giving an interview about their experiences of using the Patient Suitcase. Seven patients aged 49-83 were interviewed using semi-structured interview guides. The participants were or had been either skilled or unskilled workers and they all lived in

Funen, an island in the Southern part of Denmark. Interviews were conducted in the patients' homes and during some of the interviews the spouses also engaged in the conversation. Also the physician running the study and one nurse involved were interviewed, as was a technical advisor from the company responsible for developing the Patient Suitcase. All available written material on the Tele-heart Failure project and the Patient Suitcase was collected and one on-line consultation with a chronic heart patient was observed in the clinic. All interviews were digitally recorded and transcribed. Field notes were made after both observation and interviews. The transcribed and written material was coded and thematized and further analyzed using the tools and principles of situational analysis (Clarke, 2005). This involved identifying the human and non-human actors involved in the virtual clinical encounters and mapping their relations in and across what Clarke (2005) calls social worlds/arenas, but which we conceptualized as a broader ecology of care stressing the spatial dimension.

Division of Work in the Virtual Clinical Encounter

The visions related to telemedicine are often stated to be ones of *giving* patients responsibility and thereby making them responsible for a much larger part of their own care – e.g. for monitoring their body. In the Tele-heart Failure project this vision is explicitly framed as patient education:

The idea was that the patients can improve their compliance if they receive information in their own home, on their 'home turf', and that they will become more knowledgeable if they participate and manage the measurements of weight, ECG and blood pressure themselves (Project manager, e-mail correspondence, 2010).

In this quote the project manager links the production of both compliance and insight to participation and the self-management of measurements. But looking at the very design of the patient suitcase one may reconsider if participation and self-management is the same thing. Here the patient seems to be inscribed (Akrich, 1992) as a participant in a distributed set of tasks, rather than as a manager. These inscriptions point back in time to the initial design of the Patient Suitcase involving among others a senior physician, wanting to free up beds in the hospital, an IT company wanting to expand their business to the area of eHealth, and various governmental and regional actors partly financing innovations that could lead to a reduction of costs for healthcare (Erhvervs- og Byggestyrelsen, 2009). This large crowd of actors are indeed to be seen as part of the corporate ecology of care, but in the following we will focus on the way in which the final design of the suitcase configures both the patient and the health professional in the on-line consultation.

The patient suitcase looks like a small, black suitcase or large briefcase. When opened it is revealed that a screen, two built-in loudspeakers, a small camera lens and some sockets occupy one of the two halves, while the other half is closed off by a plastic lid, hiding the electronics inside. The Patient Suitcase has an on/off button, and an alarm button. The suitcase is the hub through which the patient and the nurse or physician can see and hear each other and data are visualized and sent. The actual production of data is not accomplished by the suitcase alone, but rather through measuring devices connected to the suitcase: ECG-electrodes, measuring electric activity of the heart, blood pressure cuffs, scales, and a small switchboard making it possible for the user to switch between the different measuring devices connected to the suitcase. Only the patient

can thus do the shifting between the various measuring tools. Most of the devices are foreign to the average home-environment. Only the scales look like something most people have as part of their household though data from this household item rarely become distributed beyond the bathroom. The measuring devices are all known items in the clinical context; however, they are the tools of the clinician. The suitcase, the switchboard and an internet connection have allowed these tools to be relocated to the patient's home without being disconnected from the clinic. The measuring devices are meant to function only in relation to the suitcase and thus do not entail that the job of making measurements is given to the patient to use autonomously, but rather that the tasks involved in making measurements is distributed spatially and temporally among more actors (nurse/physician, computer screen, internet connections, suitcase, measuring devices, switch board and possibly more) in new ways.

Below we will look closer at how this may influence whether the patients become more knowledgeable and responsible. But first, let us explore in more detail how the patient is a participant in the task of measuring in an on-line consultation:

Although there is still 10 minutes to the appointment, Ben has turned the suitcase on. It is 'to warm it up', as he calls it. Before the appointment Ben makes an electrocardiography (ECG) on his own. He attaches a moistened electrode to his wrist and ankle and waits for the graph of the electrocardiogram to be recorded. During the consultation this recording can be transferred to the health professional. Before tuning in, Ben straps the BP-cuff to his arm. After a short dial-up tone the nurse, Maria, appears on the screen. First thing, after greeting each other, Ben asks Maria if

she would like a BP-measurement. She responds positively by saying that she will now measure it, and pushes a button at her desk, that causes the cuff to inflate around Ben's arm. After about 35 seconds they have a measurement. Both of them can see the numbers. It is a bit high, they agree while Ben takes off the cuff. Moving on to the weighing, Ben turns the switch and steps onto the scales [The switch has to point at the ongoing type of measurement (ECG, BP or weight) to ensure that data can be transferred to the hospital database, ed.]. The scales are unreliable, Ben comments, compared to his own scales in the bathroom. While weighing Ben, they joke about whether Ben or Maria is ahead of the other in the course of the consultation, and they small talk about the new car that Ben will be picking up tomorrow. Maria then asks him if he has turned the switch yet, so that she can obtain the data of the ECG. He hasn't, but he then does. Maria tells him that the ECG looks fine. They continue the consultation by discussing the course of his medication – when and how much to change the dosage, how and where to obtain more medicine. They end the conversation by making a new appointment for another on-line consultation. (Field notes, 2010)

In this field excerpt Ben comes forth as a very active patient. He starts measuring even before the nurse turns up on the screen. He handles the demands of the Patient Suitcase, to be warmed up, before the consultation. He has been given instructions to do this as he was enrolled as a participant in the research project when he was found to suffer from chronic heart failure at the hospital. As we see, the patient as participant in the task of monitoring inscribed in the design of the Patient Suitcase is also enacted in the on-

line consultation. The physical separation between him and the nurse implies that he must engage in practical activities, which in conventional treatment would be attended to by the health professional (e.g. attaching electrodes to his body, fastening the BP-cuff around his arm) or which are quite novel to these types of consultations altogether (turning on the Suitcase, turning switches). Some of these activities he manages without instruction – at this point in time – by the nurse, while others, such as turning the switch on the switchboard, he is reminded to do by the nurse. Also, while he himself applies the cuff for blood pressure measurement, it is the nurse or physician, who from her or his location within the hospital activates the mechanism that allows the cuff to inflate. The set-up does not allow the patients to make this measurement nor the ECG by themselves as it depends on the coordinated activities of patient, suitcase and nurse.

So while the suitcase is in the home of the patient the task of measuring both BP and ECG is distributed more widely over various locations and actors. This implies a lot of articulation work (Strauss et al., [1985] 1997) in the course of an online consultation. In contexts of cooperative and distributed work activities as these, articulation work may be seen as the often invisible work involved in coordinating and integrating these activities (Strauss et al., [1985] 1997) – work involving and shaped by both humans and technologies, as it has been well-documented within CSCW (Schmidt & Bannon, 1992; Star & Strauss, 1999). Due to the lack of physical proximity (Malone, 2003; Oudshoorn, 2009), instructions have to be given through voice and gestures during the consultation. For example, health professionals asked patients to examine their own legs for oedema, as the health professionals could not touch them. The patients needed to touch – or palpate, to

use the clinical wording – their own legs and try to describe their sensation to the health professional in words, hereby translating a visual and tactile feeling into an audible description perceptible to others and transportable across the network. As other scholars have noted (Oudshoorn, 2009; Pettinari & Jessopp, 2001; Roberts, Mort & Milligan, 2012), this means that adequate oral and visual communication skills become obligatory points of passage and important allies for a successful cooperation and treatment.

The online coordination, the articulation work and the oedema assessment are fine examples of how work associated with clinical encounters in telemedicine shape – and is shaped by – a distributed network that clearly extends further than the health professional’s office, but also that the work and responsibility is not simply given to patients. Care work is highly collaborative (Christensen & Grönvall, 2011) and in this case patients, professionals and technology perform ‘shared work’ (Winance, 2010) in which new dependencies and independencies emerge and thus also a need for new skills. The professionals increasingly depend on the ability to verbalize instructions for this kind of ‘patient work’ (Strauss et al., [1985] 1997) that is needed for the consultation to move forward. These skills of producing ‘virtual co-presence’ are largely ignored when discussing the prerequisites for good telemedicine or telecare (Roberts, Mort & Milligan, 2012: 498). The patient may be said to become able to do independent care-work, when he or she starts the ECG procedure by attaching the electrodes and makes the reading before the consultation. This is indeed a new skill alongside others that the chronic heart failure patients in this study can be said to have acquired. However, as we will see below, this may be a too operationally segmented account of

what counts as dependent or independent, not least if we want to connect this to overall notions of new forms of patienthood.

Knowing the Numbers

When interviewing patients, they were all able to describe in much detail the tasks they had to manage in relation to the consultation: warming up the suitcase, putting on electrodes, using the switches and more. However, often they could not remember the names for the different measurements, nor did they feel confident interpreting the numbers. A patient describes her engagement in the measurements in the following way:

C: ‘... I received very good instructions. I was able to measure myself, oh what is it called.... Ah... heartcar... oh, what is it called, it is called something in particular...’

Interviewer: ‘ECG?’

C: ‘Yes, that it. I had to put the thingies on my wrists and on one ankle. And then I could measure, so it, this ECG, was done when the nurse called me up.’ (Interview with patient, 2010)

Actually, the question of independency and responsibility may be experienced as somewhat unclear, as these quotes indicate:

A: ‘I could measure... well, it wasn’t me (smiles) I just had to put it on and then... Tom [the physician, ed.] would start it, I couldn’t even turn the instrument off (...)’

Interviewer: ‘So you just told him the numbers, or, I guess he could see them, right?’

A: ‘Why yes, he did the blood pressure measurement himself, you see’ (Interview with patient, 2010)

The patients are given tasks related to measuring – turning on the Suitcase, putting on the electrodes and the cuffs, but they experience the measuring itself – inflating the cuffs, reading the measurement – as something which is done by the health professional. So even if the work may be seen as collective, the patients experience the primary tasks as being carried out by the professional.

F: ‘there weren’t that much to do... because there were, as I said, I had to be weighted and... then, when I had to have my blood pressure taken, right, then I just had to put on the cuff and then Maria [the nurse, ed.] would push the button down there [in the hospital, ed.]. She could do that. And then... then... I could see on the instrument that it... what it showed, you know. Yes, yes, that I could see, yes.’ (Interview with patient, 2010)

The patients see the measurements on a small display, which is turned on by the health professional and the number is often commented on by both participants as in the field excerpt in the beginning of this section: Ben engaged in commenting and reflecting upon the meaning of the numbers. The blood pressure was a bit high, they agreed, and Ben was annoyed that the scales are not as stable as the ones he uses in the bathroom. Ben is, through the online dialogue with the nurse, actively engaged in reading the numbers and interpreting what they might mean to his treatment. Other patients engaged with great enthusiasm in the tasks enabling the production of measurements, but in the interviews they were hesitant in engaging the interpretation of the numbers:

G: ‘Well, I don’t know anything about what those numbers mean, I don’t

(smiles), but you know, it [the blood pressure] cannot be too high when she [the nurse] doesn’t talk about it... it can’t be.’ (Interview with patient, 2010)

D: ‘Well, I weren’t told the numbers as such ... and I didn’t ask either... because he [the doctor] was the expert, you know. If he says they are fine, then I assume that’s how it is...’ (Interview with patient, 2010)

These patients perform all the tasks assigned to them – they put on electrodes, turn on the suitcase, put on the cuff – but they do not engage with the numbers. They do not experience this as a task assigned to them.

This is however in contrast to how the nurse envisions the patients’ engagement with the numbers as she expects them to become *owners of measurements*:

... Well, they simply have to get involved. They can’t just come in here [at the hospital, ed.], deliver a body on which we can do some measurements and then go on home. It is their measurements and they are the ones handling the medication. And now I am the one asking them for something too. (Interview with project nurse, 2010)

In this quote the nurse contrasts the traditional encounter in the hospital with the online consultation via the suitcase: In the former the patient ‘delivers a body’ and in the latter the patients produce their own measurements and it is the nurse, who has to ask for the data. In her account the powers have been, if not reversed, then at least balanced, because the patient has his or her own data. However, we have seen, this implied symmetry might not be as evident. The nurse does ask the patient to do certain things – put on the cuff, stand on the scales, flip the switch – and the results of the measurements are accessible

to both parties simultaneously. Though, what seems like a symmetrical and patient engaging feature about the technology might also enable and support the patient in not becoming particularly knowledgeable about the numbers, which the statements made by the patients above suggested. If the intention is to make patients more knowledgeable through actively giving responsibilities to them, the design of the Suitcase has ambiguous potentials for doing so: Ambiguous because some of the participants actually do incorporate measuring practices into their everyday life after the study has ended and the suitcase has been removed. These participants continue the practice of weighing themselves daily in order to monitor the possible accumulation of water in their body – something they have learnt from the consultations, may indicate problems with the regulation of the medication that they continue to take as chronic heart failure patients. During the course of treatment patients have grown familiar with the practice of weighing themselves (had they not already been because of repeated weighing through their life course). Through the consultation patients had been told when and why they should measure their weight, and they had done it repeatedly along with the other measurements of ECG and blood pressure. In this way measuring has become a new way of knowing their body themselves (Mol, 2000) and the domesticated bathroom scales have been reappropriated from something producing knowledge about body size to a tool for producing knowledge about the effects of a specific medication. So while the patient suitcase and the other measuring devices are removed from the home, the bathroom scales which preceded the arrangement and remain behind make it possible to retain in everyday life one of the practices introduced with the patient suitcase.

Looking at the arrangement of the virtual encounter, we have seen that the introduction of telemedicine involves a division and sharing of work and moreover demands the development of new skills from *both* patients and professionals. The patients may continue to use these skills in relation to their management of their illness after the telemedical technology is taken away – in this case with the reappropriation of the bathroom scales. Still it is important to recognize that the care a person exercises – for him- or herself or for others – is never independent of the kinds of infrastructures that contribute to this care (Danholt & Langstrup, 2012; Langstrup, 2013). What it is to be a chronic heart failure patient and which skills to acquire and activities to engage in, is definitely shaped by the distributed arrangement which includes the patient suitcase and part of the arrangement and the acquired skills may even continue to exist after the telemedical technology has been dismantled. But at the same time the virtual encounter does not seem to be best understood in terms of radical changes implied in the normative version of ‘Patient 2.0’ that suggest patients to become independent and self-managing. As far as it makes sense to label these patients as ‘Patient 2.0’ this consists in having learned about their chronic heart condition and how to deal with that – not by themselves but rather in close cooperation with health professionals that they expect to instruct them and interpret the results of their shared work. As the virtual encounters are discontinued together with delivering the suitcase back to hospital many of the skills acquired become redundant.

The room in the room

In the interviews patients and professionals alike recounted the virtual clinical encounter as being in a sense ‘the same’ as a visit to the clinic – now they just do not have

to travel to the hospital (something which all patients appreciate immensely). As we have already suggested above, it involves particular skills to establish a virtual space in which the patient and the professional 'meet' and achieve this virtual co-presence (Roberts, Mort & Milligan, 2012). Also, it may be experienced as intimate and affectionate rather than 'cold' and dis-embodied, something that has also been found in other studies (Roberts, Mort & Milligan, 2012; Pols & Moser, 2009; see also Mort & Smith, 2009). Moreover, both parties described the atmosphere of the consultation in spatial terms, as 'a room' where they could be together. The nurse said:

...you get the impression, that this is the kind of room where only the two of us exist... they have me in their living room, or in the office or where ever I am, and I have them on the screen and in my headphones. And then, in that sense, it is a closed room... (Interview with project nurse, 2010)

Her statement reflects that she experienced a clearly delimited space, where only she and the patient had access. A patient said:

... We felt we were in the same room... you know, that's how you feel... (Interview with patient, 2010)

So not only was it a closed room, it felt as if they were physically together in the same room. Furthermore, the spouse of the above quoted patient had witnessed several consultations from a chair in the background in the living room and he added:

... well, it seemed quite as if they were together. (Spouse, at interview with patient, 2010)

From these statements we see that the consultation configures a closed room, in which the nurse and patient can be together. Apart from demonstrating that intimacy may be achieved in a virtual co-presence, this also draws attention to what is obviously not the same in this encounter compared to other clinical encounters in medicine. This difference has to do with the emplacement of the virtual encounter in a wider set of spatially enacted relations. The fact that the virtual encounter *takes place* in the home (and the clinic) is not inconsequential. It is a room established within another room. When the husband above comments that he senses a space emerging in his living room through the consultation, this implies that he is positioned on the outside as a spectator. This inside-outside observation implies that the emerging room has boundaries, telling us that the work related to the consultation is also a kind of boundary work demarcating 'the room where they could be together' from the rest of the home – and from the hospital. Here we find an interesting paradox arising in which the virtual consultation is both 'the same' as any other clinical encounter between a health professional and a patient and at the same time unarguably different in that it is taking place in the home of the patient.

Emplacing telemedicine in ecologies of care

Until now we have focused on the establishment of the virtual encounter and the extent to which this may be said to change patient roles or not. However, as the above section has pointed toward, the virtual encounter is taking *place* spatially in the home. Through the use and manipulation of available spaces and resources (de Certeau, 1984) the virtual encounter in these cases becomes a meaningful place for the sharing of work in relation to care. As noted earlier, place-

making is a continuous achievement and a physical, geometrical space may be different according to different uses, interpretation and times (Tuan, 1999). However, as we will see more clearly now, the accomplishment of a particular room, demarcated from the surrounding room – the home – may be a fragile accomplishment. This fragility and sometimes ambiguity of the boundaries relates to the very same resources involved in its establishment. The home is not just a geographical site, but rather in itself a situated and meaningful place we inhabit and share more often than not with spouses and other close relations (see Langstrup, 2013 for a discussion on the meaning of home in chronic illness). Relatives and spaces are part of the resources that need to be used, managed and sometimes manipulated for the infrastructure to work and the virtual encounter to emerge. So, even if it is possible to create a discrete ‘room’ in which the shared work of the consultation takes place, this accomplishment involves the activities – directly or indirectly – of other actors inhabiting the home (Langstrup, 2013). Although it was a precondition for entering the study that patients were able to handle the Patient Suitcase and carry out the associated tasks on their own, it was not uncommon that the spouse took part in the consultation. Typically, the spouse would assist at measurements by putting on the cuff or turning the switch. In one instance, the assistance of the spouse was urgent as the patient was paralyzed on one side of her body and another had a hearing impairment. Under these circumstances, enrolling relatives strengthens the infrastructure, because they become participants in the shared work involved in the virtual consultation. One patient recounts:

...then Gertrude [the wife, ed.] stood and orchestrated the events and pushed the buttons and what not... (Interview with patient, 2010)

In his account the wife almost took over the central activities of the consultation, but later in the interview he also suggests, that after some time, he did most of the tasks himself.

But relatives are not always allies in the establishment of the virtual encounter. They might have other goals than the health professional and/or the patient. For example, the wife of a patient had reacted very adversely to the nurse’s suggestion during a consultation that, to make easier to stop smoking, the patient could consider asking his wife to stop smoking together with him. The wife, then, had sworn, ‘*you can forget about that!*’ from somewhere in the living room (in a place where the nurse looking at her monitor could not see her).

So even if it may be possible to achieve an intimate room, this room may be quite fragile due to its emplacement in another room – the home – and the relations, emotions and meanings implicated here. The nurse reflects on the difficulties of handling un-cooperative relatives:

Nurse: ‘I felt like telling him to do it [the tasks involved in the consultation, ed.] himself, but in the end it worked out. She wasn’t there anymore.’

Interviewer: ‘But you didn’t have to say anything?’

Nurse: ‘No, I didn’t say anything, because I can’t really interfere when this is their home [...]’ (Interview with project nurse, 2010)

The examples illustrate how the patient suitcase and the virtual encounter may both depend on and become challenged by the actors already residing in the space in which this healthcare practice is to be emplaced, that is in the home. Thereby, healthcare practitioners may become acutely aware of the wider context in which the consultation, and more broadly speaking treatment, is

taking place. Cooperative work is – whether computer supported or not – shaped by the places in which the work is done: a point well-recognized in CSCW (Harrington & Dourish, 1996; Dourish, 2006). But what may need to be learned from this case and others on the emerging care-infrastructure that mobilized the home as a central node in treatment is that cooperative care work which involves patients and relatives at home is different from work involving actors in different, distributed professional settings. The virtual encounter may be seen as a corporate space rather than a private space, as a dyadic focus may have otherwise mislead us to believe (May, 2007). But, trying to find its place in the home the virtual encounter is faced with the unruly actors and multiple agendas of everyday life that may have been kept out of a physical visit at the clinic – though rarely out of treatment as such (Langstrup, 2013). The wife in this situation is simultaneously implicated in establishment of the virtual encounter as an actor in the home, and ‘other’ to it as resisting the effort to include her in the clinical room. Home may be seen as ‘a material and an affective space, shaped by everyday practices, lived experiences, social relations, memories and emotions’ (Blunt, 2005; Langstrup, 2013). The virtual clinical encounters in telemedicine literally have to be fitted in, meaningfully, with other kinds of practices and encounters in this ecology. The skills – or tactics, as de Certeau might call them (de Certeau, 1984) – demanded for this, are not inscribed in the technologies in question. Furthermore, the emerging room, that we have seen, may not be there all the time. It comes into existence through the shared and distributed work of consulting through the Suitcase. So while others describe telemedicine as potentially intrusive of the home (Fisk, 1997), our study indicates that work related to telemedicine is *not* necessarily continuously made part

of the home and the life led here. As also López and Sánchez-Criado found, the boundaries of the home are not given, but rather continuously negotiated and enacted in relation to the specific socio-material practices found here (López & Sánchez-Criado, 2009). Still, the home is made available at times, by technology, patients, spouses, as a place that can become reconfigured as a part of the corporate ecologies of care, which seeks to make individual illness trajectories into problems that are manageable for corporate entities, such as healthcare authorities (May, 2010). And as a place that have other identity shaping and preserving functions (Douglas, 1991), both for the patient involved in virtual encounters and for spouses and other relatives for whom this space is home, it may impose new challenges and complexities into corporate ecologies of care. In that sense, technologies like the Patient Suitcase not just giving responsibility for care to the patient but rather – by re-distributing the shared work on more actors and emplacing healthcare in the home – introduces more complexities to be managed as part of both healthcare workers and citizens having these technologies introduced in their homes.

Conclusion

Telemedicine is again and again promoted for its ability to ‘give back’ power to patients. Specifically in our case of the Patient Suitcase and the Tele-heart Failure project, patients are suggested to learn to care for themselves and become more independent of medical experts. But as our analysis of the collaborative actions of the health professionals, patients, relatives and technology involved in the virtual clinical encounter has shown us, the Patient Suitcase does not take work, knowledge and power away from one actor in the

clinical encounter to give it to another. Both patient and health professional acquire new skills through their different usages of the patient suitcase. It is notable, however, that the patient users of the Suitcase find the health professional to be the manager of the virtual encounter and the interpreter of data, while they find themselves to be authorized to do practical tasks. Some of these tasks and the skills associated with them obviously become obsolete when the technological setup and thus a major part of the care infrastructure is dismantled and the Suitcase travels back to the clinic. We may only speculate if a different kind of telemedical equipment or a different sample of participants (younger or better educated) would have resulted in more profound changes as to their engagement in their medical treatment. We would welcome more studies on these questions as the rising market for self-diagnostic tools and monitoring do suggest that some favour a more patient-led demand for health services. What constitutes a patient is however highly contingent on the infrastructures of care and their durability and specific to the present case is that work was highly shared in the virtual clinical encounters. All the while the arrangement of the patient suitcase was in place the technology demanded cooperative efforts – also efforts concerning making the virtual encounter a meaningful place within an existing place – namely the home. We have argued that emplacing the patient suitcase in the home – making a room in a room – demands continuous sharing of work, development of new skills and involvement of at times unruly actors. Decentring our view and looking at the place-making involved in setting up and sharing work in the virtual clinical encounter may make us more alert to the demands put on patients, professionals and relatives to manage the at times diffuse and ambiguous boundaries between the place established for sharing the work and the

place of the home, which may have many other functions in terms of developing or preserving the inhabitants' sense of self. For it is not at all obvious precisely where the clinical encounter starts and the home ends, or where the patient role begins and the other and potentially contrasting or conflicting roles and responsibilities end. The notion of Patient 2.0 – even if by nature of its numbering encompasses networked technology – does not give many clues as to these new challenges in managing relations between place, self and other, as it has a tendency to make us look at the level of the individual when searching for effects of new technologies in healthcare. But as May has argued, 'the clinical encounter itself is only one part of an assemblage of complex organizational, institutional and disciplinary resources and practices, in which units of analysis are to be found at diverse organizational interfaces – and where subjectivities are constructed and worked out in multiple and diverse ways in relation to new managerial technologies' (May, 2007: 41). Emplacing the 'managerial' technology of the Patient Suitcase in the homes of patients creates such new interfaces with possible implication for subjectivities for all those involved – whether they are patients, health professionals or relatives. But in terms of getting a better understanding of what changes telemedicine implies, we may get more interesting insights if we decentre our attention from the individual patient – 2.0 or otherwise – and look at the implications of distributing the management of healthcare on more actors, technologies and places in corporate ecologies of care.

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Travelling Frictions: Global Disease Self-Management, Local Comparisons and Emergent Patients

Annegrete Juul Nielsen and Casper Bruun Jensen

Contemporary disease self-management programs aim to renegotiate the terms on which patients participate in their own health care. Though the notion of 'patient 2.0' has mainly been used to speak to patient empowerment through IT, we therefore propose to view self-management as eliciting "the patient" in a different shape. In this paper, we explore the embedded assumptions, imagined potentials and concrete practices of the Stanford Chronic Disease Self-Management Program (CDSMP), in order to understand how this program reconfigures a particular form of global patient. To analyse this process we consider the CDSMP as a traveling technology. First, we demonstrate that its successful globalization has been enabled by tying together specific forms of theorizing, evidence-basing, and scripting in a theory-methods package. Second, we show that the globalization of the program entails various forms of localization in the national health care setting of Denmark. In this context, we examine different kinds of efforts required to maintain the 'global' identity of the program even as it is 'localized'. In particular, we show that the insertion of the program into Danish health care generates frictions. Such frictions are brought to light comparatively as Danish health care policy-makers, practitioners, consultants and chronic patients engage with and reflect upon the characteristics of the program. We argue that this analysis holds implications for 'patient 2.0', both as practical accomplishment and as a conceptual tool for social studies of medicine and health care.

Keywords: comparison, friction, globalization

Introduction: New Forms of Global Patients?

The current global focus on patient involvement is often described as a response to the fact that health strategies have failed to recognize how people can play a positive part in building healthy lives (cf. Department of Health, 2001; Danish

National Board of Health, 2005a). Over the past decade, various self-management programs have seen the light, aiming to empower patients to perform self-care and participate in their own treatment. In the UK alone, more than 80.000 patients have participated in the so-called *Expert Patients Self-Management Course*.¹ Disease self-management programs would thus

seem to play a central role in the discursive construction and practical enactment of new forms of patients.

The notion of patient 2.0 is mostly used to characterize patient empowerment achieved through the use of information technology. Bos et al., for example, define patient 2.0 empowerment as 'the active participation of the citizen in his or her health and care pathway with the interactive use of Information and Communication technologies' (Bos et al., 2008: 167). It is not surprising that the terminology of patient 2.0 is affiliated with IT; after all, the notion mimics terms such as web 2.0. Even so, this usage, which specifically defines the new patient in terms of his or her interactions with information systems, is too delimited. And indeed, this special issue invites us to explore patient 2.0 as a rubric with which to sharpen analytical attention on all manners of novel patient configurations. Thus, our starting point is that in disease self-management programs, patients, too, come face to face with new roles and expectations. Such programs, too, aim to reconfigure the terms of patient participation and create new forms of empowerment. Thus, they instantiate emergent forms of patient 2.0.

Supporters of disease self-management programs argue that they bring about a win-win situation. Not only the individual patient but the health care system at large benefits when patients are trained in disease self-management. Such programs are said to empower individual patients to interact pro-actively and competently with health care systems. Their aim is to put the patient at the centre of the care process. In turn, this is thought to increase the quality of life among the chronically ill. When patients emerge as active, responsible and self-caring, resources are freed that can be spent on less resourceful patients (Lorig et al., 2001).

But if self-management programs create new forms of patients, they raise important questions in turn. Which assumptions about patients are embedded in these programs? Where do they come from? How are they expressed in practice? Such questions are crucial to address in order to understand the consequences of these programs, both for health care systems and for (new kinds of) patients.

We ask these questions with reference to the Stanford Chronic Disease Self-Management Program (CDSMP), which is concerned with the social and mental aspects of living with a chronic disease. Teaching its participants methods and techniques of problem solving in the context of living with chronic disease, this program has effectively framed itself as a global health care solution to the problems of chronic patients.

In the following, we explore several aspects of the CDSMP to learn more about the construction of a particular version of patient 2.0. First, we examine the process through which the program has managed to achieve its astounding level of success. Second, we examine how the program works to maintain its 'global' identity and coherence in the Danish national health care system. Third, we show that the insertion of the program into Danish health care generates frictions. Such frictions are brought to light *comparatively* as Danish health care policy makers, health care practitioners, consultants and chronic patients engage with and reflect upon the characteristics of the program. We end with a discussion of the implications of the analysis for an understanding of patient 2.0 as practical accomplishment and as a conceptual tool for social studies of medicine and health care.

Methods and Empirical Materials

The paper is based on two sets of material. In order to explore how the CDSMP has been turned into a standardized health care package and enabled to travel globally, we rely on articles, reports and manuals published by Kate Lorig and her colleagues (e.g. Lorig et al., 1998; 2000; 2003) at the Stanford Patient Education Research Center. We also view as part of our data material psychologist Albert Bandura's (e.g. 1986, 1997) writings on self-efficacy theory, the assumptions of which are embedded in the CDSMP. This 'data set' is completed by other research that has critically engaged the CDSMP (e.g. Lindsay & Vrijhoef, 2009). These approaches are themselves part of the data, since they help us understand the emergence of the CDSMP as a theory-method package.

In order to examine the entrance of the CDSMP into Danish health care settings, we draw on whitepapers and reports concerned with the Danish adoption of the program. Most substantially, we draw on Nielsen's fieldwork, which concentrated on the enactment of the CDSMP in Danish health care (Nielsen, 2010). This fieldwork was conducted between November 2006 and July 2008, and in the fall of 2009. During these periods, Nielsen carried out participant observation at a municipal health centre in Copenhagen and with the CDSMP trained leaders program. Additionally, she participated in two Danish networks related to CDSMP: a network within Region Zealand, in which trained leaders and municipal coordinators exchange experiences, and a network, which organizes yearly national workshops and meetings for CDSMP-coordinators and trained leaders. From this substantial body of material we draw in particular on one patient's reflections on the frictions generated by the implementation of the

CDSMP in the Danish health care system. Her observations are especially evocative because of their explicitly comparative dimension and their marked contrast with official evaluations. Obviously, we do not claim that this patient represents all Danish perspectives on the matter. We choose to engage her concerns, well aware of their singularity, because of the particular clarity with which they articulate the frictional processes to which the travelling CDSMP gives rise.²

Scripts, Packages, and Travelling Comparisons

Our approach is informed by a number of concepts developed in STS generally, and studies of science, technology and medicine in particular. We take as our starting point Annemarie Mol and Marc Berg's observation that 'medicine is not a coherent whole. It is not a unity. It is, rather, an amalgam of thoughts, a mixture of habits, an assemblage of techniques' (Mol & Berg, 1998: 3). This is why a focus on the 'ideals and ideas of medicine' is insufficient; it is necessary also to pay attention to 'practices and performances' (Mol & Berg, 1998: 3).

How to keep in view ideals and practices at once? Madeleine Akrich (1992) proposed one way forward in her work on technological scripts (see also Dodier, 1998: 53-54 on 'frames'). When creating objects, Akrich argued, innovators 'necessarily make hypotheses about the entities that make up the world into which the object is to be inserted. Designers define actors with specific tastes, competencies, motives, aspirations, political prejudices, and the rest' (Akrich, 1992: 207-208). They then inscribe these properties in their objects. For the analyst who would unpack such processes, this entails the requirement to 'go back and forth continually between the designer and the user, between the

designer's project user and the real user, between the *world inscribed in the object* and *the world described by its displacement*' (Akrich, 1992: 208-209).

In her studies of molecular biology, Joan Fujimura (e.g., 1987; 1988) offers a related view, which addresses the issue of standardization. She suggests that the packaging (cf. Akrich, 1992: 215) of theories and methods into standards makes for 'highly transportable' entities through the 'deletion of context' (Fujimura, 1988: 266). Fujimura discusses the benefit conferred on practitioners who use such packages in terms of 'doability'. Problems, she argues, 'are more or less doable depending on how difficult it is to articulate among levels to create alignment' (Fujimura, 1987: 262); for example, between specific scientific experiments, laboratories, and broader social worlds of research and application. Standardized packages that can travel between the 'levels' increases doability by decreasing articulation work (Fujimura, 1987: 277).

These analyses indicate that the ability of entities, programs, or technologies to travel is strongly related to standardization. Our case brings out this insight, which also suggests that the making of 'patient 2.0' is as much about homogenization as it is about enabling the recognition of diversity and individual choice. Yet, this is only one side of the story. For, as Akrich (1992) emphasized, tracing the actual effects of any package requires a continual movement: 'back and forth between the designer and the user'. This analytical movement makes visible that standards by themselves are not able to standardize (Jensen, 2010: 51-68), since they are dependent on a heterogeneous set of other actors. Accordingly, CDSMP cannot be understood simply in terms of homogenization, for its users also attempt to translate, challenge or undermine the program through *their* activities. Patient

2.0 is the *effect* of this interplay between standardization and translation.

Packages like the CDSMP never travel effortlessly, and the larger the distances (in terms, for example, of geography, or forms of organizing health care work or cultural understandings of health) the more effort is required to keep standards standardizing. Hence, travelling packages often gives rise to what the anthropologist Anna Tsing has described as frictions: 'Rubbing two sticks together produces heat and light; one stick alone is just a stick. As a metaphorical image, friction reminds us that heterogeneous and unequal encounters can lead to new arrangements of culture and power' (Tsing, 2005: 5). Broadly stated, frictions are generated when projects with universal aspirations encounter actors and institutions with different ideals and practices. In particular, we argue, frictions may intensify when travelling theory-methods packages *insist* on their unproblematic universality. Whereas Annemarie Mol and Marianne de Laet (2000) beautifully showed the flexibility of technologies designed with fluidity in mind, our case is about frictions arising when a deliberately inflexible technology travels.

These insights into travelling packages, standardization and friction form an indispensable backdrop to our analysis. We add to these concerns a discussion of comparative devices inspired by the anthropologist Atsuro Morita (Morita, forthcoming). In his ethnography of Thai mechanics, Morita noted that the Japanese harvesting machines they used were not only 'practical', technological devices, but also objects that evoked cultural comparison. Thus, the breakdown of a rotary cultivator was interpreted by the mechanics as resulting from the difference between Thai and Japanese environments. Morita argues that this knowledge was derived comparatively by Thai mechanics' interpretations of the 'relations embodied

in the machines they manipulate' (Morita, forthcoming). The breakdown of the cultivator, he suggests, 'produced a double vision in which the Thai and the Japanese environments were seen *at once* through their difference.'

In the following we draw on Morita's insight to analyze the CDSMP as a travelling health care package, the movements of which gives rise to travelling comparisons and frictions (Morita, 2013).

From Medical Compliance to Self-Management

Diagnosis based patient education has been part of Western health care systems since the 1980s (Lorig, 1996). Traditionally, patient education has targeted specific groups such as diabetics, asthmatics or heart-patients and aimed to increase patient compliance by providing patients with knowledge of their disease, medication and symptoms (Danish National Board of Health, 2005b; 2009). In contrast with these initiatives, the CDSMP represents a new type of patient education. The novelty is in its focus on the social and mental aspects of disease rather than on compliance.

The CDSMP was developed during the 1990s by Dr. Kate Lorig, based at Stanford University, in collaboration with the California based health organization Kaiser Permanente.³ In 1979, Lorig created the Arthritis Self-Management Course, which became the prototype for the CDSMP. According to Lorig and her colleagues (2003), existing types of patient education did not address the issues that really mattered to patients. For example, traditional arthritis education programs focused on disability management, while the major concern of patients was pain. Referring to the work of the medical sociologists Juliet Corbin and Anselm Strauss's (1988), Lorig and her colleagues argued that arthritis education programs should teach information about

managing disability *in the context of pain management*. Inspired by psychologist Alfred Bandura's work on self-efficacy, they further argued that patient education programs should relate to problems as *perceived by patients*.

The CDSMP can thus be characterized as a psycho-educational program designed to increase the capacity for self-management of people with chronic conditions. The aim is to improve participants' self-efficacy and their 'performance attainment' (Lorig & Holman, 2003), thereby enabling them to manage their health conditions more effectively. Concretely, the program is organized as a series of practical workshops that run for six weeks. Twelve to eighteen people with different chronic health problems participate in these workshops, which cover techniques to deal with frustration, fatigue, pain and isolation, appropriate exercises for maintaining and improving strength, flexibility, and endurance. Also, the program offers advice on the appropriate use of medications, on communicating effectively, and on how to evaluate new treatments (Lorig et al., 2000).

In these workshops, psychologist Albert Bandura's (1986; 1997) concept of self-efficacy is operationalized in different ways. In weekly plans, for example, patients are requested to identify tasks that they feel confident they are able to carry out, such as 'This week I will walk around the block once before lunch on Monday, Tuesday, and Thursday'. Self-efficacy is thus linked to *individual control* as expressed in the ability to determine tasks that are accomplishable and to actually conduct these tasks. But whence did self-efficacy arrive?

A Matter of Control

Lorig's (1996) early arthritis studies were more or less a-theoretical. However, she became increasingly interested in creating an analytical foundation for understanding

observed improvements in health status. Lorig hypothesized that these improvements were related to patients' feelings of being more in control of their illness. During this period, the CDSMP came to draw increasingly on Albert Bandura's notion of self-efficacy. As Bruno Latour (1987: 22ff.) famously argued, the credibility of scientific statements depends on the gradual 'deletion of modalities,' through which what are initially controversial claims end up as unequivocal representations of facts. We therefore consider the appeal of self-efficacy for CDSMP, and look into how its 'modalities,' problems, and qualifications, were removed and evidence in its favour rendered indisputable.

At the time of Lorig's arthritis studies, Alfred Bandura, also at Stanford University, had been refining his psychological theory for years. His famous *Social Foundations of Thought and Action: A Social Cognitive Theory* from 1986 offered a wide-ranging discussion of psychological 'models of human nature and causality' (Bandura, 1986: 1-47). *Social Foundations* also defined Bandura's own contribution – the social cognitive model, which was later renamed as self-efficacy theory.

The intellectual context for the development of the concept of self-efficacy was one in which many psychologists were wary of the excess of 'environmental determinism' affiliated with radical Skinnerian behaviourism. Bandura, however, did not completely retreat from the implications of behaviourism. Rather he aimed to put cognition back into the picture. In *Social Foundations* he proposed a model in which 'human functioning is explained in terms of a model of triadic reciprocity in which behaviour, cognitive and other personal factors, and environmental events all operate as interacting determinants of each other' (Bandura, 1986: 18). Thus, he characterized 'human functioning' by

three forms of 'capability': symbolizing, forethought and vicarious.

One might wonder how the environmental determinism of behaviourism can be connected with symbolization and forethought. Bandura solved this problem by suggesting that behaviourists had failed to extend the environment *far enough*. People do act in response to their environment, he argued, but this environment includes *even their own minds*. Thus, even though: 'self-regulatory functions are fashioned from, and occasionally supported by, external influences,' he emphasized that an act 'includes among its determinants self-produced influences' (Bandura, 1986: 20).

Yet, this interactive argument faded to the background as *Social Foundations* turned to description of types of motivators and self-regulatory mechanisms located within individual agents. This inclination towards individualism was radicalized in the discussion of perceived self-efficacy. Perceived self-efficacy was defined as 'beliefs in one's capabilities to organize and execute the courses of actions required to produce given attainments' (Bandura, 1997: 3). Thus, Bandura argued that perceived self-efficacy is an especially generative capability that often allows subjects to overcome environmental obstacles. Precisely this claim was picked up by Kate Lorig and embedded in the CDSMP (1996).

Centred on individual control, self-efficacy theory is deeply infused with a common-sense Anglo-American perception of agency. Famously designated 'possessive individualism,' this perspective assumes the agency of people to be exhibited in the form of autonomous and individualized acts (MacPherson, 1962; cf. Stam 1987). In this: 'version of agency ...self-contained agents who "own" their actions, and demand to be accorded a series of rights and responsibilities' (Brown, Ashmore & MacMillan, nd: 24). As we shall see, this

is just how patients are conceived in the CDSMP.

Evidence-Basing the CDSMP

Evidence has become a key word in the medical vocabulary (Timmermans & Berg, 2003). As Eric Mykhalovskiy and Lorna Weir observe, evidence has gone well beyond the confines of medicine proper (Mykhalovskiy & Weir, 2004: 1060). Thus it is of little surprise that evidence-basing was a crucial factor in allowing the CDSMP to travel globally. For the developers this raised the thorny question of how it would be possible to evidence-base a self-management program. Bandura's (1986; 1997) work on self-efficacy offered a set of hypotheses and experiments, which in turn provided both an analytical foundation and a practical inspiration for accomplishing this feat. Bandura's experiments had centred on measuring the effects of self-efficacy. Yet, self-efficacy as such cannot be observed and thus cannot be directly measured. However, by focusing on perceived self-efficacy, it seemed possible to circumvent the problem. Thus, individuals can estimate their ability to accomplish some task (holding a snake, for example) and this estimation can be compared with their subsequent ability to actually do so.

On this basis, Lorig's experiments proceeded to determine whether changes in perceived self-efficacy were associated with changes in health status. In the mid 1990s, a randomized controlled trial was conducted to evaluate the effect of CDSMP. Approximately 1,000 people with heart disease, lung disease, stroke or arthritis participated in this three-year test. When compared to a group of patients who did not follow the program, the participants demonstrated improvements in exercise, cognitive symptom management, communication with physicians, self-reported general health, health distress,

fatigue, disability, and limitations in social activities. They also spent fewer days in the hospital, and had fewer outpatient visits and hospitalizations. Lorig and colleagues argued that their data suggested a cost to savings ratio of approximately 1:4 (Lorig et al., 2001).

But what was the status of this evidence? In fact, self-efficacy did not shed its modalities easily. Critics of Bandura had argued early on that 'self-efficacy theory is conceptually problematic,' since 'the central concept of efficacy expectations is not unambiguously differentiated from outcome expectations' (Eastman & Marzillier, 1984: 213). Very similar criticisms were raised against the evidence base of the CDSMP. Thus, Brady (1997) argued that studies that purport to measure self-efficacy levels in relation to managing arthritis, in fact measure outcome expectations. But like Bandura's dismissive response to earlier criticisms, Lorig and Holman (1998: 155-7) argued that Brady had simply misunderstood the concept.

A number of additional methodological and analytical issues were also raised (cf. Lindsay & Vrijhoef, 2009). Taylor and Bury (2007) noted that Lorig attributed the positive effects of the self-management program to enhancement of participants' levels of self-efficacy rather than to obtained information or learning specific techniques. Several studies problematized the claim that the CDSMP leads to a reduction in the use of health care services (Gately et al., 2007; Greenhalgh et al., 2005; Lindsay et al., 2009). Finally, Greenhalgh argued that the randomized trials were based on carefully selected patients and biased towards white patients with health insurance (Greenhalgh, 2009)

As far as we are aware, none of these criticisms have had any significant influence on the subsequent development and testing of the CDSMP. Indeed, the fact that the program has generated vigorous debate

may have helped it to gain visibility and authority (Nielsen, 2010). In turn, this has vastly improved the ability of the program to travel. In the current perception of health care administrators and policy-makers, the program is indeed based on evidence (Danish National Board of Health, 2009). Evidence-basing the program allowed its developers to simultaneously present scientific credentials *and* use research articles as a platform for telling the story of the importance of CDSMP in multiple venues. As a testament to this strategy, a selected list of publication on the program's homepage in 2012 counted 70 articles and 11 books. Among them were articles and commentaries in highly esteemed medical journals like *British Medical Journal* and *The Lancet*. Thus, the efficacy of self-efficacy had been established.

Scripting Global Health Care

We have argued that a particular translation of self-efficacy theory into the CDSMP and a subsequent effort to evidence-base the program facilitated the ability of the program to travel. Now if evidence of effect is a crucial feature of the program, it is of central import to ensure that the program remains the same when it leaves the laboratory and moves into 'natural' health care settings. To understand this effort to *maintain identity*, we draw on Madeleine Akrich's (1992) analysis of the scripts embodied by technical objects. So how has the CDSMP been scripted?

As mentioned the CDSMP was developed as a collaborative research project between Stanford University and Kaiser Permanente. In 1997, The Garfield Foundation funded a 3-year process evaluation of the dissemination process (Lorig et al., 2005). Based on the results, Lorig and her team developed a number of recommendations for global dissemination

of the CDSMP. These were later turned into an implementation manual (Stanford, 2008).

The implementation manual contains a detailed description of all aspects of the program. It describes the process of training expert patients to run the program, and outlines how each part must be conducted and how patients should be selected and managed. Rigid adherence to this detailed script is required because it ensures that the program remains evidence-based no matter where it goes. Every minute of the course is organized using a 'Leader's Manual', which covers content as well as interactions between leaders and workshop participants.

The program is built around a hierarchy of certified trained leaders. At the top are the so-called t-trainers (trainers of trainers), who are allowed to teach and certify master trainers. T-trainers are educated by leading a master trainer course while receiving supervision from another t-trainer. Such trainers can only be certified at Stanford University. In the middle of the hierarchy we find master trainers. The master trainer is allowed to train patients who lead the program. In four-day workshops, the 'master trainer aspirant' leads a trained leader workshop and reflects on the purpose of each activity. Master trainers make it possible to sustain the CDSMP locally since they are allowed to recruit and certify trained leaders. Finally, at the lowest ladder, we find these trained leaders. At trained leader workshops every activity in the program is rehearsed by participants and master trainers.

Trainers are taught at the same time how to identify patients fit to join the program and patients fit to become trained leaders of the workshops. As regards the latter, the manual admonishes trainers to 'be a little cautious' about whom they encourage. Problematic types include persons whose 'main focus in life is their chronic condition';

‘people who are super achievers despite their chronic condition’ (exemplified by ‘people who have had an amputation and run marathons’), ‘people who are judgmental’, ‘people who have “found the answer” to their disease and want to share it with the world’ and people ‘too sick to teach effectively’ (Stanford, 2008: 7-8).

The second dimension of the CDSMP script is licensing. Although the CDSMP is meant for public use and benefit, the program is also for-profit. Thus, Stanford copyrighted its training program for leaders of the CDSMP. Before an organization can offer the CDSMP it must therefore purchase a license. The license establishes the legal obligations of the implementing organizations and protects Stanford’s intellectual property. It also enables Stanford to keep track of the network of all licensed organizations.⁴

In combination, these requirements and procedures instantiate the CDSMP script. The script packages together training of (patient) leaders inside a structure that facilitates a particular selection of patients via a licensing agreement that ensures that Stanford is able to control its global use. Each of these requirements is bound up with the need for the program to remain evidence-based, thereby enabling it to travel. Thus, self-efficacy, evidence-basing and scripting are all tightly interconnected. Together, they have turned the CDSMP into a globally travelling health care package. We now turn to consider how it travelled to Denmark.

The CDSMP Travels to Denmark

Danish health care is a so-called Beveridge-type system, which means that it is based on general taxation and covers all inhabitants. Most services are offered by public providers at the regional or local level. Access to a wide range of health

services is basically free of charge (Olejaz et al., 2012). Currently, a range of self-care and disease education programs form part of Danish national health services. They are offered by municipal and regional health care institutions and by patient associations (Danish National Board of Health, 2005c; Grøn et al., 2012). Among these, the CDSMP is presently the most widespread. In 2012, 71 out of 98 Danish municipalities offered this program. How was this astonishing coverage brought about?

In November 2005, the Danish National Board of Health sent out a press release, which stated that the board recommended the adoption of CDSMP as part of the national health system. It described the CDSMP as ‘a cheap and effective tool to secure the many hundred thousand Danish citizens living with a chronic condition a better life’ (Danish National Board of Health, 2005d).

Prior to this announcement, the board, in partnership with the Danish Arthritis Association and the counties of Copenhagen and Ribe, had conducted a pilot test with thirty-two arthritis patients. The purpose had been to determine whether the CDSMP was culturally acceptable in the Danish context, and to examine the appropriateness of the organizational set-up within the Danish health care system. In conjunction with the pilot test, managing doctors, nurses and occupational therapists participated in a number of workshops, where a representative from the Stanford Patient Education Research Center demonstrated the program. Also during this period, the official program course book was translated into Danish, and seven people were educated as master instructors at Stanford (Danish National Board of Health, 2005b).

The excitement with which the CDSMP was greeted was not unique. Indeed, at the start of the new millennium, self-care, self-monitoring, holistic patient trajectories

and patient education were much debated in Danish health care policy. The general context of these debates was the pressing question of how to strengthen national health care with a view to future challenges, especially the increasing number of chronically ill (Danish National Board of Health, 2004; 2005a; 2006). In 2003, the National Board of Health initiated the Public Disease Project, the goal of which was to develop an idea catalogue of disease prevention that would enable the integration of health promoting efforts and treatments. The CDSMP was selected as a test case and became one of the initiatives targeting patients suffering from muscular and skeletal diseases.

The idea catalogue lists a number of reasons for choosing to test the CDSMP (Danish National Board of Health, 2004). First, the CDSMP aligned with the above-mentioned political interests. Second, the use of experienced patients as workshop leaders and role models was emphasized as an asset. Third, this meant that the CDSMP was cheap: Apart from the cost of training patients to lead the program, and the purchase of the course itself, it required few resources. Finally, the program was described as effective, since it had been evidence-based. It was thus found to be implementable within the existing organizational structure of Danish health care.

Highlighting the effectiveness of the CDSMP, the catalogue pointed to the fact that the program was also used in many other countries. Indeed, the pilot group had visited both Norwegian and English health centres to gain first-hand knowledge of their experiences. The catalogue refers to the British experiences in very positive terms: the results included increased patient involvement, documented effects of better self-care, more physically active patients and less contact with the National

Health Service. Summarizing, the catalogue presented the CDSMP as a catch-all program, which would be effective across different chronic conditions and patient populations (Danish National Board of Health, 2004: 12-13). Shortly after the catalogue was published, the Danish National Board of Health purchased a CDSMP license from Stanford.

Global Standards Meet 'Cultural Diversity'

The CDSMP has travelled to countries as diverse as Denmark, Saudi Arabia, Japan, Australia and South Africa. As noted, the program is both sold and bought on assumption of its universality. Even so, the contexts in which the program will be put to use are not universal, but specific, often national. This relation between universality and specificity creates the potential for frictions. Frictions arise as the assumptions embedded in the program's script rub up against the expectations of its new users; it is a 'reminder of the importance of interaction in defining movement, cultural form, and agency' (Tsing, 2005: 6). From the point of view of CDSMP's developers, the aim is to maintain the global coherence of the program even as it travels. This is probably why the CDSMP are at pains to address issues of cultural appropriateness (Stanford, 2008). From the point of view of its users, however, the program has to somehow fit into a complex set of already existing health practices.

The CDSMP implementation manual takes a great deal of care to describe special considerations for working with the program in different cultural settings - as it is said: 'even your own.' The concept of cultural humility is used to designate an approach to cultural issues, characterized by avoiding stereotypes since: 'One size seldom fits all' (Stanford, 2008: 24). Even so the manual also insists that its program activities are:

designed to be as near as possible culturally neutral. This means that they are usually acceptable in any cultural setting as long as the leaders and participants are from the same culture (and sometimes socioeconomic status) and the workshops are offered in a site and at a time that is culturally acceptable for the population being served (Stanford, 2008: 23).

The manual gives examples of the smooth adoption of the CDSMP in very diverse settings. As an example it offers the case of First Nations People in Canada:

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

Strikingly, the 'necessary changes' among rural First Nations communities are very minor and strictly 'cosmetic.' In the Danish context, too, cultural diversity issues were raised and resolved with reference to cosmetic adjustments.

Circular Comparisons and Cosmetic Adjustments

As noted, the CDSMP was tested to determine whether the program was acceptable in the Danish context. The National Board of Health hired a private consulting company, Rambøll Management, to conduct the evaluation. The evaluation report provides an entry point for analyzing the traveling frictions and local comparisons of the CDSMP.

To determine whether the program was appropriate, Rambøll defined a number of indicators. They related to such themes as relevance, the quality of course materials and cultural transferability. The overall conclusion was that the program was indeed transferable and that patients with chronic conditions would benefit from it. However, despite the recommendation to disseminate the program in Denmark, the evaluation also indicated certain problems:

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

In fact, the report mentions several problems and challenges. Participants questioned different aspects of the program including its length, particular activities and

effects. However, each line of criticism is rebutted in the way illustrated by the quote. The recurring answer is that the program rests on many years of experience and has been thoroughly tested. Each criticism has been encountered before and is already taken into account. Readers are assured that the effectiveness of the program means that eventually 'resistance disappears.' This is a striking example of what we might term *circular comparison*. What is at issue is the question of cultural difference. When something resembling such difference is encountered, however, it is rejected because the program is already known to be globally effective. Since the program is solidly based on experience and evidence, there can be no truly important cultural issues. Therefore, there are no such issues. While differences are thus by no means overlooked – since they are explicitly discussed – they are analysed in such a way that they cannot help but be subsumed under the program's taken for granted universality.

An interesting example is afforded by the question of cultural applicability. Eight out of thirteen participants from the pilot demonstration in Ribe County in Western Denmark responded that they regarded some aspects of the program to be problematic. In comparison, none of the participants from Copenhagen had any similar reservations. The evaluation report interpreted these differences in the following way:

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

On the one hand, the report thus argued for the importance of ensuring cultural applicability. On the other hand, concrete questions or reservations were dismissed, or explained away, with reference to peculiar cultural tendencies, such as a 'generally sceptical attitude' said to characterize 'provincial participants' in contrast to the supposedly more internationally oriented Copenhageners. Eventually the report reached the conclusion that the only relevant 'cultural adaptation' was the removal of an activity where participants had to assign 'A durable power of attorney'. This requirement was found by Danish participants in general to be 'too American'.

In conclusion, the report reiterates the necessity of appropriateness:

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

The report does not elaborate what is meant by the 'American approach' but assumes the ability of Danish readers to recognize it. More importantly, however, the quote suggests that, whatever the American aspects of the program might be, they are located at an outer layer that can be peeled off. What will be left after such peeling has taken place is the core of the program: precisely that which is not American but universal. The National Board of Health accepted these arguments and concluded that the program could be implemented with only minor adjustments.

Eliciting Comparative Frictions

As far as Rambøll and the National Board of Health were concerned, Kate Lorig's perspective on the CDSMP was thus vindicated. In this interpretation, the Danish health care system and its patients may have a few distinct traits, but this does not subtract from the universality of the CDSMP. Rambøll's circular comparisons evoked no real frictions.

Yet some Danish patients engaged in different comparisons. In these comparisons, the qualities of the CDSMP approach were elicited, not as global and universal (with an American coating), but as distinctly *un-Danish*. In contrast with Rambøll's interpretation, these comparisons did bring to light frictions. In this section, we focus on a set of comparisons made by one critical patient participant. Of course, we do not think that this patient is representative of the views of Danish patients at large. We choose to engage in detail with this comparative statement because it offers a particularly vivid depiction of the frictions to which the CDSMP gave rise as it entered Danish health care. This is important, not least, because these frictions are so perspicuously absent from official documentation like the Rambøll report.

Here is what the patient told us:

Whoever has conducted it [the evaluation of CDSMP] has made a strong selection of patients. And that's what you have to be careful about because that is what is selling the program. I am quite critical about precisely that issue. Because you lose everyone else. You put this group of patients on a pedestal and say they are great, it's just the others that can't be bothered. I am being too crude but it [the CDSMP] requires so many resources. It definitely has in my case,

with this condition, and it is no joke. It really has taken a lot of effort.

This statement, we suggest, offers a sophisticated comparison between the embedded assumptions of the CDSMP and the Danish health care system. First, the patient accuses the evaluation of a selection bias. In this, she unknowingly repeats academic criticisms of the CDSMP (Greenhalgh, 2009). She then notes that the claim to 'catch all' patients is a matter of salesmanship. Her experience is that the program is not for everyone as it 'requires so many resources'. According to this participant, the program includes only 'elite' patients. At the same time, it individualizes blame for those unable to join by suggesting that they simply cannot be bothered. Doing so, the program risks 'losing everyone else', that is, losing the majority of weak patients. Pointing to the strongly individualized version of patient-doctor relationships enacted by the CDSMP, the description articulates friction between the program's universal claims and the realities of at least some Danish patients.

In addition, the statement embeds a comparison of the different institutional contexts of American and Danish health care.⁵ It defines the CDSMP as a zone of friction where different concepts of health care encounter one another. The individualized mode of interaction that undergirds the CDSMP exemplifies such a difference. Specifically, the participant's assumptions about the role of the health care system as a 'care taker' of sick citizens are challenged by the CDSMP. To reiterate, our point is not to judge the accuracy of the patient's view. Rather, the aim is comparative. Clearly, for this patient, the CDSMP 'produced a double vision' in which Danish and American health care environments 'were seen *at once* through their difference' (Morita, forthcoming).

Though the patient personally finds the CDSMP rewarding, her comment circles around the expectation that the health care system should be for everyone regardless of individual capacity. She complains that a program focused on self-management and efficacy is prone to lead to unequal health outcomes, privileging those who have sufficient resources to fulfil its obligations. In that sense, she articulates one of the central pillars of the welfare state: that the individual is never entirely free but always to some extent shaped by 'environmental factors'. If certain patients cannot be 'bothered' to join the program, this can be presumed to relate to their social position (cf. Danish National Board of Health, 2009: 87ff). Her critical remarks also make clear that the health care landscapes inhabited by patients (new or old) are moral ones. Pointing to the difference between welfare health care as it 'ought to be' and as it 'is becoming' with the introduction of the CDSMP, the comment points to the existence of social and institutional differences that are not merely cosmetic and that cannot be resolved by minor adjustments. These are differences in the relationship patients have to themselves, to the health care system, and even to society at large.

Unpacking this single quote has allowed us to glimpse a whole set of presuppositions, embedded in the CDSMP, about the relationship between patients and health care systems. An entire 'institutional analysis', which makes clear that the assumptions of the CDSMP are by no means universal, is thus wrapped up in this comparison. Reversely, the assumptions of the participant herself are *also* brought to light as a consequence of the distinctions she draws between her expectations of Danish health care and what the CDSMP delivers. In this sense, too, we are witness to comparison as a 'double vision', one that inevitably also has its own blind spots.

Traveling Frictions: Holding Together the Global and the Local

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

By now the CDSMP is a tightly scripted program that comprises a number of interrelated components. As a theory-methods package, it has succeeded in turning chronic disease management into a 'do-able problem' (Fujimura, 1987) on a worldwide scale. It is sold as a universal solution and it has global success.

We have shown that CDSMP's ability to "go global" was achieved by some very specific means. It involved transforming the program from an un-theorized, 'experiential' entity, into a theorized, evidence-based one. It involved constructing a detailed script which interrelated every part of the program in a standardized whole. Finally, this standardized solution was premised on the configuration of a new form of patient, who is individually self-possessed, 'self-efficacious' and capable of taking charge of his or her own health destiny. Yet to our Danish patient interlocutor, and to other critics of the program (such as those briefly mentioned, only to be dismissed, in the Rambøll report) this universal patient seemed to carry traces of its American context of development. The CDSMP, in other words, is at once global – since it has spread all over the world – and local – since its assumptions are by no means universally held. While packaging the CDSMP into a tightly interrelated whole has facilitated its dissemination, various components of the program were also contested as it travelled. Thus, we have highlighted some

of the ongoing efforts, and the continuous vigilance, required to maintain the program's global identity.

Outside of Stanford, a host of actors with different interests in, and interpretations of, the CDSMP became entangled with it. In particular, we emphasized how the program gave rise to a series of comparisons in the Danish context. Rambøll and the National Board of Health evoked a number of circular comparisons that downplayed issues of institutional or cultural difference. Looking closely at the critical and evocative remarks made by one patient participant, we elicited a different set of comparisons, which addressed the CDSMP from the point of view of its assumptions about the relations between patients and the health care system at large. Viewing the CDSMP as a technology, we were thus enabled to trace some of its travelling frictions. This analysis suggests that the program not only embodies a script; it attempts to transport an entire standardized context. It is precisely the discrepancy between this context and the Danish one that is articulated by the patient's comparisons.

As already noted, we do not claim that this comparison provides us with a basis for making general claims about the reception of the CDSMP among Danish patients. Indeed, even if the vividness of the comparison and its exemplary status in contrast with official views is granted, the scope of the analysis that we have offered might yet be queried. After all, the patient herself qualifies her interpretation as 'too crude'. The crudeness to which she refers is in the claim that the CDSMP unequivocally distinguishes between good patients, who are put on a pedestal, and bad patients defined by their laziness. The analytical crudeness that we might replicate in relying on this depiction is one that sees the CDSMP as wholly individualized in contrast with a wholly social Danish system. Insofar as we had traced in ethnographic detail the new

sociotechnical networks into which patients are spun, this black and white picture would quickly blur (see Nielsen & Grøn, 2012).

However, rather than taking this route, by now so routine in STS, we have aimed to engage these on-going transformations of health care systems and patients from the point of view of the comparative 'double vision' to which the CDSMP gave rise. While this has enabled us to trace some connections in the emergent networks of global healthcare, the central issues on which we have focused are different. In particular, our analysis raises comparative questions concerning why and how culture, society and institutions matter for health care initiatives – and, not least, for patients. So what does the trials and tribulations of the CDSMP teach us about patient 2.0?

Patient 2.0 as Fiction and Practice

As noted in the introduction, patient 2.0 is often defined in terms of the use of information technology for health purposes. The increasing availability of health information means that patients may gain a more active role in managing their diseases. This is said to reconfigure the role of patients, and empower them vis-à-vis doctors. As we have seen, a similar ideal of patient empowerment inspires the CDSMP and other self-management programs. Indeed, new forms of patients may be created by much more varied transformations of and in health care than those directly relating to the use of information technology. At the same time, our analysis allows us to pose certain critical and reflexive questions concerning the notion of patient 2.0. Thus, we note that arguments for patient empowerment via information technology and via self-management are premised on similar dreams of universality. 'The universal bridge to a global dream beckons to us' in both cases (Tsing, 2005: 85).

One way to understand patient 2.0 is to consider the term as describing a new form of patient that is emerging globally. This approach accepts that initiatives like the CDSMP produces qualitatively different kinds of patients. This is a claim that Kate Lorig and her colleagues would support: it is one they are already making (Stanford 2008). Yet it is quite insufficient from the point of view of social studies of health care and medicine, which must look closer at the frictions 'between aspiration and practical achievement' (Tsing, 2005: 85, see also Mol and Berg, 1998). For such studies, we need to focus not only on ideals and aspirations of health care but also on 'messy and surprising' practices (Tsing, 2005: 3). We are obliged to consider in much more detail whether, how, and how generally, new forms of patients are produced – and with what consequences. Only by doing so can we know whether self-management allow us to glimpse new and truly global forms of patients or, rather, bring us face to face with the emergence of groups of 'expert' patients that, while certainly new, are very specific (Nielsen, 2010).

Thus, we need to pay careful attention to the way in which the notion of patient 2.0 thrives on a rhetoric of generalization and universality. After all, there is nothing universal about the multifarious ways in which patienthood is enacted in different countries, cultures, or institutional settings. For the same reason, there is little reason to think that *any* concept, no matter how encompassing, can encompass all these diverse ways of doing health care. Thus, we conclude that adopting patient 2.0 as a guiding conceptual vision for social studies of health care and medicine is risky. In particular, it risks replicating on analytical territory the same kind of global dream that is embedded in the CDSMP. Reflexively, therefore, we are best served by viewing patient 2.0 as an analytical fiction. But of

course, if treated with care, fictions can be both powerful and generative.

Finally, then, our case also testifies to the emergent reality gained by the CDSMP's travelling package of theory, methods and practices. Indeed, it is particularly noteworthy that the program continues to generate universalizing health care futures (Jensen, 2010: 31-51) and travelling frictions alongside one another. The CDSMP emerges as a global health care platform not because chronic disease is really everywhere the same but because the program aims to recreate the same context everywhere and thus to turn chronic disease into the same global problem. The process through which this happens is also the process whereby a particular form of patient 2.0 may gradually become more universalized. Such processes deserve careful analytical, and critical, attention. Here we have argued that a focus on travelling health care programs, their frictions and comparisons, and the new forms of patients to which they give rise, can help focus our attention.

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- 3 Kaiser Permanente is an integrated health-care system that serves over 8 million members in the United States.
- 4 See <http://patienteducation.stanford.edu/licensing/>.
- 5 What is the "American context" of health care? We do not claim to know this in much detail. We do know that American health care delivery and financing is privatized to a degree unimaginable in Denmark. We also know that the question of public, not to mention national, health insurance, is politically fraught. But our task is not to compare and evaluate the "real" differences between Danish and American health care systems. It is, rather, to explicate how differences come to be experienced and articulated comparatively, when the CDSMP, perceived by some Danish patients to be distinctly American, becomes part of the Danish system.

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Notes

- 1 See www.expertpatient.co.uk.
- 2 This analytical strategy is similar to Michel Callon and Vololona Rabeharisoa's article "Gino's Lesson on Humanity: Genetics, Mutual Entanglement and the Sociologist's Role", where the authors grapple with the single case of Gino, a muscular dystrophy patient who refuses to understand the "lessons of genetics" (Callon and Rabeharisoa, 2004). Callon and Rabeharisoa offer this specific case as singular but *exemplary* (cf. Jensen, 2011); that is, as allowing them to address much broader issues of agency and subjectivity in medicine.

The Patient 2.Many: About Diseases that Remain and the Different Forms of Knowledge to Live with Them

Jeannette Pols

The emancipation of patients, their organisation and their participation in medical research and health care policy has expanded tremendously. With these successful attempts at participation, however, there is one problem that has so far hardly been articulated and seems to be unrecognized in conceptions of the Patient 2.0 as an informed and active patient. This is the assumption that there is only one kind of knowledge that matters to patients, and to which they can contribute: biomedical knowledge. The paper explores different kinds of knowledge that patients need to engage with in their life with chronic disease, and articulates a particular form of knowledge – patient knowledge – as a form of practical knowledge that patients use and develop in order to relate to medical knowledge and live their daily lives with disease. The analysis of a small webcam community of Dutch patients with an incurable lung disease will show that patients need to *translate* medical knowledge in order to make it useful to their daily lives, and need to *coordinate* health care aims with other aims in life. Rather than looking for ways to *legitimate* their knowledge, patients try out strategies that may *work* in specific situations, even if temporarily. The paper argues for a better support of the development of patient knowledge and the practices for developing it, rather than singularly equipping people with medical knowledge that is often oriented towards cure rather than towards living with a disease that will not go away.

Keywords: public participation in science, patient knowledge, patient organisations

Introduction

An emotional breast cancer patient on the news is angry about the investment activities of Pink Ribbon, the organization that tries to bring breast cancer to the attention of the public: 'Stop the pink violence! Instead support research to find out how metastases come into being and how we can prevent these

from emerging. And how we can assure that people no longer *die* from breast cancer! That is what we want to know, and the money simply is not spent on this.' In the same news item, a representative of Pink Ribbon responds that the improvement of the quality of life of breast cancer patients instead of research is the aim of the organisation.¹ (News broadcast, 16 November 2010)

The angry patient in the quotation represents a paradoxical change in the attitudes of Dutch patient associations towards medical science, particularly those organizations that are dedicated to funding medical research.² The quoted patient argues that finding a 'cure' is of central importance and criticizes an organization for aiming to improve patients' 'quality of life.' Quality of life used to be of central importance for patient organizations, in addition to representing the interests of their members, organizing support for them, and lobbying for improved care. Modern medicine, on the contrary, is, in this quote, invested with the potential to 'cure', whereas breast cancer is a particularly good example of how modern medicine does not cure formerly fatal diseases, but turns them into chronic ones.

In these new alignments there seems to be no disagreement between the research practices of biomedicine and these patient organizations, and neither do their tasks appear complementary. Quite the contrary, patients and their organizations have become quite successful in participating in agenda setting in biomedical research and in guiding its development – even if critical studies have expressed doubts about the *effectiveness* of their participation. Rabéharisoa and Callon (2002), for instance, show that different types of patient organizations provide different types of input (see below), while a systematic review on studies in the participation of patients in guideline development shows that the actual contribution of patient representatives is judged by the participants to be quite meagre (Bovenkamp & Trappenburg, 2009).³

The closer relationship between these often large patient organizations and medical research practices in their joint struggle for 'curing disease' has disadvantages. One of these is that the individuals with chronic disease who were formerly represented by patient organizations have

been transformed into terrifying – and sometimes even guilty – examples in the struggle to prevent others to become 'like them.' The lobbying attempts of these associations appear to be turning patients into undesirable presences by presenting their diseased condition as unacceptable, preventable or curable. They are not the target audience of the campaigns of these organizations; instead, the 'healthy' general public is (see picture 1 for an example).



Picture 1. COPD [a severe lung disease] is fatal. The text states: 'I have COPD. I used to crave cigarettes, now I gasp for air.' The image does not address COPD patients, but warns healthy individuals to quit smoking in order to avoid becoming COPD patients.

A related problem is that the public funds spent on funding (studies into) care and support for individuals with chronic diseases have decreased as compared to funds spent on research to 'find a cure.' As Moser (unpublished paper) has pointed out: millions are spent on research to develop treatments for Alzheimer's disease while

investments in initiatives and studies that aim to improve the situation of those who have to live with this disease are relatively modest. Although the chances of finding a treatment are slim, the utopian dream to eradicate Alzheimer's disease – and the fear to succumb to this condition – remain.⁴ In the meantime, everyday care practices in which people live with a chronic condition are understudied.⁵

This paper explores yet another disadvantage of the intimate involvement of patient organizations and the biomedical sciences, which is the implicit belief that only one type of knowledge is relevant to patients. This knowledge is typically defined as *information* that stems from biomedical research practices concerning treating and curing disease. Wider notions of the Patient 2.0, in particular policies on the 'expert patient' (Edgar, 2005; Greenhalgh, 2009) or the 'informed patient' (Henwood et al., 2003; Hart et al., 2004; Kivits, 2004; Lupton, 1997) in the UK, and on the Patient 2.0 in the Netherlands (RVZ, 2011; Frissen, 2011; Van der Clauw & Flim, 2011), reinforce this idea. In these policies, patients are individuals who should learn to manage their lives better with the aim of bringing increasing health care costs under control. It is expected that providing patients with (more) medical information and technologies will support them in these efforts. Self-management here means complying with doctor's orders, while assuming that there are no conflicts between medical regimes and daily life settings (Schermer, 2009), and that patients manage – and prefer to manage – their diseases alone.

Patients emerge in different ways as active participants in policy and health care initiatives (Barbot, 2006), and in the Netherlands even in official, government sponsored *professional* patient organizations. These professional organisations form one of the key

negotiating partners in developing health care policy, together with health insurance companies and care providers. This allows the government to step back from directing health care developments and make health care function as a 'regulated market' (Bovenkamp & Trappenburg, 2011; Bovenkamp, Trappenburg & Grit, 2010). Knowledge, in these discourses, is either taken to be of no interest to patients (rather, their demands and preferences are) or as identical to medical knowledge.

Multiple Knowledges and Patient Knowledge

The issue I aim to explore in this paper is how patient knowledge can be articulated as a form of knowledge amidst the multiplicity of forms of knowledge within medical practices and to argue for the need to better develop and share it. In her now classic account, Annemarie Mol (2002) has demonstrated how different forms of knowledge are present within biomedicine. One could think of genetics, physiology, and anatomy to understand these different forms of knowledge or 'epistèmes' as differences in framing objects of knowledge by enacting them within the particular practices and conditions (methods, concepts, technologies, laboratories). In this paper I aim to add to this variety by outlining what the knowledge of people living with a chronic disease or handicap might entail in relation to other forms of knowledge, and to argue for its development. What is patient knowledge, how does it relate to other forms of knowledge, and how can it be made useful to people with chronic disease?

Intuitively, it is obvious that people who live with chronic disease possess knowledge needed to do this. However, this knowledge is hardly studied in academia and is not widely available to people who might benefit from it. What *is* known is that

people rarely do what their physicians tell them to do. Rather than interpreting this as patients being ‘incompliant’ (un-foldable), the concept of patient knowledge helps to demonstrate why it may be perfectly reasonable for patients not to follow the doctor’s orders. Rather than accusing patients of non-cooperation or sabotage, my analysis might lead to more constructive ways of negotiating treatment options. The critique on incoherence is nothing new (see e.g. Strauss, 1984; Willems, 1992), but I will attempt to add to the understanding of this critique by articulating that what people with chronic disease bring to the table can be understood in terms of *knowledge*.

To explore this, I will analyse how the understandings of patients have been conceptualized in relation to the biomedical sciences, and report some findings of an ethnographic study into a small community of Dutch people with Chronic Obstructive Pulmonary Disease (COPD) who organized themselves with the use of webcams. Through these webcams they discuss matters relating to their disease and daily lives. I will show how the knowledge they use and develop can be conceptualized as a form of practical knowledge that people use to *translate* knowledge from different sources (such as medical knowledge) in order to make it useful in their daily life, and how they need to *coordinate* this knowledge with their other tasks and goals. This means that a Patient 2.0 does not only have the task of gathering ‘knowledge about his or her condition,’ but that s/he has to deal with different and at times conflicting types of knowledge while putting in effort to make these types of knowledge useful to their daily practices. The metaphors of translation and coordination show how ‘patient knowledge’ is different from ‘medical knowledge,’ although the two are not mutually exclusive.

Sameness and Difference

How can patient knowledge and medical knowledge be different but not exclusive? One way of exploring this is to trace how they *are* often taken to be mutually exclusive. This has to do with the division of labour between the social sciences and the humanities on the one hand, and medical knowledge and biology on the other.⁶ Roughly speaking, the humanities represent patients as subjects who give meaning to their illness and articulate narratives about it, which has previously also been discussed under the broad category of ‘knowledge of experience.’ These meanings and experiences emerge when they *diverge* from medical knowledge, or they would not be patient interpretations and observations, but *patient expertise*, showing patients who have become proto-professionals in medical thinking (Pols, 2008).⁷

Medical science, on the contrary, is assumed to study patient bodies and diseases as objects of medical interventions. It studies material and causal relationships and tests medical interventions to learn about their probable workings. Hence, culture and nature seem to be part of mutually exclusive domains. In such a dichotomy, patients have no knowledge about bodies, whereas the medical sciences have no space for narratives. This paper joins the critical analyses that question this divide by studying *practices* rather than accounts *or* bodies (Mol & Law, 2004; Pols & M’charek, 2008; M’charek, 2010; Mol, 2002; Pols, 2012).⁸

What does this mean for understanding patient knowledge? Vololona Rabéharisoa and Michel Callon distinguish three types of *concerned groups*, patient and family organisations that actively engage with biomedical research to change their situation and social identities (Rabéharisoa & Callon 2002; Callon & Rabéharisoa,

2003; 2008 Callon 1999; 2005). The first one consists of *auxiliary groups* (Rabéharisoa & Callon 2002). These are Epstein's (1995) 'lay experts', De Swaan's (1988) proto-professionals, and the patient associations I mentioned earlier. These groups consist of patients who are thoroughly socialized in the vocabularies and habits of medical scientists. The authors point out the limits of the influence of these auxiliary groups. They may either *delegate* research to scientists, or *participate as equals* by acquiring academic expertise. This leaves the auxiliary groups without anything authentic or substantial to contribute once the scientists start conducting their research. They do not challenge the 'paradigms' of biomedical research or add additional knowledge or insights. When the knowledge that patients bring to (medical) science does not differ from the knowledge that scientists produce, it becomes redundant for the production of this knowledge after research agendas have been set.

The second group Rabéharisoa and Callon (2002) describe is the *oppositional group*, which is not significant for their project. This type of group is not a concerned group that wants to *interfere* in scientific practices. Instead, they find different ways to help themselves or stick to uttering protests. However, when the concern is not 'influencing medical science' but a curiosity for different types of knowledge, it is a very interesting group for studying what these groups claim is useful knowledge to patients and to learn about its differences with the knowledge medical science has to offer. For instance, work has been done on diseases not recognized by medical experts (e.g. RSI in Arksey, 1994 and endometriosis in Whelan, 2007) and on diseases for which patients find medical knowledge and interventions unhelpful (as some 'mental health care survivors' claim, see e.g. Mowbray et al., 1998). These scholars describe patients as

forming more or less coherent epistemic communities or communities of practice (Whelan, 2007; Akrich, 2010).

Rabéharisoa's and Callon's (2002) third group, for which the association concerned with Muscular Dystrophy they studied is the exemplar, is the *partner association*.⁹ Characteristic for these groups is that they have knowledge of their own that they bring into play within the scientific practices they interfere with – or even help establish. They are the 'experts by experience', who formalize and organize collective expertise to produce a type of knowledge that is just as objective and authentic as that of medical specialists, Rabéharisoa and Callon argue.

In the partner associations there is a difference between the knowledge of the concerned groups and the knowledge of scientists; they are *complementary* knowledges (Callon & Rabéharisoa 2003: 196). But, given these differences, Callon & Rabéharisoa also argue that there is no intrinsic (2003: 169) or fundamental difference of status (2003: 197) between both kinds of knowledge. The people with chronic disease may use 'proto-instruments' for doing 'research in the wild', i.e., outside of the walls of laboratories, but this wild research is comparable to laboratory research in the sense that experiments are done, instruments are used, interventions are evaluated, while knowledge is accumulated, debate takes place, and results are written up (Callon & Rabéharisoa, 2003: 197-198).

How to understand sameness and difference here? Are there different forms of knowledge, different yet comparable as primitive methods? Do researchers in the wild ask different questions while developing knowledge that is equally valued? Or do they ask the same questions, but in different ways and spaces of production? Is experience medicalized, untouched, or both? Callon and Rabéharisoa (2002; 2003)

do not actually *show* their readers what the knowledge of the organization they study consists of and how it is produced. That there *are* differences is obvious, or concerned groups would cease to be influential in the production of knowledge. In this paper I want to learn more about the *particularity* of the knowledge present in the practices of people with chronic disease and disability, avoiding both the pitfall of harmoniously synchronizing their knowledge to scientific knowledge, and of opposing them by making patient knowledge so different that it drifts out of the realms of what one may call knowledge. Insight into this particularity may be helpful if patients are to have a more creative role than raising alarms and being the watchdog of the medical sciences.

Case Study: The Community of People with COPD

I will analyse one case study as a starting point for exploring patient knowledge. The case is a small community of Dutch people suffering from severe Chronic Obstructive Pulmonary Disease (COPD). COPD is a progressive lung-disease known by many as 'lung emphysema', with mine-workers, smokers, and workers in the chemical industry as the most common victims. The lungs increasingly lose their elasticity and sufferers run out of breath easily on exertion. The more severe the disease, the fewer possibilities remain for patients to move about, and some individuals hardly leave their couch at all (Habraken et al., 2008).

The patients I worked with were in a rehabilitation clinic for COPD where they stayed for a three months program, or I met them after they had just finished their three months in the clinic. Some of the patients who had returned home became friends and stayed in touch with each other using the webcams provided by the clinic.

In the clinic, patients were trained by a multidisciplinary team of professionals. They had physiotherapy classes, did sports, learned to use tools like walkers and mobility scooters, went to psychology sessions, and so on. The goal was to make people live with COPD in a better way. I conducted fieldwork and interviews over a period of six months in the rehabilitation clinic, talking to patients, carers, technicians, and managers, and attended meetings and training courses in computer use. I also followed one patient on her days in the clinic while visiting different professionals. I conducted in-depth and auto-ethnographic interviews with seven professionals and 11 patients at their homes, where I found out about the existence and the workings of the webcam community. Auto-ethnographic interviews are interviews in which the researcher asks the respondents to observe their own practices, foregrounding what they *did* next to what they thought or felt (Pols, 2010).

Patient Knowledge

The analysis gives some examples of the kind of knowledge practices the people with COPD developed to run their daily life. To frame this, I build on the work of Georges Canguilhem (1968) and Michel Foucault (1973) (see also; Struhkamp et al., 2008; Greco, 2008). Canguilhem contrasts *clinical knowledge* used by clinicians for treating patients and *laboratory knowledge* produced in the laboratory as two *épistèmes* (forms of knowledge) that are shaped in scientific and clinical practices, each with their own object and socio-material conditions for crafting this object. Being out of breath, for instance, is a different object in the laboratory than in the streets (Barbot & Dodier, 2002; Pols, 2011b). I will explain the theory along with the analysis of the fieldwork examples when I explore the relationships between medical

knowledge and the everyday practices of COPD patients.

Translation

For Canguilhem (1968), the laboratory stands for the medical knowledge that is scientifically produced, using methods agreed upon by – since Canguilhem: multiple¹⁰ – medical scientific communities. Scientific practices aim to generate knowledge about the way bodies behave in particular conditions. The clinic, on the other hand, stands for knowledge developed by clinicians who treat individual patients. Their knowledge is experience-based, and is fed from various sources, such as scientific knowledge, medical tests, patients reporting trouble, and so on. It is constantly shaped and re-shaped in practice – it is tinkered with (Mol, 2008; Mol et al., 2010).¹¹ This also applies to patient knowledge, the patients' equivalent of clinical knowledge, but the aim and the way this knowledge is used is different. It is aimed at living daily life with disease or disability in a good way. What this 'good' entails is highly dependent on the contexts and the aims of individual patients, as I will show, as well as on their use of medical technology and scientific knowledge. What is important is that, in order to make technology and scientific knowledge useful, patients have to *translate* it. They have to make it practical. As an example, I relate the case of Mr. Hansen:

Mr. Hansen says he was admitted to the hospital regularly and he has a supply of prednisone and antibiotics in his closet, so he may start treatment quickly when it is needed. When he is admitted, he is put on a drip with corticosteroids and antibiotics immediately. He tells me that his last admission was three years ago. He says: "The most important thing

is not to panic when I get out of breath. That helps you a long way.'

Mr. Hansen has assumed his physician's task to decide when it is appropriate to take antibiotics. In theories of self-management this may be interpreted as Mr. Hansen having obtained professional knowledge, and having become a proto-professional or expert patient, using the knowledge and know-how of professionals on the workings and use of antibiotics. And indeed, Mr. Hansen knows: 'antibiotics cure inflammations.'

From a perspective of practical knowledge, however, Mr. Hansen has different concerns. He has developed a way of knowing that is specific to the situation he is in. He needs to find out *when* he has to take his medications, and if he has to take them *now*. To explore this, his breathing is both an instrument that should be attuned for obtaining knowledge (he should not panic in order to find out what is wrong) as well as the object of knowledge (is his breathlessness caused by inflammation or something else?). Not panicking could be the intervention as well (not panicking may be the proper way to stop being out of breath). When he finds out the likely cause of his breathlessness he needs to decide if he needs medication or whether other strategies are possible.

The distinction between medical expertise and lay knowledge loses its salience here, although one could say that Hansen engages in practical ways of knowing that came from the expertise of his physicians. When articulated as a proposition ('antibiotics cure inflammations'), this knowledge is abstract. For Mr. Hansen, however, it has become *embodied* knowledge that has been transformed into a lived practical knowledge that may tell him whether he needs antibiotics *in this situation*.¹² This is a translation from clinical concerns with

antibiotics (what is in it, what does it do, and for which symptoms) towards practical ones (do I need to take these pills now, is this the proper situation for doing so?). Mr. Hansen cannot use routines, skills, or rules of thumb, but has to explore open questions every time breathlessness strikes (what is going on, what can I do).

Note that it makes sense to speak of different bodies here. The laboratory body present here is about the inflammation of lung tissue that produces breathlessness. The solution for this body is to feed it medications that cure the inflammation. Mr. Hansen's body at home is a body that may panic when out of breath, making it unable to diagnose itself while anticipating the worst scenario. Here, the remedy is to become calm. Also at home, Mr. Hansen has to find out what caused his breathlessness in this particular situation, as there may be different reasons for being out of breath. There is also a body that is shared by Hansen and his clinician, which is a body that is generally in doubt about the need to see the doctor or not. A 'bag of pills' at home is the preferred option over having patients like Mr. Hansen see his GP when in trouble, guided by the idea that Hansen is able to treat himself more promptly on his own initiative.

Palen and Aalökke (2006) describe patients who need to take different types of medication regularly. They show that these patients are not particularly concerned with the exact nature and working of every pill they take anymore. They translate 'pills for high blood pressure and cholesterol' into a task of *remembering* to take 'the blue pills thrice a day with the meals, and the white ones two times, but not with the meals, yet with milk'. They try to do this without turning their home into an open medicine cabinet by leaving visible cues for all visitors to see. They creatively invent material cues: they put the medications with the breakfast

items, store the pills in different places and sequences in order to remember to take them. Hence, they translate medical remedies and technologies into practical and workable strategies within their daily socio-material practices. One may analyze this as the creation of material memories, distributed cognition or the workings of the extended mind (Bowker, 2006; Hutchins 1995; Clarke & Chalmers, 1998), here, to make the environment take part in memory work.

Coordination

The practical knowledge of patients is aimed at living everyday life with disease or disability in a good way, where what is 'good' needs to be established locally. In their daily practices, taking care of their disease is only one of the concerns these patients have. They need to combine care for their condition with other matters of importance. Apart from being ill, people are also parents, employees, partners, and so on. Even though the laboratory, the clinic and everyday life may not be in opposition to each other, they are not the same either (Strauss, 1984; Willems, 1992). They need to be *coordinated*.

Interviewer: What did you learn in the clinic?

Mrs. Yildirim: Well, my family, eh. [laughs] To divide my energy, particularly with the kids, and also my domestic work. Because, you see, I always love my house being tidy and clean, *too* tidy and clean sometimes. And I know that, that when I have a bad day, that I should say: just look through the mess. And when the next day arrives, when I feel well again, I should not try to do everything at once, but keep dividing the work into small chunks. And with the kids too, I have to make it clear to

them: this is what mum can do. And yes: because mummy is short of breath now, mummy cannot, cannot do things.

It is not Mrs. Yildirim's body that is the object of doctoring. It is her love for 'tidy and clean,' and for the tireless kids who want to play continuously. She needs to find ways to coordinate these matters and has to develop knowledge, skills and talent for improvisation in concrete situations. The household as well as the upbringing of the children had to be re-arranged. A clear distinction between professional and lay, or medical and non-medical concerns does not do justice to the complicated mixture of relevant variables that need to be coordinated and reorganized here. Lungs, children, love and norms of cleanliness all play a part.

Patients reported yet other problems to deal with, such as relinquishing work, difficulties and guilt feelings of involving one's spouse, the sudden depression that emerged from having to face a life very different from the one imagined before, and so on. The patients had to coordinate these matters by developing practical knowledge about them, often without professional advice to help them do so.¹³ They need to coordinate different matters of concern, to set priorities and weigh different goals against one another in order to formulate an acceptable course of action. And this is not always what the doctor would think is best, or rather, this constitutes a situation in which a creative clinician may support imagining solutions. The love for a tidy and clean household may be just too strong.

Legitimation

Another difference between the 'épistèmes' of scientific and clinical (professional) knowledge is the way in which knowledge is legitimized. The knowledge of Evidence

Based Medicine, for instance, provides statistical evidence to show the probable workings of particular treatments for specific groups of patients. Clinical knowledge derives its authority and reliability from the experience of the clinician that is built on a great number of observations on the way patients react to treatment and advice, as well as on the ongoing process of observing, intervening and evaluating *this* particular case. Does the patient improve? If not, what else could be done? Clinical knowledge is about tinkering and adjusting treatment and care for individuals, not about finding general evidence.

Tinkering is also part of the struggle of patients trying to deal with disease in their daily life practices. Their knowledge practices are about *improving* their situation, rather than proving that certain facts are true or effects probable (Mol, 2006; Moser, 2010). They need feasible individual strategies rather than probabilities for populations.

Mr. Torenstra: With working it is even more difficult. When I was present at a meeting on a building site, I sometimes just stood there to watch things. And these things did not interest me in the least, if I may say so, but I needed air so badly that I would just stand somewhere to look at something with great interest. To not show your colleagues that you were out of breath. So I often came in when they were finishing their third or fourth cup of coffee. And well, at a certain point, this does not work anymore. [his face drops and the mood shifts to sadness]

I: Then you had to relinquish work. Jeez.

R: Yes, that is quite a blow, really. That ... erm, yes ... Because you think you have lots of friends, but if you are out of a job, very little remain, really [laughs].

Torenstra's strategy of using breaks for studying his environment to mask his breathlessness worked for some time, but when the situation changed, it failed. Gazing at things is not a strategy that needed proof of its probable working, but can be tried out and used temporarily. Evidence-based remedies are backed up by research, but may not work in individual cases. 'Practicing patients' have to tinker with new strategies when the old ones become obsolete. A good (legitimate) strategy here is a strategy that *works* in the setting of a particular situation, and patients find out if it does by trial and error. What 'works' may be considered in different ways, for instance by weighing short term goals with long term goals, or health gains with other concerns. There rarely is only one strategy available. Alternatives need to be considered and may also be acquired by practice.

Physiotherapy session: The exercise is to pick up a small sandbag that lies on the floor while standing. Not putting the feet right next to each other helps: taking a step provides more stability. Then move the upper body down, bend through the knees, use support from a wall if possible. Two women grumble that support is not often readily available. 'You can also ask someone to pick up something for you.' the physiotherapist says brightly. The women snort: 'They will look at you: are you crazy?!' 'It's not written on your head that you have COPD.' It is pretty clear to me that they do not consider asking for help as a valid option.

What used to be a very simple task has become a difficult thing. There are different ways to deal with these difficulties, each bringing new complications. To get something from the floor may demand agility, but one could also ask for a helping hand, which implies a very different way to

deal with the situation. These are among the different technical and social abilities one has to learn in order to deal with the situation, and may demand help from different resources and the training of different skills: to learn how to bend down in a better way, or to ask somebody for help. If one has trouble conquering stairs, one may take them in tranches, invite people to one's own stair-less house, take extra medication, or stop seeing stair owners. This is something patients have to figure out in each new context they are in –taking temperaments and norms into account.

Organizing Knowledge Practices: Caring Communities versus Managing Individuals

Knowledge to deal with disease may be used and developed by individuals. However, sharing experiences in a group of experts with the same type of bodies makes the development of knowledge much easier. Some of the COPD patients in my study formed a community through their webcams after leaving the rehabilitation clinic. They provided each other with support, providing advice and getting some in return. At times, they talked 'just to have a chat' or cheered up a friend who had a bad day. In this way, they provided each other with distraction, but also with knowledge.

Mrs. Jaspersen: 'She [the webcam friend] told me some crazy things. She said that when she gets out of breath, she puts two chairs beside her own, one to the left, one to the right, and then she puts her arms on the back of the chairs.' Mrs. Jaspersen looks at me slyly, as if daring me to challenge her. Having convinced herself that I am interested, she adds: 'You know what? I tried it and it really helps me too!' Mrs. Jaspersen points out how she has pre-set the

chairs inconspicuously around her dining table so that she can quickly take up this position by only moving one chair. Dragging furniture around is not easy when you are out of breath! The arrangement has to be subtle; there is no other option when one wants the house to look spic and span at all times.

The example demonstrates how advice was exchanged and strategies refined. These kinds of practical solutions of easing breathlessness were typical for these patients. They could not be found on the internet, but demanded active 'clinical trials' by the patients. However, their findings did not travel outside this specific circle of friends and hence remained unknown to other people with COPD – and their professional caregivers

Patients also helped each other assessing what might be the matter in particular situations, foregrounding the activity of knowing rather than the exchange and development of techniques. They did this in various ways. For instance, they knew their friends well, and could see if something was wrong with them by looking at changes in their familiar appearance on the webcam. They noticed something was wrong even if the person did not report trouble verbally. They also used their bodies as diagnostic instruments for each other, by sensing if there might be reasons for being breathless other than inflammation of the lungs, such as low air pressure, pollution or panic. They used each other's bodies and experience to assess if they were dealing with a change in the weather, or whether it was time to go and see the doctor or take medication. Together they tried to figure out what was wrong and what strategy would fit this particular diagnosis.

Mr. van Leeuwen: The contact with my fellow patients is really nice. There's

always a night when you wake up short of breath, things are not working out, and then you think: Is this me, is it my illness, or what? If you can talk to another patient, and he or she feels just as bad, then you think: Well, I'm not the only one suffering today. Then it turns out that there is a storm depression coming or weather like that. That has the same effect on you as going up a mountain: less air pressure. If your breathing is bad and there's less oxygen in the air, you notice it right away, definitely. And then you see: Well, it's not just me.

With their practice, patients showed that self-management, as a way in which well-informed individuals manage their own life with the help of up-to-date medical knowledge and technologies, is not a model that fits the situation of the COPD patients. It is no fun to have a chronic and progressive disease. It helps if one can talk to knowledgeable others – experts – for advice when in doubt. The relationships in which one is not only a patient asking for help, but also a person caring for others, is motivating and rewarding, and is different from the a-symmetry of a professional caring relation. It is much easier to consult a friend when one is not sure if there *really* is something wrong. And it is also different from having to figure out things for oneself. The exchange and development of practical knowledge is facilitated by participating in a community of *patient experts*.¹⁴

Problems with Organizing Practices of Patient Knowledge

The Patient 2.0 as an active patient with unlimited access to *any* kind of knowledge and groups of people to share experiences with on the internet does not exclude the development of practical

patient knowledge. The internet allows for extensive networks and freedom to connect to and build communities that may be useful and rewarding to participate in. These communities do, however, develop different types of knowledge as well. The way of 'collecting data' through websites such as 'patientslikeme.com', or the collection of narratives on sites like www.patientervaringsverhalen.nl (patient experience stories) is very different from the articulation of active practices of knowing the COPD patients had organized, a form of knowledge development and exchange that is also common in smaller patient organizations. My suggestion is to articulate this latter form of knowledge or epistème of practical patient knowledge in order to make it available for others and stimulate its development. One way to do this would be to make it easier for patients to get organized, with the internet and webcams as possible tools to do this.

However, my research into webcams in a home-care setting also demonstrated that it is difficult for people to find ways to get organized. Patients experience webcam contacts as intimate contacts; they are not prepared to call 'just anyone in the phonebook'. Good relationships and friendship turn out to be a prerequisite for individuals to connect with each other through webcams. Sharing the same disease is not sufficient to connect to someone else, face to face or through webcams.

Mrs. Quest: I'm seldom in touch with the others [COPD patients, by webcam]. I don't have time, I don't really feel like doing it. What would you get? You'd both go: 'Oh, I suffer this or that, I've got pains in my arms and legs.' And then I'd think: I don't want to know, and they don't have to know this about me. Sounds crazy, maybe, but I don't want to burden other people with my ailments. These people

[others in the project] have COPD too. And if they said: 'Oh, I'm so out of breath and I need my inhaler!' Well, same here, but why tell everybody about it? Who needs to know? That's what I think, at least. Maybe others think it is wonderful to discuss that together. But as for me, so far, I don't need to know about other people's sufferings.

For communities assisted by ICT (or not) to emerge, creative strategies were needed to bring people together. This organization of communication needs more effort, interest and research, but it may prove to be a good strategy. People may exchange and develop practical knowledge and find this more rewarding than merely asking and receiving care from professionals or attempting to 'manage' their condition by themselves. This also fits the recent policy concerns about how to care for an aging population with a decreasing number of carers. It may be a worthy task for patient organizations to take on.

Sharing Knowledge

The small community of Dutch COPD patients constitutes only one case study. More analyses of different patient groups, using different technologies, is needed to draw both more general and more specific conclusions on what epistème can be called patient knowledge – and how many epistèmes there are. Some conclusions are already clear though. The COPD patients showed that medical knowledge from laboratories and clinics are part of their repertoire, but that people with chronic disease have to translate these knowledges and coordinate these with the different goals they have in life. Patients are not looking for a legitimation in the form of statistical evidence to test their home-made solutions. Instead, they need strategies and techniques

that *work* in their particular situation, here and now. These strategies may be of a (well-researched) medical nature or come in the guise of a suggestion to push around chairs.

The idea that patients manage their disease on their own proves to be erroneous and undesirable. People do not become alone when they become ill; they have family, friends, fellow patients, employers and others to deal with and to learn from. The COPD patients in my case study were often scared and insecure, and enjoyed to get advice and support – and provided it in return. They (we!) are socially and materially embedded individuals, not individual managers of individual lives. The technologies provided to us may support and expand on this sociality by organizing patients (e.g. through the use of webcams) or restrict this sociality by imagining care as a matter of individuals receiving cure and managing their lives.

Because of the need for a particular type of practical knowledge to support a life with disease, it is important that this knowledge does not get stuck locally, but can be practiced and shared with others. This would be a worthy task for patient associations. Rather than focusing only on biomedical research to find a cure, they may stimulate the systematisation, development, and sharing of patient knowledge needed to live with chronic disease as well as the organization of practices to do this. Scientists other than biomedical researchers might be engaged in this work: ethnographers and other social scientists, maybe nurses and physiotherapists, patients who are researchers, clinicians who understand what it means to live with disease, or mixtures of these.

Patient organizations could also engage in their classic task of organizing people with chronic disease, to provide breeding grounds for patient knowledge. There is a

task for health care practices here as well. The organization of care for people with chronic diseases in groups would mean a shift from the understanding of disease as a concern for individual bodies only. This would provide people with chronic disease with places to meet and would facilitate the formation of supportive networks. Technologies like webcams and the internet can be mobilized to support caring communities and shape the Patient 2.0 as someone to share and develop practical knowledge with. This requires – at least for part of the time – letting go of the dream of cure and its paradoxical appeal to demand attention and money for something that cannot be done away with. Chronic disease is here to stay – people will have to appreciate the limits one faces when one has a chronic disease, but they can also be encouraged to creatively explore the *possibilities* that emerge for living with chronic disease in a good way. Developing and sharing knowledge and learning to relate different forms of knowledge might be just the thing for Patients 2. Many.

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- 5 But see recent studies in care for examples how this may be done: Mol et al. 2010; Mol 2008; Mol & Law 2004; López & Domenech 2009; Winance 2006; Moser 2010; 2011.
- 6 There are of course 'disciplinary trespassers', such as Foucault 1973; Jonsen & Toulmin 1988, Toulmin 1976; Shaikh et al. 2008; Schmidt et al. 2007; Potofsky et al. 2011, but there is no research tradition into clinical knowledge that is part of the medical curriculum. Clinical knowledge is transferred through 'bedside teaching', classes and case histories, but it is not a discipline in (medical) research in itself.
- 7 For an extensive review of the vast literature on patient experiences and the relation to knowledge, see Pols 2012b.
- 8 Foucault has eloquently criticized this division in the 'Birth of the Clinic' (1973), see also Osborne 1992 and Pols 2012, ch 2.
- 9 Michel Callon described another variety between the auxiliary and the partner association in 1999: associations that do not change scientific work, but enrich results with the richness of local and concrete situations.
- 10 As I mentioned, Mol (2002) and others showed how laboratory knowledge may be understood as multiple.
- 11 Tinkering comes from the French term 'bricolage', coined by from Lévi-Strauss 1966, but see also: Prior 2003; Barbot & Dodier 2002; Hester 2005; Mol et al. 2010.
- 12 Elsewhere I called this form of knowing 'know-now', to signal the situated and semiotic nature of this active way of getting to know things (Pols 2012b). It differs from 'skills', because it is never completely automatic.

Endnotes

- 1 See <http://nos.nl/artikel/314030-pink-ribbon-gaf-18-procent-aan-onderzoek.html>
- 2 The big funding organisations are, for instance, for cancer, cardiovascular disease, and recently: COPD and Asthma. Other large patient organisations (e.g. for diabetes) are engaged in developing 'standards of care', engaging, so to speak, in doctors' tasks.
- 3 See also the special issue of STHV on these matters edited by: Kontopodis, Niewöhner & Beck 2011.
- 4 The sociology of expectations shows how the sciences expand not by referring to matters of fact, but by cultivating hope (see Brown 2003; Brown & Michael 2003; Borup et al. 2006).

- 13 Habraken et al. (2008) show that many Dutch COPD patients do not get help with these kinds of daily life questions. They see the pneumonologist once a year, and when they are lucky, a COPD nurse every four months. It depends on the GP whether he or she will be of assistance here, because the patients usually do not ask for help. GP's may feel they have little to offer, looking at medical solutions that are lacking, rather than coaching patients in daily life problems.
- 14 As a contrast to *expert patients*, patients who have medical expertise, *patient experts* possess knowledge on the practical concerns of living with disease.

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Jean-François Blanchette: Burdens of Proof: Cryptographic Culture and Evidence Law in the Age of Electronic Documents
The MIT Press: Cambridge and London, 2012. 264 pages.

In *Burdens of Proof*, Jean-François Blanchette examines the development of digital signatures, and the associated attempts to integrate them into evidentiary regimes. As such it is a welcome addition to our understanding of security technologies, given the somewhat triumphalist accounts of the development of digital signatures and their cryptographic underpinnings in the popular literature. It also chimes well with an emerging literature that is critical of cyber-utopianism and the hubris often encountered in discussions about the transformative power of the Internet.

Similar to the way written signatures are used to ensure the authenticity of paper documents, digital signatures are technologies that can be used to ensure the authenticity of electronic documents. This is achieved through the use of public-key cryptography. First proposed by Stanford computer scientists Whitfield Diffie and Martin Hellman in 1976, digital signatures have since been seen by many as crucial to the successful realization of electronic commerce, the paperless office, and more generally, the information society. However, integrating digital signatures into legal frameworks designed to consider written evidence has proved difficult. Similarly, other promised developments based on public-key cryptography, such as electronic cash, have largely failed to materialize. In *Burdens of Proof*, Blanchette aims to shed light on digital signatures' "failure to perform", and in doing so, provides one of the first sociological books to offer a detailed

examination of modern cryptographic technologies.

Blanchette makes three overlapping arguments. Firstly, that the characterization of cryptography and digital signatures as fundamentally immaterial has made their translation into hardware and software artefacts problematic. Secondly, that attempts to mathematize certain areas of cryptography, with the aim of providing provable security, have marginalized areas of research that, although resistant to mathematization, can deliver a greater social impact. Thirdly, that the way in which cryptographers have modelled digital signatures has served to obscure the trade-offs inherent in producing cryptographic technologies that are to function in the real world.

Much of the evidence for these arguments is drawn from the attempts by the French legal system to integrate digital signatures into their evidentiary regime. Blanchette is particularly well placed to describe this, given that he was a member of a French Ministry of Justice task force charged with providing guidance about digital signatures to the French courts. Blanchette focuses on specific examples, such as the introduction of the *Réseau Electronique NotariAL* (REAL) electronic notarial system. In this case, the models on which digital signatures were based, concerned as they were with highly technical or mathematical attacks, did not map well onto the primary requirements of the system, which included the physical presence of the notary, and long-term integrity and legibility lasting 100 years.

According to Blanchette, requirements like these evolved alongside the paper-based materials used to realize them. Although many have moved away from John Perry Barlow's 1996 claim that, in cyberspace, "... concepts of property, expression, identity, movement, and context do not apply", because "they are all based on matter, and there is no matter here", ideas about the immateriality of the digital persist (Barlow, 1996). However, Blanchette argues that, in the case of digital signatures, the belief that they occupy an immaterial world of pure information has only served to make requirements like physical presences harder to confront, whilst also obscuring some of the traditional security affordances of paper.

This isn't a long book, but it covers a lot of ground. As appears to be standard practice for books on cryptography, the early chapters are devoted to explaining some of the fundamental ideas that have shaped the history of cryptography. The techniques used to describe, say, the mechanics of a simple substitution cipher will be familiar to those who have read any of the many available technical primers. Nonetheless, Blanchette does a commendable job of introducing concepts that are not easily described in writing. Through his use of colourful examples, Blanchette convincingly shows that, throughout history, cryptography has been material, uncertain, and its success dependent on the context in which it was deployed. The Enigma Machine, one of the most well known implementations of cryptography, was a tangible piece of technology, and its downfall lay partly in the fact that it was so easy to use. Operators began to use it to encrypt routine communications, they became careless in their use of the machine, and this allowed Allied cryptanalysts to gain a foothold that eventually led to their ability to read Enigma-encrypted messages.

The focus is then narrowed from cryptography to digital signatures. We

are brought up to date on how the field has developed, particularly in terms of how scientists and mathematicians conceptualized digital signatures, and how they modelled the problems and threats that they would encounter. Was the electronic document actually signed by the person it claims to have been signed by? Could it have been intercepted, modified, or signed by someone else? Blanchette claims that these questions were answered in particular ways. A one size fits all approach was adopted, and potential adversaries were endowed with the technical competences one would associate with intelligence agencies. The discrepancies surrounding materiality and context are cemented with Blanchette's description of how scientists grappled with the idea of provable security, and the epistemological status of various mathematical techniques for assessing algorithms. Towards the end of the book, we are introduced to some of the ways in which scientists have begun to engage with the problems surrounding mathematization and materiality in cryptography, and Blanchette makes a good case for continuing to think along these lines in the future.

This highlights a disconnect between theory and practice in cryptography. On this point, Blanchette's evidence is compelling and his claims are convincing. However, it is difficult to fully understand how scientists developed their models of how cryptography would be used without also understanding the institutional contexts in which they were working. Similarly, the public policy debates over the regulation and appropriate use of cryptography, sometimes referred to as the Crypto Wars, that occurred alongside much of this work should have been given a more prominent place in the descriptions. Blanchette stated that he did not want to revisit these debates, but I would argue that a significant portion of the work on cryptography from the 1990s onwards was done so with these debates

in mind, and is particularly relevant to claims made about how cryptography was modelled. Nonetheless, this is an engaging and nuanced account of the development of an increasingly important technology that has much to teach us about the relationships between science, technology and society.

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Wiebe E. Bijker, Thomas P. Hughes and Trevor Pinch, eds:
The Social Construction of Technological Systems. 2nd edition.
MIT Press: Cambridge, MA, 2012. 425 pages.

**Sergio Sismondo: An Introduction to Science
 and Technology Studies. 2nd edition.**
Wiley-Blackwell: Chichester, West-Sussex, 2010. 244 pages.

The Social Construction of Technological Systems, first published in 1987 as a classic statement of the social construction of technology's (SCOT) research agenda, has been republished 25 years later, unchanged except for the addition of a new introduction and foreword. In this review of the new edition we consider the book's relevance as a STS teaching tool setting it alongside a recently published second edition of Sismondo's *An Introduction to Science and Technology Studies*, first published in 2004. The two texts both situate themselves as teaching tools in their introductions.

The first thing to say about these books is that they are very different types. The Bijker et al. is an edited collection of case studies that came out of a workshop that brought together scholars from different disciplines to think about technology in new ways. The Sismondo is a textbook that gives an overview that is organised around themes and approaches to STS, laying out the field as a whole. It is interesting when thinking about these books as teaching tools to think about the kind of literary technologies that they are and the way they enact a field. As technologies – textbooks and edited collections – these books do different work.

There is a way of putting these books in relationship with each other where their difference is a matter of positioning. It could be said that the books offer two different

views of the field of STS. The Bijker et al. book can be defined as a foundational book, a collection that set the agenda for much of what came next in STS, whereas Sismondo's text book presents a relatively well defined field, a map of the terrain, a view from above if you like. This way of thinking about the books and their relationship to the field of STS is reinforced by the changes that have been introduced in these second editions. Sismondo has reorganised the chapters to better reflect the key influences on the field as it stands today, and has revised his original view as influences become more apparent, and the field of STS grew. And the new edition of Bijker et al., with only a new introduction, looks back and reflects on how far we have come, the beginnings unchanged. The two books compliment each other and can be read together in this relationship: view from the beginning; view from today.

But this way of situating the books and their relationship to each other is perhaps a fairly simplistic view of the field of STS: the Bijker et al. text becomes one lineage. It incorporates a number of different lineages that converge. And this is very much the sense one gets when reading the preface to Sismondo's second edition where he discusses the changes that he has made to the text, for example, the merging of S&TS and STS, where the field is tamed and made

singular by the very organisation of themes and approaches. This is done in a way that suggests that the second edition offers an account of the field that is more true to the field's history, where history and the field are something we can gain a clearer and more true account as we are now further along the path of time.

Of course it is exactly this way of thinking about a field of study that is complexified in an STS perspective. There the very idea of knowledge as 'out there', as discoverable and on which over time we gain a better picture of, has been problematized.

Further, this simplistic way of thinking about these books and their relationship to each other also shifts somewhat when the books are opened up; when we attend to the texts in more detail. In elaborating on that we first reflect a little on our reaction to reading the Bijker text. The new edition's side by side introductions are interesting as a historical narrative. The inception of the field, the 'turn to technology', is imagined as a moment with Trevor Pinch, a sociologist of science, and Wiebe Bijker, a sociologist of technology clinking their champagne glasses, a beautiful romantic setting, marking the coming together of the two fields. We enjoyed this opportunity to look back to the workshop in Twente, Italy, when a group of young scholars gathered together to talk about exciting new ideas. We enjoyed the glimpse into a time when these scholars were young, enjoyed the voyeuristic opportunity offered by this introduction. The new introduction in the 25 year anniversary edition situates the Bijker et al. book as an important landmark in the field of STS, this is the work that 'commemoration' does. But we were also disconcerted by what we felt namely a tension between the work in the book, the case studies and what they are trying to achieve, and this new introductory narrative. In a field that has done so much to trouble the idea of the lone inventor, the

introduction offers an inception story that is all too romantic and in tension with these aims.

Perhaps the tension between a field that opens up identity, singularity, and foundations and an inception story that highlights a moment in time is inevitable and is to be expected, but the tension also highlights something important about 'the field' when thinking about teaching STS and the work that these technologies do in enacting that field. It is important that we remember that 'the field' of STS is heterogeneous. At the 2012 EASST/ 4S meeting in Copenhagen this was very apparent. Outside of our own familiar networks we found ourselves at sea in a vast landscape and we could not always identify familiar features in the terrain. In that situation it is good to have a map, one that identifies possible points of reference between where we are situated, and the rest of STS. In this respect Sismondo's textbook offers a good point of stabilisation, a point of reference, a good map of themes, while the Bijker et al. text is a good reference to the emerging struggles that specific research schools were grappling with in the early days. Sismondo offers a useful tool for navigating the way our own work relates to the large body of work that constitutes STS today.

It is important when using texts such as these to teach STS to encourage questions about what has been left out in these versions of 'the field'. We should encourage learners to be troubled by an origin story such as the one offered by Pinch and Bijker and wonder: what might have been invisible back in the late 1980s? And we may also be troubled by a textbook version that maps the terrain in a way that stabilises a field that is more messy than can easily be represented. Of course no text can be all things, and we are not criticising these texts for what they leave out, nevertheless we want to make the

point that when using these texts to teach STS, it is important to highlight the way texts are themselves situated.

This is important in relation to the kinds of stories that texts tell about what makes 'the field.' Whilst we are both currently situated in the North West of England as we write this review, one of us has travelled here from South America where 'the field' of STS has its own geographical skew. We think that it's important to highlight that in enacting 'the field' these texts are targeted to English speaking communities in the U.S. and Europe (Australia and New Zealand as well). When using these texts for teaching STS we think they should be situated in a course structure that allows some of these issues to be made visible. In this respect we think of the texts as artefacts for thinking about STS. We think that given the global diffusion of STS, the sheer heterogeneity of the field, we are troubled by the unnoticed Euro-American centrism of the assumption that texts like these constitute 'the canon' of the discipline.

Thinking more about the contents of the two books, we reflected on the difference in their styles. In his foreword Sismondo states that case studies are the 'bread and butter of STS' and he makes use of classic case studies to illustrate his points throughout his book. But he is clear that it is not enough to read the textbook alone, and he urges his readers to read the classic case studies he makes reference to alongside his text. One way of thinking about the use of case studies in the two texts is to think of the Bijker collection as case studies 'in the wild' and the Sismondo cases as catalogued in a museum. (The analogy will only work if we don't push it too far, but we use it to illustrate our point.) In the museum artefacts are taken out of their contexts and offered as part of a curated narrative. And as we have said, this is a useful way to get an overview, a sense of the issues that are important to

'the field.' It is a useful way to get a sense of a history of ideas. But as STS scholars, it is not enough to learn about STS in this way. The empirical focus of the work of STS, the way of thinking through and with case studies also needs to be nurtured. One could say that as students of STS it is important to develop a sensibility that we feel is not easily nurtured (perhaps impossible to nurture) through the textbook. To be scholars of STS we need to go out and get dirty, to leave the safety of the museum.

Reading the Bijker text in 2013 we are reminded that much of the vernacular that we take for granted as STS scholars was not available 25 years ago, the conceptual and methodological space from which we write today was not yet forged. And the introduction to the 'anniversary' text, by its very nature frames the case studies and locates them in a time and a place. In this respect the case studies are enacted as artefacts, and the introduction does museum work. In this viewing case we see a field in the making. But the museum analogy reminds us that artefacts displayed in museums have a relationship with colonial pursuits. The very making of a field, of a vernacular, is difficult to think in ways that are not frontier-like. The book as a whole, through its introduction, tends to pull the reader towards a field conquered. We were discomforted by this.

But putting this aside, what of the case studies themselves? Although 'of the past,' they still have life. What do we mean by this? When thinking about teaching STS we felt that case studies offer a way of seeing the author struggle with emerging concepts and ideas. And this is impossible to see in a textbook where the terrain is mapped, or closed off. Teaching with case studies helps students to develop a sensibility, an attention to detail, to the nuanced and to the specific. The case study is an approach to knowledge production that leaves visible

the relations of data and method which offer a critical approach to knowledge making that is difficult to impart through a textbook, but is visible in a good case study. The upshot of this is that science studies can't be learnt with just the conclusion of the debates. The relations between theory, method and data are very visible in the case study and these classic texts offer some signposting of the debates and struggles that have happened and as such, these debates are not closed off, they may offer new creative thoughts, take students in new directions, are not linear, and reveal an iterative process. Furthermore, case studies offer stories about the making of an idea, and as scholars we think our own case studies differently in relation to new calls, new collaborations, and the same must be said of old case studies. And this is part of their importance in teaching. But we recognise the museum can also be useful. It offers us a way of understanding the history

of things. But it is important to remember that this is a history curated.

When teaching STS, the case study in the wild, even case studies written 25 years ago, are still very useful and in fact we would go as far as saying necessary. The curated textbook has a role in orientation. But texts, whichever we use, need to be properly situated. Teaching STS through these books is a great opportunity for following the making of the field in action and for thinking about how it is enacted in location.

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**Mario Biagioli, Peter Jaszi and Martha Woodmansee, eds:
Making and Unmaking Intellectual Property: Creative
Production in Legal and Cultural Perspective
The University of Chicago Press: Chicago and London, 2011. 480 pages.**

The reading of *Making and Unmaking Intellectual Property* is a kaleidoscopic journey both inside the forms that intellectual property (IP) assumes and through the contexts in which it is shaped and used. The essays in this collection explore the cultural, social, political, economic and material factors that influence the production and exploitation of IP (and related knowledge), highlighting the relations between the actors involved in it. In doing so, the book puts into question the apparent stability of IP rights as legal objects, developing a more controversial picture showing the dynamics through which the forms of IP emerge, the clashes of interests around them, and their use (or rejection) by various actors for different purposes.

The scholars who have contributed to this volume come from different research fields: law, cultural studies, STS, anthropology, economics, communication studies, and disciplines dealing with the arts. This collaboration is not simply an attempt to provide an interdisciplinary outlook, but rather “[...] the result of the actual migration of IP [...] into all these disciplines” (p. 10). The reader can approach the book both comprehensively or selectively on the basis of his/her own interests, by following the thematic sections in which the essays are arranged, the particular research questions addressed by the single chapters (see the book’s introduction), or by searching the academic profiles of the scholars included

at the end of the volume in order to identify disciplinary discourses on IP.

The editors have here collected twenty-three studies in five clusters. The book opens with the section ‘High and Low: IP Practices and Materialities’, which historically analyses the practices and materials behind the working of the U.S. patenting system. The second part, ‘Before and after the Commons and Traditional Knowledge’, tackles the problematic relationships between IP and the groups of people – both indigenous and working communities – that use or reject it. The volume continues with ‘IP Crimes and Other Fictions’, which considers the infringement of IP rights from the perspective of the “pirates”, the “owners”, and the artists. The fourth cluster, ‘Old Things into New IP Objects’, exemplifies the problems encountered when subsuming “things” under the categories of law, their migration between different forms of IP, and the possible effects on the legislation itself. The book is concluded by the section ‘Doing and Undoing Collaborative IP’, that explores the issue of collaboration around IP in various directions. Together these five clusters of argumentation – each worthy of becoming the theme for a book in its own right – aim at reaching a wide range of readers, offering glimpses of the broad and rich themes embedded in IP. That, however, sometimes undermines the overall coherence of the volume.

Of course not all the essays concern science, technology, or nature; nevertheless

an STS reader can find direct and indirect stimulating insights to reflect on IP in connection with STS issues, following both human and non-human actors. For example, insights can be found regarding the intersections of IP with environmental exploitation/protection, globalization, the appropriation/circulation of techno-scientific knowledge, the use of the Internet, the ethical and political implications of science and technology, the cultural and social aspects of figures such as the inventor and the scientist, and the inventing, discovering and creative practices.

Of direct relevance for an STS scholar are the entire first and fourth sections. The first group of essays look at the practical backstage of the patent law – giving therefore the opportunity to delve into a form of IP that is central to the exploitation of technology and science. In this sense, Mario Biagioli shows how the introduction of the ‘patent specification’ document enabled the realization of the modern conceptualization of patents as rights based on a bargain between the inventor and the state. This perspective emerged in connection with the development of representative politics. By focusing on the U.S. patenting system in the 19th century, Kara Swanson analyses how the applications were produced and evaluated before and after the professionalization of the patent examiner. In doing so, she highlights that the patent is “an unauthored bureaucratic text that yet is interpreted as” (p. 50) representing an individual figure (the inventor). Finally, William Rankin discusses how the changing standards of the U.S. patent drawings in the period 1870-2005 reflect the changes in the characterization of “the ideal audience of patents” (p. 72), privileging the interests of the inventors over the legibility of the documents for the general public.

The fourth section provides examples of the application of IP to the products of

science, technology, and nature, drawing attention to the strategies devised to exploit them and the related manoeuvres around the forms of IP. The first two essays tackle the issue of the property rights on living organisms. Daniel Kevles presents the practices adopted by animal and plant breeders to retain the control on their products before patent law was applicable to living organisms. Alain Pottage and Brad Sherman (1930) begin precisely from the first legislative extension of this kind to reflect on the conceptualization of ‘invention’ when both man and nature are the “agents”. After these essays, the focus is turned towards pharmaceuticals. Cori Hayden shows how the notion of ‘generic drugs’ is differently characterized according to the economic and regulatory contexts – as in the cases of Argentina and Mexico. Jonathan Kahn, instead, discusses “the strategic use of race as a genetic category to obtain patent protection and drug approval” (p. 305). A case concerning informatics closes the cluster: Pamela Samuelson analyses the attempts of controlling the ‘software interfaces’ based respectively on trade secrets, *sui generis* IP forms, copyright, patents, and regulated licensing.

Important considerations regarding the use of IP by technologists and scientists are presented also by two other studies. Christopher Kelty reconstructs the creation of the first pattern of ‘information commons’ – the General Public Licence (GPL). Far from being a consequence of the hacker ethics – which was rather one of the outcomes of the controversy as narrated by the author – the GPL emerged as a means of managing a collaborative working community that was developing both outside industry and university, and that had to reckon with a changing IP legislation. Through the ‘oncomouse’ case, Fiona Murray discusses how the mouse geneticists responded to the introduction of patents in their research

field, arriving to integrate them in their academic 'cycle of credit' within which patents have assumed a new function.

Another interesting topic is tackled by Adrian Johns, who sketches a history of the piracy detection and the enforcement of IP law. Johns points out the central role played by the little-known "IP policing industry", highlighting its techniques and the tracking technologies used. Finally, Tim Lenoir and Eric Giannella issue an important methodological challenge to the STS community. By using patent data and the notion of 'technological platforms' to map the landscape of the radio-frequency identification technologies, they bring to the attention of STS scholars the adoption of quantitative research tools in order to

study the actor networks underpinning the development of technology on a large scale. *Making and Unmaking Intellectual Property* is thus a very useful starting point to delve into the dynamics of intellectual property and to think about how to proceed in the direction of including more of its issues within the social studies of science and technology.

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Browne, J. (1998) 'I Could Have Retched All Night: Charles Darwin and his Body', in C. Lawrence & S. Shapin (eds), *Science Incarnate: Historical Embodiments of Natural Knowledge* (Chicago, IL: The University of Chicago Press): 240-87.

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