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.

Acknowledgements

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