

# Shaping the future e-patient: The citizen-patient in public discourse on e-health

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This paper investigates how public discourses, as articulated in EU policy and Austrian media documents, take part in the creation and stabilisation of a new patient figure – the e-patient. The documents we analysed act as one material form for enacting, performing and giving meaning to the changes occurring when a new technology enters established networks in the medical realm. Our analysis will show that the public discourses we studied deploy three rather different forms of discursive registers, each of which address and perform a specific relation between currently new information and communication technologies and citizen-patients. From one place, moment or problem-solution package to the next a slightly different hybrid and ‘multiple citizen-patient’ is being shaped, discussed, observed or concealed. The multiplicity we observed reveals crucial tensions and contradicting expectations expressed towards the future citizen-patient, showing the challenges for e-health in the making.

*Keywords:* citizen-patient, e-health, doctor-patient relations, health governance

Recent discussions in the social studies of medicine have addressed the ever-closer relationship between socio-technical change and the ways of thinking and practicing medicine. With the increasing permeation of information and communication technologies (ICTs) in the medical field yet another round of fundamental re-orderings has taken place. They touch on the way medical knowledge gets produced, distributed and consumed (Nettleton, 2004), but also on how traditional hierarchies and established roles are re-negotiated. This re-ordering happens at a time when

health systems are challenged on both national and European levels. Rising demands for health services due to an ageing population, increasing mobility within the European labour market – and thus also patient mobility – a growing “disease burden” and issues like occupational accidents/diseases are the most visible issues at stake.

In the European policy scene ICTs in the form of “e-health systems and services”<sup>1</sup> – Internet information-platforms, electronic patient records, health (insurance) cards and tele-medical devices – appear as *the* technical

solutions expected to “deliver significant improvements in access to care, quality of care, and the efficiency and productivity of the health sector” (EC, 2004: 6). At the time of writing this article in some countries such as the UK, policy solutions based on ICTs are being formulated through a nationally co-ordinated system of e-health called “Connecting for Health”, which is accompanied by the powerful rhetoric of “standardised, cost-effective and flexible care” (Webster, 2007: 114). In parallel we observe an increase in a discourse on citizen’s/patient’s participation and informed decision-making deeply rooted in the very idea of knowledge society (Stehr, 1994): rational decision-making should be based on “the right” techno-scientific knowledge, which is conceptualised as “neutral” (Felt et al., 2009b).

The processes of reshaping health policy with regard to ICTs happen in many different places simultaneously, involve various actor constellations and do not occur without creating tensions. Much of the analyses of these changes has focused on understanding how patients deal with these new circumstances, how doctors and the medical establishment embrace (or reject) new technologies, how national health systems have materially incorporated them and on what new possibilities or limitations emerged. However less attention has been directed at the broader discursive framings in the public sphere shaping the relationship between ICT and the health domain and how they often tacitly impose normative visions on the addressees of health care.

This paper aims at addressing this lacuna in focusing on what we want to label citizen-patients, i.e. an often unclear hybrid between “still healthy” and “already ill” and on how they are enacted discursively with ICTs in two

important public arenas: policy and media discourse. Starting from Jasanoff’s (2004: 2-3) argument of co-production, namely that “the ways in which we know and represent the world (...) are inseparable from the ways in which we choose to live in it“ we will investigate how media and policy documents develop articulations of ICTs, health issues and citizen-patients. Scientific/medical knowledge, but also the different kinds of technological innovations are thus understood as both embedding and being embedded “in social practices, identities, norms, conventions, discourses, instruments and institutions” (Jasanoff, 2004: 2-3).

Through studying media and policy discourse on e-health, we aim to get a deeper understanding of the “heterogeneous engineering’ in which bits and pieces from the social, the technical, the conceptual and the textual are fitted together” (Law, 1992: 2). Both arenas are conceptualised as “laboratories” in which experimentation with articulations between ICT, the networks that stabilise them and citizen-patients takes place and where social acceptability is tested (Oudshoorn, 2003). Media and policy documents, then, are important contributors to framing the issues at stake. Such frames encourage certain interpretations and discourage others, carry specific meanings and eventually induce a change in routinised social practice, material arrangements and normative obligations. Our analysis thus focuses on the repertoires of narratives produced and on how they conceptualise and shape a set of new patient figures – the “e-patient” – in the process of technological change.

This paper investigates European policy discourse, and the more nationally focused print-media discourse in the

Austrian context. Although both discourse contexts are public, they get inscribed rather differently and follow different rationales. Bringing together discourses ranging from the regional (European) to the more local provides an understanding of the broader discursive repertoires, their similarities and differences.

We start by reflecting various, partly contradictory discussion strands concerning patients in relation to new ICTs in current academic debates. After presenting our data and methods, we continue to analyse the different discursive enactments of the e-patient as well as the accompanying broader envisionings of future health systems. In the conclusion we reflect on what the creation of such contradictory e-patient figures and the lack of explicit articulation between them entail for the relationship between patients and the health system.

### **ICT, medical information and the citizen-patients**

Not only European policy-makers greeted e-health with much enthusiasm but also a new and rather diverse academic research field emerged. Here we examine some of the major strands in that research. One prominent academic debate revolves around ICT innovations and their potential for improving health care (e.g. Lohr et al., 1998; Fox and Rainie, 2000). While celebrating the innovations, however, such research offers little critical reflection on the socio-political context and the social values framing these socio-technical developments. Rather, the technologies at stake are constructed as “neutral” with potential problems being predominantly linked to the implementation process. Hence, in an effort to avoid potential problems, technology advocates invoke a mantra

of educating users<sup>2</sup> while highlighting the need for standardised information, accredited quality labels to guide users and reinforced security measures. Being in line with the dominant policy discourse these reflections can be seen to support the stabilisation of a particular vision of e-health.

The way patient roles change through the implementation of ICTs has become a second strand of analysis, in particular focusing on online health information in its role to “inform” and “empower” patients. Here the Internet has often been framed as a site of struggle over expertise on medical issues. By providing access to information via the web, health care is expected to become more open and democratic as doctors and patients are supposed to become collaborating partners (Anderson et al., 2003). The buzzword “empowerment” represents the hope that this process of technological change will trigger a reconsideration of classic doctor-patient relationships. In analogy to Giddens’s “reflexive self”, Hardey (1999) conceptualised the Internet as an instrument for giving patients access to a global health information market, which is expected to turn them gradually into “reflexive consumers” (1999: 821).

However, numerous empirical studies have shown drawbacks in this newly imagined doctor-patient constellation by noting the ambivalent feelings expressed by both doctors and patients. First, doctors expressed scepticism about the concept of an “informed patient” because they feared a challenge of their social power (Broom, 2005). Second, patients often did not want to tell their doctor about their Internet searches (Diaz et al., 2002). This links to observations made by Henwood and co-authors (2003) that patients who tried to discuss with their

doctors treatments based on Internet-information experienced rejection. Oudshoorn and Somers (2006) showed that even in cases where self-help groups created web-resources, patients were absent from the process of providing information. So the ideal of an informed and participating patient seems fragile and difficult to realise.

Furthermore in all the enthusiasm about the new information possibilities it is vital not to overlook studies that also point to situations in which patients deliberately decide to take on a “passive patient role” (Lupton, 1997) and follow the advice of doctors they trust, which was a finding we also confirmed through our own analysis (Felt, 2008). Other motivations also caused people to become non-users of the Internet. Wyatt and co-authors (2005) identified four categories of non-users – the resisters, the rejecters, the excluded and the expelled, stressing that “the first two groups may well be exercising agency in choosing not to have access and should not simply be dismissed as ‘laggards’ or ‘luddites’” (Wyatt et al., 2005: 203).

The third strand of discussions about ICT and health revolved around the conceptualisation of medical knowledge, standardisation issues becoming highly relevant with the introduction of ICT into the health sector. In particular with the rise of evidence-based medicine (EBM) in the 1990s, health care is expected to move towards an “exact science”, gradually replacing the mere “craft” of traditional clinical practice. Formal guidelines are developed to offer clear instructions about which treatments to prescribe, when to provide medical services or how long a patient should stay in hospital (Timmermans and Berg, 2003: 3). Standardised procedures for specific clinical circumstances are supposed to make (global) health care more equal

and efficient (Lohr et al., 1998), and the way ICTs are being integrated into the health system supports and reinforces the tendency of standardisation.

The shift in medical practice from case-based to population-based medicine, and the accompanying trend towards highly standardised and routinised medical practices have been criticised. It creates important tensions between the individualised-empowered and the collectivised-standardised patient – two figures that apparently co-exist in the health reform debates without having their obvious contradictions addressed.

Finally research on e-health also has addressed new issues of time and space in the medical system. Telemedicine in particular has been perceived as a technological way of reducing inequalities in health care by, for example, bringing medical expertise to previously excluded regions. ICTs have largely been seen as enabling diagnoses and treatments and as mediating the monitoring of health states, thus leading to important socio-technical rearrangements (Mort et al., 2003). Through ICTs doctors and patients separated in time and space could be connected. Some commentators (e.g. Cartwright, 2000) even argued that telemedicine has the potential to construct a new geography of health by increasingly including remote regions into a “global health care”. Thus the issue of fair distribution of resources and the centre-periphery debate have become prominent in e-health issues.

In addition, the complex data-sets distributed across space and time have effected a continual process of decomposition and re-composition of human bodies and have consequently caused real patients to partly disappear in the face of their abstracted e-incarnations (Brown and Webster, 2004).

## Data and method

The data we used for this paper were generated as part of a broader qualitative investigation that explored the ways in which the intrusion of ICTs changes entrenched relationships in the context of the Austrian health system. The empirical material collected for the broader project was comprised of the following sources: a selection of media articles and policy papers; forty-one scenario experiments wherein participants' search strategies were observed and interviews conducted; more than six-hundred short questionnaires on patients' Internet use collected in twelve medical practices; thirty-one qualitative interviews with patients; interviews with ten medical practitioners that supported data collection; and seven interviews with health information providers. For this paper we focus specifically on European policy reports and Austrian print media articles from 2000 to 2007 because they frame in important ways the imaginations and expectations with regard to ICT and health.<sup>3</sup> Concretely, we selected four key policy documents dealing with e-health, and 135 media articles from 26 Austrian newspapers and magazines, which we analysed as one pool of media productions.<sup>4</sup>

Policy documents and media reports are understood here as doing important reconfiguration work, trying to stabilise particular visions of the relationship between ICTs, the medical field and the citizen-patients. We recognise that the European policy documents are produced through complex negotiation procedures between member states and are part of a network of other documents. Hence the language of these documents is highly standardised and techno-bureaucratic. European policy

documents generally tap into a limited set of discursive elements, which are rhetorically highly coded and symbolic; that is, the descriptions, analyses and solutions used remain mainly on a macro-level. For our analysis we read the policy documents as exercises in imagining and framing European futures. They give life to a set of buzzwords and standardised visions, which in turn proliferate, and participate in the shaping of e-citizen-patient figures.

Media reports play on different registers and have different opportunities of intervention. They are tied into more local constellations where they take part in a process of acculturation. Media articles shape and are simultaneously expressions of local techno-political cultures (this localism definitely still holds true for Austrian media). Directed towards a diverse media readership they not only tap into the broad pool of cultural imagination and local experiences, but they also set agendas and provide new cultural frames. Media stories about the imminent e-future frame possibilities and stoke imaginations.

The issue of e-health was first raised in the action plan "*eEurope 2002: An information society for all*" (EC, 2000b) that stressed the need for better Internet access and for more investment in people and skills in order to increase use of the Internet in various fields including health. In the subsequent action plan, "*eEurope 2005: An information society for all*" (EC, 2002a) e-health was further elaborated as one of four central axes that included e-government, e-learning and e-business. From 2000 to 2005 e-health grew from a minor element to an independent topic in European policy debates, which culminated in an e-health action plan (EC, 2004) with the ambitious title "*e-Health – making healthcare better*

for European citizens: An action plan for a European e-Health Area". Further we selected a document dealing with online health information: "eEurope 2002: Quality criteria for health related Websites" (EC, 2002b). These four key-documents are embedded in broader political visions and discussions on the future of Europe, most notably the Lisbon declaration, the "i2010 – A European Information Society for Growth and Employment" (EC, 2005) and the "Digital Divide Forum Report"<sup>5</sup>.

Austrian print media coverage of e-health was selected via a keyword search of all major Austrian newspapers and magazines and restricted to articles explicitly dealing with e-health and doctor-patient relations.<sup>6</sup> During our period of investigation notable shifts in issues were observed: From 2000 to 2002 the Internet as a health information source and its consequences for medical practice was dominant; in 2003, more infrastructural aspects of e-health such as the Austrian health insurance card (e-card) or patients' files became major issues; a strong coverage of the e-card in 2005 mirrors its implementation in Austria; in 2006 and part of 2007 the one new dominant topic we found entering media discussion dealt with the dangers of purchasing medication over the Internet.

Using the grounded theory approach (Strauss and Corbin, 1990) we first identified major discursive strategies and categorised them. In a second step we then coded the passages that focused on citizen-patients in relation to e-health, including passages where we considered patients to be clearly absent presences; in other words patients were constructed by silencing or masking them. We then interrogated our data to decipher and make more explicit some of the networks in which the imagined citizens/patients

were embedded or out of which they emerged, to explore how normative conditions determine the degree of action attributed to citizen-patients, how these roles were imagined and in which ways technologies were perceived as framing forces.

### **E-configurations of citizen-patients**

Through our investigation of the spectrum of forms and formats of discursive production concerning e-patients in policy documents and media, we identified three categories with different argumentative logics. In turn, we analysed the citizen-patient figures that emerged through these discursive registers to understand how they were configured in relation to ICTs and stabilised as well as what degree of action was attributed to them.

#### ***Between distribution and reconfiguration of e-patients***

The first category of discursive interventions across policy documents and media articles was centred on data bodies, their production, distribution, reconfiguration and their relationship to "real patients". These discursive networks were comprised of a specific sub-set of e-health technologies (electronic patient records, patient files exchange systems, health-insurance cards and tele-medical devices), accounts of their power to restructure and standardise health care practice, the promotions of technical problem-solution packages and narratives of efficiency and of patients' readiness to comply.

***Policy discourse.*** As mentioned earlier, policy discourse was formed initially from the assumption that a well-integrated health care system that allows

medical data and technical solutions to travel with mobile patients is the foundation for an efficiently functioning European health area. According to this logic, “standardisation of system components and services such as health information systems, health messages, electronic health record architecture, and patient identifying services” (EC, 2004: 13) became a major goal and imposed a particular conceptualisation of European e-health.

While acknowledging the “amount and complexity of health-related information and knowledge”, the e-health action plan stressed that ICTs would support not only “progress in medical research, better management and diffusion of medical knowledge”, but also a “shift towards evidence-based medicine” (EC, 2004). Thus e-health tools were framed as supporting improved “aggregation, analysis and storage of clinical data”. There was much reflection on the creation of not only “integrated and comprehensive” but also of “comparable” data sets, which was to lead eventually to a kind of trans-local medical knowledge beyond individual patients. Following the paradigm of EBM, we witnessed the discursive crafting of what we labelled “distributed standardised patients” – assemblages of medical evidence stored in the form of different standardised data sets that were accessible from different locations. Given the policy papers’ focus on producing and handling the data body, the physical patients not surprisingly disappeared in these discursive registers and were replaced with terms such as “patient information” (EC, 2004: 13), “digital patient specific data” (EC, 2004: 8) or “patient identifiers” (EC, 2004: 16).

Telemedical devices and their role in monitoring patients are frequently addressed as a

context where both standardisation and distributedness are put in practice. For example, for some areas of routinised control, policy reports widely deemed the replacing of medical personnel with the monitoring of a set of transmitted patient data assumed to be relevant indicators of patient wellbeing (e.g. surveillance of the heart) as a scenario of success. Thus a trade-off is performed between a new liberty for patients by shortening hospital-stays (EC, 2004: 7) and the temporary reduction of medical wellbeing to a set of measurable medical indicators.

These policy accounts were all similar in their obvious focus on technical rather than on social aspects of health. Seldom were potentially problematic aspects of technical applications raised, and even in the rare instances when problems were acknowledged, the proposed solutions were also technological. Data protection – the most prominent example for measures to be taken against potential negative effects – was not debated as a delicate issue in and of itself, but as merely in need of a carefully crafted technical solution. The possibilities of data distribution and availability were mainly extolled as unique opportunities that created unprecedented win-win situations for all participants, including patients. Likewise, just as policy documents did not address challenges posed by standardised data production with any profound questioning of the underlying values and assumptions, they did not address different traditions of dealing with and describing medical conditions, or make reference to implicit forms of local knowledge, or offer any reflection on the way technological changes in medical practice may reshape “real” patients’ roles.

*Media discourse.* Similarly, media accounts also seemed attracted to the increasing production and distribution of patient data. The media, however, speculated more on what digitalisation through e-health applications means once a “real patient” becomes reconfigured through the data.

We traced two positively connected lines of argument in media reports regarding the e-patient. First e-applications meant simplifying patients’ responsibility in keeping track of their records (e.g. x-ray pictures) because doctors could easily access patients’ digitised data from anywhere and thus efficiently share and work with the data. Second digitised patient data was regarded to allow medical personnel to reconfigure patients into “virtual humans”, or “3D models that are good enough to replace real patients”,<sup>7</sup> particularly in the context of medical education where e-incarnated patients were expected to efficiently supplement or supplant flesh and blood in training doctors.

Yet, closely intertwined, reflections around the notion of the transparent patient emerge. This particular expression of the technologically reconfigured patient was mainly addressed in the context of data protection issues regarding electronic patient files. The view of a transparent patient produced ambivalent feelings in particular in the context of the e-card: On the one hand electronic data availability could save a patient in case of emergency; on the other hand the same availability advantage evoked threatening Orwellian visions of data misuse. Indeed concern remained palpable even though journalists called upon representatives of the medical community to vouch that “there must not be self-service with confidential

patient’s data”<sup>8</sup> and that “the patient will keep control of his data”<sup>9</sup>. In contrast to the policy domain, the media underlined the central role of more local actors, such as consumer protection agencies to exert some external control.

As in policy discourse, the media addressed telemedicine, the definitive ICT for reconfiguring medicine in time and space, in terms of its ability to play an active part in patients’ control over their health and to shorten hospital stays. Through ICTs “top medicine should be available everywhere and at any time”<sup>10</sup>. Media reports reflected not only on telemedicine’s health monitoring role but also on its role as a patients’ “digital guardian angel”<sup>11</sup>. A monitoring device could say, “Franz, your blood pressure is too high, you should take your medicine. Or should I contact the doctor?”.

Overall we identified two main arguments in the media in favour of e-health. First media articles stressed that the introduction and public acceptance of e-health technologies had the potential to equalise access by reducing the traditional dichotomies of inclusion-exclusion and the centre-periphery. In other words, through ICTs networks of expertise became available to patients, physical distance being less of an issue: As access to quality care became better distributed and decentralised, an equitable health care system was to emerge that did not discriminate between location or type of care. Second, the media used comparisons to frame e-health technologies in progress-oriented discourse and as the only reasonable path to follow: For example, their saying “High Tech instead of a nursing home”<sup>12</sup> attempted to discourage the public from considering alternatives to technological progress. So, although the media more than policy writers



focused on the patients' perspective, the patient appeared in a strictly passive role, and only little attention was given to critical reflections accompanying changes produced through ICTs.

*Patient as responsible health manager or doctor's partner*

The second category of discursive interventions revolved around issues of social relations, responsibility and empowerment. Media and policy reports perceived online health information, the primary technology involved in this category, as giving rise to citizen-patient with an enlarged capacity to act on their own behalf. According to discourse on patient autonomy, ICTs were supposed to reshape both the way citizen-patients handled their health status and the classic doctor-patient relationship.

*Policy discourse.* Our analysis of policy documents quickly revealed that the notion of "patient" was frequently replaced by the notion of "citizen" that was expected to develop necessary self-management capacities with regard to his or her health. However, the imagined "not-yet-patient figure" was perceived as needing support for "managing [her or his] own diseases, risks, including work-related diseases, and lifestyles" (EC, 2004: 7). The underlying policy assumption was that because "a growing number of people are looking proactively for information on their medical conditions", they – the newly incarnated citizen-health-managers – would use Internet information to take preventive action. The "right information", as provided by evidence-based medicine, was supposed to quasi automatically guide the "right actions". The provision of "timely information tailored to individuals in need" was to be assured by e-health services by offering "specialised online resources (...) for

health education, safety and security at work, and lifestyle management" (EC, 2004: 7). More concretely, the European Commission expressed a commitment to establish "a European Union-wide public health portal that will provide a flexible information technology platform to disseminate evidence-based information on public health relevant to European citizens, and to provide a single point of access to information on health" (EC, 2004: 19).

Within the policy line of reasoning we noted a contradiction in staging the citizen as an empowered self-responsible manager while at the same time underlining the utmost importance of providing and controlling "the right information" and "education" for enabling people to select and apply the information. Thus within policy documents we found statements stressing that citizens "want to be involved actively in decisions related to their own health, rather than simply accepting the considerable discrepancy ('asymmetry') in knowledge between themselves and health professionals" (EC 2004: 7) while underlining the need to educate users so they would know "what they ought to expect from a good health website" (EC, 2002b: 4).

In conjunction with the "right information" logic, the quality of web information became a central concern in EU policy discourse. Thus in addition to their own health portal, policy authors sought to establish European-wide quality criteria and tools for pre-selecting health information for citizens:<sup>13</sup> "The purpose of quality marks is not, however, simply to provide access to qualified information but also to assist the citizen in coping with the torrent of information (...): it has been said that 'trying to get information from the internet is like drinking from a fire hose. You don't even

know what the source of the water is” (EC, 2002b: 13). This dramatic simile imagines an overwhelmed citizen and then morally supports the political mission of pre-selecting information regarded as valid and relevant.

Overall, ambivalence towards the citizen-patient was expressed in policy documents. While they promulgated citizen empowerment as ideal, policy-makers demonstrated limited trust in people’s capacities to handle their health issues and consequently decided that they, the authorities, must make central and delineate guidance and education policies. Hence policy-makers advocated that citizens should fully comply with the policy script of ICTs in the health system and follow predefined information paths to assure the e-health technologies’ success story.

*Media discourse.* Although online health information was also a prominent topic in the media reports, the effect of online information was debated in the context of changing doctor-patient relationships. The media assumed that patients, more now than ever, were expected to take responsibility for their health state, which “eventually seems possible for only the informed patient”<sup>14</sup>; hence the media imagined an intertwining of patient responsibility and information. Yet in media articles more than in the policy discourse, patients were presumed in principle to be capable of “self-confidently making health decisions”<sup>15</sup> when needed and ready “to take on more responsibility”<sup>16</sup>.

The media also framed online information as a necessary pre-condition not only for having patients assume a more active part in decision-making processes – that is, to be empowered – but also for realising a more equal relationship between doctors and

patients. An empowered patient, the media assumed, would want to challenge the authority of the medical establishment. This desire for change would hold for “the majority of ill people (who) want to be an empowered partner with the doctor and shape treatments according to their needs. This is possible because they have access to knowledge about their illness”<sup>17</sup>. “The more a patient is informed”, their logic ran, “the more the relationship with the doctor becomes equal”<sup>18</sup>. Virtually no doubt was raised regarding the naive connection between access to information and empowerment. Furthermore, the media viewed the Internet in certain cases as offering an opportunity to transcend the individual situation to form a “community of knowledgeable patients”<sup>19</sup> that would then allow individuals to encounter the medical system in fundamentally different ways through exchange (e.g. self-help groups).

The media perceived gains for both doctors and patients: “The informed patient can pose more targeted questions; the doctor can follow the information needs of the patient in a more purposeful way”<sup>20</sup>. The patient could thus be transformed into a “co-responsible confidante”<sup>21</sup>, who wants to have a say, to collaborate with the doctor and to be involved in treatment decisions. However the situation of having Internet-informed patients was also sketched as a kind of pressure on doctors “to get regularly informed about new developments”<sup>22</sup>. Doctors could no longer remain “gods in white”<sup>23</sup>, “guardians of the grail of medical information”<sup>24</sup> or hold a “monopoly of information”<sup>25</sup>, but would have to share their position with patients. Having medical information available on the Internet was further portrayed as an issue of competition, whereby doctors have to live with virtual counterparts labelled in

headlines as “Doctor Internet”, “Cyber-Doc”, “Doctor WWW” or “Dr. Google”<sup>26</sup>. However as in the policy documents the media accounts of the empowered patient were also accompanied by a discourse on the risks of Internet reliance in that the danger of wrong or inappropriate information or charlatanry could lead to people becoming “more unsure than enlightened”<sup>27</sup>. Health portals were seen as a “balancing act, as medicine cannot be simply taken from the book”<sup>28</sup>, and thus doctors’ advice and interpretation were expected to remain the essential core of medical intervention. So to assure quality in patient information, as the media imagined, doctors could take a more active role in counselling patients regarding applicable web pages. Another scenario the media discussed regarding the empowered patient imagined patients becoming too demanding, asking too many questions and wanting to control the doctor. “Doctors must be prepared: In the future they will have to deal with patients that come in with a heap of Internet-printouts and demand a special kind of therapy, or at least want a serious discussion”<sup>29</sup>, argued one health expert. The media implied in such accounts that doctors regretted their loss of authority.

The media thus envisioned an active citizen-patient figure that uses the new information technologies to expand his/her degree of decision-making and above all to challenge the traditional hierarchy in the medical system. Yet the media simultaneously expressed doubts about whether the average patient would be able to live up to their expectations.

#### *E-ducated patients or independent consumers?*

The third discursive register was distinguished in the introduction of a market paradigm in the reconfigured health care system. In these instances our

sources’ references to the “e” in “e-health” related predominantly to medical services, online pharmacies or online health information, which offered goods to be selected by the newly incarnated patient-consumer. Thus consumption – or economy-related issues such as market forces, regulation, quality-assurance and consumer protection were central discursive indicators for the patient-as-consumer.

*Policy discourse.* The producers of policy documents expended much effort not only in establishing the Internet as a central information source but also in situating European citizens as “avid consumers of health related information” (EC, 2002b). As in the case of the health-manager discourse we found a double construction of the Internet: While the technology offers new opportunities, it also represents a tricky, even partly dangerous territory. Consequently the consumption discourse generally appeared concomitantly with “consumer e-ducation”; that is, the e-consumer was expected to acquire new skills for dealing with the offers. Whereas citizen-patients had been accustomed to handling traditional information channels, they now required an extended capacity for dealing with Internet information and other offers. While we found that the consumer and health-manager discourses overlapped and were similar in many ways, we also noted an intrusion of dense market-vocabulary in the former. For example the policy documents used a repertoire of economic notions such as e-health markets, cost benefits assessments, productivity gains, efficiency, competition and growth, e-health related jobs, consumer satisfaction, and many more. An underlying focus of consumer discourse here appears to be that of promoting

a particular kind of “health related consumption” into European (cyber) space.

To make e-health a success, policy-makers advocated preparing the public on a grand scale. Consumers of online health information were expected not only to recognise the importance of quality labels, but also to follow the guidelines elaborated and to integrate the implicit understandings and values embedded in them. They were thus definitely not conceptualised as independently capable of judging the quality of web-information, but as in need of being told how to correctly assess the quality of a web page (through user guidance tools, filtering tools, etc.; EC, 2002b: 11) and to acquire a basic value system of what constitutes reliable information and of who produces valid medical information. We interpreted the strong focus on standardised quality criteria and the recurring phrase of “educating the consumer” as policy writers’ desire to regain control over what seems to be Europeans’ uncontrollable acquisition of information.

*Media discourse.* The media on the contrary again focused more on the e-patient as an individualised actor in this newly opened economic terrain. Because of its flexibility the web was portrayed as a “medium of direct customer care”<sup>30</sup> offering a range of services. Patients thus became a new and quite independent target group<sup>31</sup> that industry had to address. The consumer notion was embedded in a reflection on the potential growth of the IT market, while the “savings for the health care system” aspect was also promulgated. However with the introduction of ICTs, health care clearly gained a transnational dimension. To capture the new consumers, Internet

health services and online pharmacies marketed new notions of distance and space that were embodied, for example, in the recurring slogan-metaphor, “just a mouse-click away”<sup>32</sup>.

Health care and above all prevention (also linked to life-style issues) were framed as a new market and as being important to the development of Europe’s knowledge economy. Hence the consumer had to be given more attention from economic health-actors such as online pharmacies, insurance companies and providers of e-health services on the web; in the logic of “buying services”<sup>33</sup> those actors had to make them “patient-friendly”<sup>34</sup>.

The media promulgated the advantages of the Internet not only as a provider of broad information and services, but also, as they frequently stated, as a means for saving time and money. As the following quotation illustrates, the consumer was positioned to choose freely and to combine different offers to better meet individual needs: “From the daily increasing supply of health-websites the e-health-consumer gets advice from cyber-doctors or support from chat-experience groups. Furthermore [the consumer] can research a specific medical condition and order subscribed medicines, beauty- and wellness products online”<sup>35</sup>. Contrary to the e-patient figure framed as partner of the doctor, the media conceptualised the consumer as an independent actor in an e-health market tied into multiple relational networks.

While consumer protection was evidently also a major issue for the media, they addressed the issue differently than did the policy writers. The media saw the consumer as being vulnerable and in need of protection from “dangers” lurking on the web, such as the increasing

impossibility “to distinguish between scientifically-founded and not seriously vetted reporting”<sup>36</sup> or to determine precarious online pharmaceuticals. Yet at the same time they also stressed that consumer overprotection may simply help in keeping current power-networks in place. Some sceptics were reported as interpreting the suggestion that “doctors should give web-page recommendations”<sup>37</sup> or continuous warnings concerning online pharmacies, as simply a way of serving the interests of classic medical players.<sup>38</sup>

## Discussion

Analysing policy and media discourses shows how they partake in constituting both the citizen-patients as well as the practices that surround them. As Berg and Bowker (1997) argued for the medical record – that through these new technologies both “bodies and bodies politic (...) are reinscribed into novel places, broken apart in new ways, and configured into spaces and times” out of patients’ control, – we argue that with the proliferation of ICTs in the health field and the accompanying discourses patients have been reconfigured too.

Not surprisingly, differences in how media and policy are produced and distributed leads to different enactments of the citizen-patient. Whereas policy-makers generally tried to craft a singular, clear, normative and prescriptive system-reality of how health should be dealt with under these changing conditions and how citizen-patients should respond to it, the media proposed different, more intertwined stories that cast “ICT, health and patients” in dispersed, open and less definite and coherent ways. The latter give more room for ambivalence to be expressed towards these changes and to allow for multiple realities to cohabitate

in the textual space. The core purpose of our investigation was to show the repertoire of these citizen-patient figures that were manifested, and to discuss the imagined possibilities but also limitations introduced through these new technological options.

We find in both media and policy documents that the patient figures bring to light a central tension around what Mol (2002) called the “politics of who”; that is, who should be positioned to decide for the good of whom or who should be given agency and what form should that agency take in the process of reconfiguring the health system. The first two citizen-patient figures in public discourse – the distributed figures in public discourse – emerge from the way data are produced, handled and distributed in the newly emerging health system. The process of decomposing and recomposing patients (Brown and Webster, 2004) is posited as an unquestionable good for all and was hardly scrutinised in regards to the increasing reduction of the patient to a set of data or to the process’s effectiveness in achieving the cherished ends. Instead e-health technologies have become the central preoccupation, giving little or no agency to patients. Rather, patients are expected to allow (and silently support) the creation and distribution of an ensemble of standardised packages of health data through ICTs. They are expected to contribute to the efficiency and (European) standardisation of health care by allowing data and files to speak for them, and they are not to derange the “medical workflow” with inconvenient questions or actions. The technology and all the efforts accompanying its implementation are here imagined as a major ordering force that creates quasi-automatically an appropriate environment and improved health care system. In a wider sense

this vision of a compliant e-patient thus corresponds to the “objectified patient” framed in literature discussing EBM and telemedicine developments (Timmermans and Berg, 2003, Mort et al., 2003).

Our observation that Austrian media largely adopted an optimistic perspective of ICT-related technology<sup>39</sup> while only rarely expressing explicit worries about possible Orwellian aspects associated with data mining corresponds well with findings from other projects on biomedicine in the Austrian context. We interpret the Austrian response in matters of e-health as being part of Austrian techno-political culture that tends largely to cherish medico-technical innovations, work in a hierarchical, paternalist medical model and be characterised by a general mood of conflict-avoidance (Felt et al., 2009a).

However, the other e-patient manifestations distilled from our material are clearly in opposition – though in different ways – to a techno-reductionist vision. Because we focus explicitly on patient-figures, we question the degree of agency afforded to them. We find two strands of arguments in discourses on agency: one discourse strand deals with a civic model of engaging the citizen-patient in making his or her own health choices; the other strand focuses on the patient in the rationale of making health markets visible to her or him.

The discursive interventions around empowerment and responsibility that led to the patient-figures of health manager and of doctors’ partner clearly relate to the civic model of engagement. Yet citizen-patients’ choice is by no means open-ended. Rather s/he is supposed to be educated to understand a specific version of the collective dimension of the health care system and to act accordingly. Hence a form of “disciplined engagement

and participation” is thus envisaged. In other words managing an individual’s health is more than simply a matter of remaining healthy; it further implies that the citizen-patient makes a contribution to the collective by following a shared logic. While policy and media producers accept the idea of prevention as a “self-determined obligation”, the media also discursively intervene in the intrinsically problematic hierarchy between patients and health professionals. Here again the media extol ICTs as a technical solution for reconfiguring a socially entrenched and notoriously sensitive relationship, while not delving far into the actual practice.

Addressing the politics of who via a market model of ICTs with medical interventions and information being displayed on the counters also poses the question of agency attributed to the e-educated and the independent consumer. Media and policy discourses show two commonalities in their view of the patients’ role: First, they share an assumption that e-health is a source of danger and in particular that seeking on-line health information and buying medication on-line constitutes a multi-layered risk; second, the consumer is perceived as an individual that makes choices, and so far less collectivistic rhetoric is used than in the cases where the patient is configured as his or her own health manager and as e-patient-as-partner. However the policy-makers show less trust than the media in the capacity of the citizen-patients as consumers to find the right “goods” for his or her specific needs. Consequently, policy writers employ strong rhetoric advocating for potential patient-consumers to be educated first before engaging with online services. The push for e-education for patients in turn reinforces the position of the medical profession as the obligatory

point of passage for consumers on their way to exposure to market forces.

Thus for all four of the latter e-patient figures we observe a simultaneous deconstruction and reconstruction of medical authority. Although one could have expected the emergence of an empowered e-patient because of the dense and open politics of information distribution and access, our analysis suggested that through the policing of this information (e.g. through quality labels, reinstalling the doctor as information trader) the medical establishment retains its authority. Hence, while in all their e-incarnations patients are granted substantive agency on one level, their agency is often limited because of their assumed need for guidance and education to negotiate the realm of e-health.

## Conclusion

We have focused in our analysis on the ways citizen-patients are reconfigured in European policy documents and in the Austrian media in the context of ICT and health. In doing so we understood both arenas as kinds of societal laboratories in which experimentation with different ways of linking ICT, the health system and citizen-patients takes place. Analysing these discourses and the imaginations which are developed through them thus seems essential, as they get inscribed into and form part of what could be labelled “civic epistemologies”, that is “culturally specific, historically and politically grounded, public knowledge-ways” (Jasanoff, 2005: 249) – in our case knowledge-ways of potential articulations of health, ICT and the citizen-patients.

Based on our identification of three dominant discursive registers, we elaborated on the partly contradictory

manner in which the citizen-patients are imagined and performed. Taking shape in regard to different expectations, linked to distinct sets of e-health technologies (information web pages, data storage systems, e-cards, telemedicine, etc.) and to partly contradictory normative framings, the e-patient remains an elusive figure. For example, the presumption of an informed, self-responsible citizen-patient that takes health matters in his or her own hands contradicts the simultaneously portrayed image of the patient that must silently obey prescribed medical treatments derived from standardised evidence-based elements or must consume only pre-screened information. Yet in the narrations ICT, health and patients in all their complexities simply co-exist. Our research with patients carried out in the same project has informed us that these tensions play out in relevant ways in how patients imagine their potential to act, the rights they have and when change is possible. The tensions would thus require serious consideration to give life to new kinds of e-health systems that offer more potential involvement for citizen-patients (Felt, 2008).

In instances where individuals were supposed to be empowered through their use of ICTs, this could only happen after “adequate” education, imposing the “right way of seeking and handling information” and of responsibly looking after his/her health state yet only as long as s/he is conceptualised as healthy. The enactment changes when the citizen-patient becomes predominantly a patient. Then increasingly standardised decision-making processes based on clinical evidence and “informed compliance” (Felt, 2008) is expected, where the patient is supposed to support the system and not to act independently. Thus what is at

stake here is not only a *politics of who* gets a voice but also the implicit politics of when voice is given or denied. Currently a citizen-patient's "guided choice" seems imaginable and acceptable only as long as s/he is considered healthy. Once an individual assumes the role of patient, the system's "predefined choice" modes are activated. The last question for which we recommend further investigation is from where is the citizen-patient supposed to act? Is an individual to act from a standpoint that considers personal experiences and values or from an already normatively pre-conceptualised and more system-oriented position?

These observations closely link to broader debates around governance and participation in techno-scientific choices, where citizen participation is rhetorically staged as the gold standard, while not reflecting the framings in which they are supposed to happen. More critical commentators have argued that the governance discourse may be interpreted as an element of a neo-liberal mode of governance that shifts responsibility to citizen groups and have shown how choice would actually be quite importantly narrowed down by the very ways of enacting participation. Requesting citizen-patients to be e-educated first in order to make choices, or to follow quality labels and doctors advice in the information selection, clearly starts from the assumption of a well-defined rationality that needs to be "learned" in order to make "the right" choices (Felt and Fochler, 2008).

We recall Jasanoff's idiom of co-production to argue for an understanding of the ways citizen-patient figures are constructed, of the multiple forms they are given and of the inherent and unaddressed contradictions to grasp some of the pervasive conceptualisations

that tacitly shape the articulations of ICT, health and citizen-patients. Together with in-depth studies of social practices in these changing health contexts this might lead us to a better understanding of the process of co-production of both techno-scientific innovations and societal change in the e-health domain.

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## Notes

- <sup>1</sup> We do not here enter the debate around the meaning of the notion of e-health or offer further definition. We note, however, that although *e-health* has become a widely used label there is no clear common understanding of the way in which this notion is used (Eysenbach 2001).
- <sup>2</sup> Much of this corresponds to the classic deficit model criticised in much of



the critical public understanding of science literature.

<sup>3</sup> Originally we had planned to analyse Austrian policy documents as well. At the time of our analysis however the Austrian e-health working group, which consists mainly of industrial actors, had just been implemented (autumn 2005) and thus only a first draft of a rather technical working paper existed. Hence, we did not include this paper in our analysis.

<sup>4</sup> We would like to briefly reflect on two limitations of our data used in this article. First one might question the power of EU discourses on the concrete national contexts and thus on the framing the e-patient might take in concrete contexts. Yet we would argue that even though the EU policy might not create a direct impact on the discursive framing, the dominant notions and imaginaries become a repertoire from which nation states also pick their references. Second, one might argue similarly about media. Indeed throughout the project we observed how citizens and patients move through this new information landscape opened by the Internet and use quite different resources to build their position. Yet imaginaries and potential roles offered by the media could be seen as a shared background resource people can refer to.

<sup>5</sup> See [ec.europa.eu/information\\_society/europe/i2010/docs/implementation/ddf\\_report\\_final.pdf](http://ec.europa.eu/information_society/europe/i2010/docs/implementation/ddf_report_final.pdf)

<sup>6</sup> Our articles were taken from the APA-DeFacto database, which allows a search in all major Austrian newspapers and magazines. Our search resulted in 279 articles from 11 newspapers and 15 magazines, from which we chose 105 sources dealing particularly with citizen-patients. Word

length was between 200 and 600; only a few articles, mainly in magazines, were longer.

<sup>7</sup> Kurier 25.6.2000: *Das Handy wird zu unserem digitalen Schutzengel*

<sup>8</sup> Presse 01.12.2004: *Ärztealarm - Sorge um Patientendaten*

<sup>9</sup> Die Presse 14.12.2006: *Krankenscheinersatz: Patient ist Herr seiner Daten*

<sup>10</sup> Die Presse 11.6.2004: *Telemedizin: Kein Hautkontakt in der Dermatologie*

<sup>11</sup> Kurier 25.6.2000: *Das Handy wird zu unserem digitalen Schutzengel*

<sup>12</sup> Die Presse 19.02.2005: *medizin von morgen: Ambanduhr registriert Infarkt*

<sup>13</sup> Both of them not realized at the time of writing.

<sup>14</sup> Format 2.10.2000: *Gesundheit: der vernetzte Patient*

<sup>15</sup> Bestseller 15.11.2001: *Wachstumsmarkt E-Health*

<sup>16</sup> E-media 24.2.2003: *Dr. Internet*

<sup>17</sup> Neue Kronen-Zeitung 10.2.2001: *Internet-Hilfe für Krebspatienten*

<sup>18</sup> E-Media 24.2.2003: *Dr. Internet*

<sup>19</sup> Format 2.10.2000: *Gesundheit: der vernetzte Patient*

<sup>20</sup> Horizont 7.12.2001: *E-Health macht die Patienten mündiger*

<sup>21</sup> Format 2.10.2000: *Gesundheit: der vernetzte Patient*

<sup>22</sup> Wirtschaftsblatt 26.9.2001: *Gesunde Geschäfte im Internet*

<sup>23</sup> Format 23.12.2004: *Das Jahr der Revolutionen*

<sup>24</sup> Format 2.10.2000: *Gesundheit: der vernetzte Patient*

<sup>25</sup> Der Standard 11.10.2001: *Der informierte Patient*

<sup>26</sup> E-Media 16.11.2007: *Doktor Google und Schwester Wiki*

<sup>27</sup> E-Media 24.2.2003: *Dr. Internet*

<sup>28</sup> Der Standard 18.04.2007: *Gesundheitsportale sind Gratwanderung*

<sup>29</sup> Kurier 27.06.2003: *Der Patient der Zukunft wird anspruchsvoll sein*

- <sup>30</sup> Format 22.1.2001: Onlineberatung: Lebenshilfe für Cyberbürger
- <sup>31</sup> Bestseller 15.11.2001 *Wachstumsmarkt E-Health*
- <sup>32</sup> Computerwelt 27.10.2000: *Dicke Luft um Online-Apotheken*
- <sup>33</sup> Format 23.12.2004: *Das Jahr der Revolutionen*
- <sup>34</sup> Computerwelt 27.10.2000: *Dicke Luft um Online-Apotheken*
- <sup>35</sup> Gewinn 1.10.2000: *Marketing-Trends aus den USA: Besseres Leben aus dem Netz*
- <sup>36</sup> Kurier 28.8.2000: *Das Bild von den Göttern in Weiß gehört auf die Müllhalde*
- <sup>37</sup> Bestseller 15.11.2001 *Wachstumsmarkt E-Health*
- <sup>38</sup> Profil 15.11.2004: *Pillenklick*; E-media 16.11.2007: Doktor Google und Schwester Wiki
- <sup>39</sup> Oudshoorn (2003) makes similar observations in the Dutch case she investigated.
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