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# DISSERTATION

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**Mediated Knowledge:**

**Sociotechnical practices of communicating  
medical knowledge via the web and their  
epistemic implications**

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## **1 Introduction**

Medical knowledge is no longer exclusive to the medical school and the medical text; it has "escaped" into the networks of contemporary infoscapes where it can be accessed, assessed and reappropriated. (Nettleton and Burrows 2003: 179)

### **1.1 The "e-scape" of medical knowledge**

Lately I entered a small pharmacy in the city of Vienna, where I became a silent observer of the following situation: A middle-aged man was standing at the counter demanding a specific pharmaceutical product. As he appeared to have no prescription, the pharmacist asked him whether his doctor had recommended the product to him, which seemed to be the standard procedure. The man answered straightforwardly, "No, I read it on the internet". The pharmacist shook her head slightly, turned around, and went away to search for the drug, which she then handed over to the customer. I mention this episode because it illustrates current developments in the medical field, which are tightly intertwined with the spread of information and communication technologies (ICT). The customer may be interpreted as an "informed patient" – a widely discussed figure in public and academic debates (Hardey 1999, Henwood et al. 2003, Felt et al. 2009b). The buzzword "informed patient" suggests the substantial changes the patient role is currently undergoing. In the context of wider techno-scientific developments in current "knowledge" or "information societies", patients are no longer expected to be passive recipients of medical advice, but rather active agents who are engaged in medical decision-making and challenge medical authority. Drawing on Giddens' (1991) notion of the "reflexive self", Hardey (1999) conceptualizes the informed patient as a "reflexive consumer" taking health matters into his or her own hands.

In an age of reflexive modernization, where life has become a project to be actively managed by the individual, as Giddens (1991) argues, health and illness have become a domain to be taken care of by the patient. Provided with a multiplicity of medical treatments, the patient or "consumer" is supposed to actively choose from multiple options rather than passively obeying the doctor. The growing trend towards procedures such as "informed consent", which require the patient to consent to medical therapies, may be seen as the institutionalization of this changing patient role. While Giddens (1991) argues that choice may be both liberating and troubling for the individual, the notion of the "informed patient" is widely linked to positive images of patient empowerment. In many of these debates, informed patients are seen as acting in an empowered way in regard to doctor-patient relations and everyday practices of handling health issues. In these discourses, the term "patient empowerment" should not be seen as having a clear-cut meaning, but rather multiple, often contradictory ones, as will be critically discussed

in this thesis. It will further be shown that ideas of empowered patients – in all their different facets – have gained ground in society. Despite hints that empowered patients sometimes experience constraints in medical practices (Henwood et al. 2003, Broom 2005a, 2005b), the notion of the empowered patient has become omnipresent in narratives around current developments in the medical field, particularly in regard to the web, as I will show. But how do patients actually manage to get empowered?

As the notion of the “informed patient” implies, access to knowledge is regarded as a central precondition for patient empowerment. “At the heart of medical autonomy is exclusive access to ‘expert knowledge’” (Hardey 1999: 823). Ideas of empowered patients are tightly connected to the growing relevance of ICT in enabling and expanding access to “expert knowledge”. Medical knowledge has been described as having “e-scaped” medical halls and spread into society through various types of media and ICT (Nettleton and Burrows 2003, Nettleton 2004). One central location where medical knowledge is provided, distributed, and acquired these days is the internet. Like the customer in the pharmacy, more and more Austrians are turning to the world wide web to acquire medical knowledge. According to “Statistik Austria”<sup>1</sup> (2008) nearly 50% of Austrian internet users employed the web to inform themselves about medical issues in 2008, and the number is expected to rise in the next few years. This makes Austria part of a global trend. Half of EU citizens use the web for medical purposes, a recent EU-wide survey has stated (Kummervold et al. 2008). In the United States, numbers are even higher. More than 60% of American internet users search for health-related topics, making the act of looking for medical information one of the most popular online activities (Fox and Jones 2009). Although numbers of course vary between statistics, they all agree that the web has become a central source for health information around the globe.

Whether the web should be seen as *a valuable information source*, however, is controversially discussed. Much academic and public debate celebrates the web as broadening access to the production and use of medical knowledge (Hardey 1999, Anderson et al. 2003, Broom 2005b, Felt et al. 2009b). In these interpretations the web is seen as offering heterogeneous medical information ranging from expert to non-expert accounts (Nettleton 2004), and thus blurring traditional hierarchies between expert and lay knowledge. In this context the web is also described as democratizing medical knowledge through giving voice to previously marginalized actors, patients in particular. Here, the web is described as a “bottom-up medium” (Anderson et al. 2003) facilitating the publication of medical information. The democratic potential of the web as a health information source may be seen as linked to wider concepts of the web as a provider and distributor of knowledge on a decentralized, more egalitarian basis – an aspect critically

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<sup>1</sup> Statistik Austria is a research institution conducting quantitative research and surveys in Austria on various issues including ICT use in Austrian organizations and households on a regular basis.



challenged in this thesis in the particular medical context.

Instead of interpreting the web as democratizing medical knowledge, members of the medical establishment and policy makers display a rather reluctant attitude towards the web as a health information source (European Commission 2002, Henwood et al. 2003, Broom 2005a). Like the pharmacist described in the episode above, medical professionals often shake their heads and doubt the quality of medical information provided online compared to professional medical criteria. In this context, the web is seen as endangering patients by spreading misinformation and harm (Broom 2005a, Eysenbach et al. 2002). One central reason for the reluctant attitude of doctors is the fear of losing their knowledge monopoly (Broom 2005a), a flipside and consequence of patient empowerment. As a solution to the problem, policy makers and medical professionals try to regain control over "e-scaped" medical knowledge and its use through introducing standardized quality labels for medical websites supposed to direct users to the "right" information as defined by medical experts (European Commission 2002, Eysenbach et al. 2002). In these debates the web turns from a valuable information source interpreted as democratizing medical knowledge from the bottom up into a source of risk to be governed and regulated from the top down. Why strategies of regaining control over "e-scaped" medicine from the top down rarely work out in practice will be shown in the course of this thesis.

The controversial discussions of the web as a health information source show that these debates center on the diversity of online health information and its potential for changing medical practices, for better or for worse. These discussions may be seen as embedded in the wider struggles over medical knowledge that may currently be observed in the medical field, as will be discussed. However, while much has been speculated about online health information and its quality, little is known about the way medical knowledge is actually communicated via the web. How do different types of actors provide medical knowledge online, and how do different users – such as the customer in the pharmacy above – employ the web to obtain medical knowledge from the web?

## **1.2 Mediated act of communication**

Scholars in the field of critical public understanding of science (critical PUS) have shown that the communication of scientific knowledge should not be seen as a linear transfer of knowledge from scientists to laypeople. Rather than passively receiving knowledge from the top down, laypeople should be seen as engaging with the knowledge provided by relating it to and embedding it in their own experiences and bodies of knowledge (Michael 1992, Wynne 1992). Particularly in the medical context, laypeople make sense of expert knowledge by connecting it to their own life stories, individual day-to-day routines, and

embodied knowledge (Busby et al. 1997). Further, not only knowledge itself, but also categories such as trust and credibility are central in these acts of communication. The institutional affiliation, behavior and credibility of “experts” are of central relevance in practices of acquiring and interpreting scientific knowledge (Wynne 1992). Hence, scholars in the tradition of critical PUS have concluded that laypeople actively select, interpret, and make sense of knowledge not necessarily corresponding to experts’ visions (Wynne 1992, Michael 1992) – an aspect that will be further discussed in regard to the web as health information source. In current information societies laypeople obtain scientific – and most particularly medical – knowledge not only in face-to-face interactions, but increasingly from multiple media, the web in particular. The question thus arises of how medical knowledge is communicated via the web in a highly technically mediated act of communication. How do different actors offer and distribute medical knowledge via the web, and how do they try to evoke trust and credibility on the user side? How do users browse through, select, and interpret medical web information, and how do they evaluate its credibility? And what wider epistemic implications are involved in these mediated acts of communication? Those are central questions to be answered in this thesis by investigating practices of providing and acquiring medical knowledge via the web and related narratives.

In comparison to face-to-face communications between medical professionals and patients, this technically mediated act of communication is characterized by crucial differences: First of all, not only medical professionals, but also organized and individual patients, commercial actors such as the pharmaceutical industry or health portals, providers of alternative medicine such as homeopathy and traditional Chinese medicine, and newly emerging platforms such as the user-generated online encyclopedia Wikipedia may be seen as configuring and co-shaping medical web information. The “e-scape” of medicine may thus be seen as triggering tendencies of *knowledge proliferation and diversification* corresponding to wider societal developments, as I will discuss. But the “e-scape” of medicine triggers not only tendencies of knowledge proliferation, but also *transformations of knowledge* due to its technical mediation or “informationalization”, as Nettleton and Burrows (2003) argue. Drawing on Lash (2002), they explain that discursive medical knowledge should be seen as increasingly displaced by “informational knowledge” interpreted as fragmented, disembedded and ephemeral, as I will describe in detail when clarifying the terms knowledge and information. “This means that the conditions of its consumption via networked technologies make a reflexive engagement with information more difficult than is supposed in many theoretical accounts in reflexive modernization” (Nettleton and Burrows 2003: 181). This shows that a closer look needs to be taken at the strategies involved in practices of providing and, most particularly, obtaining medical knowledge via networked technologies such as the web. This, however, draws the technology into the story. It indicates that the “complex media” and “sociotechnical arrangements” (Michael 2002: 366) through which knowledge circulates

today need to be taken into account according to Michael (2002), an aspect widely underrepresented in the field of critical PUS.

This thesis aims to take Michael's request seriously by investigating how knowledge is communicated via the web in the context of medicine where expectations regarding patient empowerment are high. Contrary to much web research focusing on the way knowledge is communicated via particular web 2.0 platforms such as Wikipedia (Pentzold 2007) or online patient support groups in the medical field (Loader et al. 2002), I focus rather on traditional practices of providing and acquiring medical knowledge via the web. I am particularly interested in the heterogeneity of medical web information and its consequences, which have been widely discussed in the literature. Accordingly, I aim to investigate how different types of actors contribute to and co-shape the "mass of health information" (Hardey 1999) by configuring a website and relating it to other web information to attract users, and how users browse, interpret, and make sense of medical web information out of the plethora offered to them. Concretely, I am interested in the way various actors – including medical professionals, patients, and commercial actors – communicate their respective medical knowledge through websites and how different users – varying in age, medical backgrounds, and technical skills – pick up medical information from multiple websites and distill knowledge out of it. To put it briefly, I aim to explore many-to-many interactions between multiple types of website providers and users.

Hence, I conceptualize providers and users of medical web information as two distinct yet not homogeneous actor groups. The distinction between website providers and users – not self-evident in regard to the web – reflects the fact that the majority of users searching for medical information do not actually contribute information. Less than 10% of patients using the web for medical purposes actively add content by posting information in an online discussion, listserv or other patient group forum, as a recent US study has shown (Fox and Jones 2009). While the distinction between providers and users of information may indeed be seen as blurring in regard to web 2.0 applications, it has generally held up concerning traditional information practices in the medical field. The set-up of this study recognizes this circumstance by focusing on the mediated acts of communication between different website providers and users. As the communication between website providers and users may not be directly observed, being highly technically mediated, I will explore website providers' and users' practices separate from each other. I analyze them as reciprocal information practices, enabling me to draw conclusions about the mediated relation between website providers and users.

Consequently, the technology and its specificities mediating between website providers and users need to be considered equally. Scholars in the field of new media studies have argued that a range of "information politics" (Rogers 2004) are involved in the provision,

distribution, and use of web information. Contrary to democratic visions of the web, they have shown that websites should not be seen as equally distributed. Rather, some websites manage to become dominant hubs, while others appear to be marginalized (Barabási 2003). Further, search engines have entered the picture. Users widely rely on search engines when browsing through the web, making them “information gatekeepers” (Diaz 2009). Because of their weighted algorithms, they have been interpreted as introducing hierarchies of new kinds running counter the democratic ideal of the web (Introna and Nissenbaum 2000). Besides information-political considerations, ICT have been discussed as potentially contributing to information fragmentation, as will be argued in detail. A central question thus is how “information politics” and processes of information fragmentation enter the medical realm and shape practices of providing and acquiring medical knowledge across different websites. Only when it is understood how medical knowledge is actually communicated between website providers and users and how the web and its technical gestalt shape these mediated acts of communication can the empowering potential of the web as a health information source – in whatever sense – be seriously discussed.

### **1.3 Exploring sociotechnical practices: Research questions, analytical framework, and methods**

The empirical part of this thesis will focus on the way medical knowledge is communicated between different types of website providers and users and what epistemic implications this technically mediated act of communication involves. Central question guiding the analysis will be these: How do different website providers engage with the technology to communicate their respective medical knowledge through providing and positioning a medical website, and how do different users interact with the technology to browse, select, and interpret medical web information and obtain knowledge meeting their needs? How do technical entities such as links, search engines, HTML code, design elements, and other materiality shape and mediate between website providers’ and users’ practices? How do different types of website providers try to evoke trust on the user side, and how do different types of users evaluate medical web information and its credibility? And what underlying epistemologies may be seen as embedded in website providers’ and users’ practices?

To fully understand practices of providing and acquiring medical knowledge via the web and their epistemic consequences, both social actors and technical entities need to be considered, as indicated above. A theoretical framework serving this purpose is the actor-network theory (ANT). ANT allows for understanding practices of both providing and acquiring medical knowledge as sociotechnical practices shaped by social actors such as

different types of website providers and users, but equally by technical entities such as links, HTML text, search engines and their algorithms, and the like. It enables to combine technical and social elements within one explanatory structure (Latour 1987, 2005, Law and Hassard 1999), which I will discuss in more detail. This analytical perspective helps to develop a fine-grained understanding of the heterogeneous entities and their complex sociotechnical relations involved in the way medical knowledge is communicated between website providers and users and the role the mediating technology plays.

To empirically explore sociotechnical practices of communicating medical web information, I draw on material that has been developed in the research project "Virtually Informed", which investigated the internet as a health information source in the Austrian context from multiple perspectives<sup>2</sup>. For the purpose of this thesis I particularly draw on hyperlink networks, qualitative analyses of different medical websites including a homepage of a doctor, websites of an individual patient and a patient association, a health portal, and a site of a pharmaceutical company, as well as qualitative interviews with their providers. These multiple data afford insights into the way different types of providers offer and distribute medical web information, and the ideas embedded in their practices. On the user side, I draw on search experiments carried out to capture how users varying in age, education, medical preferences, and internet experience browse through the web and order and select information when looking for a medical issue. In addition, successive qualitative interviews with these users have been conducted to get an understanding of the filtering and evaluation strategies underlying their information practices. All together, these different viewpoints enable me to understand how medical knowledge is provided and acquired by different types of website providers and users, what mutual ideas accompany providers' and users' practices, how trust and credibility are negotiated in these practices, and how the technology contributes to this mediated act of communication.

Thematically, I focus on the supply and acquisition of diabetes-related knowledge. Diabetes is one of four chronic diseases that were chosen in the research project, under the assumption that a chronic disease would result in an increased need for knowledge to be met with the web, an assumption that was confirmed in the course of the project. For the purpose of this thesis I exclusively focus on diabetes so as not to get drawn into different topical directions in the empirical analysis. Diabetes serves as a case study by means of which sociotechnical practices of providing and acquiring medical knowledge via

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<sup>2</sup> The project "Virtually Informed: The Internet in the Medical Field" was carried out at the Department of Social Studies of Science, University of Vienna, from 2005-2009 (project lead: Univ.-Prof. Dr. Ulrike Felt, collaborators: Lisa Gugglberger, Bernhard Höcher, Sonja Österreicher, Astrid Mager, Paul Ringler; financed by the Austrian Science Fund (FWF), project number P 18006. Further information to the project: <http://sciencestudies.univie.ac.at/research/completed-projects/virinfo/?L=2> (accessed March 2010).

the web will be observed. This thesis aims to combine and integrate different methods and perspectives to reach a new view of the sociotechnical dynamics involved in the communication of medical web information. To handle this complexity, diabetes has been chosen as a focal point holding these different sorts of material together. Hyperlink networks show the diabetes information landscape from a bird's-eye perspective, analyses of different diabetes websites and interviews with corresponding providers enable me to zoom in and explore how diabetes websites are provided and distributed online, search experiments show how users browse through and obtain diabetes web information from multiple websites, and successive interviews enable me to get hold of users' own interpretations of searching for knowledge on diabetes. Further, focusing on diabetes as a case study allows for juxtaposing providers' and users' reciprocal information practices and narratives that center to a certain degree on the same websites.

In the course of this PhD project a number of choices have been made for the sake of the argument that trigger certain limitations. One choice was to focus the theoretical parts of this thesis on broader discussions around knowledge, information, and ICT in the medical field and beyond. Consequently, I do not focus on diabetes as a disease, as this would open up questions of very different kinds. Another choice was to analyze information practices across different websites from a macro perspective to get a broader picture of the web as a health information source, which is, in my view, lacking. This, however, means that micro communication practices happening on particular websites, in a discussion forum, for example, will not be considered in detail, as this would go beyond the scope of this already challenging study. Finally, I decided to focus on website providers and users of medical web information and will thereby exclude non-users. Despite the rising number of users employing the web for medical purposes there are still many people who do not – and do not want to – acquire medical information from the web, most likely elderly users. I mention this aspect so as not to lose this perspective in the following pages, where online practices are given centre stage.

#### **1.4 Outline of the thesis**

In the first chapter I embed my empirical analysis in broader discourses framing *current societies as knowledge or information societies*. A central question will be this: Why are knowledge and information seen as central features of Western societies, and what do the terms "knowledge", "information", and "informational knowledge" signify in these discourses? I argue that neither "knowledge" nor "information" appears to be clearly defined in these discourses, which embrace quite different societal developments. Against the multiplicity of these concepts, I argue that a concept needs to be developed how knowledge, information, and ICT relate to one another. These considerations enable me

to observe how medical knowledge is communicated via the web and which consequences the technical mediation of knowledge may trigger.

What makes knowledge, information, and ICT central in contemporary medicine is the main question to be answered in the second chapter. I argue that ambivalences in debates over the web as a health information source may be seen as embedded in the broader *struggles over medical knowledge* I discuss under the labels of “patient empowerment” and “evidence-based medicine”. Drawing on work that has specifically explored and discussed the web as health information source and the quality of medical web information, I finally argue for a shift of attention *towards information practices*.

In the third chapter I draw on work from the field of new media studies to discuss the range of “*information politics*” involved in the supply and use of web information across particular websites. Central questions will be these: What role do hyperlinks play in strategies of positioning websites on the web? How do search engines and their algorithms shape the provision, distribution and use of web information, and what consequences do they trigger? Finally, I discuss how insights gained in this research field serve the exploration of practices of providing and acquiring medical knowledge in the medical context.

This further requires presenting actor-network theory and how it will serve my analysis as the central analytical approach, which I do in the fourth chapter. The central question here is how to conceptualize *website providers’ and users’ online practices as sociotechnical practices*. What concept of agency enables us to understand both social and technical entities as actors in this mediated act of communication? And what advantage may be drawn from such an analytical shift? Drawing on central concepts from the tradition of ANT, I argue that this analytical perspective enables me to shed new light on sociotechnical dynamics and power relations involved in the communication of medical web information and explore its wider epistemic implications.

In the sixth chapter I draw together insights gained from the various theoretical resources to set the stage for the empirical analysis, formulate the central *research questions*, and discuss the *methods and empirical material* used to answer these questions in greater detail.

The next four chapters contain the empirical analysis. In the first of these chapters (Chapter 7) I describe how website providers and users themselves *conceptualize the web as a health information source*. Do they refer to the empowering potential of the web as discussed in many academic and public discourses, and how do they themselves interpret patient empowerment? Do they see the web as a dangerous information source, and what other interpretations do they bring to the fore? Secondly, I discuss the different

*motivations* that different types of website providers and users express for using the web for medical purposes to underline the heterogeneity of both actor groups. Further, I discuss how different agendas and medical backgrounds shape which medical information is actually provided and searched for by them.

In the eighth and ninth chapters I discuss website providers' and users' socio-technical practices in detail. In the eighth chapter I discuss *how website providers and users find each other in the online medical marketplace*. I analyze strategies website providers employ to position their medical websites to attract users and which strategies users employ to find medical information meeting their individual needs. I finally ask how technology, and search engines in particular, mediate between websites providers' and users' practices, and what consequences result from these practices. In the ninth chapter I analyze *how website providers and users communicate medical information via websites*. I discuss how website providers present their medical websites and assemble information and how users browse and acquire information from medical website in reciprocal information practices. Further, I explore how technical features mediate between, but also contribute to, website providers' and users' practices.

In the tenth chapter I elaborate the *underlying epistemologies related to website providers' and users' practices*. How do providers try to make their medical information credible and evoke trust on the user side? And how do users interpret and evaluate medical web information and distil knowledge out of it? In this analysis I show that website providers' and users' epistemic practices are shaped by a complex network of "thought styles", individual motivations and agendas, and strategies for interacting with the technology. I further show that website providers and users conceptualize medical web information differently, in ways closely related to their reciprocal interactions with the web and its features.

In the concluding chapter I discuss the wider implications of my empirical results, focusing on three central aspects. First, I show how ideas of the web as democratizing medical knowledge are challenged by sociotechnical dynamics triggering "*information politics*", *hierarchies*, and *inequality* of new kinds. Second, I argue that a range of *skills and knowledge work* are required to empower oneself through obtaining medical knowledge from the web, in contrast to notions of becoming empowered through the web. Third, I argue against top-down regulations of online health information and strategies of "educating" users. Rather, I suggest *engaging with "informed patients" on an equal basis*, particularly on the side of medical professionals, because visions of patient empowerment – however interpreted – will remain futile otherwise.



## **2 Knowledge, information, and ICT in present-day societies**

Present Western societies are widely described as either “knowledge” or “information societies”. These descriptions pervade and shape virtually all corners of society, including the medical field. They provide a discursive framework for current developments in medicine, and the growing importance of the web as a health information source in particular. The purpose of this chapter is to provide an overview of these characterizations, identify multiple concepts of knowledge and information inherent in them, and ask what role information and communication technologies (ICT) play in these considerations. Against the background of these theories, I develop a concept of the way knowledge, information, and ICT relate to one another that helps to conceptualize and analyze how medical knowledge is communicated via the web.

Although knowledge has become a central characteristic of present-day societies, as buzzwords such as “knowledge society”, “knowledge-based society”, and “knowledge-based economy suggest”, the term “knowledge” itself remains rather vague. These labels are used to discuss diverse developments ranging from the growth of the service sector, to the increasing importance of scientific knowledge in present-day societies, to the multiplication of knowledge as a source of power and risk. The confusion grows when we take literature dealing with the information society into consideration. The label “information society” is employed when talking about the growing importance of ICT, the growth and multiplication of information, and the transformations information is undergoing in present-day societies. It seems as if we live in an age where the amount of knowledge and information is growing, while its meaning is vanishing. In much of the literature the terms “knowledge” and “information” are used synonymously without defining either. This fact may be simply dismissed as imprecision of the authors. However, it may be more productive to take the fact itself as an expression of the transformations knowledge is currently undergoing, tightly intertwined with the spread of ICT. Let me discuss this argument by critically examining theories of the knowledge and information societies and the role ICT plays in these multiple bodies of work.

I start by presenting various concepts of knowledge inherent in different theories of the knowledge society. I criticize the rather narrow concept of knowledge equated with rational, “objectified” scientific knowledge exclusively residing with “experts” presented in EU policy debates (European Commission 2000) and the original concepts of the knowledge society (Bell 1973). I then position my thesis in work showing that boundaries between scientific and non-scientific or “expert” and “lay” knowledge seem to blur in reflexive modernization or the late modern age (Nowotny et al. 2001, Stehr 2001, 2005). I show that actors producing knowledge are increasingly diverse and that different types of knowledge reside side by side. A central question thus is what consequences derive from the multiplication of knowledge for the individual or “reflexive self” (Giddens 1991)

and what skills are needed to interpret and make sense of knowledge in the late modern age. Work in the field of critical PUS (Wynne 1992, Michael 1992) has shown how laypeople perceive and evaluate scientific knowledge, as I will discuss in greater detail. But how do people interpret and make sense of different types of knowledge, particularly when circulating through the web?

While scholars writing about the knowledge society generally neglect mediated forms of knowledge and information, authors framing current societies as information societies primarily focus on information and how media, particularly ICT, contribute to the “informationalization” of society (Lash 2002, Webster 2002). In this context I primarily position my thesis in sociological work, arguing that information is seen not only as spreading, but also as crucially transforming in current societies (Lash 2002). In this interpretation, information – or “informational knowledge” – is described as increasingly fragmented, disembedded, and diminishing in meaning (Lash 2002). The question thus arises whether and how new technologies such as the web contribute to tendencies of information fragmentation and decontextualization? And what consequences do these tendencies trigger on parts of users searching for knowledge, rather than for disembedded, fragmented information?

To empirically explore this question a shift of perspective is needed. To conclude this chapter I argue that the focus of attention needs to be shifted from distinct notions of knowledge, information, and ICT towards a relational concept of these three domains. This enables me to observe how website providers translate their respective medical knowledge into information through configuring a website and how users interpret and make sense of heterogeneous medical web information and create knowledge out of it, as I will discuss.

## **2.1 Multiple types of knowledge in “knowledge societies”**

Research and technology account for between 25 and 50% of economic growth and is a principal driving force for competitiveness and employment. In the knowledge based society, they will, more than ever, be an engine of economic and social progress. In the global economy, technology and research represent tomorrow’s jobs. (European Commission 2000: 18)

This quotation comes from the Lisbon Agenda, the European policy paper that has become central in policy debates around the knowledge society. It illustrates that European policy makers clearly define the knowledge society on the basis of economic factors. Research and technology are seen as central driving forces making Europe more competitive by creating jobs and ensuring sustainable growth. Interpretations of the

knowledge society primarily based on economic change are common in the policy realm, as the Lisbon Agenda (European Commission 2000), OECD reports (OECD 2001), and other policy papers indicate (Heidenreich 2002). The concept of the knowledge society advanced by European politics may be seen as rooted in original ideas of the knowledge society formulated in the 1960s and 70s by authors such as Daniel Bell (1973), Peter Drucker (1969), and Robert E. Lane (1966). Their basic argument is that all societal spheres, and most importantly the economic sphere, are increasingly penetrated by knowledge as the foundation of social action. In his book *The Coming of Post-Industrial Society*, Bell describes the newly emerging society as a knowledge society for two major reasons:

- (1) "the sources of innovation are increasingly derivative from research and development (and more directly, there is a new relation between science and technology because of the centrality of *theoretical* knowledge)", and (2) "the weight of the society – measured by a larger proportion of Gross National Product and a larger share of employment – is increasingly in the knowledge field." (Bell 1973, cited in Stehr and Ericson 1992: 7, emphasis in original)

The similarities between Bell's concept and recent political interpretations of the knowledge society are striking. Both refer to knowledge as a principal source of economic production and employment. Concretely, Bell distinguishes two dimensions of the knowledge society. Like the Lisbon agenda, he identifies a shift from goods to services by referring to GNP and employment figures in his second point. Drawing on statistics, he argues that the goods-producing sector of the US workforce declined, while the service sector increased, which he relates to the growing importance of knowledge. One of the central indicators Bell describes is the increase of "knowledge workers". In Bell's view, the most crucial group of knowledge workers are scientists, who figure as human resources for innovation, followed by teachers, librarians, lawyers, architects, and engineers, to name but a few, but also medical and health staff.

#### *Scientific knowledge residing with "experts"*

In his first point, however, Bell makes perfectly clear what type of knowledge he has in mind when talking about the knowledge society. Not all types of knowledge are gaining equal importance in the knowledge society; most important is scientific knowledge, in terms of codified "*theoretical* knowledge", Bell (1973) claims. He discusses how the growing importance of scientific knowledge triggers innovation and a new relation between science and technology. This new relation is characterized by an accelerated pace of the translation of knowledge into technology, disseminating science in all societal spheres, a highly relevant topic when following discussions on the EU policy level. The notion of knowledge inherent in early theories of the knowledge society has been interpreted in the light of modernity, where scientific knowledge clearly figures as

superior to other forms of knowledge. Focusing on the "*Culture and Power of Knowledge*" in current societies, Stehr and Ericson (1992) criticize Bell's concept of the knowledge society as mirroring the Enlightenment faith in rationality and progress: It indicates a "primacy of theory over empiricism" (Stehr and Ericson 1992: 9), reflecting the great optimism of the 1960s that common sense and irrational forms of thought would be displaced by scientific reasoning, Stehr and Ericson argue. The narrow concept of scientific knowledge these theories embody becomes strikingly clear when we read how Lane (1966), another central proponent of early concepts of the knowledge society, imagines how members of the knowledge society act. According to Lane members of the knowledgeable society let their actions be guided by "objective standards of veridical truth, and, at the upper levels of education, follow scientific rules of evidence and inference in inquiry" (Lane 1966: 650). Similar statements may be found in policy debates over "educating" the public about science and technology issues, which has widely been labeled "classical" public understanding of science (PUS). This notion of PUS (Bodmer 1985) suggests a concept of the public as having a knowledge deficit and thus being in need of education in techno-scientific issues (Felt et al. 2009a). In this context, knowledge is clearly seen as objectified knowledge exclusively on the part of scientists. The public needs to be "enlightened" by scientists from the top down – an idea similarly raised in regard to the web as a health information source, as discussed in the next chapter.

### *The blurring of boundaries between "expert" and "lay" knowledge*

This narrow concept of knowledge equated with scientific knowledge hardly helps to understand the different types of medical knowledge patients are confronted with today. The web in particular has been interpreted as juxtaposing orthodox medical knowledge, lay expertise, alternative medicine, and commercial types of knowledge, dissolving boundaries between expert and non-expert knowledge (Nettleton 2004). I therefore draw on broader notions of knowledge implicit in debates around the multiplication and diversification of knowledge related to broader socio-political changes that present-day societies are undergoing (Nowotny et al. 2001, Stehr 2001, 2005). In their book "*Rethinking Science*", Nowotny et al. (2001) argue that great conceptual and organizational categories of the modern world, such as the state, the market, culture, and science, should no longer be seen as distinct domains, but rather as highly permeable and transgressive. In the context of these developments, a multiplication of actors producing knowledge may be observed, and hybrid sites where knowledge is communicated evolve. This leads to "heterogeneity, pluralism and fuzziness" (Nowotny et al. 2001: 19), eroding clear-cut boundaries between "expert" and "lay" knowledge, the authors conclude.

To illustrate their argument, Nowotny et al. (2001: 210ff) refer to patient organizations as emerging agents of knowledge production. Drawing on Epstein (1996), the authors

describe how, through the acquisition of scientific knowledge and engagement with the scientific community, AIDS activists from the movement "Act Up" finally managed to participate in the design and set-up of clinical trials. Patients thus figured as producers of high-end medical knowledge, blurring boundaries between expert and lay knowledge the authors argue. The multiplication of actors producing knowledge may be seen as particularly applicable to the medical context, where struggles over knowledge have a long tradition, as will be further discussed in the next chapter. The broad notion of knowledge developed by authors such as Nowotny et al. (2001) makes it possible to understand the multitude of medical and health-related knowledge circulating in present-day societies. The web in particular may be interpreted as a location where multiple types of actors, including medical professionals, laypeople, and providers of alternative medicine such as homeopaths, but also various types of commercial actors, try to communicate their respective medical knowledge to the public. The question thus is how different types of actors provide their respective knowledge online, and what consequences this multitude of knowledge triggers for the individual.

### *Knowledge as a source of power and insecurity*

The multiplication of knowledge present-day societies experience is ambivalently discussed by a number of authors (Giddens 1991, Beck 1992, Stehr 2005). Nico Stehr (2005) has argued that the proliferation and diversification of knowledge leads to paradoxical consequences. First, and most importantly, it triggers the empowerment of marginalized groups and individuals. In this context, knowledge clearly figures as a source of power. Although his work is generally positioned in a scientific context, Stehr formulates a fairly clear definition of knowledge per se. Drawing on Bacon's translated statement "scientia est potentia", Stehr defines knowledge straightforwardly as a "capacity to act" (Stehr 2005: 6). In his interpretation, knowledge is seen as a "capacity to set something in motion" (Stehr 2005: 35). It increasingly figures as a foundation for social action, making it an integral part of present-day societies (Stehr 2005). In a late modern age, the individual or "reflexive self" (Giddens 1991) is increasingly supposed to take matters into his or her own hands on the basis of knowledge he or she gathers autonomously. According to Giddens, self-identity is no longer inherited or static, but rather a "reflexive project" (Giddens 1991) to be actively worked and reflected on in a post-traditional order. Choices are no longer pre-defined by customs and traditions, but have to be actively thought about and made by the individual. Particularly in the medical context, access to knowledge is seen as a necessary precondition for patient empowerment, in that it raises the patient's ability to take action and challenge medical authorities, as I indicated in the introduction and further discuss in the next chapter. The question of how patients actually become informed remains widely unanswered in euphoric discourses around patient empowerment. This thesis aims to provide answers by investigating how users obtain medical knowledge from the web and how their practices

relate to the way medical knowledge is provided and distributed in form of mediated or "informational" knowledge. Only then may relations between the web and patient empowerment in its multiple variations be critically discussed.

Besides its empowering potential, Stehr (2005) also indicates problematic consequence the proliferation of knowledge triggers in present-day societies. While individuals and marginalized groups gain power through their growing access to knowledge and its production, traditional institutions such as the state, the church, and the military lose power as they are undermined by these new actor groups. In this view, the multiplicity of actors producing knowledge is seen as creating uncertainty and risk (Beck 1992, Stehr 2005). According to Stehr (2005), science itself is seen as generating probabilities and controversial forms of knowledge rather than absolute "truth" in late modernity. Scientific expertise is challenged by counter-expertise, particularly in the medical field, where the "second opinion" has become commonplace. Consequently, the individual is confronted with a growing mass of competing knowledge, weakening trust in scientific authority, as Stehr (2005) concluded. The loss of trust in traditional societal actors and scientific knowledge involves the passing of responsibility to the individual, according to Giddens (1991). He argues that choice can be both liberating, in the sense of raising agency and self-fulfillment, and troubling, in the increased stress and expenditure of time necessary to analyze and reflect on available choices and minimize the risks that present-day societies are increasingly aware of, as Beck (1992) discusses. In this view, becoming informed is not seen solely as an act of empowerment, but also as a necessary duty and precondition for managing daily routines. The growing importance of informed consent procedures may be seen as an expression of these developments in the medical field. Informed consent procedures require the active compliance of the patient with medical decisions on the basis of information given by the medical establishment. Procedures of this sort illustrate the increasing passing of responsibility from the medical establishment to the individual patient, which creates a duty to act as an empowered patient – a facet widely underrepresented in discourses around the "informed patient" as a "reflexive consumer" (Hardey 1999).

### *Knowledge politics and laypeople as "epistemic actors" in their own right*

Because of the risks and uncertainty co-evolving with the multiplication of knowledge, Stehr (2005) called for a new type of "knowledge politics" to regulate and govern the growing number of controversial forms of knowledge on a societal level. The increasing number of ethics committees and public participation events in Austria and beyond may be seen as an attempt to cope with technoscientific innovations and competing types of knowledge in the wider society. In the medical field, the increasing desire for standardization and regulation of research, therapy, and medical practices, widely referred to as "evidence-based medicine", may be seen as an expression of the wish to

regain control over the multiplication or “e-scape” of medical knowledge. In the context of the web, standardized quality criteria and websites that direct users to the “right” medical information as defined by experts may be seen as attempts to reify modern hierarchies of approved and non-approved knowledge (European Commission 2002, Eysenbach et al. 2002). Such initiatives resemble classical PUS strategies of “educating” the public from the top down, neglecting how laypeople themselves interpret and evaluate expert knowledge, as I discuss in detail in the next chapter.

Critical PUS scholars have criticized top-down initiatives, arguing for acknowledging how laypeople themselves make sense of expert knowledge and initiating a mutual dialogue between experts and laypeople. A number of authors have shown that laypeople do have elaborate techniques for making sense of scientific knowledge that do not necessarily correspond to experts’ visions (Wynne 1992, Michael 1992). In his investigation of how British sheep farmers cope with radioactive fallout, Brian Wynne (1992) observes that laypeople interpret and re-contextualize scientific knowledge by locating it within their own social contexts and experiences. He demands that we acknowledge the “reflexive capability of laypeople of articulating responses to scientific expertise” (Wynne 1992: 301) that bears on their personal situation. This shows that laypeople should not be seen as passive recipients of knowledge, but rather as actively interpreting and reconfiguring knowledge according to their personal needs. They may be seen as epistemic actors in their own right, having their own lay epistemologies. Further, trust in and credibility of the speakers play a central role in these practices. Whatever the actual knowledge communicated, the “social body language” (Wynne 1992: 297) of the scientists is of crucial importance. Social body language encompasses categories such as institutional affiliation, the scientists’ actual behavior, and the way they organize their knowledge. The latter aspect particularly applies in the medical context, as will be shown. The central question, however, is how laypeople make sense of the heterogeneous types of knowledge increasingly spread through media such as the web. What epistemic practices do users display when acquiring medical knowledge from the web, and what role do trust, credibility, and the “social body language” of the “speakers” play in technically mediated acts of communication?

To answer these questions, the technology and its specifics need to be taken into consideration. Recent contributions in the field of critical PUS have argued that laypeople increasingly use media, and most importantly the web, to share and acquire scientific knowledge (Michael 2002), most particularly in medical contexts (Novas and Rose 2000). Consequently, Michael argues for taking “complex media” seriously.

What this suggests is that the analysis of the process of engagement with expert knowledge should also take into account the various media – the sociotechnical arrangements – through which this, and related, knowledge circulates (Michael 2002: 366)

Drawing on the philosopher Whitehead and his term “apprehension”, signifying an act of taking hold, seizing, or grasping, Michael (2002) suggests conceptualizing the uptake of knowledge as a corporeal practice. Both the message that travels to the receiver and the subject receiving the message need to be considered when trying to understand practices of making sense of science. Acknowledging insights gained in ANT, Michael argues that an understanding has to be developed of the way science is grasped not only through representation, “but also in everyday material encounters with, for example, technology and nature” (Michael 2002: 373). This thesis takes Michael’s demand seriously by focusing on the web as a prime example of a “complex medium”. It will explore how different types of actors communicate their respective medical knowledge through the web and how users interpret and make sense of medical web information and distill knowledge out of it that may indeed figure as a source of empowerment.

This undertaking, however, requires developing a notion of mediated knowledge or “information”. This is the task of the following sections. First, I discuss multiple concepts of information inherent in theories of the “information society”, which are closely related to the spread of ICT. Secondly, I elaborate on the relation between knowledge and information and the role ICT plays in this relationship, and explain how these considerations serve to conceptualize the mediated act of communicating medical knowledge via the web.

## **2.2 Fragmentation of information in “information societies”**

Toward the end of the second millennium of the Christian Era several events of historical significance have transformed the social landscape of human life. A technological revolution, centered around information technologies, is reshaping, at accelerated pace, the material basis of society. Economies throughout the world have become globally interdependent, introducing a new form of relationship between economy, state, and society, in a system of variable geometry. (Castells 1996: 1)

These are the opening sentences of Manuel Castells’s three-volume study “*The Information Age*”. Castells (1996) identifies ICT as a central driving force for societal change. He postulates a new mode of economic development, in which the source of productivity lies in technologies of information generation, processing, and communication. He argues that different societies operate with different means of achieving productivity and that the emerging mode of development is informational; he refers to “the emergence of a new technological paradigm based on information technology” (Castells 1996: 17). In his view, ICT is at the core of new social structures closely related to the spread of capitalism and globalization. One indicator for the global economy is that organizations have increasingly to manage and respond to global flows of



information. Instead of the local resources that are central in industrial societies, the decentralized circulation of information has become the dominant feature of global capitalism and culture according to Castells (1989, 1996). But what does the term "information" signify?

### *Information as mediated content*

In much of the literature, the term "information" is used synonymously with the term "knowledge" in discussions of economic changes and the growth of the service sector. This work also draws on Daniel Bell (1973) and his colleagues to demonstrate that information has become central in the "information economy" as they coin it. What turns out to be significant, however, is that information society thinkers closely relate information to media and technologies, most importantly ICT, as exemplified in Castells' (1996) quotation. They argue that ICT triggers a growth of information in terms of data, bits, and flows of information, and this causes social change ranging from the economic to the cultural realm. In this view, "information has come to denote whatever can be coded for transmission through a channel that connects a source with a receiver, regardless of semantic content" (Webster 2002: 24). Information is conceptualized as everything that may be transferred via a medium or technology. This notion of information makes it possible to quantify and measure the growth of information that present-day societies are faced with. To develop a more comprehensive understanding of information itself, a comparison between knowledge and information may be made to identify the specific qualities of information. In the introduction to their anthology *"Knowledge: Critical Concepts"*, Stehr and Grundmann (2005) formulate a comparison between knowledge and information valuable for the purposes of this thesis:

In other words, knowledge – its acquisition (see Carley 1986), dissemination and realization – requires an active actor. Knowledge involves appropriation rather than mere consumption or "transfer". (...) Information is something actors have and get. It can be reduced to "taking something in". (Stehr and Grundmann 2005: 6)

In this quotation, the authors conceptualize information as something that may be transferred. Information can be exchanged between actors in terms of "taking something in", while the acquisition of knowledge requires an actor that actively appropriates knowledge. In his book *"Knowledge Politics"*, Stehr (2005) relates the appropriation of knowledge to a process of cognition. The bottom line of these two quotations seems to be that information may exist disconnected from its speaker and recipient. Stehr (2005) further suggests that information needs interpretation. Information may be seen as a "means" to obtain knowledge (Stehr 2005: 48). He interprets information as a step toward obtaining knowledge. This leads to the conclusion that information may turn into knowledge through interpretation, an aspect I further elaborate later. In its unprocessed

state, however, information may be seen as useless. Information exists “regardless of semantic content”, as Webster (2002) puts it. This basic notion of information applies to all types of information, regardless of the medium, which may be a simple piece of paper or a complex sociotechnical arrangement such as the web. The central question thus is what makes present-day societies into information societies besides the growth of information?

### *Information fragmentation and “disinformed information society”*

In his book “*Critique of Information*”, Scott Lash (2002) focuses on profound consequences of the ongoing “informationalization” (Lash, 2002: 154) of society stemming from the spread of ICT. He postulates a great contradiction in present-day information societies.

The great contradiction of the information society is that what is produced with the highest knowledge and rationality as factor of production, in its unintended consequences leads to the pervasion and overload of the utmost (also informational) irrationality. At issue indeed is the *desinformierte Informationsgesellschaft* (disinformed information society). (Lash 2002: 76, emphasis in original)

In his view, the means of production and social relations in a more general sense have become informational, resulting in the “out-of-control anarchy of information diffusion” (Lash 2002: 146). Modernity is ordered, while modernity’s consequences are disordered, he argues. Contrary to the majority of information theorists, who focus on the growth of information due to ICT, he demands a shift in attention towards the unintended consequences: information-laden societies potentially turning into “disinformed information societies”. Drawing on Marshall McLuhan’s famous statement “the media is the message”, Lash suggests that new technologies and media create new forms of content. Consequently, the content itself can only be understood in terms of the technologies constituting it. In the technological age, linear units of meaning are compressed into abbreviated, non-extended, and non-linear units of information or “informational knowledge”, as Lash argues. This sort of information has to do with information overload, with spinning out of control.

Such information loses meaning, loses significance very quickly. This might also be a clue to the way that value might be understood in the information society. (...) Unlike discourse or discursive analysis, it does not subsume particulars under universals. It is instead a mass of particulars without a universal. (Lash 2002: 144)

In Lash’s view, “informational knowledge” figures as disembodied, de-contextualized, and partly meaningless. It appears ephemeral, and unlike discursive knowledge it has no logical or analytical meaning. This notion of information goes beyond arguing that

information is simply traveling disconnected from both speaker and recipient. Lash suggests that information as such is crucially transforming in present-day societies and that technologies play a central role in this process.

But what consequence does this trigger? Relating Lash's considerations to the medical context Nettleton and Burrows (2003) suggest that "its consumption via networked technologies makes a reflexive engagement with information more difficult than is supposed in many theoretical accounts in reflexive modernization" (Nettleton and Burrows, 2003: 181), as indicated in the introduction. They argue that more research is needed on the way people actually engage with "informational knowledge" deriving from multiple media, the web in particular. This thesis takes a step into this direction by investigating information practices and skills involved in these practices that may prevent societies from turning into "disinformed information societies", as Lash (2002) put it in his rather dystopian vision. For this purpose the distinction between knowledge and information running through the literature on knowledge and information societies is hardly helpful, as I finally conclude.

### **2.3 Conclusion: Relations between knowledge, information, and ICT**

In the previous sections I elaborated multiple concepts of knowledge and information, and discussed the role ICT plays in these concepts. The broad notion of knowledge relating to the multiplicity of actors and sites producing knowledge helps to frame the web as a location where tendencies of knowledge proliferation and diversification may be observed today. But how do multiple types of actors actually communicate their respective medical knowledge online and how do users interpret and make sense of heterogeneous medical web information and create knowledge out of it? To answer this question the technology needs to be drawn into the story. Going beyond arguments of information growth through ICT, Lash (2002) argued that information increasingly figures as fragmented and decontextualized overwhelming present-day societies with "informational knowledge", as he coined it. This indicates that information may not only be seen as growing these days, but also as transforming through its technical mediation. The central question thus is whether and how tendencies of information fragmentation may be seen in the communication of medical knowledge via the web? And which challenges this poses for the individual trying to obtain medical knowledge from the web, rather than fragmented, disembedded information?

To answer this question in a comprehensive way, the distinction between knowledge and information observed in the literature will not be helpful. My goal of observing in practice how different types of actors provide their medical knowledge on the web and how different users employ the web to acquire medical knowledge makes the distinction

between knowledge and information futile. Quite on the contrary, insights need to be gained in the way knowledge and information relate to one another and intertwine in practices of providing and acquiring medical knowledge via the web. How do website providers transform knowledge into web information when configuring a website on the level of content and code? How do they try to make their medical web information credible and which underlying epistemology accompanies their practices and narratives? May tendencies of "information fragmentation" (Lash 2002) be observed and which epistemic consequences do they trigger on the user side? How do users evaluate medical web information and its credibility and distill knowledge out of it conceived as a "capacity to act" in Stehr's (2005) terms?

According to Stehr information may turn into knowledge through interpretation, through a "process of cognition" (Stehr 2005), as he put it. In his interpretation information may be seen as a step towards, or a "means" to obtain knowledge. But how may information be interpreted? Scholars in the field of critical PUS have given insights into the way laypeople interpret and make sense of (scientific) knowledge. They have shown that laypeople make sense of expert knowledge through locating and embedding it in their own contexts and bodies of knowledge. Further, they have argued that the credibility and "social body language" (Wynne 1992) in terms of institutional affiliation and behaviour of the speakers are central in these practices.

But how do these categories play out in mediated acts of communication and how does the technology contribute to that? On the web, not only medical professionals, but rather heterogeneous actors ranging from experts to non-experts try to communicate their medical knowledge and experiences to the public. The question thus is how different types of actors try to evoke trust on the user side and how different users evaluate the heterogeneity of medical web information? To acknowledge how these differences may shape processes of cognition I draw on Fleck's (1981 [1935]) concepts of "thought styles" and "thought collectives" later. Besides, I will analyze how the technology and its specificities – most particularly search engines – contributes to and shapes providers' and users' epistemic practices. This enables us to understand whether new technologies such as the web and its technical gestalt contribute to knowledge transformations and fragmentation, as argued above, and which epistemic practices this triggers. Only when gaining insights in the way medical knowledge is actually communicated online, and which implications technically mediated acts of communication trigger, may the web and its empowering and endangering potential seriously debated. In the next chapter I present discussions around patient empowerment and evidence-based medicine, and explain how they shape controversial interpretations of the web as health information source.

### **3 Medical knowledge and the “informationalization” of medicine**

The purpose of this chapter is to critically examine the struggles over medical knowledge observed in present-day medicine and describe how these debates influence ambivalent perceptions of the web as a health information source. Medicine may be seen as one societal area where the ongoing proliferation and diversification of knowledge described in the previous chapter may be observed. In recent decades, orthodox medical knowledge has lost its monopoly because other forms of knowledge such as complementary and alternative medicine (CAM) have gained importance (Broom 2005a). Further, patients themselves have become producers of medical knowledge, as described above (Epstein 1996). New media, and most importantly the web, have been seen as fuelling these developments by broadening access to the production and use of medical knowledge, or rather information. Alongside various actors from the medical field, new actors such as general health portals or Wikipedia have evolved, introducing new types of knowledge (Pentzold 2007). In the following, I discuss processes of diversification of medical knowledge and strategies of reifying traditional knowledge hierarchies that shape debates around the web as a health information source. Secondly, I focus on the “informationalization” of medicine and the web as health information source, setting the stage for the analysis of website providers’ and users’ information practices. Finally, I argue that discourses around knowledge and information in present-day medicine employ a rather economic terminology, widely conceptualizing health care as an industry or market. Accordingly, I discuss the web as a medical marketplace where medical knowledge, or rather “informational knowledge” (Lash 2002), is traded today, presenting a view of the sociotechnical dynamics involved in the production and acquisition of medical web information.

#### **3.1 Patient empowerment and evidence-based medicine**

The broadening access to the production and use of medical knowledge and related pluralization tendencies is ambivalently discussed, mirroring wider societal debates. First, these developments have been interpreted as empowering patients (Broom 2005a, 2005b). In this view, knowledge is generally seen as a powerful “capacity to act”, in Stehr’s (2005) terms. Second, the growing trend towards “evidence-based medicine” (Timmermans and Berg 2003) may be interpreted as an attempt to regain control over “e-scaped medicine”. Here, the notion of medical knowledge as objectified, scientific knowledge superior to other forms of knowledge (Bell 1973) may be seen as becoming reified through standardization. I position my thesis particularly with respect to these debates because they may be seen as paradigmatic examples of two opposing viewpoints on the struggles over medical knowledge that fuel discussions of online health information

and its quality.

### *Knowledge as a source of action and challenge to medical authority*

In the medical context, the proliferation of knowledge has primarily been discussed as eroding traditional knowledge hierarchies. While patients are seen as gaining agency, medical professionals are seen as losing authority (Roberts 1999, Broom 2005a, 2005b). In these discussions, the notion of patient empowerment is central, although weakly defined. Some authors define patient empowerment in a very broad way.

Gibson (1991) suggested that empowerment is best understood as the absence or decrease of powerlessness, helplessness, hopelessness, alienation, victimization, subordination, oppression, paternalism, loss of a sense of control over one's own life and dependency. (Gibson 1991, cited in Broom 2005b: 327)

Reversing this quotation, empowerment may be said to describe an increase of power, hope, control over one's own life, independence, and the like. In this sense it strongly resembles Giddens's (1991) notion of the "reflexive self" actively leading his or her life as a project. In both conceptions, independence and a sense of control over life seem to be central for empowerment.

Linked to these discourses, a move towards consumerist approaches to medical care has been discussed in both academic (Lupton 1997, Broom 2005b) and policy contexts (European Commission 2002). Here the empowered patient is described as a consumer or "reflexive consumer" (Hardey 1999). Provided with a range of treatments and medications, the patient is seen as a consumer provided with many choices. In the context of empowerment discourses, choice and increased patient or consumer responsibility for health are positively interpreted, as indicated earlier. The particular notion of the consumer is linked to rights, power, and empowerment. The fact that rights also carry responsibilities – the duty to get information, for example, as Giddens (1991) argues – is often neglected in these debates.

Finally, and most importantly in regard to the web as a health information source, empowerment is discussed in regard to doctor-patient relations. In this context the patient is clearly seen as empowered towards medical professionals. Roberts (1999) formulates this straightforwardly:

Whilst there is no consensus amongst analysts regarding how best to define 'patient empowerment', at the very least, this concept entails a re-distribution of power between patients and physicians. Empowered patients attempt to take charge of their own health and their interactions with health care professionals. (Roberts 1999: 91)

Here the patient is seen as actively engaging in medical decision-making and challenging medical authority. As a result, a new model of doctor-patient relations is expected to emerge. In contrast to the paternalistic model, the new doctor-patient relationship is supposed to turn into a partnership where doctors and patients make decisions in a shared manner (Anderson et al. 2003). Having discussed multiple aspects of patient empowerment, Broom (2005b) further argues that empowerment should be seen as a concept unique to the individual, rather than a set of abstractions or behaviors. This aspect will be further discussed in the empirical part of this thesis. Discussing how the interview partners themselves perceive the web as a health information source, I will show that the different concepts of empowerment people bring to the fore may be seen as tightly intertwined with their individual backgrounds and models of health and illness.

ICT, and most particularly the web, are clearly seen as strengthening tendencies towards patient empowerment, especially in the context of medical practices:

At the heart of medical autonomy is exclusive access to "expert knowledge" (Giddens 1991) and the ability to define areas of expertise and practice. The Internet provides a possible threat to this situation. (Hardey 1999: 823)

This exemplifies the way the web is widely described as an actor intruding into and changing medical practices. Because of knowledge gathered from the web, patients are supposed to turn into empowered agents acting self-responsibly in medical practices and beyond. In this context, the web is clearly seen as increasing agency on the part of patients, enabling them to take health matters into their own hands. In discussions of the web, the empowered patient is often labeled an "informed patient" (Hardey 1999, Henwood et al. 2003), as I argued in the introduction. Further, patients themselves are increasingly seen as producers of medical web information, an aspect on which I further elaborate when discussing the web as a health information source in greater detail. Buzzwords such as "informed consent" or "informed choice" further reinforce the idea that information may increase agency on the part of patients. In these discourses the notions of knowledge and information are often used synonymously mirroring the unspecific use of the terms in literature on the knowledge or information society. In discourses on the "informed patient" online health information is widely equated with knowledge as a "capacity to act" (Stehr 2005), rather than fragmented information. How patients actually engage with "informational knowledge" and which skills are required in these practices remains widely unanswered in these discussions. This thesis aims to provide answers to this question and open up a more critical view of the web as a health information source by arguing that access to information alone is not enough to trigger patient empowerment.

A number of studies have challenged euphoric interpretations of current developments in the medical field. They identify drawbacks and ambivalent feelings of both doctors and patients towards the empowerment of patients. Investigating doctors' viewpoints on "informed patients" and online health information, Broom (2005a) finds that medical professionals display a rather reluctant attitude towards empowered patients. A number of doctors are afraid of losing their knowledge monopoly and authority, and therefore simply try to reject patients who act questioning and engaging. This connects to studies showing that patients often experience a hard time discussing treatments with their doctors and reaching a cooperative decision (Henwood et al. 2003). Having investigated doctor's attitudes towards the internet and "informed patients" Broom (2005a) argues that some doctors have indeed difficulties with internet-informed patients. These doctors perceive the internet as contesting their profession and conceptualize internet-informed patients as challenging their expert status and complicating medical practice by asking questions and discussing treatments. However, Broom (2005a) has further found out that some medical professionals embrace the internet because it motivates patients to take part in decision making. And this circumstance triggers practical benefits for medical practice in their perception.

In particular, and somewhat paradoxically, actively involving the patient and allowing them to feel in control of the decision-making process was viewed as positive for their motivation and thus compliance with the treatment regime. (Broom 2005a: 327)

This suggests that even doctors principally displaying a positive attitude towards the web and internet-informed patients sometimes express a rather narrow view of patient empowerment, equating it with increased patient compliance. The widespread reluctance of doctors towards patient empowerment may be seen as highly problematic, given the ongoing growth of the web as a health information source and the skills involved in obtaining medical knowledge from the web, as will be discussed throughout this thesis.

Moreover, patients themselves sometimes decide to take on the "passive patient role" (Lupton 1997) and prefer to follow the advice of doctors rather than aiming at participating in medical decision-making. Lupton (1997) argues that patients feel a certain tension between behaving as consumers and investing trust and faith in medical professionals. In regard to online health information, Henwood et al. (2003) find that for certain patients "ignorance is bliss sometimes" (Henwood et al. 2003: 1). The authors further conclude that many users have problems obtaining medical knowledge from the web because they lack internet skills, a circumstance that I further discuss below. Besides internet skills, however, more profound knowledge work is needed to use the web as a health information source, as will become clear in the course of this thesis.



Discourses of patient empowerment may be seen as mirroring wider societal debates around the pluralization and diversification of scientific knowledge in present-day societies and the ambivalent consequences these may trigger. Hardey (1999) argues that trends towards patient empowerment are associated with "a demystification of medical expertise and increasing lay skepticism about the health professionals" (Hardey 1999: 821). The current spread of evidence-based medicine, an attempt to reify traditional knowledge hierarchies in an age of uncertainty, may thus be seen as a response to this trend.

### *Re-imagining medicine as an exact science based on "evidence"*

The central buzzword in the current standardization movement is "evidence-based medicine". The term embraces different dimensions, but usually refers to the use of clinical practice guidelines, as Timmermans and Berg (2003) argue in their book *"The Gold Standard"*. The authors describe these guidelines as "instructions on which diagnostic or screening test to order, when to provide medical or surgical services, how long patients should stay in the hospital, and other details of clinical practice" (Timmermans and Berg 2003: 3). The crucial point of these guidelines is that they are framed as being based on scientific "evidence". This evidence derives from a systematic analysis of randomized clinical trials and therapies, and predicts the probable outcome of each intervention. The results are intended to guide medical professionals in their treatment decisions. Instead of drawing on experiences and individual knowledge, doctors are increasingly supposed to base their decisions on standardized guidelines distilled from aggregate patient data.

These developments are not new. Timmermans and Berg (2003: 30ff) identify the introduction of the patient record at the beginning of the 20<sup>th</sup> century as the central foundation on which standardization developments have been built. The replacement of the doctor-centered casebook with the patient record accessible to everyone in the clinic made it possible to collect and compare data on a grand scale. The patient record thus figures as a necessary precondition for the development of standardized protocols and guidelines. With the introduction of ICT, these developments accelerated in the 1980s. The digitization of patient records allowed patient data to be centrally collected, stored in huge databases, merged, and transferred through internet technologies around the globe. Further, the web may be seen as fuelling the spread of evidence-based medicine by providing access to a huge amount of data and standardized guidelines distilled out of patient records. The website of the Cochrane Library is a good example of the accumulation and diffusion of standardized guidelines on the web. The Cochrane Library<sup>3</sup>

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<sup>3</sup> The Cochrane Library is a database of systematic reviews summarizing and interpreting medical research and therapy. On its website it provides access to a large number of results of controlled trials. It has therefore been described as a key resource in evidence-based medicine: <http://www.cochrane.org/> (accessed March 2010).

provides access to data and protocols regarding all kinds of diseases, to be applied in medical practices around the globe. ICT may thus be seen as contributing not only to the diversification of medical knowledge, but also to the spread of evidence-based medicine and its consequences.

Evidence-based medicine has been controversially debated. The electronic patient record has raised criticism over privacy issues. In Austria, this issue has been frequently discussed in relation to the introduction of the electronic health insurance card or "e-card". More crucially, however, critics have argued that evidence-based medicine alters medical practices. Berg (1998) contends that the roles of both doctors and patients are impaired by the implementation of standards in medical practices. He argues that doctors are turned into mere administrators of standardized protocols, following "recipes" without consulting their own intuition and experience. Patients, in turn, are reduced to collectives to be treated according to standardized guidelines without regard to individual conditions that may not fit these standards. Evidence-based medicine has been described as reducing medicine to a "'cookbook' medicine" (Timmermans and Berg, 2003: 19). The question, however, is why trends towards evidence-based medicine continue despite constraints they may pose on the patient empowerment widely desired in the academic and public domain.

I suggest that in a late modern age where trust in medical knowledge, institutions, and practices is declining, evidence-based medicine may be interpreted as an attempt to reify and anchor modern values of objectivity and rationality. Evidence-based medicine has been described as bringing "order to a modern world" (Timmermans and Berg 2003: 19). According to Timmermans and Berg, proponents of evidence-based medicine praise the standardization of medical practices as "the gold standard" because it would enable them "to move the health care field in the direction of an 'exact science'" (Timmermans and Berg 2003: 19). The possibility of "objectively" measuring treatments and their effectiveness with the help of data accumulation and clinical guidelines may be interpreted as creating scientific "facts" and security where insecurity and a loss of trust in medical authority have become commonplace. In regard to online health information, demands for standardized quality criteria and labels for medical websites may be interpreted as part of the trend towards standardization that may help to regain control over the multiplicity of online health information, as I later discuss.

Further, the electronic documentation of treatments and their effectiveness makes it possible to identify the most effective therapies according to cost-benefit considerations. In the US, standardized guidelines serve as a central basis on which insurance contracts between insurance companies, patients, and medical professionals are built. These "managed care" contracts have the purpose of providing benefits in a way that is cost-effective for all three parties (Belkin 1997). It comes as no surprise that European policy

makers increasingly embrace evidence-based medicine as a tool to make health care more efficient in times when health care systems face financial challenges. In this context, health care increasingly figures as an industry or market where medical products are traded in a cost-effective way. Electronic patient records and clinical guidelines are seen as part of a range of "e-health technologies" supposed to help achieve this goal (European Commission 2000).

### *Economization of health care*

The previous discussions have shown that medical knowledge is a subject of struggles. Despite constraints, trends towards the diversification of medical knowledge have widely been celebrated as empowering patients and blurring boundaries between expert and lay knowledge. Voices from the medical and policy realm, however, advocate standardization as an attempt to reify modern knowledge hierarchies through "evidence-based medicine".

Despite their different, partly contradictory viewpoints, both discourses employ economic terminology hinting at the ongoing economization of health care. Given the challenges health care systems face around the globe, treatments, therapies, and medication increasingly figure as "goods" to be traded efficiently. In discussions of patient empowerment, patients are increasingly seen as consumers provided with a range of medical treatments and drugs and expected to actively make "reasonably informed choices" (Giddens 1991). Information is widely seen as a necessary precondition for these choices. With the spread of ICT, the web has become a central location where medical information is exchanged between multiple website providers and users. The web may thus be seen as a market place where medical information is increasingly traded, as I will discuss.

### **3.2 "Informationalization" of medicine and online health information**

Medicine has been described as increasingly intruded upon and transformed by ICT. Scholars such as Webster (2002) and Nettleton (2004) have argued that medicine may increasingly be understood "as information" (Webster 2002: 450). These authors describe a development towards an "informational medicine" (Nettleton 2004) triggered by the introduction of sophisticated technologies, most importantly bioscience and ICT. In line with discourses on the "information society", they see technologies as central actors in the shift from "biographical medicine" to "techno-medicine" (Webster 2002: 444). Evidence for this is manifold and of different kinds. One indicator is that medicine has increasingly taken on the language and practice of biology, which itself has become an information science (Webster 2002: 450). Metaphors inspired by cybernetics characterizing the human body as carrying a genetic code that can be mapped, decoded

and read by medicine as the “book of life” (Kay 2000) may be taken as an expression of this. Further, medicine has become informational in relation to its delivery and management through telemedicine, telecare, and health informatics. Here, the physical presence of the patient’s body has given way to electronically mediated patient information and data (Nettleton 2004: 670).

Most importantly for the purpose of this thesis, medicine has been interpreted as having left traditional medical institutions and “e-scaped” into society by means of media, and most notably new media (Nettleton 2004: 637). The web in particular has become an important location where medical knowledge is provided, circulated, and acquired, as I discussed in the introduction. With the increasing availability and use of the web, the web as a health information source has been widely viewed as intruding on and potentially challenging medical practices, as argued earlier. For the purpose of this thesis, I further examine discussions of the web and its medical information itself. The web is seen as democratizing medical knowledge from the perspective of website providers (Anderson et al. 2003, Loader et al. 2002), as a source of risk to be governed from the top down from the perspective of medical professionals and policy makers (Eysenbach and Diepgen 1998, European Commission 2002), and as a source of information to be individually interpreted and made sense of from the perspective of users (Adams et al. 2006, Höcher 2008). Given these insights, I finally argue for shifting focus onto information practices, making it possible to understand how sociotechnical dynamics shape the production and acquisition of medical knowledge.

### *The web as democratizing medical knowledge?*

The web has often been discussed as facilitating access to the production of health information, fuelling the multiplication of this information. Orthodox medical information, alternative medicine, commercial accounts, patient support, and new forms of medical information, such as the one provided on general health portals or Wikipedia, exists side by side, goes the argument. In this context the term information is primarily employed mirroring discourses around the information society also employing the term information when talking about mediated forms of content – circulating through ICT, in particular. While the term online health information has become a stable phrase in both academic and public debates, the term “online health knowledge” is practically nonexistent in comparison. According to Hardey, “anyone with a few technical skills and access to a suitable computer can add to the mass of health information on the Internet” (Hardey 1999: 823). In this context the web is seen as giving voice to different types of actors and their medical knowledge and expertise, patients in particular. Having analyzed a diabetes self-help network, Loader et al. (2002) conclude that virtual self-help groups are valuable sites “where discursive learning about one’s condition can be undertaken on a more equal basis” (Loader et al. 2002: 64). Gillett (2003) argues that the web offers the

possibility of challenging dominant media representations and providing alternative accounts of diseases such as HIV/AIDS. Novas and Rose (2000) conceptualize practices of posting, reading, and replying to messages in web forums as “techniques of the self”, in which patients, or potential patients such as “persons at genetic risk”, can discuss their own ways of understanding and responding to medical issues. Research focusing on the perspective of producers of online health information, most particularly patients, may thus be seen as strengthening the ideal of the web as an empowerment tool. Moreover the web has been described as embodying democratic values by giving voice to previously marginalized actors such as patients and patient organizations. Anderson et al. (2003) see the web as offering the possibility to publish medical information in a relatively simple and inexpensive way arguing that the web may be seen as democratizing medical knowledge in a broader sense (employing the term knowledge to underline the powerful role of the web). Discourses around democratic promises of the web in the medical context may be seen as embedded in broader debates about the web as a kind of new “public sphere” giving voice to marginalized actors (Kahn and Kellner 2004), as I further discuss in the next chapter.

This euphoric viewpoint is challenged in multiple ways. First of all, Novas and Rose (2000) indicate that only a minority of patients actively contribute to internet forums, a circumstance recently confirmed in a quantitative study in the US context (Fox and Jones 2009). Having analyzed how patient organizations actually construct their websites, Oudshoorn and Somers (2006) argue that providing a health-related website on a large scale requires extensive financial resources and labor that may be difficult to muster, particularly for smaller organizations with limited funding. The authors therefore conclude that the analysis of the way patient-oriented websites are actually provided helps to “understand the constraints and challenges of realizing the democratic potentials of the Internet” (Oudshoorn and Somers 2006: 658) in the sense of giving equal voices to different types of actors. The empirical analysis of this thesis will underline this approach.

Constraints on the web’s democratic potential become even more striking when we look at the way online health information is distributed in search engine results. Having analyzed how the issues of breast and prostate cancer are represented online, Seale (2005) hints at barriers medical websites may experience gaining visibility online. With a mix of methods including querying topics in search engines as well as analyzing dominant websites and their link networks, Seale (2005) found that net-savvy mainstream websites, such as major cancer charities, succeeded better in gaining presence in search engine rankings, arguably at the expense of counter-cultural voices. Nettleton et al. (2005) also found that the first 20 Google results on eczema, asthma, and diabetes were dominated by websites from charities, medical institutions, and pharmaceutical companies, concluding that conventional institutions and medical material have become foregrounded on the web. They argued that “traditional” sources of health information

also dominate the web (whether this still holds true will be seen in the following chapters). Drawing on Seale (2005), Nettleton et al. concluded that

there has been a convergence in content between the 'old' and 'new' media that is undercutting earlier celebrations and concerns about the internet as a medium that promotes a complex diversity of perspectives on health and illness. (Nettleton et al. 2005: 976)

Both Seale (2005) and Nettleton et al. (2005) agree that more research is needed to explore the underlying dynamics and mechanisms involved in the production and distribution of online health information and enable us to take a more critical stance towards the web as a health information source. This thesis takes a step in this direction by analyzing strategies that different types of website providers – both patients and other actors – employ to configure a medical website and try to gain visibility online. Acknowledging what consequences this triggers on the user side and how the technology, particularly search engines, contributes to them will raise questions about the sociotechnical dynamics and market mechanisms involved in the production of medical web information – questions crucial to understand when reasoning about the web and its democratic and empowering potential in medical contexts.

### *Online health information as a source of risk to be governed from the top down*

In the medical and policy realms, the quality of online health information has been questioned according to medical criteria defined by "experts". The quality issue has been framed as particularly important in the medical context "because misinformation could be a matter of life or death" (Eysenbach and Diepgen 1998: 1). This quotation illustrates the trend towards a risk discourse dominant in medical research and policy papers. A broad range of studies have explored the quality of medical web information on the basis of standardized medical criteria, concluding that much medical information lacks "accuracy and completeness" (Eysenbach et al. 2002). Consequently, medical professionals and policy makers have called for standardized quality criteria and labels for websites (Eysenbach et al. 2002, European Commission, 2002).

The quality label "Health on the Net" (HON) serves as a prominent example in this respect. In 1996 the Swiss NGO "Health on the Net Foundation", chiefly composed of medical professionals, published the HON code of conduct, offering "a multi-stakeholder consensus on standards to protect citizens from misleading health information"<sup>4</sup>. The HON quality label is meant to give authority to websites corresponding to standardized criteria, while denying it to others. The user is to be guided to "right" information: "evidence-based information" as defined by medical experts. According to EU policy makers, these

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<sup>4</sup> To be read on the HON Websites: <http://www.hon.ch> (accessed March 2010).

labels should not only guide users to good information, but also help users evaluate medical web information:

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, which a search on a health related subject might produce (European Commission 2002: 13)

This quotation exemplifies the attempt to govern medical web information by reifying traditional hierarchies, between certified scientific knowledge as defined by medical expertise on one hand, and insecure, non-approved knowledge on the other. It further illustrates the desire of policy makers to "educate" users in dealing with medical web information. Standardized quality criteria are seen as instruments to "assist the citizen in coping with the torrent of information", reflecting the wish to educate users from the top down that is expressed in much of the policy realm. In an analysis of public discourses on e-health technologies, my colleagues and I (Felt et al. 2009b) show that EU policy makers partly buy into the rhetoric of patient empowerment and consumerism when discussing the web as a health information source. However, we further show that in the view of policy makers, patient empowerment "could only happen after "adequate education"", which imposes the "right way of seeking and handling information" (Felt et al. 2009b: 38) on users. The attempt to govern online health information and its users from the top down may thus be seen as resembling policy strategies to "educate" the public in science and technology issues discussed under the label of classical PUS (Felt et al. 2009a), as described earlier.

Similar desires may be found in the medical realm. Studies finding that users hardly recognize, let alone check, standardized quality labels have concluded that users have "sub-optimal" search techniques (Eysenbach and Köhler 2002). This quotation demonstrates that studies carried out in the medical realm also employ a rather narrow imagination of patient empowerment guided by medical experts and their criteria. This is consistent with medical professionals' view of the web as a tool helping them to increase patient compliance, as Broom (2005a) has shown. All these examples illustrate how medical professionals and policy makers try to regain control over "e-scaped" medicine with the help of standardized quality criteria and websites in the tradition of evidence-based medicine.

### *Online health information to be interpreted from the bottom up*

Strategies of governing knowledge from the top down have been widely criticized by critical PUS scholars, who argue for shifting the focus onto laypeople and their bottom-up concepts and strategies of knowledge, as argued in the first chapter. This particularly applies to the health context. Lambert and Rose (1996) conceptualize patients as "'health

workers' actively seeking to understand and make sense of science they see as relevant" (Lambert and Rose 1996: 71). Their own health contexts and bodily experiences enable them to articulate responses to knowledge that matters to their own personal situation. Busby et al. (1997) show that patients interpret medical knowledge according to their own life situations and individual bodies of knowledge. In the context of musculoskeletal disorders, the authors analyze how patients interpret medical knowledge according to their very personal life experiences. This body of work enables us to conceptualize the acquisition of scientific medical knowledge as a highly complex social practice. Further, trust in and credibility of scientists, in terms of their institutional affiliation and "social body language" (Wynne 1992), turns out to be relevant in face-to-face interactions, as argued earlier. In the context of the web, however, it is not only scientific medical knowledge that is at stake. Rather, multiple types of actors communicate their respective medical knowledge online. Further, knowledge may be seen as figuring as "informational knowledge", as Lash (2002) put it, potentially posing new challenges for patients acquiring medical knowledge from the web, as Nettleton and Burrows (2003) speculated. The question thus is how people engage with the web and make sense of heterogeneous medical web information? How do they assemble and interpret medical web information in relation to their own medical backgrounds and distill knowledge out of it in the sense of a "capacity to act" (Stehr 2005)? What role do website providers and their "social body language" play in these practices? And how does the technology contribute to these practices?

Nettleton et al. (2005) have started to investigate these questions by interviewing parents and children about their use of the web to research chronic childhood diseases. In this study, they find that the interview partners roughly categorized websites according to different types of website providers rather than by checking the sources of the sites. Having analyzed what they call "rhetorics of reliability" (Nettleton et al. 2005: 979), they conclude that the interview partners trusted "real" institutions more than "virtual" institutions and non-commercial websites more than commercial websites. Further, they prioritized codified and professional information and information from local sources over experiential and non-professional information and information from abroad. Finally, the authors identify a strategy they label "going with the majority view" (Nettleton et al. 2005: 983): people kept "finding the same thing" (op.cit.: 983), and therefore trusted this information. The authors hint at the fact that differences may be found between what interview partners say and what they actually do in their search practices. Most qualitative studies of the already small number investigating patients' search behavior, however, have relied on interviews (Hardey 1999, Henwood et al. 2003, Nettleton et al. 2004, 2005)

An exception is the work of Adams et al. (2006), who conducted qualitative interviews with patients about their last internet search on a medical issue, and then let the



interview partners demonstrate this search on their computers. Additionally, the users were given standardized questions on which to search for information. Despite its hypothetical character, interesting insights may be gained from this study. Like researchers from the medical realm who assess user practices against narrow medical criteria, Adams et al. (2006) observed that users hardly checked the sources of websites, but rather went with "the majority view", as Nettleton et al. (2005) put it. Instead of framing users' practices as "sub-optimal search techniques" (Eysenbach and Köhler 2002), they focus on the users' practices themselves and their approaches to searching for medical issues online. They argue that users piece together information from different websites, basically creating answers to their questions. In this process they tend to compare pieces of information from different websites with each other, rather than asking who the provider of a site is. The authors conclude that reliability is not a "yes-or-no kind of attribute" (Adams et al. 2006: 109), as widely imagined by policy makers, but that "the reliability of information for the patient becomes intertwined in the search process" (Adams et al. 2006: 111). Consequently, users' search practices partly contradict experts' viewpoints explaining why standardized quality criteria and labels for medical websites such as HON hardly work out in practice, as my colleague Höcher (2008) argued in detail. This indicates that further research is needed on how search practices relate to the way medical information is provided and distributed online and how the web contributes to these practices.

### **3.3 Conclusion: The web as a health information market**

The foregoing discussions show that the web may be seen as continuing traditional struggles over medical knowledge. Voices advocating the empowerment of patients embrace the web as democratizing medical knowledge by broadening access to the production and consumption of medical information, but generally neglect constraints. They may be seen as drawing on traditional debates about patient empowerment fuelled by the ongoing proliferation of medical information. In contrast, medical professionals and policy makers widely interpret the web as a source of misinformation and harm, and argue for governing online health information from the top down with standardized quality criteria and labels for medical websites. In line with the idea of evidence-based medicine, they may be seen as trying to reify traditional knowledge hierarchies between approved and non-approved medical information as defined by medical experts. In their view, which reminds of debates about classical PUS in other scientific contexts, users are to be guided to the "right" medical information and educated from the top down.

Despite differences both viewpoints echo the ongoing economization of health care. In the market paradigm patients are seen as consumers provided with multiple medical treatments, medication and products to choose from. They are described as "reflexive

consumers" (Hardey 1999) supposed to actively make choices on the basis of knowledge they autonomously acquired (partly running counter ideals of evidence-based medicine and related imaginations of cost-effectiveness). In this interpretation the web may be conceptualized as a central medical market place where medical knowledge is traded these days – in form of technically mediated information.

Offering medical knowledge via the web requires strategies of configuring and positioning medical websites "in the mass of health information" (Hardey 1999) to entice users. There are hints that search engines challenge the democratic ideal of the web through hierarchizing medical web information and foregrounding traditional medical accounts strengthening the idea of "media convergence" (Seale 2005, Nettleton et al 2005). Further, "informational knowledge" (Lash 2002) may pose new challenges to the user, as argued earlier. The question thus arises how users engage with the web to obtain medical knowledge that may indeed figure as a source of empowerment, rather than fragmented, messy information? Adams et al. (2006) indicate that new practices of making sense of medical web information emerge and that more research is needed to explore the way technology shapes users' practices. Instead of research bemoaning that users would employ "sub-optimal search techniques" (Eysenbach and Köhler 2002), more qualitative work is needed investigating users' information practices and how these relate to the way medical web information is provided and distributed on the online medical marketplace.

Both practices of providing and acquiring medical knowledge via the web may be seen as shaped by the social actions and mutual images of the respective other, but also by technical elements that introduce dynamics and market mechanisms that need further consideration. The question is how different types of website providers configure medical websites, and what strategies they – patients and others – employ to win the battle for attention and entice users? On the user side, the question is how users browse through the online health information market, filter, select and interpret medical web information, and how their practices are shaped by sociotechnical dynamics underlying this medical marketplace? To answer these questions, not only social actors such as website providers and users, but also technical entities involved in the production, distribution, and acquisition of web information need to be considered. For an initial approach to the "information politics" (Rogers 2004) and market dynamics likely shaping the mediated act of communicating I aim to observe, I draw on insights gained in the field of new media studies.

#### **4 “Information politics” involved in the production and use of web information**

In the previous chapters, I argued for taking technology into consideration when trying to understand how medical knowledge is communicated via the web. The online medical marketplace may be seen as populated by a range of heterogeneous entities, including different types of website providers and users, but also software packages, metatext, hyperlinks, keywords, search engine algorithms, and the like, all participating in the way “informational knowledge” is exchanged between website providers and users. While the previous chapter primarily focused on social practices, this chapter focuses on technical entities, most particularly links and search engines, and their role in mediated acts of communication.

New media scholars argue that not all web information should be seen as equally prominent – focusing on mediated forms of content the term information is central in these discussions again. Rather, they suggest that the web embodies power relations and hierarchies that crucially influence the way web information is provided, distributed, and delivered to users (Rogers 2000, 2004, Elmer 2002). Rogers calls techniques of serving web information in a strategic manner “information politics” (2004). He distinguishes two types of information politics: front-end and back-end. Front-end information politics takes place on the surface of (political) websites through the way a site’s features, such as discussion forums, are regulated, and the degree of participation and agency that is permitted to users, for example. Back-end information politics refers to the dynamics behind the delivery of web information, such as the competition between websites vying for visibility (Rogers 2004: 3). In the realm of back-end information politics, linking strategies and search engine politics in particular have taken centre stage.

In the following sections, I discuss links and search engines as central actors in the ordering and hierarchizing of web information, and describe the socio-political values they embody. I start by discussing visions of the web as embodying democratic values because of its decentralized structure, and I show how the hierarchies deriving from several linking policies that website providers employ challenge this democratic ideal. Second, I discuss search engines, and particularly Google, as central in the hierarchization of web information, and what consequences this involves in the use of that information. These discussions explain why both social and technical features of the web need to be taken into consideration when trying to understand how medical web information is communicated and what epistemic implications this mediated communication involves.

## 4.1 A vision of democratic information networks

Historically, various modes of ordering knowledge have existed. Traditional classification systems such as the encyclopedia – but also libraries in a wider sense – organized knowledge in a hierarchical way. Consisting of categories and sub-categories, knowledge was structured following the principle of an index or a tree. Widely applied in natural scientific contexts such as the evolutionary theory, these epistemological structures were metaphorically shaped like a “tree of life” (Darwin 1859). In contrast to these hierarchical modes, the network as a general idea has been suggested as a more flexible way of organizing knowledge. As early as in the mid-18th century, the French writer Denis Diderot and the natural scientist D’Alembert envisioned an encyclopedia with cross-references, or, as we would put it today, hypertext elements. Their aim was to provide the “entire knowledge of the world” in a networked way that would respond to the complexity of the sciences (Selg and Wieland 2001).

Similar ideas inspired Berners-Lee to develop the world wide web protocol. He also expressed a vision of “anything being potentially connected to anything” (Berners-Lee 2000: 1). Knowledge that is distributed and received via the web, however, figures as “informational knowledge” or merely information. In an analogy to the brain, which is made up of neuronal networks, Berners-Lee conceptualized the web as allowing for associative links between related pieces of information. Framing the web as a “global brain” (Berners-Lee 2000: 298) consisting of websites interconnected with each other, he imagined that the “reader” of the web would have the ability to browse the information universe by benefiting from links other users had established. This narrative evokes a vision of the web as an inclusive information network without borders, hierarchies, or limits. The euphoric claim that emerged with the technical infrastructure of the web was that a decentralized network of information would enable more freedom than hierarchical classification systems ever could. In this vision, websites are conceptualized as lying co-equal next to each other, constituting a decentralized web space. Particularly in its early days, the decentralized quality of the web was framed as embodying democratic values. The web was described as a “new public sphere” allowing for participation and empowerment by giving equal voices to all types of actors, particularly those that were marginalized previously. Grass-roots movements, such as the Zapatista movement in Mexico, which was organized through the web, for example, were taken as indicators of the web’s democratic potential (Kahn and Kellner 2004). Despite work that has critically discussed limitations of the democratic potential of the web, most particularly in China and North Korea, where huge numbers of websites are blocked (Diebert et al. 2008), traces of these techno-utopias may still be found in recent discussions of the web. In the medical context, the idea of the democratic potential of the web is partly reproduced in descriptions of the web as giving equal voices to various actors from the medical field, patients in particular, by broadening access to the production of medical information, as

argued earlier. Given the range of newly emerging hierarchies involved in the communication of medical web information, however, this euphoric viewpoint needs to be reconsidered, as I will show in this thesis. In line with Seale (2005) and Nettleton et al. (2005), I argue that further attention needs to be put on the strategies and politics involved in the production of medical web information and the consequences this triggers on the user side.

## **4.2 Information hierarchies through linking politics**

Recent work in the field of new media studies challenges ideas of the web as a democratically distributed information network. To understand the hierarchies and power relations implicit in linking strategies, new media scholars have mapped and analyzed link networks from a bird's-eye perspective (Rogers and Marres, 2000, Park and Thelwall 2003, 2006). These studies discuss which websites are dominant in certain issue areas and which ones are marginalized because of their link connectivity. They further show that links do not have a single meaning, but rather multiple ones. Rogers and Marres (2000a, 2000b), for example, analyze which websites are dominant in the representation of specific issues such as climate change or GM food, and what their positions on the issues are. They interpret hyperlink networks as debate spaces, conceptualizing hyperlinks as recommendations of web resources in the field, which, taken together, constitute issue networks.

The acknowledgements of relevance Webmasters make by linking may disclose what we have called an issue-network. Interlinkages of Websites addressing a common issue can be seen as a collective staging of the issue. (Rogers and Marres 2000a: 121)

In their view, to link means to recognize. Non-linking, on the contrary, is a "sign of non-recognition, or, more radically, is an act of silencing through inaction" (Rogers and Marres 2000b: 157). Both linking and non-linking do not happen randomly, but rather as conscious acts, the authors argue. Besides thematically linking to relevant issues, webmasters link to relevant actors, recognizing them as meaningful participants in the debate, they further show. In this interpretation, groups of links may be read as social networks. Park and Thelwall (2006) similarly analyze links as indicators of social relations. By mapping and interpreting link networks of Asian and European universities, they find that universities of larger and richer countries tend to be better linked than universities of poorer countries. They conclude that offline power relations and hierarchies are to some extent transferred to the web. Finally, webmasters employ strategic link practices. Shell, for example, links to Greenpeace as an act of window dressing – "all voices have a right to be heard" – while Greenpeace would not link back, Rogers and Marres (2000a: 121) show. In this context, links appear as tools to position oneself in the "right"

neighborhood, while enabling one to deny connections to the “wrong” actors. This suggests that commercial websites link differently than non-commercial websites, as Rogers and Marres conclude by identifying different “linking styles” (Rogers and Marres 2000b) of .com, .org, and .gov websites. In regard to search engine politics, however, strategic link practices take on yet another important meaning, as will be discussed in the next section.

All these examples illustrate how links may be seen as central tools for structuring web information beyond single websites. They allow website providers to position their information in the “right neighborhood”, to embed their content in similar information networks, and to reveal their social relations. The central question for the purpose of this thesis thus is how the issue area of diabetes is organized by different types of website providers. What linking strategies do different providers employ to position their websites on the online medical marketplace? What information hierarchies emerge by the various linking strategies? And how do users go about using links to browse through and find medical information meets their needs?

### **4.3 Search engines as “information gatekeepers”**

Like links, search engines have become central in discussions of “information politics”. In a market where individuals are confronted with a multitude of competing information, search engines have become important tools to search for, filter, and order web information. Search engines have become central to users’ online practices both in the US and in Europe, as studies have shown (Jansen and Spink 2006). Further, tendencies of monopoly formation have been observed. Media critics point to the fact, that a few search engines dominate the online information market. “Whereas users were once distributed across many portals and individually relied on several different search engines, today they stick to a few, overwhelmingly popular sites”, Diaz (2008: 25) argues, referring to Yahoo!, Microsoft, and Google. Particularly Google has become an issue of debate, as buzzwords such as “the Google society” (Lehmann and Schetsche 2007) and “Googlization” (Rogers 2009), describing the creep of the company’s search technologies into more and more web applications, suggest. In the health sector, “Googlization” may be seen in services such as “Google Health”<sup>5</sup>, a web-based service to manage electronic patient data, or “Google Flu Trends”<sup>6</sup>, which predicts upcoming epidemics on the basis of aggregate search data. Further, recent investment in gene sequencing startups such as

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<sup>5</sup> “Google Health” offers an online platform to store, organize and share electronic medical records from doctors, hospitals and pharmacies: <https://www.google.com/health/> (accessed March 2010).

<sup>6</sup> “Google Flu Trends”: <http://www.google.org/flutrends/> (accessed March 2010).

"23andMe"<sup>7</sup>, which offers ready-made DNA tests online, have pushed Google into the middle of other controversies. All these services, and most particularly online DNA tests, which involve data about users' diseases and potential future diseases, have raised fears of data abuse in public debates (Angrist 2008). They give companies access to delicate patient data, which may be used in a discriminatory manner if it falls into the wrong hands, including those of health insurance companies, employers and other actors.

More fundamentally, Google has been criticized in regard to its search algorithm and the way it hierarchizes information. In this context Google has been discussed as a "gatekeeper" (Diaz 2008), increasingly regulating access to web information. A number of authors argue that Google creates an information visibility hierarchy by directing users to certain sources of information and not to others (Battelle 2005, Diaz 2008). Its algorithm for defining the order of search results has particularly been discussed in this respect. According to its developers, Brin and Page (1998), the PageRank algorithm uses the number and quality of links a website gets as an indicator of the value of that website. These incoming links are weighted according to the significance of their source site. A hyperlink from a website rated as important counts more, than a hyperlink from an unimportant site. Hyperlinks are seen as votes for a website, in a way that resembles the concept of recognition or citation (Brin and Page 1998). The PageRank algorithm should thus not be seen as an entirely new method. Rather, it draws on the much older tradition of sociometry and bibliometrics, as Mayer (2009) discussed in detail. While Google claims to use "the collective intelligence of the web to determine a page's importance", as may be read on its website<sup>8</sup>, new media scholars have started to criticize its algorithm. These authors argue that the PageRank algorithm produces a content bias (Introna and Nissenbaum 2000, Hindman 2003, Elmer 2006, Rogers 2009). In systematically giving prominence to bigger websites at the expense of smaller ones, say Introna and Nissenbaum (2000), search engines run counter to the democratic ideal of the web as a public sphere in which all actors have equal voices. Instead, big and well-connected sites, mostly commercial sites, are systematically preferred at the expense of smaller sites. This applies equally to medical web information, as discussed earlier (Seale 2005, Nettleton et al. 2005). Diaz (2008) further discusses the self-perpetuating effects this triggers:

The problem is this: a well-linked page appears predominantly on search engines like Google; this page therefore enjoys greater traffic; and, as users become even more aware of the site, they link to it on their own pages, increasing the document's PageRank and visibility even further (Diaz 2008: 17)

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<sup>7</sup> The California-based company "23andMe" offers a ready-made DNA test on the basis of a saliva sample users send in. Despite the dubiety of the scientific method itself, users are provided with their genome without significant interpretation or medical advice: <https://www.23andme.com/> (accessed March 2010).

<sup>8</sup> Corporate information on "Google Technology": <http://www.google.com/corporate/tech.html> (accessed March 2010).

This clearly shows how search engines and the Google monopoly create information hierarchies by giving visibility to certain pieces of information while denying it to others. This phenomenon may also be described with Merton's (1968) notion of the Matthew effect, which explains how prominent, well-cited academic articles get more citations and credit than comparatively unknown papers, even if the work is similar. This effect may be extended to well-connected websites, which accumulate more and more prominence at the expense of smaller, less prominent sites.

As users mainly remain within the first 10-20 hits of the result list, search engines have further been discussed as creating competition amongst website providers to occupy one of the "top ten seats" (Introna and Nissenbaum 2000: 174). This competition may lead to strategic linking practices on the provider side, the authors therefore conclude. Röhle (2009) argues that webmasters game the ranking system in order to boost the position of their websites through search engine optimization (SEO) strategies. On the provider side, they create competition by making links a valuable currency in struggles to gain visibility online. Consequently, big and commercial websites are more successful at occupying the "top ten seats" because of their financial resources. This creates the effect that "traditional" medical institutions are foregrounded in search engine results at the expense of counter-cultural voices, as Seale (2005) and Nettleton et al. (2005) show in the medical context. On the user side, search data becomes a valuable means of making money. This newly emerging business has been described as a "personal information economy", in which the standard exchange is "service-for-profile" (Elmer 2004, Rogers 2009). Users are provided with free services, such as search tools, and users' search data is stored and used for advertising purposes in turn. In an age where advertising is increasingly matched to the customers' preferences, Google's search data has become a valuable product. Consequently, Röhle (2009: 128f) describes search engines as introducing "disciplinary regimes" of linking politics on the provider side and "advertising schemes" for gaining statistical knowledge of a population on the user side. Search engines may thus be seen as triggering new types of market mechanisms. Discussions of search engine algorithms and advertising schemes show that the web may be seen as a market that follows an economic logic of competition and financial gain. Communicating medical information via the web may thus be seen as entering a highly commercial arena. Whether website providers and user are aware of these dynamics, whether they consider them in their information practices, and what consequences this triggers in terms of the empowering potential of the web will be central questions in this thesis.

But search engines may be seen not only as serving information hierarchies and commercial agendas, but also as influencing the shape web information currently takes. Elmer (2006) argues that the "web browser-search engine couplet represents a disentangled web, where pages are taken out of their hyperlinked networks, and placed into keyword-subject indexes or linear rankings of individual pages" (Elmer 2006: 10).



Search engines quantify link networks, but also split them up and reorder websites in linear rankings of individual pages, creating a “disentangled web”. This may be seen as a first indicator for tendencies of “information fragmentation”, as described by Lash 2002. This idea, widely unacknowledged in web research so far, will be further investigated in this thesis when exploring epistemic implications the web and social practices surrounding it may trigger.

#### **4.4 Conclusion: Technical entities as part of the online health information market**

In the previous sections I have shown that both links and search engines appear to be central in the production, distribution, and use of web information. Link networks and multiple meanings embedded in link connections deeply influence how web information is hierarchized and which actors manage to become more dominant hubs than others. The question thus is whether and how different website providers employ links to attract attention in the online medical marketplace, and how different users employ links to navigate through the multitude of health information provided to them. In addition to links, however, search engines, and Google in particular, have become dominant actors in shaping the way web information is delivered and browsed. Because of their algorithms and advertising schemes, they have become objects of criticism. Here, the question is how search engines and their content biases and commercial agendas enter the medical field. Do website providers adapt their websites to gain a “top ten seat” (Introna and Nissenbaum 2000), and do users consider market dynamics when browsing the web? Which wider consequences do ordering instruments such as Google trigger in regard to the way medical information is communicated via websites? And which epistemic implications regarding strategies of interpreting and evaluating medical web information and distilling knowledge out of it may be observed?

To answer these questions, I explore website providers’ and users’ practices as sociotechnical practices co-configured by social agency and technical “actors”. But how may technical entities such as links and search engines be conceived as “actors” in the supply and acquisition of medical knowledge via the web, and what form of “agency” do they possess? To answer these questions, I draw on actor-network theory and introduce concepts central to the empirical analysis in the next chapter.



## **5 Actor-network theory: From “the social” and “the technical” towards “the-social-and-the-technical”**

In previous chapters I explained how heterogeneous actors, including different types of website providers and users, policy makers, links, and search engines and their algorithms, contribute to the way medical knowledge is communicated via the web. Further, software packages, hypertext, design elements, keywords, and web browser configurations are central in this mediated communication, as will be seen in the analysis below. To explore how these heterogeneous actors work together and shape each other in practices of providing and acquiring medical knowledge online, a perspective on both social and technical elements is needed. We require an analytical framework conceptualizing not only social actors, but also technical entities as “actors”, without falling into the trap of techno-determinism. But how can search engines, for example, be seen as “acting” in introducing hierarchies into the medical marketplace, and what kind of agency do they possess? And what new insights about technically mediated forms of communication does this allow? Below, I present actor-network theory as a central analytical tool for this purpose. I explain how ANT may be used to explore sociotechnical practices of providing and obtaining medical knowledge via the web and their epistemic implications.

### **5.1 Social reality as a “heterogeneous actor-network”**

Actor-network theory (ANT) has been developed to overcome the “unhappy” (Law 1991: 8) distinction between “the social” and “the technical” deeply built into sociology. Sociological thinking tends to distinguish between people on one hand and machines on the other, Law argues:

Sociologists (...) tend to switch registers. They talk of the social. And then (if they talk of it at all which most do not) they talk of the technical. And, if it appears, the technical acts either as a kind of explanatory deus ex machina (technological determinism). Or it is treated as an expression of social relations (social reductionism). (Law 1991: 8)

Latour has similarly argued that sociology has long been conceptualized as a “sociology of the social” (Latour 2005). Its primary aim has been to explain the social by means of the social.

As soon as you believe social aggregates can hold their own being propped up by ‘social forces’, then objects vanish from view and the magical and tautological force of society is enough to hold *every thing* with, literally, *no thing*. (Latour 2005: 70, emphasis in original)

Technology, on the contrary, has generally been conceptualized differently. It has been seen as different from nature, different from culture, and different from society. Hence, technology has not been completely ignored by sociology, but it has not been “productively integrated in large parts of sociological imagination” (Law 1991: 8), Law concludes.

The distinction between social action and technical components is widely reproduced in research exploring the production and use of web information. Particularly in the medical context, much research concentrates on the way the web intrudes into and potentially changes medical practices, as if it were a factor external to social reality (Hardey 1999, Broom 2005a, 2005b). Despite its constraints, it is widely seen as an empowerment tool, for better or for worse (Anderson et al 2003, Broom 2005a, 2005b), and sometimes as a source of risk and harm (Eysenbach and Köhler 2002). In all this research, the web is largely treated as if it were a black box distinct from offline power relations and social practices. Only recently have studies focusing on online health information begun considering the technology and its specificities, and demanding that others do the same, as argued in the previous chapter. Internet studies, in contrast, generally focus on technology and the “information politics” (Rogers 2004) it creates, arguing that they crucially shape how information is provided, distributed, and used online. These studies, however, often lose sight of providers and users and their actual behavior. This suggests that the “unhappy” distinction between “the social” and “the technical” that ANT scholars bemoan may be seen as reified in web research to a certain degree. This thesis aims to overcome this distinction by focusing on the way social practices and technical entities mutually relate to and shape each other in providers’ and users’ information practices. This will lead to conclusions about the mediated act of communication between website providers and users.

The STS researchers Bruno Latour, John Law, and Michel Callon introduced actor-network theory to challenge the sharp distinction between the social and the technical. Instead of focusing either on social or on technical entities, they suggest that we “ignore” (Latour 2005) this distinction and focus equally on all kinds of actors and their heterogeneous relations to one another. They propose to talk about “the-social-and-the-technical” (Law 1991) all in one breath. In practice, neither is the social purely social, nor is the technical purely technical, the argument goes. Drawing on Thomas Hughes’s (1986) historical study on electric power, Law (1991) argues that each social order has to be considered as a “sociotechnical order”. Hughes (1986) explores the generation, transmission, and distribution of electric power as a complex socio-technical network. He impressively shows how the system’s builder, Thomas Edison, described as a “heterogeneous engineer”, pieced together physical materials, devices, architects, economics, law, text, and other heterogeneous elements to make the whole electric power system work. Neither the technical nor the social is decisive in the end, Hughes (1986) concludes.

Instead, they may be seen as co-constructing each other and creating a socio-technical order. Law (1991) uses this example to illustrate that “wherever we scrape the social surface we will find that it is composed of networks of heterogeneous materials” (Law 1991: 10). To conceptualize the symmetric approach towards the social and the technical, ANT has formulated the central argument that social reality is an outcome of heterogeneous actor-networks. According to ANT, social reality is configured in a network of “materially and discursively heterogeneous relations that produce and reshuffle all kinds of actors including objects, subjects, human beings, machines (...)” as Law (2007) puts it in a recent online article.

Like the electric power system, the web and the social practices surrounding it may be seen as sociotechnical. HTML, browsers, websites, pieces of code, interfaces and surfaces, hyperlinks, and a variety of applications and search tools, as well as the programmers developing the code, the people writing the websites, the Google work force, and the users selecting and deselecting the search tools, websites, and portions of text, may all be seen as actors participating in the configuration, distribution, and acquisition of web information. Drawing on ANT, I conceptualize practices of providing and acquiring medical knowledge online as sociotechnical practices shaped by both social and technical components. This theoretical perspective makes it possible to grasp how technology contributes to and mediates between website providers’ and users’ actions. But how can the web and its technical components be conceived as “actors”? What agency do these “non-human” entities possess, and what power relations may be seen through the lens of ANT? To answer these questions I present central concepts in ANT. I start by discussing how ANT explains technologies as “full-blown actors” shaping social practices in certain situations. I further discuss ANT’s specific concept of “agency”, which makes it possible to consider both social and technical entities as “acting”, in the sense of “changing a state of affairs”. Finally, I show that not all actors should be considered to have the same power, but that certain actors may become more powerful by installing themselves as “obligatory passage points” (Callon 1986). This helps in understanding how certain actors such as search engines gain a more powerful position than others in the online health information market, as I show in my analysis.

## **5.2 Technology as a “full-blown actor”**

The field of STS has a long tradition of arguing that technologies are configured by social relations and may thus be seen as socially constructed. Scholars investigating what has been described as “Social Construction of Technology” (SCOT) have neatly shown that new technologies should not be seen as outcomes of linear innovation processes, but rather as results of complex negotiations between different actor groups, particularly developers and various user groups (Bijker et al. 1987). They have shown that socio-

political values may be seen as inscribed in the creation and design of technologies. More specifically, Akrich (1992) has argued that suggestions for future uses of a technology are built into its shape. In her article "*The De-Description of Technical Objects*", she argues that "like a film script, technical objects define a framework of action together with the actors and the space in which they are supposed to act" (Akrich 1992: 208). According to her technologies may be interpreted as embodying a "script" proposing how the technology is supposed to be used. These scripts, however, should not be seen as rigid and fixed. Rather, they may be adjusted, redefined, and altered when they encounter real circumstances and users, or change sites. Akrich's (1992) work shows how ANT accepts that technologies are shaped by social relations, but also how ANT aims to go beyond the arguments of SCOT. While SCOT generally focuses on the genesis of technologies, ANT also asks how technologies come to play an active role in social reality. It seeks to identify the mechanisms that make technologies act in their own right, without conceptualizing technology as fully determining society. Mechanisms of this sort are the delegation of human action, morality, and politics to things; the black-boxing of technology; and the punctualization of actors, as I discuss below.

To exemplify the delegation of human action to things, Latour and Akrich (1992) vividly discuss a range of mundane artifacts and their role in social action. A notice that the automatic door opener is "on strike" may remind us that we have delegated the concierge's role of opening and closing doors to a technical artifact. According to Latour and Akrich, this involves a crucial reshuffling and redistribution of competences and dependences in our society. "When humans are displaced and deskilled, nonhumans have to be upgraded and reskilled" (Latour and Akrich 1992: 232), the authors conclude. Discussing the seat belt in a car, the authors further ask whether technologies might even take over our morality. Seat belts are supposed to save us from dying in car accidents. When we try to start the engine without buckling the seat belt, the car flashes a light requesting the driver to fasten the seat belt and starts to make an alarm sound. This tiring noise forces the driver to give in and fasten the seat belt to protect himself. The "script" of the seatbelt may thus be seen as forcing the mindless human to obey the law. Like the automatic door opener that has taken over the competence of opening and closing doors, the seatbelt may be seen as having taken over morality. These examples illustrate Latour's argument that "*Technology is Society Made Durable*" (1991). They show that technologies may be seen as having socio-political values inscribed that make the individual act morally through the material intervention of the object.

This argument becomes particularly striking in Winner's (1986) case study on the height of bridges in New York. Winner argues that the low bridges in New York prevent poor, and most particularly African-American, people from going to the recreation areas these bridges are supposed to make accessible. According to Winner, the architect of the bridges, Robert Moses, built the bridges low so that public buses, predominantly used by

people who cannot afford cars, cannot pass the bridges. Winner draws the conclusion that Robert Moses built his supposedly racist ideology into the bridges, which continue to act as technical artifacts. To sum up his argument, Winner (1986) coins the term "political technology", which has been taken up in various contexts, particularly in regard to search engine algorithms (despite debates whether Winner's empirical observation is actually valid or not). Introna and Nissenbaum (2000) frame search engines as political because their algorithms systematically prefer big, well-connected websites at the expense of marginalized ones, as argued earlier. This is particularly relevant as the majority of users do not know how search engines actually work, and rank their results as will be seen in my analysis. Like car users who smoothly pass Moses's bridge without recognizing the political ideology it embodies, users employ Google without recognizing the PageRank algorithm it uses, or the resulting Matthew effect (Merton 1996). In these contexts, technologies may be seen as black boxes acting as "full-blown" actors in their own right.

ANT scholars originally used the term "black box" to describe scientific knowledge taken for granted as "facts". In early laboratory studies, Latour and his colleagues (Latour and Woolgar 1986, Latour 1987) trace how scientific results become black-boxed by gradually becoming detached from their genesis and the socio-technical networks involved in their development. Transferring these insights to the technical realm, Latour (1987) argues that technical objects get black-boxed through routinization. Discussing the can opener we routinely use in the kitchen, Latour describes this process as follows:

We consider the opener and the skill to handle it as one black box, which means that it is unproblematic and does not require planning and attention. We forget the many trials we had to go through (blood, scars, spilled beans and ravioli, shouting parent) before we handled it properly, anticipating the weight of the can, the reactions of the opener, the resistance of the tin. It is only when watching our own kids still learning it the hard way that we might remember how it was when the can opener was a "new object" for us, defined by a list of trials so long that it could delay dinner forever. (Latour 1987: 92)

Latour describes the can opener as a stabilized object, analogous to stabilized facts. In contrast to new technical objects under scrutiny, stabilized objects such as the can opener are used in an uncritical way. Like "hardened facts", stabilized objects are widely taken for granted without hesitation. The object's complex inner life, its processes of development, and the socio-cultural values involved have disappeared in the course of its routinization process. Like the can opener, Winner's (1986) bridges and search engines such as Google may be conceived as black boxes. Their politics act through their technical materiality without being acknowledged on a large scale. They may be seen as acting in their own right.

The mechanism involved in turning heterogeneous actor-networks into actors in their own right has been described as "punctualization" in ANT terminology. "Punctualization" (Law

and Mol 2002, Law 2002) describes the process of black-boxing to reduce the complexities present-day societies are faced with. It enables complex actor-networks to figure as actors in their own right in certain situations. Let me take search engines as an example of the process of punctualization.

Using ANT, we can see a search engine as a heterogeneous actor-network. It is an outcome of complex relations between hardware and software components, mathematicians, programmers, and commercial actors, and their concepts and socio-political approaches towards technology. This complex inner life, however, remains largely hidden from the user, who simply interacts with the "browser-search engine couplet" (Elmer 2006) as a single object. The effect labeled "punctualization" allows the reduction of a complex actor-network to a single node in a bigger network. Consequently, each actor turns out to be an actor-network when we "depunctualize" it by zooming in. To do this all the time, however, would make social reality too complex to manage. That is why punctualization takes place in everyday practices such as searching the web, and also in research processes investigating these practices. Analyzing social reality inspired by ANT means opening up certain black boxes, while leaving others closed. In my analysis, I employ ANT to "depunctualize" online health information by exploring how it is actually practiced by website providers and users and what role technical actors play in their practices. What actors – both human and non-human – are involved in the communication of medical web information, and how do they interact? In this analysis I discuss the perspectives of different website providers and users, but not search engines. Hence, I open up or "depunctualize" search engines only as far as the interview partners themselves open them up, as I further discuss in the section on methods. But how can technical entities such as search engines be seen as "acting" at all?

### **5.3 Objects too have agency**

ANT's definition of an actor is radically different from the standard sociological definitions. Building on philosophical concepts, sociology usually conceptualizes an actor as a rational human figure (De Laet and Mol 2000). With this definition, things, objects, and materials of all kinds are excluded from being actors per se. In contrast, ANT suggests that both humans and other entities may figure as actors. In ANT terminology, entities take their forms and acquire their attributes as a result of their relations with other entities. ANT is a "ruthless application of *semiotics*" (Law 1999: 3). Accordingly, being an actor is not a quality an entity possesses or not, but a result of its relations to other entities in the network. Actors are network effects. This means that being an actor or not does not necessarily correspond to being human or not. An object may be an actor, while a human being may turn out to be a passive intermediary in certain situations, and vice versa, as Latour (2005) argues. It depends on the role the entity plays in the network.



The crucial point in terms of agency is that actors – whether human or other – act, in the sense of changing a state of affairs. Instead of “silent intermediaries”, actors are “full-blown mediators” in social practices. Latour (2005) distinguishes intermediaries from mediators as follows:

For intermediaries, there is no mystery since inputs predict outputs fairly well: nothing will be present in the effect that has not been in the cause. (...) For mediators, the situation is different: causes do not allow effects to be deduced as they are simply offering occasions, circumstances, and precedents. As a result, lots of surprising aliens may pop up in between. (Latour 2005: 58f)

According to this definition, intermediaries function as mere transmitters, transferring something from A to B without changing it. Mediators, on the contrary, are “doing” something in between A and B, creating unexpected reactions. Latour explains that “agencies are always presented in an account as *doing* something, that is, making some difference to a state of affairs, transforming some As into Bs through trials with Cs” (op.cit.: 52f).

To fully grasp ANT’s concept of agency, the notions of transformation and translation originally connected to the term “actor-network” need to be explored in greater detail. Latour (1999) notes that the term “network” originally meant a series of transformations, translations, and transductions. In his work on practices of manufacturing scientific knowledge, Latour (1987, 1996) identifies technologies and materiality in a wider sense as central actors because they translate nature into text. Accompanying scientists working in pedology in Boa Vista, Latour (1996) finds that technologies such as measuring tools, classification systems, and visualization tools play a central role in translating the Brazilian jungle into “facts” codified in the final publication. But what kind of agency do these instruments possess? Instruments with strange names such as “pedo comparator” and “Munsell code” help scientists to sort, compare and re-assemble samples to identify patterns they have not seen before. They “tell” the scientists how to order the accumulation of different specimen and soil samples by translating nature into patterns and patterns into text. They “act” by transforming natural objects into text, working with other actors, including the scientists, the laboratory, and a range of materiality populating the lab. The scientists have to lose the jungle in order to learn about it, Latour concludes.

But Latour further argues that technologies participate not only in scientific practices, but also in everyday life. Having elaborated how mundane artifacts shape social practices, he concludes that technical objects permit certain behavior through their technical specificities, through the “scripts” they embody. Discussing the remote control that turns us into couch potatoes, Latour (2005) concludes that things act as though they “might authorize, allow, afford, encourage, permit, suggest, influence, block, render possible,

forbid and so on" (Latour 2005: 72). They appear to be "full-blown mediators" because they change a state of affairs by transforming our actions. Accordingly, I ask how software packages, links, and search engines may be seen as mediating between website providers and users. How do they influence the transformations medical web information undergoes because of its technical mediation or "informationalization"? And how do they contribute to power relations and information hierarchies? To answer the last question, I end the chapter by discussing Callon's (1986) work on the way power is constructed and stabilized in heterogeneous actor-networks.

#### **5.4 Power is always an effect**

In ANT, power is not seen as a pre-existing starting point, but rather as an outcome of complex actor-networks. Like agency, power is not a given status an actor possesses or not. Rather, power is seen as a "relational matter, one of the effects of a heterogeneous network of sociotechnical elements", as Law (1991: 179) says. To illustrate this argument, I draw on Callon's (1986) notion of the "obligatory passage point", which has become central in ANT thinking. In the 1980s, Callon went to St. Brieuc to investigate a scientific controversy over the domestication of scallops. More specifically, he sought to trace the establishment and evolution of power relations in heterogeneous actor-networks. The starting point for the case study was the dwindling of the population of scallops – a gourmet specialty in France – in St. Brieuc Bay and the efforts of three scientists to counter this trend by implementing a new breeding system from Japan. Callon follows the three scientists from the presentation of their idea to their final field experiment. He traces how the scientists managed to convince other actors to join their project, how they built alliances, and how they succeeded in becoming indispensable obligatory passage points, at least for a certain period of time. Using the language of ANT, Callon describes this general process as a process of translation, "during which the identity of the actors, the possibility of interaction and the margins of manoeuvre are negotiated and delimited" (Callon 1986: 203).

The first step the scientists took was to install themselves and their research project as an "obligatory passage point", as Callon (1986) describes. They developed a solution to the problem of working with three disparate actor groups. Neither the scallops, the fishermen, nor the researchers' scientific colleagues could reach their goal by themselves. But they could reach their goal by supporting and building alliances with the three researchers. The crucial next step for the researchers was to convince the other actors to support the project and act their parts. They did so by translating the others' interests into their own and distributing roles to the actors involved. Callon calls the actions by which the scientists imposed and stabilized the identities of the other actors "intéressement", because to be interested is to be in between. If the intéressement is

successful, the actors accept their assigned roles. They are successfully “enrolled”, in ANT terminology. In the process of translation, both human and non-human actors were translated. The identities and roles of the actors were defined and distributed throughout the course of action. The scientists managed to become powerful actors by mobilizing other actors by translating their interests into their own. At the end of the translation process, a network of relationships and alliances had been established to support the scientists. The scientists’ power may thus be seen as an effect of the actor-network around them. Their power was stabilized by and hence dependent on other actors. This relational concept of power allows us to turn away from deterministic viewpoints conceptualizing power as a given, towards a concept of power as constantly constructed and stabilized by practices.

This concept of power has been applied to very different contexts. Like the scientists in Callon’s case study, the power of business managers may be seen as constructed by heterogeneous actor-networks. Having investigated how power is “made” in an organization, Law (1997) argues that the power of the central manager of the organization is stabilized by a complex actor-network of collaborators, discourses, and materiality involving heterogeneous entities such as machines, paperwork, and money. Drawing on Callon’s (1986) insights, I pose the question of how search engines become a dominant node or “obligatory passage point” in sociotechnical practices of providing and obtaining medical knowledge via the web. Why do both website providers and users adapt their practices more and more to search engines such as Google, and what consequences derive from the resulting “information politics” (Rogers 2004) and market dynamics? And what epistemic implications does the dominance of search engines have for the communication of web information, particularly in the medical context? Those are the questions to be answered in the following chapters. Drawing on ANT’s concept of power as a network effect, I shift my attention to practices of constructing and stabilizing power relations in providers’ and users’ information practices. This enables me to shed new light on discussions of search engines as “information gatekeepers” that threaten the democratic potential of the web as if they were an external factor.

## **5.5 Conclusion: Technical entities mediating between website providers and users**

In this chapter I have drawn on ANT to conceptualize practices of providing and acquiring medical knowledge via the web as sociotechnical practices shaped by social actions and technical entities. While ANT may be interpreted as dehumanizing humans and their abilities by flattening the distinction between human and non-human actors, I perceive it rather as a helpful concept for thinking about technical entities as active participants in online practices. It enables us to put the focus on “the social-and-the-technical” delivering

insights into the way social practices and technical entities mutually influence each other. This perspective gives us a broader picture of the way social and technical elements of various sorts work together in practices of providing and acquiring medical knowledge via the web, and the way certain actors, such as search engines, attain powerful positions in the practical exchange of medical web information.

It allows me to answer question such as these: How do different types of website providers and users “enroll” technical actors in their practices, and how do these technical actors shape the providers’ and users’ actions? How do heterogeneous entities such as links, software packages, search engines and their algorithms, web browsers, keywords, pieces of text, and other entities work together in website providers’ and users’ practices? How are power relations and information hierarchies constructed and stabilized in these information practices?

On a more abstract level, the ANT perspective enables me to explore whether the web – and dominant actors such as search engines – may be seen as contributing to information fragmentation by “informationalizing” medical knowledge. Does the web “act”, in the sense of changing a state of affairs, by mediating between website providers and users? Does the information change on its way from website providers to users? Can the web be seen as an actor contributing to tendencies of “information fragmentation” (Lash 2002), as claimed in literature on present-day information societies? What epistemic consequences does this trigger, and what abilities and skills need to be developed to obtain medical knowledge instead of fragmented information? These are central questions to be answered in my empirical analysis. Only by focusing on both social practices and technical elements and their mutual relation to one another may answers to these widely unacknowledged questions be found. Consequently, a more critical perspective on the web as a health information source and its empowering potential for patients should be developed, as I will show in the following chapters.

## **6 Context of the study, research questions, and methodological tools**

In the foregoing chapters, I presented theoretical resources and analytical tools to conceptualize and explore sociotechnical practices of communicating medical knowledge via the web and the epistemic implications of these practices. Discussing theories of the “knowledge” and “information society” (Chapter 2), I showed that medical knowledge should be seen not as a stable concept, but rather as transforming in the context of broader techno-scientific developments. I showed that (scientific) knowledge is multiplying and diversifying in present-day societies. I argued that tendencies of knowledge proliferation have been described as raising power and agency on the parts of individuals, but also as contributing to uncertainty and loss of trust in authorities. Drawing on theories of the information society, I argued that ICT plays a central role in these developments. Aside from the growth and pluralization of information, I argued that information increasingly figures as disembedded and fragmented not least through its technical mediation posing new challenges for members of the “information society”.

I also discussed how these tendencies are seen in the medical field (Chapter 3). Much sociological literature celebrates the web as broadening access to the production and use of medical knowledge, contributing to ongoing trends of patient empowerment. In this view, access to medical knowledge is equated with gaining power and agency to question medical authority and make reasonably informed choices. Voices from the realm of medical professionals and policy makers, in contrast, display a rather reluctant attitude towards the web and internet-informed patients conceptualizing the web as contesting the medical profession. Consequently, whether the web should be seen as as valuable information source is controversially discussed. While academic and public debate widely embraces the web as giving voice to multiple types of actors strengthening the democratic ideal of the web, medical professionals and policy makers try to regain control over “e-scaped” medicine. A central means to achieve this goal are standardized quality criteria and labels for medical websites in their perception, which may be seen as corresponding to wider trends towards “evidence-based medicine”. While a lot has been disputed about online health information and its quality, little is known about information practices, and how the technology shapes these practices. Following work that has already started to investigate these issues this thesis puts the focus on practices of providing and obtaining medical knowledge via the web, and which epistemic implications this technically mediated act of communication may trigger. To do so I conceptualize the web as a medical marketplace where medical knowledge is dominantly communicated today recognizing the market paradigm of present-day health care, where patients are conceptualized as “reflexive consumers”.

To explore how medical knowledge is actually exchanged on this market in form of web information, technology and its specificities need to be drawn into the picture. Using insights from the field of new media studies (Chapter 4), I showed that not only website providers and users of different sorts, but also technical entities, search engines in particular, may be seen as participating in the production, distribution, and use of medical web information, configuring hierarchies and market dynamics. This raises the question of how website providers and users engage with the technology and its sociotechnical dynamics. Work in the field of critical PUS has shown that laypeople engage with knowledge by embedding it in their individual backgrounds, and that the credibility and “social body language” of the speakers are central in these practices. However, research is needed how heterogeneous website providers and users communicate medical knowledge via the web and how the technology mediates between and shapes their practices. An analytical framework serving this purpose is actor-network theory, as I further explained (Chapter 5). ANT enables me to conceptualize both social and technical entities as actors in the provision and use of online health information, which I label sociotechnical practices.

## **6.1 Research questions and empirical material**

Equipped with these theoretical concepts and tools, I explore sociotechnical practices of providing and acquiring medical knowledge via the web and the epistemic implications this mediated communication may have. Concretely, I analyze website providers’ and users’ sociotechnical practices as reciprocal practices and mutual imaginarios attached to these practices, enabling me to draw conclusions about their mediated relation to one another. I seek to show how different types of website providers send their respective medical knowledge on the journey through the web and how users engage with and interpret medical web information and distill knowledge out of it. Further, I analyze how the web and its technical gestalt mediate between and shape providers’ and users’ actions.

Concretely, the following three sets of research questions will guide my empirical analysis:

- 1. How do website providers and users find each other in the online medical marketplace?*

This first research question explores the notion of the web as a market where medical information is exchanged between different types of website providers and users. Central questions are these: What strategies do website providers employ to *position their medical websites* to be found by users, and what strategies do users employ to *search*

*for, filter, and select websites* out of the plethora offered to them? What impressions of their respective counterparts accompany providers' and users' actions? And how do technical entities such as links and search engines shape their doing?

2. *How do website providers and users communicate medical information via websites?*

The second research question investigates *websites* as locations where medical information is provided by website providers and encountered by users. Here the questions are these: How do different website providers *configure, structure, and design their medical websites* to serve and entice users, and how do different users *navigate through, read, and acquire information* from medical websites? What mutual ideas are related to their practices? And how do technical elements and the agency they grant to website providers and users shape their actions?

3. *What epistemologies are embedded in website providers' and users' information practices and narratives?*

The third research question puts the focus on providers' and users' epistemic practices as related to their respective interactions with technology. In this context, questions to answer are these: How do different types of website providers *try to make their medical information credible and evoke trust* on the user side? How do different users *interpret, evaluate, and make sense* of medical web information and create knowledge out of it? What epistemologies are embedded in providers' and users' practices, and how does the technology with its specificities contribute to them?

To answer these questions, I draw on empirical data collected in a larger research project. The research project was called "Virtually Informed. The Internet in the medical field: Investigating the role and impact of the world wide web as a health information source in the Austrian medical context", and was carried out from 2005 to 2009 at the Department of Social Studies of Science at the University of Vienna. In this project I collaborated with Ulrike Felt, the leader of the project, as well as Lisa Gugglberger, Bernhard Höcher, Sonja Österreicher, and Paul Ringler, whom I kindly thank for the intellectual input they gave. The purpose of this project was to investigate the possibilities and challenges the web poses as a health information source in the Austrian medical context. We sought to investigate the web as health information sources with multiple methods and from various perspectives including doctors, patients, website providers, and users, as well as policy documents and media articles dealing with e-health technologies.

All together, the empirical material comprises a collection of hyperlink networks exemplifying well-connected communities of health-related websites, 7 qualitative

interviews with health information providers, 41 “scenario experiments” observing participants’ search strategies, 41 qualitative interviews with the participants of the experiments, 644 short questionnaires on the internet use of patients collected in 12 medical practices, 33 qualitative interviews with patients (out of the 644), 10 qualitative interviews with medical professionals, and a range of media articles and policy papers on e-health developments. The project focused on four diseases: diabetes, rheumatism, asthma, and eczema. These diseases were chosen because all of them are chronic and closely related to lifestyle issues such as nutrition and sports. We supposed that this characteristic would create an increased need for information, to be met with the web (and other information sources), which was confirmed in the course of the project.

## **6.2 Methodological tools**

For the purpose of this thesis I draw on data collected to investigate the supply and acquisition of medical web information, as I discuss below. I focus on diabetes as a thematic context holding the different perspectives on medical web information together, as explained in the introduction. This focus enables me to concentrate on website providers’ and users’ information practices and ideas without getting drawn in different directions by various diseases. Hence, diabetes serves as a case study in which the communication of medical web information between website providers and users may be observed. Although topical examples come from the field of diabetes, the focus of analysis is sociotechnical information practices and their epistemic implications. Below, I discuss concretely what methods were chosen to investigate how medical web information is communicated between website providers and users in the specific context of diabetes.

### *Website providers’ practices and narratives*

Website providers’ practices of configuring and positioning their websites are hard to observe directly. We thus employed a trio of methods to draw a conclusion about the ways different types of website providers assemble medical information on their sites and try to gain visibility online. We started by developing hyperlink networks with the software IssueCrawler<sup>9</sup> to get a grasp of diabetes-related websites and their connections from a bird’s-eye perspective. On the basis of these link networks and users’ search experiments, five different types of well-positioned websites offering diabetes-related information were selected for deeper analysis. Additionally, qualitative interviews with the providers of these sites were conducted. The trio of methods allowed us to gain insights into both website providers’ sociotechnical practices and their narratives of providing and

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<sup>9</sup> IssueCrawler is by the govcom.org Foundation, Amsterdam. For further information, go to <http://www.govcom.org/> (accessed March 2010).



positioning their websites. Let me discuss each of the methods in detail to explain their purposes:

Work in the field of new media studies has shown that links play a central role in distributing web information across individual websites. Links enable connections between websites that address the same issues, share social relations, or simply have a financial affiliation, as will be seen in my analysis. But how can different linking practices be identified? Drawing on work from the field of *hyperlink research* (Rogers and Marres 2000a, 2000b, Park and Thelwall 2003, 2006), we started this undertaking with the software IssueCrawler. IssueCrawler performs a co-link analysis to map densely interlinked communities of websites, which means it performs two steps of "exclusion". Consequently, not all linked websites are visualized, but only those websites that get a link from at least two of the original starting points. The interrelations between these "survivors" are finally displayed as a network with websites as nodes and hyperlinks as links between them (Rogers 2006). Developing hyperlink network maps makes it possible to identify dominant websites in a particular issue field, such as diabetes, according to their connectivity and relationships, as may be seen on the left side of the illustration below:

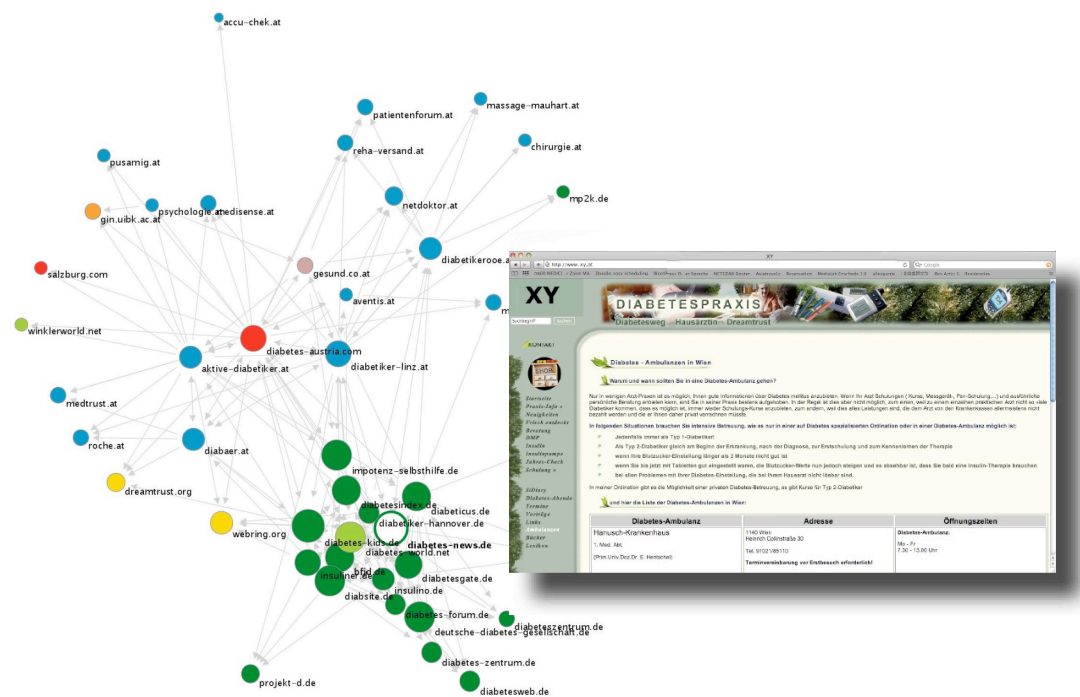


Figure 1: Left side: Hyperlink network displaying lay-oriented diabetes sites, created in 2005. Right side: One of five diabetes-related websites analyzed in detail, saved in 2006.<sup>10</sup>

<sup>10</sup> Except from hyperlink networks developed by the software IssueCrawler all illustrations have been designed by Michael Mastrototaro: <http://www.reizfeld.net> (accessed March 2010).

Immediately, the network shows that diabetes-related websites are not equally distributed on the web. Rather, certain websites are heavily interlinked nodes, while others are weakly connected, triggering consequences in terms of visibility. Well-linked hubs are much more likely to attract users who are directed there by other websites, but also users who rely on search engines – an aspect I will discuss in detail below. Linking politics may thus be seen as challenging the democratic ideal of giving an equal voice to all actors. Instead, power relations and hierarchies between websites may be observed when looking at the web from a bird’s-eye perspective. Hyperlink networks thus help to identify well-connected websites in particular issue areas, such as diabetes, and form a first impression of the linking strategies different website providers employ. How these link networks actually come into being, what ideas website providers inscribe in their link connections, and what consequences to visibility linking politics trigger will be seen throughout this thesis.

First impressions of linking practices formed from hyperlink networks were deepened through *content analyses of five Austrian diabetes-related website* and interviews with their providers to understand underlying motivations embedded in these link networks and additional strategies of positioning websites on the medical marketplace. To cover the diversity of different types of medical information circulating online, these websites included the sites of a diabetes self-help group, a general practitioner specializing in diabetes, a general health portal, and a pharmaceutical company producing insulin and medical devices for diabetics. A kind of hybrid between commercial and non-commercial web information was chosen to round out the picture. This site was managed by a patient afflicted by diabetes and also making a living from the site. The information provided by these sites ranged from orthodox medical information to experiential information to commercial information. Because of the marginalized presence of alternative medicine in both link networks and search engine results, no website offering alternative medical approaches were included in the study on the provider side. (Some users explicitly searched for this kind of information, however.) The five websites were analyzed according to dimensions such as the types of information provided on the different sites, how the information was structured and designed, how website providers presented themselves, whether images and quality labels were displayed, and how links were assembled on the site.

Finally, *qualitative interviews* were conducted with the providers of these websites to understand how they configured and positioned their websites. All together, six interviews were done, in 2006 and 2007. The six interview partners included the chairman and the webmaster of the diabetes self-help group, the patient providing the semi-commercial diabetes website, the general practitioner specializing in diabetes, the director of the general health portal, and the PR manger of the pharmaceutical company. The providers were asked why they provided websites, how they built the sites and whether

professional webmasters were involved, how they assembled the information and tried to make it credible, how they interlinked their sites, and how they tried to attract and entice users. Further, the web as a health information source and the quality of the information provided online were discussed in a more general sense. Finally, the network maps were discussed with the website providers to get an idea of how they viewed their own positions in these hyperlink networks. Results of these interviews were then juxtaposed with insights gained from the network maps and website analyses.

The combination of these different methods lead to conclusions about the sociotechnical practices website providers employ to configure and position their respective medical websites in the plethora of online health information, and what impressions of users and epistemology accompany their actions.

### *Users' practices and narratives*

To investigate the user side, online search experiments and subsequent qualitative interviews were carried out in 2006 and 2007 to examine how users browse through, select, and understand diabetes-related information out of the multitude offered to them. The combination of search experiments and qualitative interviews allows insights into users' sociotechnical practices as well as their impressions of providers and epistemologies related to their practices. Below, I discuss the methods and their purposes in detail.

In the research project, 41 participants were recruited via bulk mail to do a web search on a chronic disease. Out of these 41 people, 10 searched for diabetes. The users varied in gender, age, educational background, internet skills, and medical preferences, to represent the variety of people searching for health information online. The participants had no prior experience with the disease. Each of the participants was given a fictive scenario stating that she or he had just come from the doctor with a diagnosis of diabetes and some additional information about the disease. The participants were then asked to turn to the web to search for information relevant to them in this particular state of health. On the laptop used for the *search experiments*, two different browsers were installed. Each of the browsers opened with a blank page to provide the users the possibility to freely choose how to start their searches. This was to prevent imposing a certain browser, website, or search engine on the participants that they would not use otherwise. The participants' online searches were saved with a piece of software called "My Screen Recorder"<sup>11</sup>, which captured desktop activity and stored it as a video file:

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<sup>11</sup> The commercial software "My Screen Recorder" captures a computer's desktop activity and saves it as an AVI file: [http://www.deskshare.com/pricing\\_details.aspx?ID=21](http://www.deskshare.com/pricing_details.aspx?ID=21) (accessed March 2010).

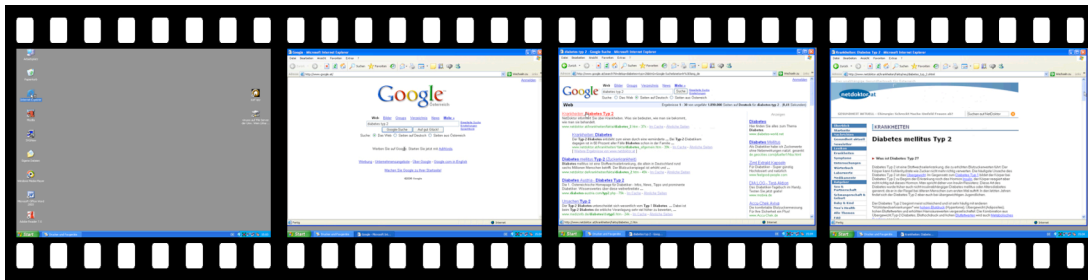


Figure 2: Illustration of a web search on diabetes carried out in 2006.

How patients do web searches on a medical topic and how they talk about those web searches may not be the same, as researchers of online health information have argued (Eysenbach and Köhler 2002, Nettleton et al. 2005). These search experiments enabled us to observe how users actually did an extended web search on a particular health-related issue such as diabetes. Further, we assumed that researching on the web requires a set of skills and implicit knowledge that is hard to explain. These experiments thus helped users to experience a health-related web search before talking about it. This would help users to talk about their search practices and evaluation strategies more easily, we thought, a prediction that was confirmed in the study. Patient interviews conducted in the larger research project showed that practices of using the web for medical purposes change over time. In the course of time, looking for medical information becomes an occasional practice embedded in social networks, other information sources, and most particularly doctor-patient relations. These search experiments thus allow an understanding of how users do an extended web search on a health-related issue for the first time, an activity difficult to observe otherwise. The film material was analyzed by identifying search patterns according to questions such as these: How did users begin their searches? How did they select websites? How long did they use a website? How did they go through a site? How did they switch between websites? And did the searches change over time?

Impressions formed from the film material were further deepened through *qualitative interviews* with the participants. Immediately after the search, the participants were asked how they started their search, what information they found, if they were confident with the information, how they selected websites and switched between them, how they evaluated and interpreted the information, and what role website providers played in these practices. Further, the web and its medical information were discussed, as well as similarities and differences between the fictive scenario and “real” health searches that users had done. Finally, some users were confronted with their own searches and invited to comment on them to get an idea of how they themselves perceived their search strategies.

The hyperlink networks, websites, and search films were systematically analyzed by identifying categories and patterns that enabled us to compare different networks, websites, and search strategies with each other. The interview material was fully transcribed, coded with the qualitative research software *ATLAS.ti*<sup>12</sup>, and analyzed following a Grounded Theory approach (Glaser and Strauss 1968). All analyses were guided by the three central sets of research questions, which ask how website providers and users find each other in the online medical marketplace, how they communicate medical information via websites, and what underlying epistemologies accompany providers' and users' sociotechnical practices. Additionally, an analysis was done of the way website providers and users themselves perceive the web as a health information source and the motivations they express for using the web for medical purposes; these motivations deeply shape their practices, as will be seen.

### **6.3 Conclusion: Multiple methods, their limitations and performance**

The multiple methods presented above allow us to grasp how medical knowledge is communicated via the web and the epistemic implications this may involve from the perspectives of different types of website providers and users. These are the "actors" I follow in my analysis, to use ANT terminology. This focus makes it possible to explore the variety of sociotechnical practices involved in the supply, distribution, and gathering of medical web information.

My understanding of the different methods employed, as well as my analysis, should be seen as influenced by recent contributions in ANT (Law 2004). Instead of seeing these methods as simply reporting on a pre-existing reality, I understand them rather as performing this very reality at the same time. Both the hyperlink networks and the search experiments may be seen as envisioning and constructing a certain web reality through the parameters built into them. They bring certain aspects of reality to the fore, while concealing others. Hence, my methods may be seen as having certain limitations. IssueCrawler does not simply visualize a pre-existing "link reality" out there, but rather constructs it at the time of its use with a specific algorithm. Further, the choice of points from which the software starts to crawl and other settings the individual researcher may choose, influence the way the networks are constructed. Visualization tools of this kind may thus be seen as perfectly exemplifying the performativity of methods extensively discussed by John Law (2004).

The search experiments, similarly, carry certain limitations in their set-up. Conducting online search experiments with people not suffering from diabetes creates some of these

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<sup>12</sup> ATLAS.ti Scientific Software Development GmbH: <http://www.atlas.com> (accessed March 2010).

limitations. First of all, the idea of doing a longer web search after receiving a (fictive) diagnosis was imposed on the participants by giving them about one hour of search time. Secondly, although it addressed different dimensions of the disease – such as the medical term for the disease, possible influencing factors such as nutrition and sports, and suggested medication – the information given may partly have determined the search that followed. Finally, the participants neither experienced an encounter with the doctor themselves, nor felt symptoms of the diseases. Hence elements such as urgency, specificity, and embodied symptoms involved in “real” health searches were lacking, which may have influenced the participants’ search strategies. In the later interviews, the hypothetical search situation was compared to real health searches to contextualize the material gained in the search experiments and prevent excessively biased results. Just as IssueCrawler reflects certain technical parameters and assumptions, the search experiments may be seen as having various ideas built into their set-up that shape the “reality” they construct.

But it is not only visualization tools and experimental methods that construct realities in a certain way. Quite on the contrary, classical research methods such as interviews may also be interpreted as shaping realities. Choosing an interview partner means taking a particular standpoint, following a certain actor and not another. This implies opening certain nodes in the network, while “punctualizing” others, as argued earlier. In this sense, the multiple methods I have chosen should not be understood as presenting different perspectives on a single object, online health information, but rather as allowing for an understanding of the way health-related web information is differently practiced and understood by different actors and how this relates to sociotechnical dynamics present in the online medical marketplace, as will be shown in the following analysis.

## **7 Website providers' and users' approaches towards online health information**

In the following chapters I discuss sociotechnical practices of providing and obtaining medical knowledge via the web and epistemic consequences the technical mediation or "informationalization" of knowledge may involve. Before addressing how "informational knowledge" (Lash 2002) is communicated in practice, I discuss how website providers and users perceive current developments in the medical field, and the web as health information source in particular. Much has been said about the broader societal debates around online health information, but how do the interview partners themselves perceive the web as a health information source? Do they conceptualize it as an empowerment tool, and what does patient empowerment mean to them? Do they perceive it as dangerous and harmful, as do medical professionals and policy makers? Do they acknowledge its commercial dimensions? Further, I analyze motivations different types of website providers and users express for turning to the web for medical purposes. Why do website providers employ the web to communicate their medical knowledge to a broader public, and why do users go online to search for medical knowledge meeting their needs? How do these goals differ between various interview partners according to their agendas and models of medicine? These motivations deeply shape how different providers and users employ the web for their purposes and interpret and evaluate medical web information and its credibility, as will be seen in the following chapters.

### **7.1 The rhetoric of patient empowerment**

All website providers and users broadly agreed that the ideal patient is supposed to act in a self-responsible way and contribute to health-related decisions today. When talking about the web as a health information source, the majority of the interview partners referred to the figure of the "empowered patient" celebrated in much of the literature (Hardey 1999, 2002, Anderson et al. 2003, Broom 2005a) and in public discourses (Felt et al. 2009b). As in these discussions, however, the term "patient empowerment" does not appear to have a single clear-cut meaning, but rather multiple ones. It figures as a buzzword embracing quite different concepts, ranging from patients acting as equal partners with doctors, to patients critically scrutinizing their doctors, to patients acting in self-responsible ways and actively coping with health conditions in everyday contexts, as I discuss below.

Mirroring academic and public portrayals of the web as a health information source, the interview partners primarily referred to patient empowerment in the context of doctor-patient relations. Both website providers and users broadly described empowered patients

as ideally challenging medical authority and becoming collaborating partners with doctors. The web administrator of the diabetes self-help association expressed his vision as follows:

W4m: This is an age where one should really say that a patient should be empowered, and only then is he a good partner to the doctor. Because it's not like, "Please doctor, heal me". That does not work. One has to act on one's own, and the doctor is the manager and counselor, right? But I have to be able to discuss with him and say, "Listen, I've heard this. Does it apply to me?" (Q1, patient association)<sup>13</sup>

This quotation illustrates that the patient is no longer expected to rely exclusively on the doctor to get healed, but rather to actively contribute to this process. The patient is imagined as an active figure taking part in medical decision-making. The doctor, on the contrary, is seen as an advisor to the patient discussing and evaluating the patient's information and viewpoints with him or her. Like the member of the patient association, users – in their role of patients or potential patients – similarly described patients as actively contributing to medical decision-making. Their articulations are strongly reminiscent of the model of shared decision-making discussed in the literature, which similarly describes the doctor-patient relation as a partnership model (Anderson et al. 2003). To realize this euphoric vision would require doctors willing to deal with empowered or "informed patients", a number of interview partners added, a possibility that was strongly doubted by them. The older generation of doctors, especially, was widely seen as resistant to empowered patient behavior, making a partnership model of doctor-patient relations hard to establish in practice. This viewpoint was also expressed by patients "really" suffering from diabetes, who were interviewed in the larger research project<sup>14</sup>. The skeptical attitude of doctors towards informed patients and their web information described in the literature (Broom 2005a, Wyatt 2005) may thus be seen as acknowledged by patients themselves, at least in the Austrian context.

While some patients may be discouraged from challenging their doctors, others try to secure a more powerful position in doctor-patient relations nevertheless by examining their doctors in a critical way. A participant in the search experiments articulated his viewpoint as follows:

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<sup>13</sup> All quotations have been translated by the author, and the original German quotations may be found in the Annex of this thesis. The code at the beginning of the quotation, W or U, indicates webmaster or user. The number is to identify the speaker, and m or f stands for male or female. The code at the end of the quotation indicates the number of the quotation and gives further information on the interview partner. Website providers have been categorized according to their offline identities: patient association, patient, doctor, health portal, or pharmaceutical company. Users have been categorized according to their age and occupation.

<sup>14</sup> To put it briefly, these patients were asked about the way they use the web to become informed about their chronic disease, diabetes among them, how they evaluate different medical web information, and what they do with the information obtained from the web.



U40m: But the fact is that one should not take at face value everything that doctors say. It definitely makes sense to compare it, either to the literature or to forums. If someone there says, well, that is something that does not help at all, that did not help him at all, and that recurs twenty times, then that is something that, if it is proposed, of course needs to be closely questioned. (...) And then you see whether he (the doctor, A.M.) can argue for it or not. Or he says, "Ah, you don't, you don't understand that anyway," and then you go to a different one. So that's definitely a clarification of expertise, let's describe it like that. (Q2, 26-40, engineer)

Talking about his search, the interview partner describes doctors not as all-knowing, but rather as sources to be questioned by comparing their knowledge to information from other sources, including literature and online patient forums. In his view, the additional information enables the patient to evaluate the doctor's competence at their next encounter. The idea of scrutinizing doctors by posing critical questions recurs in many interviews. In comparison to the partnership model, this model of the doctor-patient relationship is based much more on skepticism towards medical authority. Instead of sharing information with the doctor, the patient is seen as challenging the doctor with information from other sources, increasingly the web. This perception of changing doctor-patient relations points towards expectations that informed patients will challenge medical authority – at least to a certain degree – discussed in public and academic debates (Anderson et al. 2003, Broom 2005a, 2005b).

The patients' skepticism may, however, be seen partly as triggered by doctors and their resistant behavior towards informed patients. The "real" patients, when interviewed about their use of medical web information, for example, said that they would sometimes pose critical questions deriving from web information without explicitly mentioning the term "internet" so as not to irritate doctors. This indicates that patients find ways of bringing information acquired from the web into doctor encounters without offending the doctors. It further shows that patients partly expect doctors to act in a reluctant way towards „informed patients“ and adapt their behavior accordingly. This suggests that patient behavior should be seen as tightly intertwined with doctor behavior. Whether patients share information acquired from the web with their doctors or instead challenge them in an implicit way strongly depends on the attitude medical professionals display in medical practice. If doctors do not take patients' viewpoints seriously, the patients may either find ways of challenging the doctors without offending them, or even opt out of the doctor-patient relation altogether and look for a more open-minded doctor on the medical marketplace (which is possible in the Austrian health system, but would not be possible in other countries, such as France or Great Britain). How far patient empowerment goes may thus be seen as closely related to medical professionals, and to the local health system in a more general sense. The widely perceived negative attitude of doctors towards empowered patients, however, may be seen as a crucial obstacle to patient empowerment in all its different facets, as I conclude towards the end of this thesis.

Further, interview partners described patients acting in an empowered way not only in regard to doctors, but also outside the medical domain. In their view, a medical condition is not something merely to be met with standardized medical solutions provided by medical professionals. Rather, it is something to be experimented with, integrated, and embedded in everyday life practices, such as, in regard to diabetes for example, cooking and participating in sports. Talking about her web search, one participant explained her approach by describing what she would do with the information she found as follows:

U21w: I have saved quite a bit of information, and I know, well, I would now continue with this information and start experimenting. So I would arrange a nutrition schedule and would feel encouraged in some things, because I do them anyway, would do more exercise and so on. I would arrange a plan and would know that anytime, if questions arise or something, I could check up and ask anytime. (Q3, 41-60, homemaker)

Having searched for practical information and tips, this participant clearly argues that she would use the information found online to assemble a “plan” for better coping with her newly diagnosed health condition, diabetes. Like her, other participants said that they would use the information found to take health matters into their own hands. Here, patient empowerment is primarily seen not as strengthening patients in doctor-patient relations, but rather as strengthening patients in their day-to-day handling of health and illness. This view of empowerment mirrors descriptions of the patient acting as a “reflexive self” (Giddens 1991) and taking over more and more responsibility for health and medical issues (Hardey 1999). The web is seen as enabling users to better cope with their health conditions, take preventive action, and make “informed choices” (Giddens 1991). In all these narratives, information is interpreted as a “capacity to act” in Stehr’s (2005) terms, as I discuss below.

### *Information as a precondition for patient empowerment*

The previous section showed that the interview partners generally adopted the rhetoric of patient empowerment present in academic and public discourses. In their views, information was a central precondition for patient empowerment. Conceptualizing empowered patients as active parts in the doctor-patient encounter, the director of the general health portal straightforwardly said:

W3m: Someone who lacks information usually does not have the heart to question at all, but it takes a certain basis of information to question more deeply in a doctor encounter. Well, this is the basic philosophy behind saying that language and communication are essential parts of that what happens in medicine. (Q4, health portal)

Like him, the majority of interview partners, especially website providers, talked about information as a necessary precondition for taking action in medical contexts. Here,

information was seen as a powerful source of action in Stehr's (2005) terms. It is important to note that the interview partners themselves did not sharply distinguish between the terms information and knowledge. As the interviews focused on the web as a health information source, they generally employed a notion of information that echoed broader debates over "online health information" rather than "online health knowledge", as indicated earlier. In certain situations, however, when the interview partners talked about the empowering potential of information in the handling of a health condition, the term knowledge was also employed, underlining the interview partners' perceptions of the web as a powerful information source. This shows that the concepts of knowledge and information should not be seen as clear-cut concepts, but rather as tightly intertwined particularly in regard to the web, as argued earlier. How knowledge is encoded in websites to be sent on the journey through the web as medical web information, and how medical web information is translated into knowledge figuring as source of action, rather than fragmented information, needs to get further attention.

Diabetes in particular was seen as a health condition requiring a great deal of knowledge to be successfully handled by the patient. It was described as a condition requesting diabetics to learn how to measure blood sugar, how many bread units to eat per day, what kind of sports could improve their health state, how to inject insulin, and many other things necessary to cope with this condition. The website provider suffering from diabetes himself described this circumstance as follows:

W2m: You need to know something about the disease, otherwise you can't cope with it and will tank quickly. My personal therapist, Professor XY from hospital YZ, always says that it is like driving a car. If you want to drive a car you have to get a driver's licence. If you don't do that you'll hit a tree sooner or later (...), or another car, right? Well, diabetes is not a car that one is happy to drive, but one that you get put in without wanting it, so to speak. Nevertheless, one needs to, needs to learn how to drive it. And that was something I learned in her course, and out of this it logically developed that I thought, well, if I know it and I can cope with it, then I don't want to replace the Professor or her course or anything, but I would like to, well, fill my colleagues with knowledge. Because the more they know, the better they can cope with it. (Q5, patient)

This quotation illustrates that patients need to know a lot to cope with diabetes, according to this interview partner. It further shows that he therefore aims to support patients with his knowledge and experiences, instead of mere information. He argues that patients may gain knowledge usually from multiple sources. The interview partner mentions classical medical institutions that traditionally teach patients how to live with diabetes. The chairman of the diabetes patient association also mentioned medical institutions and doctors as important actors in teaching newly diagnosed diabetics how to measure and control their blood sugar levels. As doctors often lack time, however, self-help groups have become important actors offering diabetics practical knowledge to better cope with

diabetes, according to him. Recently, more and more medical knowledge of this kind is spread via the web, both interview partners agreed. But why is the web gaining such an important role in communicating medical knowledge today?

### *The web as a convenient information source*

First of all, the web is seen as offering the advantage of easy access, as a number of participants agreed. Medical information can be accessed from home without the need to make an appointment with a doctor or go to a library. Further, it provides information explicitly formulated for laypeople, unlike encyclopedias or "thick books" (Q6, W2m, patient), as the patient offering the diabetes information site put it. And the web may be accessed at any time, some interview partners added. The chairman of the self-help group, for example, mentioned that this would enable diabetics with busy jobs to obtain self-help information and practical support they were previously denied because they had no time to attend "real time" self-help meetings. Finally, the web was celebrated as offering the possibility of obtaining medical information anonymously. The web administrator of the self-help group added, in this regard: "With us they do not have to declare, 'I am diabetic'. Some fear that. Some fear that that will get public" (Q7, W4m, patient association). This fact was appreciated by users. Quite a few users felt that the web offers information without any commitment. This aspect is also discussed in the literature, where studies have shown that male users in particular appreciate the web as an anonymous information source, especially in regard to delicate health conditions such as impotence (Henwood et al. 2005). In general, the web was perceived as a convenient information source offering access to medical information without much effort.

### *The plethora of medical information traded in the online market place*

Apart from convenience, the web was primarily embraced because it provides a plethora of different types of medical information at once. Echoing much of the literature, the majority of the interview partners appreciated that the web provides a multitude of information, ranging from orthodox medical information to alternative treatments, and saw the web as broadening access to the production of medical web information, fuelling tendencies of proliferation and diversification of medical knowledge. Many of the interview partners, particularly users, celebrated the plurality of the medical information that may be found online. When asked how he saw his search, one participant, for example, answered: "My first impressions are actually, (...) there is extensive information, really a range of websites, that deal with it (diabetes, A.M.), which really surprised me" (Q8, U9m, 41-60, book seller). The perception of the web as offering a plethora of medical and health-related information, however, particularly applied to diabetes, some participants added. One participant compared the search on diabetes to a previous search for a rare eye disease, where it was much harder to find relevant information, he said. The majority

of participants further added that “crap” may also be found, “as always on the internet” (Q9, U9m, 41-60, book seller). As examples, advertorial content, advertising, and products for sale, were particularly mentioned. This indicates that the commercial dimension of the web was partly acknowledged by users.

This applied to website providers to a much greater extent, especially to those with a commercial background. The PR manager of the pharmaceutical company described the web like a “media market”:

W6f: There are quality media or quality sites, and there is crap. And as it is a free medium, I really see it like a media market, there will always be all of it. And everyone needs to decide for himself: Do I invest my time in crap or do I invest my time in reading a quality site? (Q10, pharmaceutical company)

In her perception, the web is a “free market” consisting of information sources with diverse quality, and the user, as the “consumer”, has to choose what information to focus on. She conceptualizes the user as the one controlling the information she or he obtains. This echoes to Weinberger’s (2007) argument that control over web information is increasingly passing from the provider to the user, an idea further discussed later. Other interview partners, most particularly the director of the health portal, talked about competition between websites to gain visibility. “Because if you build such a website, then you’d like to communicate” (Q11, W2m, patient), as the patient offering the diabetes site simply put it. What strategies website providers actually employ to gain visibility will be discussed in the next chapters.

Aside from the market as a metaphor for competition, website providers pointed to the economic dimension. The PR manager from the pharmaceutical company straightforwardly said:

W6f: Well, the internet, here we have to stick to the truth, it exists because it creates money. Google benefits, all the ones uploading banner ads benefit. All that would not work if there were not very much money involved. (...) Well, that is also the reality. I know few people who upload informative texts for charity reasons. Besides maybe the church, but even the church will probably put an appeal for money next to it. (Q12, pharmaceutical company)

According to her, commercial dynamics pervade all issues on the web, including medical ones. Like her, other website providers mentioned the economic dimension of the web, particularly those with a commercial background themselves.

All these examples show that the market mechanisms and economic logic of competition and financial gain discussed in the literature (Röhle 2009) have entered the medical

realm, particularly in the view of commercial website providers. How market dynamics shape the way medical web information is presented and positioned online, what differences may be observed between commercial and non-commercial sites, and what consequence this triggers on the user side, remains to be seen in the next chapters.

### *What about risks and dangers?*

Unlike empowerment rhetoric, risk rhetoric, present particularly in the medical and policy realms (Eysenbach and Köhler 2002, European Commission 2002), was generally neglected by our interview partners. Although both website providers and users articulated the need to be "vigilant" in regard to medical web information, particularly towards commercial and advertorial content trying to "sell" something, the interview partners did not perceive online health information as severely dangerous or harmful – at least not for themselves. Quite some users mentioned that certain information such as detailed facts about medication may become harmful to patients, who start ordering drugs online without prescription. They themselves, however, are aware of these risks and would never use online pharmacies, what makes them feel safe.

One reason is that website providers and users generally conceptualized the web not as a substitute for, but rather as an addition to, classical medical practices. Patients were expected to discuss medical information obtained from the web with their doctors, either explicitly by openly discussing the information with their doctors to reach a cooperative decision, or implicitly by posing critical questions and challenging medical authority. One participant articulated his viewpoint as follows:

U9m: What I think is important is that one should tell the user quite plainly that – and this is something I'm also always aware of – that a doctor encounter is not avoidable. Because, well, you don't get a prognosis, a 100% prognosis 100% treatment, on the internet. That should always be carried out by the doctor. (Q13, 41-60, book seller)

This quotation illustrates how risk rhetoric was countered by arguing that medical information acquired from the web should not be seen as substituting for a doctor encounter. Rather, doctors and health professionals were seen as authorities keeping patients from treatments not meeting their health needs. (This, however, requires a functioning health insurance system, such as the one in Austria). Here, medical professionals were imagined as playing an important role in patients' management and understanding of medical web information. The majority of users appreciated trends towards patient empowerment to a certain degree, but refused to take over full responsibility for medical decision-making. Rather, they expected doctors to help them with medical information they obtained from the web and other information sources. The fact that doctors are often seen as resistant in this regard may be seen as an obstacle to

these developments, as indicated earlier. One participant further added that neither the doctor nor the web should be seen as the last authority. Rather, the benefits of multiple information sources would lie in the comparison of different sources with each other – in idea that has also gained ground on the web, although crucially transformed, as will be seen later.

## **7.2 Motivations to go online for medical purposes**

The previous section showed why website providers and users appreciate the web as a health information source from a broad perspective. In the present section I discuss more detailed reasons why different types of website providers and users turn to the web to communicate and obtain medical knowledge. These different motivations shape how providers and users practically use the web for their respective purposes and evaluate the credibility of medical web information, as will be seen.

### ***7.2.1 Website providers' aims in offering medical knowledge via the web***

To explore how the plethora of diabetes information is configured and assembled online, a number of different types of website providers were included in the study, as described earlier. All of these website providers had particular goals with their medical websites. They articulated three basic reasons why they provide their respective knowledge on diabetes online. First of all, they said that they use their websites as extensions of their offline patient services. Classical medical figures, such as the patient association and the general practitioner, in particular, explained that they use the web to support patients. How they aimed to support patients, however, strongly varied depending on their own model of medicine and doctor-patient relations. Secondly, website providers said they use their sites as means of self-promotion. Industrial actors, primarily, such as the PR manager of the pharmaceutical company producing insulin and medical devices, state that they used the web to advertise their products. Classical medical figures also mentioned this reason when describing why they originally built their sites. Finally, website providers suggested, although mainly between the lines, that they use their websites to make a profit. In particular, the director of the general health portal and the patient offering a diabetes information site referred to the economic dimension of their medical websites. Providers from non-profit websites, on the contrary, strongly opposed making a profit with their sites.

## *Supporting patients*

Three of the website providers included in the study said they provided a website primarily to support patients. These were the chairman and the web administrator of the diabetes self-help association, as well as the general practitioner specializing in diabetes. The primary aim of the patient association was to provide diabetics with practical information and support, both interview partners agreed. The chairman of the association told an anecdote to exemplify what kind of patient support they usually provided:

W1m: Or they come and say, "I have pregnancy diabetes. What should I do now?" Then I have to say two things. First, the firefighters: there are three specialists I recommend in Vienna. There are not more who I know are successful. Because the child is in danger, so you have to do something. And second, don't forget that in five, six years you'll be diabetic yourself. And these two messages – first, "firefighters – child is in danger", and second, "What do I do in the next five, six years to slow down, diabetes develops slowly, to slow down the development at an early stage or postpone it" – these two messages I have to communicate. (Q14, patient association)

The self-help association was originally set up to help patients with pressing questions such as the one above, and to provide long-term support, such as regular meetings and informational events. About five years ago, the association decided to build a website to extend their offline patient support into the online environment. Their goal was to use the website to spread their knowledge and expertise both to members of the association and to a wider public who would not necessarily contact self-help communities because of a lack of time or interest, as discussed above. The website basically functions as a platform to share experiential knowledge, to direct patients to specialists, and to advance their health-related political agendas, both interview partners said.

Patient associations in Austria are very close to the medical establishment, co-operating with doctors and receiving partial financing from pharmaceutical companies. Hence, Austrian self-help groups only articulate their viewpoints reluctantly, rather than acting as patient activists as in the AIDS patient movement described by Epstein (1996). One of the issues they critically discuss on their website, however, is the "advertising ban for ethical drugs", the chairman of the patient association explained. The advertising ban forbids everyone – particularly the pharmaceutical industry – from advertising drugs with the brand name of the product. A drug may be talked about by naming its ingredients, but not its brand, both online and offline.

This creates the paradoxical situation that patients are supposed to act in a self-responsible way, while essential information about medications is denied them, at least from lawful sources. This circumstance has triggered controversies, and various actors, including the European commission, have demanded a liberalization of the advertising



ban (Focus 2008<sup>15</sup>). In keeping with these discussions, the diabetes association decided to fight for an amendment of the advertising ban by writing petitions on- and offline. Referring to the paradoxical situation that information about drugs is communicated on all types of websites except the sites of the companies developing the products, the chairman formulated the goal as follows: "And we want to be told by the pharmaceutical industry as much as we read online anyway" (Q15, W1m, patient association). He reasoned that patients who are supposed to be increasingly informed and empowered need access to all kinds of information, including delicate information, for instance about drugs. This shows that "informed patients" or patients acting as self-responsible "consumers", as widely celebrated in public discourses, face a range of barriers in practice. Besides constraints they experience in medical practices because of the reluctant behaviour of doctors, the denial of essential information about drugs may be seen as a further barrier. This shows again that concepts of patient empowerment may be seen as closely intertwined with wider medical and health-political contexts.

Like the self-help group, the general practitioner specializing in diabetes described her website as an extension of her offline work. Unlike many skeptical doctors, she embraced the web as a tool to support patients by broadening access to medical knowledge. She explicitly said that she appreciated "informed patients" because she could start a consultation with them on a higher level, calling to mind the partnership model of doctor-patient relations discussed in the literature (Anderson et al. 2003). She described her website as pushing these developments further by providing biomedical information from the viewpoint of a medical professional. Like the participants from the self-help group, she argued against the advertising ban for medication. Although partly transgressing the legal restrictions, she used her website to communicate facts about medications and how they act in the body to patients to reach "a certain level of information, on which basis we can better talk to each other" (Q16, W7f, doctor), she explained. She also employed the website to spread her medical information and support via e-mail, she further added. She offered her patients online services such as making an appointment, ordering prescriptions, and getting quick advice concerning a medication via e-mail. Interpreted in the context of the market paradigm, she may be seen as offering extra services to patients increasingly seen as consumers who want to be satisfied, a view she acknowledged between the lines. Finally, she actively invited patients to employ her website, or other websites she recommended, to become informed. "If he then urgently switches to alternative medicine sites nevertheless and (...) tries to heal diabetes with some medical herb teas anyway, then it's ultimately his business, no?" (Q17, W7f, doctor), she added.

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<sup>15</sup> [http://www.focus.de/finanzen/news/verschreibungspflichtige-medikamente-eu-will-werbeverbot-lockern\\_aid\\_268549.html](http://www.focus.de/finanzen/news/verschreibungspflichtige-medikamente-eu-will-werbeverbot-lockern_aid_268549.html) (in German, accessed March 2010).

This quotation illustrates that in her perception patient empowerment has clear boundaries. She welcomes informed patients as long as they use web information recommended by her and stay within the framework of orthodox medicine. If they opt out of this framework, by turning to alternative medicine for example, she explicitly places the responsibility for potential harm on the patient. This underlines once again that the term "patient empowerment" has several different interpretations. While users interpret patient empowerment as attaining a more powerful position in medical practices by pursuing their own ideas on therapy or medication, the doctor interprets patient empowerment in a narrower sense, as discussing medical treatments with the patient as long as they correspond to the doctor's own model of medicine, a pattern also found in the literature. Broom (2005a) finds that many doctors with a positive attitude towards the web and informed patients make use of the web as a tool to help them to convince patients of their own viewpoints, rather than engaging with the patients' own information and opinions, as argued earlier. Broom thus concludes that doctors partly see the web as a tool to reinforce medical authority and improve "patient compliance" – a viewpoint hardly reconcilable with the empowered patient as a "reflexive consumer" acting in an independent, self-responsible way as envisioned by Giddens (1991).

In extending their offline work and services onto the web, the primary agendas of the patient association and the doctor may be described as offering medical knowledge to help and support patients. The ideas of patient support and empowerment underlying these agendas, however, differed according to their medical backgrounds. Both the providers of the diabetes self-help group and the doctor, however, opposed making a profit with their sites. The web administrator of the self-help association said, "One of our guiding principles is, we do not want to earn money with diabetes, to earn money with our disease" (Q18, W4m, patient association). According to him, making a profit amounted to selling out their website and their offline identities, which were tightly intertwined with their site and ideals of supporting patients with their offline services and support. In this sense the interview partners from the patient association and the doctor also partly framed their sites as locations for self-promotion.

#### *Websites as locations of self-promotion*

Of the participants included in the study, the PR manager of the pharmaceutical company in particular, conceptualized her site as a location for self-promotion. The primary aim in providing a website, the PR manager said, was to advertise the company and its products, such as insulin and various medical devices for diabetics. When asked why the company has set up a website, she answered straightforwardly:

W6f: The company stands by the fact that we are a research company and that we want to give patients access to our developments. Because diabetes, or type 1 diabetes as a disease that you get, that you cannot choose, is still an incurable disease. And the goal of XY<sup>16</sup> is, well, to heal diabetes some day. And we want to give the patient the opportunity to do a bit of research on how far along our company is with its noble goal for the future, of course. (Q19, pharmaceutical company)

She argued that the website had the principal goal of informing patients, as well as medical professionals and journalists, she added later, about the company and the advancements it was making in researching and developing products diabetics need. The website hence basically served as an extension of the company's business card in the online environment, a space where companies increasingly need to be present, the PR manager argued: "Well, it is not possible not to have it. I think to have no website at all would be extremely bad in terms of image" (Q20, W6f, pharmaceutical company).

Regarding drugs, the company's website was highly restricted because of the advertising ban. Unlike the doctor, who partly transgressed this legislation, the pharmaceutical company needed to stay in line with the law, as the pharmaceutical industry is traditionally under close surveillance, the PR manager said. That was why the website provided information about insulin and pens to inject insulin, but hardly any information on medication in the non-restricted area of the website accessible to everyone. In the password-protected area of the website, however, detailed facts about medication were provided for medical professionals or users posing as medical professionals (as the user's data were not checked). In addition to this official website of the company, the PR manager administered a second website. She described this websites as an information site on diabetes primarily geared towards patients. Compared to the other site, however, the fact that the website was provided by a pharmaceutical company was less obvious. Apart from the copyright section of the site, which revealed the provider of the site, no information was found on the website about the company offering it. This created the possibility of advertising specific types of new drugs between the lines, without mentioning either the ingredients or the brand of the drug. This may be seen as a common practice amongst pharmaceutical companies to spread information about their products in an implicit way. As these sites largely hide the providers and sponsors behind them, users seldom recognize the commercial background of this information, as will be further discussed in the analysis of users' information practices.

Like the participants from the pharmaceutical company, the general practitioner and the patient association also said they used their sites as locations for self-promotion, although in a very different manner. Talking about reasons why she originally decided to build a

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<sup>16</sup> The interview partners were assured of anonymity and their companies/ institutions/ websites thus got anonymized in the text.

website, the doctor said: "Well, it was surely linked to the decision to open up a practice at all" (Q21, W7f, doctor). In addition to informing patients, the website was seen as a way to attract new patients, especially in the early days of her practice. She uploaded photos, described the team working with her, and provided information about office hours and how to become a patient in her practice. The basic message she wanted to get across was that "there is a medical practice that mainly works with diabetes and one should not be afraid of it" (Q22, W7f, doctor). The chairman of the self-help association similarly explained that one of the goals in setting up the website was to recruit new self-help group members, particularly younger ones using the web to get informed about diabetes. They thus used their website to present the association, its members and groups, and activities the group organized offline. This underlines that the web was indeed seen as a market to position oneself and recruit new "customers". Even website providers not primarily following an economic agenda may be seen as embracing the web as a new market to be conquered.

### *Making a profit with medical websites*

Of the participants in the study, two website providers drew primarily on a commercial discourse when talking about reasons to provide a website. Those were the director of the general health portal and the diabetic offering a website to "fill" his colleagues with knowledge but also making a living from the site. The general health portal was provided by a small company employing a couple of people. One of the first things the director said about the site was that it had originated as part of a European corporation that had designed a health portal similar to successful American health portals spreading at that time. The central aim of the website, or the "brand", as he put it, in a rather economic terms, was to provide medical information understandable to everyone, the director said: "The primary idea always was to put essential medical knowledge, deriving from medical expertise, in a language preferably understandable to everyone, to every man and woman, and put it online." (Q23, W3m, health portal) This indicates that his primary aim may be interpreted as positioning a high-quality product on the growing market of online health information. The director of the health portal was himself trained as a medical professional, which explains the portal's focus on "evidence-based medicine", meaning medical information as defined by medical experts according to him. In addition, the portal offered news on lifestyle issues related to various diseases, diabetes among them, written in a journalistic style. To keep the site and company economically successful, the portal raised money by sponsoring contracts and advertising, "because to run this kind of portal is a cost-intensive business" (Q24, W3m, health portal), the director said. In this context he brought up the "code of ethics" the website committed itself to. One of the central features of this code was the explicit distinction between content and advertising. It was necessary to explicitly label advertising and sponsored pieces of text to make the user aware of when she or he was looking at sponsored content, the director argued. This

underlines once again that the product the website offered was seen as high-end medical information. The code of ethics thus figured as a mechanism to make money with the website while keeping its quality high in the director's view.

The patient providing the diabetes-related website also offered a rather commercial narrative when explaining why he set up the website, although in a very different manner. After being diagnosed with diabetes in the 1990s, he had turned to the web to look for helpful information, he explained. What he realized was that there was not much German information around at that time. He identified a market niche and took this opportunity to relaunch the PR agency he had been running. He described the starting point of the website this way:

W2m: (...) previously we did PR and journalism in different areas, and then we switched the company, in part because of my disease.

*I: Interesting, yes.*

W2m: Yes, and we, I said, well, print journalism I never wanted to do, because I always said the costs, that won't turn out right, and the whole distribution, and I don't know what else. But the internet I saw as a prospect right from the beginning, because I said, everyone prints what he wants. I am not busy with distribution, and thus have no, or relatively little, costs, and those should actually be recouped through sponsorship. Thus I indeed saw it eco-, economically get going quickly. Because I said, on the one hand the diabetic should get it cost-free, because he has increased costs of living anyway (...) OK, from me he should get the info for free, and the industry should finance it in the end. In such a way that it gets going, well, that everybody involved benefits from it. No sooner said than done. (Q25, individual patient)

The quotation illustrates that the primary goal of the site was to make profit by informing and helping patients. The informational product he offered was "the first website for people with diabetes" in the Austrian context, he said. The content provided was experiential knowledge written in an entertaining kind of style. Resembling of a tabloid, content and advertising appeared to be highly intermingled on his website. The provider regularly discussed a specific device, such as a blood measuring device, offered users a chance to test the device, and got money from the company in return, he said. The insertion of advertising into these pieces completely eroded the boundaries between editorial content and advertising, a practice strongly opposed by the director of the health portal.

In this context, the comparison of the web with a media market, made earlier by the PR manager, comes to mind again. Like newspapers, which provide news as a business, the general health portal and the diabetes information site provided medical information as a business. While the general health portal may be compared to a high-quality newspaper following a strict "code of ethics", the diabetic's website more strongly resembled a

tabloid, where content and advertising intermingle. Like the participants representing these two sites, providers of non-profit websites sometimes raised commercial issues as well. In particular, the self-help association had a long tradition of collecting money from sponsors to keep the association, and more recently the website, running, the chairman said. Unlike the other participants, however, both interview partners from the association strongly opposed "selling out the association" by making a financial surplus. Similarly, the doctor would never take any money for advertising products on her site, because this would threaten her integrity, she said. This indicates that website providers who have an offline identity to endanger are reluctant to make profits with their websites, as this would reflect badly on the offline identities they try to promote online.

But how did the different goals website providers expressed for providing a medical website influence how they positioned their sites on the web, how they tried to attract users with their content, and what credibility strategies they employed? Might practices also be observed that were shared amongst different types of website providers, and how did the technology trigger those? Before answering these questions in detail, I discuss different reasons users expressed for going online for medical purposes.

### ***7.2.2 Users' aims in obtaining medical knowledge via the web***

On the user side, the central question is why users increasingly turn to the web to obtain medical knowledge. In the following, I describe three basic reasons users articulated why they turned to the web for medical purposes (or would do so in case they never did a health-related web search before the search experiment). First of all, they said they go online to obtain knowledge to help them participate in medical decision-making. Users relying on orthodox medicine, in particular, said that they primarily do web searches on medical issues to better understand and negotiate with medical professionals. Secondly, users said that they do web searches to better cope with their health conditions in everyday contexts. Users trying to help themselves, in particular, said that their primary goal is to search for information enabling them to better cope with their health conditions in day-to-day routines. Before searching for this type of information, most of these users searched for orthodox medical information to get an "overview of the disease at first", as they put it. Finally, some users said they go online to look for information about alternative medicine complementing orthodox medical information. Users primarily relying on orthodox medicine, however, strongly opposed this type of information.

#### *Goal of participating in medical decision-making*

Of the participants having done a web search on diabetes in our study, half articulated that they usually try to find medical information to better understand and participate in

medical decision-making. These participants tended to rely on the model of orthodox medicine, and were predominantly men. Referring to a previous health search, a middle-aged man described his role in medical decision-making by saying that he went to the doctor and told him what his diagnosis was on the basis of the information he had found online. The doctor then treated this diagnosis, he added with a smile. He described himself as an informed patient actively taking part in medical decision-making, corresponding to models of shared decision-making described in the literature. He clearly described the knowledge he gained from the web as having empowered him in regard to his doctor. Like him, other participants talked about information gathered from the web as enabling them to participate in medical practices and better ask questions. Whether they did that by explicitly mentioning the information found on the web and discussing it with their doctor, or whether they did it by challenging their doctor implicitly relates to their model of doctor-patient relations, as mentioned earlier. This indicates that to some extent users adopted the rather simple idea, widely found in the literature (Hardey 1999, Anderson et al. 2003), that the web would automatically empower patients (at least ideally as their actual behavior in doctor-patient relations has not been observed in this study).

Users having searched for information to improve their relation to medical professionals or challenge medical authorities expressed a strong leaning towards orthodox medicine. When asked what kind of information he tried to find, a male participant expressed his medical preferences straightforwardly like this: "I rely on orthodox medicine because they detected it, and yes, I think with a change of nutrition and sufficient exercise one can get it under control" (Q26, U18m, 41-60, employee). He perceived orthodox medicine, in combination with standard practices of improving the patient's nutritional and physical state, as adequate to cope with diabetes. Accordingly, he said that information from self-help websites needed to be handled with care: "Well, one has to, one has to always remind oneself quite plainly, that people like you and me are writing, and they can write whatever they want. That doesn't mean that it is right" (Q27, U18m, 41-60, employee).

Like him, other participants trying to use the web to empower themselves in medical practices said they looked for "medical facts", meaning medical expertise as defined by experts, when going online. In the case of diabetes, this type of information included the cause of diabetes, how this health condition is diagnosed, differences between type 1 and type 2 diabetes, the development of the disease, orthodox medical treatments, and similar topics. Further, information on medication was often searched, as drugs were particularly seen as an issue to negotiate about with the doctor, according to the interview partners. This once again underlines the paradoxical situation that drugs were seen as central topic about which patients could actively contribute to medical decision-making, while exactly this information was legally forbidden on the web and thus was distributed on all kinds of websites except those of the pharmaceutical companies

producing them.

One participant also pointed to the limits of the web in regard to doctor-patient relations. Referring to a nasty backache he had experienced some time ago, he explained how he tried to use online health information to take part in medical decision-making. Having found information about a new therapy, he tried to convince the doctor to order this treatment. Only after having convinced the doctor to do a magnetic resonance examination did the patient accept that this therapy did not fit his particular health state. That made the user conclude that it may happen that "one reads something and one is tempted to relate it to oneself. (...) But then it likely doesn't relate" (Q28, U25m, 41-60, IT consultant). This indicates that shared decision-making does not always imply that the patient succeeds in imposing a certain medication or treatment on the doctor, but that in certain cases the doctor and his or her expertise trump patient information deriving from the web. This underlines the important role medical professionals may play in patients' practices of acquiring knowledge from the web.

#### *Trying to better cope with health conditions in everyday life*

The other half of the participants, most particularly women, were interested in finding medical and health-related information to help them in their day-to-day routines. They were interested in actively managing their health conditions in everyday life, reflecting the idea of the "reflexive self" (Giddens 1991). Before trying to find information of this kind, however, they tried to get a general overview of the disease, searching for topics such as the one mentioned above. They explicitly described their search as moving "from the general towards the specific" (Q29, U4m, 19-25, student). This shows that searching for medical information online should not be seen as a stable practice, but rather as crucially changing over time.

After having searched for general medical information provided by experts, they tried to find experiential knowledge enabling them to better cope with their health conditions. While four participants tried to find self-help exclusively in the orthodox medical framework, two participants explicitly said that they also tried to find alternative treatments outside this framework, as I discuss in the next section. A middle-aged user described her overall goal as follows:

U36f: Well, in principle I'm interested in, (...), what can I do. Without (coughing), without always running to the doctor, without filling myself up with medication. Well, I would try to find out what I can do and how much sense it makes. (Q30, 41-60, homemaker)

This quotation shows that the participant did not look for standardized medical solutions, but rather for actions she herself could set in motion to improve her health state.



Accordingly, the participant above described herself “not as a victim, but – what can I do? – simply taking over responsibility (Q31, U36f, 41-60, homemaker). This quotation calls to mind Giddens’s (1991) argument that the individual is increasingly expected to take over responsibility for his or her life project, health being a central part of that. It shows that the interview partners mirrored societal discourses on the changing patient role and tried to act accordingly – at least to a certain degree.

Users who brought up the notion of the responsible patient were primarily interested in experiential information of various kinds. In the case of diabetes, this content included how to deal with and control blood sugar levels, how to better cope with diabetes with the help of exercise and nutrition, what medication is needed, and what to do in emergency situations. Talking about a particular website, one user described his interests as follows:

U9m: And then a series of measures, which you can read on this site, steps that you can do yourself. And I just thought it through and considered: What can I do next? (.) Well, raise disease awareness, just be able to recognize lower blood, higher blood sugar levels, try to identify indications, what causes it, you can recognize that. Then also I looked how to measure blood sugar of course. (...) and then of course, which was crucial to me, what kind of emergencies can occur, so, this hyperglycemia, right? And only insulin helps with that, or else an emergency doctor. And with hypoglycemia, glucose and fruit drinks. (Q32, 41-60, book seller)

Additionally, he looked for specific information about devices for measuring blood sugar by using commercial websites and test reports to compare different devices with each other. A young schoolgirl similarly said that she was interested in finding tips on how to inject insulin. Against the background of her overweight and fear of needles, she tried to find information on how to cope with diabetes in her particular everyday life context. Additional topics these participants searched for were recipes, how to keep a diabetes diary, and what services self-help groups recommend. One young woman researched whether the martial arts she was doing would be useful to better cope with diabetes. This clearly underlines that these users did not try to find standardized medical solutions, but rather particular information in the context of their everyday lives. They embraced a relatively holistic perception of health, illness, and their bodies, seeing health conditions such as diabetes as embedded in and influenced by their overall lifestyles. For them, treating this disease required not only that they follow the doctor’s advice and take medication, but, much more importantly, that they adapt their everyday practices to better live with their new diagnoses. This underlines arguments from the field of critical PUS showing that people understand and interpret scientific, and most particularly medical, knowledge by embedding it in their personal situations and knowledge. How users interpret and make sense of medical web information and distill knowledge out of it, and how this relates to their interactions with the technology, will be seen in the next chapters.

### *Alternative treatments*

Of the participants searching for medical information to better cope with their newly diagnosed health condition, two participants explicitly said they searched for alternative medicine. Neither of them looked for alternative medicine exclusively, but rather in addition to other medical information. They started looking for alternative treatments after having gotten an overview of traditional medical expertise and self-help possibilities within the framework of orthodox medical information. This indicates that alternative medicine was usually seen as a supplement to classical medicine. One participant expressed her interest as follows:

U21f: And because I come from the world of homeopathy, TCM (traditional Chinese medicine, A.M.), and so on, I also looked for that. And there is plenty. Well, it's like, I say, I'm then not dependent on medication, but I can also do something homeopathically or with TCM, with Chinese herbology and so on. Thus, I must say, I feel well-equipped with that, yes. Well, really that way I can say, I am not a victim, saying wah, I have diabetes, but I can say I have diabetes, but I am not a diabetic. So I do not have to identify with it, but can really say I can do something, yes, I can take it into my own hands. And I do not at all feel left alone with it, but I can say, pah, great yes. (Q33, 41-60, homemaker)

This quotation illustrates that users interested in alternative treatments tended to conceptualize disease not as an external threat to the body, but as emerging out of the body itself. According to this holistic perception of the body and disease, the interview partner argued that medical expertise such as homeopathy or traditional Chinese medicine found online would help her to better control the disease. Instead of feeling like a victim of the disease, she perceived herself as actively dealing with the disease. This participant clearly appreciated having a sense of control over her health, illness, and body, a facet of empowerment also discussed in the literature (Broom 2005b), and linked it to her individual model of medicine. The other user similarly described her interest in alternative treatments by referring to a particular concept of the human being. Having found a "horror story" about a chemical sweetener supposed to substitute for sugar in case of diabetes, she tried to find an alternative to it, because "I have the attitude: we are humans, we come from nature, we should also ingest nature. So artificial sweeteners would not fit me." (Q34, U36f, 41-60, homemaker)

Both quotations show that underlying models of health, illness, and the body crucially shaped users' online information practices. The second example further indicates that certain interests co-evolved with the users' searches, deriving from information they found online. Of the overall 40 participants, however, only one user straightforwardly started by searching for alternative treatments in the context of the chronic disease he searched for. This participant, who strongly opposed orthodox medicine and the concept of disease it embodies, was also the only one who explicitly said that he would not take

the medication given by the doctor. On the basis of the information he acquired online when searching for eczema, he explained what he would do instead:

U35m: Well, I would take a certain amount of mare milk every day for a couple of weeks and would see what happens. Then I would work with black cumin, then I would work with herbal teas and with all sorts of things. So these prescribed things, salve, I don't know. Well, honestly I would not take the salve the doctor prescribed at least for a couple of weeks or a month. I would try to eliminate psychological factors if that's possible somehow – less stress and those things. (Q35, 41-60, self-employed)

This shows that the web also provided the possibility of opting out of the orthodox medical framework if users wanted to do so, which was only seldom the case, according to the users included in our research project.

### **7.3 Conclusion: Multiple conceptions of patient empowerment and reasons to use the web for medical purposes**

In contrast to medical professionals and policy makers, website providers and users seldom described the web as a dangerous information source that would cause risk and harm. Although sometimes acknowledging the economic dimension underlying the production of online health information, the interview partners did not conceptualize online health information as severely harmful to patients. Rather, they imagined the web as a tool for patient empowerment in medical practices and beyond<sup>17</sup>. The term "patient empowerment" should not be seen as having a clear-cut meaning in their perceptions. Rather, patient empowerment may be seen as a kind of "boundary object" (Star and Griesemer 1989) interpreted in very different ways. The term "empowerment", by being fuzzy and plastic enough, may be seen as allowing the interview partners to relate their viewpoints to wider societal debates, while also keeping their individual perceptions and models of medicine intact, as I discussed. The different ideas of patient empowerment articulated may be seen as mirroring different interpretations found in academic literature and public discourses. While some interview partners described the web as empowering patients in doctor-patient relations, either through openly discussed web information or through implicit challenges to medical professionals, others framed the web as empowering patients in their daily management of health conditions such as diabetes. The notion of the patient as a consumer was rarely mentioned explicitly. Whether the interview partners indeed acted as "empowered patients" in doctor-patient relations and day-to-day practices cannot be answered in this thesis. What abilities and skills were

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<sup>17</sup> The fact that users expressed a rather positive attitude towards online health information may partly derive from the circumstance that people who agreed to participate in this study may have tended to appreciate the web as a health information source more than did people who refused to take part.

needed to actually obtain valuable medical knowledge from the web – a widely discussed precondition for patient empowerment – and how these relate to the sociotechnical dynamics involved in the production of medical web information, however, will be discussed in detail in the next chapters.

One reason for the euphoric vision of the web as a health information source was the fact that both website providers and users perceived the web not as a sole source of information, but rather as an additional source existing next to other sources, particularly medical professionals. The web and its health information were widely expected to be compared with and checked against the advice of their doctors, who were expected to prevent them from misinformation and harm, at least ideally. These expectations, however, were partly clouded by the fact that doctors were not seen as very supportive of patient empowerment. Quite on the contrary, medical professionals were perceived as rather skeptical in general. Doctors were usually seen as resistant to “informed patients” and their web information, creating challenges for patients who try openly to discuss medical web information with them. This is consistent with the fact that even doctors in favour of the web and “informed patients” expressed a narrow idea of patient empowerment. This indicates that patients trying to act as empowered or “informed patients” in medical practices indeed likely experience barriers, as also discussed in the literature (Henwood et al. 2003, Broom 2005a). This may be seen as a problematic circumstance, given the skills and abilities needed to interpret and make sense of medical web information, as will be seen.

In addition to their general reflections about the web as a health information source, I also analyzed the concrete motivations that website providers and users articulated for using the web to communicate and obtain medical knowledge. I discussed how website providers expressed different motivations closely related to their different identities and medical backgrounds. These motivations ranged from supporting patients in conjunction with offline services, to self-promotion to acquire customers and patients, to primarily commercial interests. On the user side, I also identified three reasons why users turn to the web to search for medical information, equally bound to their underlying models of health and illness. Users’ goals ranged from obtaining a more powerful position in medical practices, to better handling their health conditions in everyday life, to learning about alternative medicine complementing orthodox medicine. I described these different agendas and discourses in detail to exemplify the heterogeneity of both website providers and users. In the following chapters, I will show that these different viewpoints crucially shape website providers’ and users’ information practices and underlying epistemologies. Aside from these differences, however, all website providers and users share basic patterns of providing and acquiring medical knowledge via the web closely related to their reciprocal interactions with technology, as will also be seen below.

## **8 How website providers and users find each other in the online medical marketplace**

In this and the next two empirical chapters I elaborate on website providers' and users' practices of communicating medical knowledge via the web, and their epistemic consequences. This ANT-inspired analysis is organized according to my three central research questions: How do website providers and users find each other on the online medical marketplace? How do they communicate medical information via websites? And what underlying epistemologies may be seen as embedded in website providers' and users' sociotechnical practices? When exploring these questions I tend to use the term information when talking about mediated content, or "informational knowledge" (Lash 2002), website providers assemble on their sites and position on the web, and users deal with and interpret when browsing on and across websites. Contrary, when talking about coherent knowledge website providers aim to communicate and users aim to obtain from the web (rather than mere information), as I did in the previous chapter, I tend to employ the term knowledge. When saying this, however, I am aware that knowledge and information should not be seen as clearly definable, but rather as relating to one another and tightly intertwined, as I discussed in the first chapter. Hence, in certain contexts both terms are appropriate. This will particularly apply to paragraphs, where I discuss how medical knowledge is translated into web information by website providers, and how medical web information is interpreted and translated into knowledge by users. These explorations will give insights in the way medical knowledge is mediated, and partly transformed in the communication via the web, and which epistemic implications and practices of sense-making this triggers, particularly on the user side.

This chapter starts with discussing how website providers and users find each other in the online medical marketplace by analyzing website providers' positioning and users' search strategies. What strategies do website providers employ to position their sites on the web to attract and be found by users? And what strategies do users employ to filter, order, and select medical websites out of the plethora offered to them? I juxtapose website providers' and users' sociotechnical practices and related narratives, and suggest what consequences may be drawn from their technically mediated interactions.

### **8.1 Website providers' strategies to make their voices heard**

The range of goals website providers expressed for providing websites deeply shaped how different types of website providers positioned their websites in the online medical marketplace. Their strategies included collaborative forms of networking, individual techniques of climbing up search engine results, and observing users' behavior, as I show

in the following.

### *Linking to gain collective visibility and exclude competitors*

The first strategy for gaining presence that website providers articulated was to establish relations to other websites – to network, to put it simply. This strategy was particularly employed by medical institutions trying to extend their offline patient services into the online environment. The websites of the diabetes association and of the general practitioner contained well-sorted links, mostly to other medical institutions in the field. On the other hand, the patient offering a diabetes information site while also making a profit with his website offered a huge link list containing both content-related links and links to corporations sponsoring the site. This underlined the hybrid role of this site, which acted as a site of patient support on one hand while following a highly commercial agenda on the other. In contrast, the websites of the pharmaceutical company and the general health portal only linked selectively, indicating their competitive relationship with other sites. This confirms studies showing that different types of website providers employ different linking strategies or “linking styles” (Rogers and Marres 2000b). But why do different types of website providers employ these different linking strategies?

The individual patient described his linking practice as follows:

W2m: Well, there is an exchange among self-help groups of course. Previously, before the internet, like now with the internet, you simply start asking, “Who else is here besides me?” It has, well, a lot has developed in parallel. (...) And we said: “Let’s simply link up, in case someone finds us, and on the linked site maybe he looks further, right? Or vice versa with you.” This is a mutual exchange.

*I: So you give a link and you get one in turn, is this the practice?*

W2m: Yes, yes. This is a kind of non-financial exchange that is certainly beneficial in the beginning. (Q36, patient)

The first step to gaining visibility, the provider said, was to contact website providers he had social relations with and propose to connect their respective websites through hyperlinks. He argued that each website would benefit from the other, as users could be channeled from one website to the other through the link connection. The link thus appeared as a central actor in the strategy of gaining presence through networking. It may be seen as creating pathways between websites that users may take, potentially generating streams of visitors. It enabled website providers to raise the popularity of other websites by linking to them and to gain popularity by getting a link in turn. The logic of networking to gain visibility may thus be seen as an example of “you scratch my back and I’ll scratch yours”, as the saying goes. Networking could be interpreted as a collective strategy for gaining presence based on mutual support. Depending on the

necessity of being found and visited by users, the practice of linking was employed to a greater or lesser degree. While providers of classical medical institutions exchanged links with only a select range of websites, the diabetic providing the for-profit site exchanged links with all kinds of websites to raise the chance of being acknowledged by users.

However, links should not be seen as all carrying the same meaning and value. Rather, all website providers offering link lists distinguished between three types of links: links to websites they maintained social relations with, links to websites providing diabetes information they recommended to users, and links to companies they got financial support from. Talking about the link list of the diabetes association, the web administrator, for example, put it like this:

W4m: Well, the links are distinguished into, first of all, into organizations like friends, with whom we collaborate, for example in Graz, the XY with his kids, and similar ones. Then homepages that I somehow chose because they offer good information. Or, for example, the homepage of the doctor YZ, the doctor who has a great homepage where she explains a lot (...) Such things we gladly pick up. This is the one row. And then there are of course, as I said, the companies, and that's basically it. (Q37, patient association)

The first type of links may be seen as representing social relations, as described by Park and Thelwall (2006). Website providers aiming to primarily support patients with their offline services, in particular, started networking by transferring their social relations from offline contexts to the online environment. Since they traditionally maintained social relations with various institutions in the field, they benefited from these relations by interlinking their websites and collectively raising their popularity. They interlinked their sites with websites from local patient organizations they knew from their everyday work, and with various health institutions operating in the field of diabetes. This type of networking may be interpreted as a strategy of gaining presence by virtually re-enacting existent social networks that mutually support each other. Accordingly, the webmaster of the diabetes self-help group immediately started to talk about the websites on the network map when I showed it to him (figure on the next page).

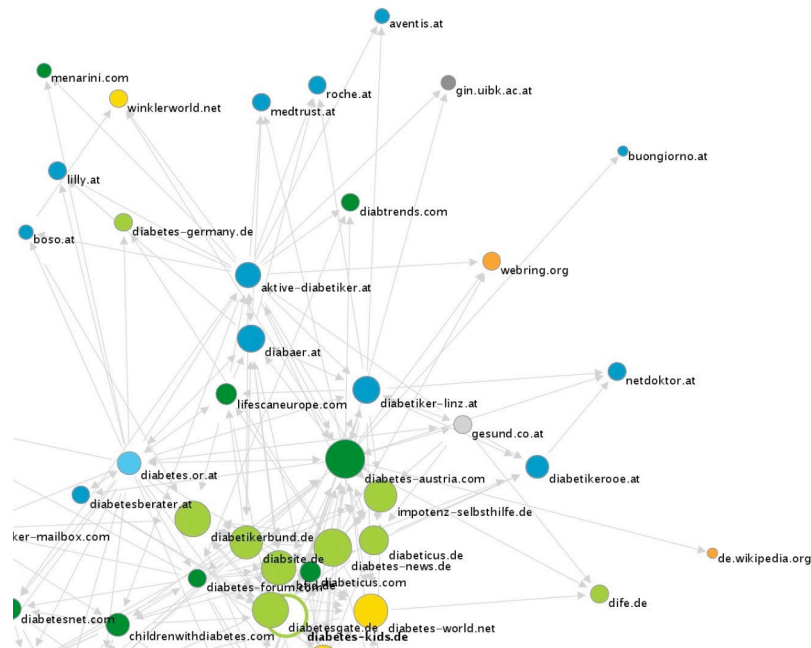


Figure 3: Network map displaying Austrian diabetes self-help sites heavily interlinked with German sites, 2006.

According to the webmaster, the blue nodes scattered on top of the image represent the lively diabetes self-help scene that has developed in Austria. These are sites from institutions collaborating offline, but also maintaining relations online, as may be seen from the network. Further, the network displays links from self-help websites to pharmaceutical companies (nodes on the edge of the network on top), illustrating that they receive financial support from them to keep their institutions running and to have a link on their sites in turn. These companies, however, do not link to each other, indicating a different linking, or rather non-linking, style, further discussed below. Finally, Austrian self-help websites heavily interlink their sites with German websites, again mostly self-help sites (green nodes interlinked at the bottom of the network). These links represent the second type of links the webmaster mentioned. They may be interpreted as establishing relations between websites dealing with similar issues and together constituting "issue networks" (Rogers and Marres 2000a, 2000b). Besides institutions they know from offline contexts, most of the providers often interlinked their sites with content-related websites based abroad. These were predominantly websites the providers considered to be of relevance to users as offering high quality information about diabetes. That is why the quality of the links provided was of high relevance in this context.

When asked whether he looked through the sites he linked to, the web administrator of the self-help association answered, "Sure. (...) I do not want to somehow relate our empowered patients with, with something like charlatanism. That's something I reject. That's something I don't do." (Q38, W4m, patient association). This quotation clearly shows that links to diabetes-related websites were interpreted as recommendations for users. This interpretation calls to mind early visions of the web as a decentralized



information network interconnecting topic-related pieces of information on the basis of association, as conceived by Berners-Lee (2000). Links are imagined to direct users to valuable and credible information. In this sense, website providers saw themselves as gatekeepers pre-selecting information and websites for the user. Here, the provider guarantees the quality of the websites she or he links to. Conceptualizing links as creating a flow of visitors in both directions, most of the providers further mentioned that not only the quality of the website they linked to, but also the quality of the websites they received links from mattered. Although not responsible for the content they linked to, they generally preferred to interlink their websites with approved content, all website providers agreed. In this context, networking may be seen as a strategy to gain visibility by creating attractive pathways for users based on trust.

The last type of link that the web administrator mentioned, sponsored links, have received less attention in the literature so far. Sponsored links may be seen as representing economic relations between institutions – in the medical field, particularly the pharmaceutical industry. Naturally, commercial websites contained many more links of this type than non-commercial sites. Compared to link connections based on social and trust relations, the virtual pathways constructed this way are less attractive to walk for users. Consequently, the chairman of the diabetes self-help association strongly opposed linking for commercial reasons on a large scale. Although strongly disapproving of making money with diabetes, as discussed earlier, even the chairman of the diabetes association admitted to maintaining relationships with selected corporations to keep the association and its website running, underlining the economic dimension of the online health information market.

Like offline networking, online networking implies not only helping each other, but also denying support to other entities by excluding them from the network. In the online world, networking may be seen as a strategy to raise the popularity of friends, but also to strategically deny prominence to competitors by “silencing them through inaction”, as Rogers and Marres (2000b) put it. In this context, the link appears not to create virtual trails to certain websites, but rather to block pathways to websites not linked. Reasons for excluding websites from the network differed according to different website agendas. The chairman of the diabetes self-help association, for example, said that they naturally did not link to websites representing institutions they had trouble with in the past. Following the logic of social networking, not only the presence, but also the absence of relations in the offline world was transferred to the web.

In addition to websites that deny presence to certain websites for specific reasons, there are websites denying visibility to websites on general principals. The director of the health portal, for example, generally rejected linking to any websites, except for links to his partners and sponsors embedded in advertorial content: “Links to outside were

traditionally hardly used. That's our philosophy, to preferably keep the user in the site as a big horizontal portal." (Q39, W3m, health portal). By saying that the portal hardly linked in order "to keep the user in the site", he implicitly interpreted links as a way to lose users. Links were seen as creating pathways channeling users away from the website. Since their goal was to provide their customers with an all-embracing informational product, directing users to other web sources would contradict the website's basic agenda. In talking about link exchanges, the provider gave an additional reason why he perceived links primarily as a risk of losing users:

W3m: I always find it kind of nice if someone comes and says, "Let's do a link exchange", and he has 5.000 unique clients per month and I have 500.000 (laughs). That, that doesn't fit. That won't work, right? That would be simply absurd. (Q40, health portal)

Referring to his number of users, or "unique clients" he put it in economic terms, the provider suggested that link exchanges supposed to create mutual pathways between websites may turn into one-way streets when the size and traffic of websites differ too greatly. The visibility generated this way would not pay off in regard to the number of users potentially lost. Further, losing users would also mean losing appeal to sponsors, threatening his business success. This underlines once again that the provider of the health portal perceived himself in a competitive relationship with other websites in the online health information market. Similarly, the PR manager of the pharmaceutical company would not link to other corporations in the field of diabetes, she said. This reveals that collective strategies of gaining visibility end where competition starts.

This analysis shows that strategies of gaining presence online should not be seen as equally used by all types of websites. Quite on the contrary, depending on the goal, type, and size of the website, "linking styles" (Rogers and Marres 2000b) strongly differed between websites. The strategy of gaining presence by networking appeared to be especially useful for self-help associations offering diabetes-related support and information to serve patients, but less effective for commercially oriented websites offering medical content merely as an informational product. Self-help groups are naturally embedded in strong social networks of institutions dealing with the same disease. The collective strategy of gaining visibility by mutually helping each other and building trustworthy pathways for users may be seen as naturally fitting their basic agenda. Networking strategies based on social and trust relations were thus particularly employed by non-profit organizations. Websites providing medical information for commercial purposes, however, usually employed networking strategies only to a minor degree. As a consequence of their primary aim of positioning their information or "brand" advantageously on the online health information market, they tended to perceive themselves in a competitive relationship to other websites. The strategy of networking based on mutual support may thus be seen as predominantly appreciated by actors

collectively trying to make their voices heard, such as self-help movements, while opposed by actors who see themselves as lone fighters in the battle for attention (and who have enough budget and expertise for professional search engine optimization strategies, as will be seen in the following).

### *Pleasing Google to win the battle for attention*

In talking about the way users reached their websites, however, all website providers focused on search engines rather than links. When asked how he expected users to stumble across his site, the chairman of the diabetes association, for example, straightforwardly answered: "By putting diabetes into Google" (Q41, W1m, patient association). The centrality of Google in users' search practices may thus be seen as well-acknowledged by all types of website providers. Accordingly, it was important for website providers to be present in search results: "Well, I put in diabetes and look now and then. It (his website, A.M.) is displayed among the, I don't know, among the top 15 to 20 hits for sure" (Q42, W4m, patient association) the webmaster of the patient association added. This quotation suggests that it was important not only to be present somewhere in the search results, but to be amongst the first 15-20 hits. Other providers similarly knew quite well how their websites were generally ranked when a diabetes-related keyword was typed into Google. Seeing Google as creating hierarchies between websites, the providers perceived the first segment of the result list – the "top ten seats", as Introna and Nissenbaum (2000) put it – as an important space to be present in.

While the provider of the self-help group was satisfied with being displayed in the 15 to 20 hits, the director of the health portal and the patient providing the diabetes site tried to be present in the first three hits. This indicates that providers of commercial websites felt a much stronger need to be present within the "top ten seats" of search results, underlining their competition with other websites. The authoritative space of the first search engine results may be seen as the space where the day-to-day business of the health care market takes place. Hence, the power relations and search engines biases described as undermining the democratic potential of the web, for instance by Introna and Nissenbaum (2000), may be seen as having entered the medical realm. Using the web to offer medical information means entering a market following rules of supply and demand. But how did different types of webmasters try to position themselves in the authoritative space of search engine results, and what strategies did they employ to win in the battle for attention and outpace competitors?

All website providers we interviewed expressed a basic understanding of the way search engines, and particularly Google, worked. Website providers offering medical information for commercial purposes, in particular, articulated a quite elaborate understanding of Google's PageRank algorithm (Brin and Page 1998). The director of the health portal, for

example, said:

W3m: Well, Google calculates the PageRank by virtue of, by virtue of the quantity and quality of the links to your site. And then there is the connection to keywords – with keywords Google looks, goes into the text, the meaning of the text. (Q43, health portal)

The provider mentions a range of heterogeneous elements the search engine considers to rank its results. He refers to links, keywords, and text as central elements co-determining the position of websites in organic search engine results (as opposed to paid advertisements, all website providers included in the study neglected). As it was impossible for website providers to directly define their positions in the result list, the providers had to use links and keywords as tools to climb up Google results.

All of the providers conceptualized links as crucial elements defining the position of their websites in organic search results. Explaining why his website appeared in the “top 3”, the diabetic, for example, said: “And then also, because we’ve been here a long time, we have unbelievably many links or references or good ratings of our site” (Q44, W2m, patient). The provider interpreted the number of links and references he had as responsible for the good position of his website in Google’s search results. The numerous links to his site the provider had arranged through link exchanges turned out to pay off in regard to Google as well. Strategies of networking may thus be seen as also serving the goal of gaining visibility in search engine results. Consequently, the diabetic providing the commercial website used link exchanges not only for networking purposes, but also to climb up the Google result list. He used his contacts to strengthen his position on the online health information market. This strategy once again underlines his hybrid position between offering patient support and following a commercial agenda. In his strategy, the link appeared as a tool to gain visibility in search engine results. It was not the quality of links, but rather the quantity of links a website got that was of importance. The various other meanings ascribed to links, as discussed in the context of networking, got lost in this process. Google translates the links a website gets – whether based on social, trust, or economic relations – into a rank the website holds. It may thus be seen as splitting up the link-networks that providers have created for various reasons, taking websites out of their hyperlinked networks, and transforming those networks into keyword-subject indexes, creating what Elmer (2006) labeled “a disentangled web”. This triggers crucial consequences in terms of information fragmentation, as I discuss in detail in the next chapter.

In addition to link exchanges, the site’s duration of existence, the prominence of the provider, and the content of the site were all seen as crucial in generating links. The provider of the diabetes site, for example, said that the longer the website existed, the more people became aware of it and the more providers tried to exchange links with it

underlining the “Matthew effect” (Merton 1968) the search engine triggers, as argued earlier. The chairman of the self-help group said his offline prominence helped to collect links to his site. As someone who regularly attended health- and diabetes-related events and spoke on health-political issues, he was well-known in the Viennese diabetes scene and beyond, he said; that was why his website was well interlinked and hence visible in search engine results. The director of the health portal further mentioned the content of the site itself as a means of enhancing the number of incoming links. Following the rationale that providing a professional information product automatically generates links, he said: “We have to do it with our content” (Q45, W3m, health portal)

In addition to links, the providers mentioned keywords as central actors in gaining visibility in search engine results:

W2m: What the webmaster also did, which we couldn't have done, is the configuration of so-called meta tags and the positioning in search engines.

*I: What are meta tags?*

W2m: They're words, the keywords you use to find a topic. Or where, if I say “blood pressure”, for example, it doesn't relate to diabetes at first sight, but actually it does, in the background, if you know it. Now if you put in “blood pressure” the search engine would display something about blood pressure, well, [www.bloodpressure.at](http://www.bloodpressure.at) would come up first, probably. But if you are, if you have that too, then you also turn up somewhere, because it's your meta tag, right? And that's something we defined well I assume. (Q46, patient)

Using the example of “blood pressure”, the provider explains that meta tags are labels website providers assign to websites, to be found by search engines. Each time someone searches for “blood pressure”, the website would be displayed, because the word is written into the HTML of the website even if the site itself does not mention it (an aspect getting less and less important in regard to search engine algorithms, however). Besides meta tags, the provider of the self-help group mentioned (key)words in the body of the website as important elements. He argued that his website was generally displayed amongst the first 15 to 20 hits because it provided huge amounts of text. As the website was primarily filled with content taken from the print magazine of the association, it contained many articles with many diabetes-related keywords. Convinced that Google considered how many times a keyword occurred on a website, he thus concluded that the large amount of text was responsible for the good position of the site in search engine results.

These examples show that all of the website providers considered visibility in search engines, and most notably Google, as necessary for being found by users. Their willingness to adapt their sites in response to search engine algorithms, however, differed amongst the sites. In addition to building alliances through actors such as links and

keywords, websites, especially those trying to position their informational product well on the online health information market, invested money to gain visibility in search engine results. When asked whether he cared about search engine optimization strategies, the director of the health portal, for example, answered: "We do our homework of course" (Q47, W3m, health portal). To be able to maintain a professional health portal, it is obligatory to get technical support from professional agencies, such as workshops on search engine optimization (SEO) and the like, he explained. Similarly, the PR manager of the pharmaceutical company said that the technical side of the website was maintained by the headquarters of the corporation in a professional way. This indicates that for-profit medical websites in particular had already started to game search engine algorithms on a large scale.

Providers of non-profit websites, in contrast, widely rejected adapting their sites to search engines to such an extent. When the webmaster of the diabetes association was asked whether he cared about search engine optimization, he said:

W4m: (...) and it isn't like we make a living from this, or our business performance is dependent on how many people look at it and buy from me, yes? We are a self-help group, which (.) actually does not earn money, and therefore we offer information, but we do not impose it on anyone (laughs). (Q48, patient association)

In this quotation, the provider associates the strategy of gaining visibility by climbing up the Google result list with selling out the website and hence the association. He implicitly frames adapting the website in response to search engine algorithms as a way of manipulating the site. The chairman further added that putting extra links on the website in order to climb up Google would run counter to his basic approach to links. He perceived links primarily as recommendation for users, and putting extra links on the site to climb up Google would create pathways misleading to users, which he disliked.

The general practitioner similarly rejected using links to optimize her position in search engines. Website providers offering medical websites as extensions to their offline services tended to be much more reluctant to optimize their websites to gain visibility in search engine results. One reason for this is that strategies of gaining visibility in search engines were partly seen as endangering the credibility of their sites, as well as the offline institutions they were trying to promote. This suggests that non-profit website providers widely interpreted aggressive visibility strategies to dominate the online health information market as threatening the original vision of the web as a decentralized information network created by meaningful link connections.

Different strategies (or lack of thereof) for pleasing search engines have crucial consequences on the user side. For-profit websites are hit and used more often by users

than smaller, non-profit websites, running counter to the democratic ideal of the web as democratizing medical knowledge, as I discuss in the next sections.

### *Observing users to attract a specific target group*

Finally, some providers followed the strategy of gaining presence by observing users. Besides anticipating keywords users might employ, a number of website providers electronically observed what search terms users did employ to reach their sites. The general practitioner, for example, said that she used the statistics page of her website, which captured users' search terms, to integrate these words into both the text and the metatext of the website. When asked what terms users mainly employed, she answered:

W7f: Oftentimes my name, so the domain XY.at with my name was definitely a good idea. I am often searched for, right? Oftentimes people know me from the ambulance, clinic, or hospital, and then they look: Where is she now? And then diabetes-specific keywords. That happens very often.

*I: And that is something you think about, that you can be found online?*

W7f: That is something I consider regularly, yes. Well, regularly, from time to time. (Q49, doctor)

This quotation illustrates that she was well aware of how users generally reached her site. The specificity of the users' keywords, such as her name, may be seen as directing the users straightforwardly to her website because she was ranked at the top of the results. That was also a reason why her website was regularly found, she further added.

The PR manager of the pharmaceutical portal similarly observed how users reached the website. She explained that she got the site's statistics from the company's head office, which maintained the website technically. The statistics showed what parts of the Austrian website had been used most, from what site to what site users had jumped, and, most importantly, what search terms they had employed to get to the site. For her, it was most important to know whether users were searching for the name of a specific product, for the name of the company, or for pharmaceutical ingredients, as this gave her the opportunity to adapt the content of the site accordingly, she further added. Website providers who "advertise" their offline institutions may thus be seen as taking advantage of their offline prominence. The doctor, in particular, benefited from users knowing her from offline contexts and trying to find her online.

Providers offering medical websites to make financial surplus were particularly interested in the number of users coming to their sites. The diabetic offering the commercial website proudly discussed the number of his visitors and what parts of his website had generated the most visitors. The director of the health portal similarly recited the number of visitors

the website had:

W3m: Well, the Standard has 1,2 million unique clients, we have 488.000, and these mostly come because they put in those terms and because we have already existed for a long time, because many websites link to us, because of Google results, and some have bookmarked the site. I would say about a quarter have bookmarked the site and come time and again. (Q50, health portal)

Comparing the site to that of the Austrian newspaper *Der Standard*, the provider underlines how many "clients" the site has, indicating how important the traffic of the site is to him. Besides the number of users, the provider mentions keywords, links, and bookmarks as important elements influencing how (and how many) users come across the site. This quotation indicates that the provider of the health portal was professionally observing the site and its uses. In addition to the statistics of the website, he conducted online surveys on a regular basis. On the basis of this data, the director was able to estimate that approximately one quarter of the users had bookmarked the website. A few sentences later, the provider explained why bookmarks were important to him. He imagined users who had bookmarked the site would automatically access it in case of any health problem. He sought to raise the number of users accessing the site via bookmarks, to establish a more direct relationship to the users. This would enable him to circumvent search engines as mediators because "the dependency on search engines is not that good" (Q51, W3m, health portal), he further added. This is something other website providers did not mention. One reason may be that they could not afford to observe users with elaborate online surveys, and hence did not have such a good understanding of the way users came to their sites. The provider of the self-help group, for example, said that he did not even have basic statistics about the website, because they cost administration time and some money, and were not worth the trouble. The strategy of observing users' behavior on a large scale may thus be seen as being especially useful for websites trying to promote their website to a specific patient community, or for websites trying to optimize their product to make it better fit their target group.

## **8.2 Users' strategies of choosing messages out of the babble of voices**

Users employed a range of strategies for browsing through the plethora of diabetes information and choosing information meeting their individual needs, corresponding to the different goals they articulated. Their strategies included employing Google as primary search tool, translating interests into keywords, selecting sites on the basis of textual elements, and going back and forth to Google so as not to get lost in the "flood of information", as I show below. Contrary to website providers' perceptions, users only partly imagined health care as a market. One reason was that the majority of the users



were only somewhat aware of the sociotechnical dynamics or “back-end information politics” (Rogers 2004) behind the delivery of web information.

### *Choosing Google as the primary search tool*

Despite the different goals users expressed for going online to search for medical issues, all users employed search engines to reach their individual aims. Nine out of the ten participants who searched for diabetes opened the search engine Google immediately, confirming Google’s importance to users in the Austrian context<sup>18</sup>. The majority of users reached Google by typing the URL into the address box when provided with a blank page in a web browser. A middle-aged user not very familiar with the internet, however, clicked on the search button in Internet Explorer. Accordingly, the MSN search page opened, which she employed throughout her whole hour of research. Out of the overall pool of participants included in the study, a couple of other elderly users were not able to find Google because they had the name of the search engine spelled incorrectly. One user, for example, wrote “Goggl” and reached a commercial site posing as the search engine but in fact selling cars. During the interviews, these users said that they did not find Google because it automatically opened on their home computers. These little glitches show that the search engine had become part of their standard web practices, having been installed as a starting page without reflection. These tendencies may be seen as further strengthened by Google’s efforts to become more and more integrated in standard configurations of computers and browsers, which has been called “Googlization” (Rogers 2009) in the literature.

When asked why they chose Google in the interviews, all users agreed that Google had become the dominant search engine, at least for the moment:

U9m: Well, this is because of the Zeitgeist. (laughs) Well, there are already expressions like ‘I google you’ and so on. One can, well, Google is the search engine par excellence. Well, whoever searches the internet, I don’t know, I think 90% of my friends and people I know google everything. (Q52, 40-61, book seller)

He says that he uses Google because everyone else uses it. Referring to the colloquial term “to google”, he suggests the importance of Google beyond his personal social environment. A few sentences later, he further added that he used Google “for everything”, like his friends. No matter if he wanted to find out how a word was spelled or translated or what his family tree looked like, he always employed Google to answer his questions, he said. The search engine thus appeared as fully integrated into his standard

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<sup>18</sup> The importance of the search engine Google was also seen in the interviews with “real” patients. Even if some of them had certain health-related websites they regularly visited, the majority of them went there via Google.

web routine. It may be seen as a pair of glasses he automatically put on when turning to the web to gather information in the medical context and beyond.

Like him, other participants equated browsing the web with using Google. The reasons they employed Google, however, differed. While some participants tried to justify rationally why they chose Google as their preferred search tool, others were less reflective about it. A number of participants mentioned technical features of the search engine that appealed to them. The size of Google's database, its speed in displaying search results, and additional services such as Google News, Google Maps, and Google Earth were mentioned in this context. Further, the design of the search engine turned out to be relevant. Comparing Google to other search engines – most notably Yahoo – some participants said that they especially like the reduced or simple design, which facilitated following one's own interests without being visually "distracted" (Q53, U18m, 41-60, employee).

Finally, many people mentioned that Google delivered the best search results, implicitly perceiving the search engine as a tool of quality assurance. In particular, the websites that were displayed and how they were ranked were seen as satisfying. Some participants simply said that they had had good experiences with the search engine in the past and therefore kept using it. Although the majority of users did not know how the search engine actually worked or what algorithms it employed, a number of participants described the search engine as a kind of gatekeeper leading them to good information, as if it were using some kind of unknown quality criterion. Only when explicitly asked whether they knew how the search engine worked did some participants express skepticism, bringing up paid links and strategies website providers might employ to push their rankings up. Others, however, answered that they were not at all interested in the way search engines worked. Comparing the internet to a car, a middle-aged user, for example, said: "What is happening in the background does not really concern me" (Q54, U20m, investment advisor). This indicates that most of the users employed the search engine in an uncritical way. Although relying heavily on Google, users generally used it as a neutral search tool. Following Latour (1987), the search engine may be seen as a routinely used black box, the complex inner life and "politics" (Introna and Nissenbaum 2000) of which are seldom considered.

The routine use of Google was also reflected in the way people introduced, or rather did not introduce, the search engine when explaining their searches. While some people explicitly mentioned that they employed Google to browse the web at the beginning of the interview, most of the participants drew Google into the story unreflectively. A young woman who had tried to find out what sports would help her better cope with diabetes in everyday life, for example, simply started her story by saying: "Well, I looked at various sites, I had a look at what Google spit out" (Q55, U13f, 26-40, university staff). The way

she phrased the sentence indicates that it was self-evident to her that one would use Google to find information about diabetes. Instead of explicitly saying that she selected Google as a search tool, she mentioned the search engine naturally, as if there were no other choice. Other participants referred to Google when talking about the huge amount or "flood of information" (Q56, U9m, 41-60, book seller) about diabetes they were confronted with. Without explicitly saying that they employed a search engine at all, they suddenly mentioned that they were searching for something and got loads of Google results back. These examples illustrate how common it has become to employ Google automatically when going online. Google may thus be interpreted as having managed to become a central actor in users' online practices.

### *Translating interests into keywords*

Once they selected Google as their principal search tool, the central question is how people interacted with the technology. One of the aspects that was crucial in the interaction with Google was the way the participants formulated their searches. One of the participants (having searched for the disease asthma, however) who had troubles finding Google in the first place also had problems using the search engine. He was exceptional, as he typed long passages of text into Google's input field, reproducing the text given to him that described his fictive diagnosis of asthma. Not being familiar with browsing the web, he was not able to formulate input the search engine could deal with. Consequently, the search engine returned websites not useful to him at all. This indicates that searching the web requires a set of skills to successfully interact with the technology. While usually remaining implicit in users' search practices, this case made the necessity of these skills perfectly clear.

Unlike him, the rest of the participants formulated their input as keywords representing the issues they were trying to find. Here, the different goals and preferences articulated by the users guided their actions. The majority of the users having searched for diabetes started their searches with general search terms such as "diabetes" or "type 2 diabetes", as written in the scenario. During their searches, however, users started to translate their particular interests into new search terms. Users interested in orthodox medical information to empower them in medical practices predominantly searched for formal medical terms such as "type 2 diabetes mellitus", "type 2 diabetes secondary damage", "type 2 diabetes and starving cells", "type 2 diabetes and death rate", "insulin sensitizer", and types of medication. In contrast, users trying to find information to better cope with their newly diagnosed diabetes in everyday contexts chose terms such as "diabetes recipes", "diabetes sports", "diabetes inject insulin", "diabetes measuring blood sugar", "high blood sugar", "blood sugar measuring devices", or even "diabetes everyday life", as the schoolgirl did. The two women interested in alternative medicine additionally chose keywords such as "diabetes alternative treatments", "diabetes homeopathy", and

"diabetes TCM". This clearly shows that keywords guided users' journeys through the web and influenced what kind of information they reached and did not reach. The more specific the issues people were interested in, the more specific the keywords they employed. In addition to their interests, however, internet skills also shaped users' actions. People describing themselves as not very familiar with the web, generally elderly users, turned out to be more reluctant to change and combine keywords, than users describing themselves as experienced users. More experienced, mostly young users, tended to play with keywords much more actively. Further, they employed strategies of excluding words or restricting the search to Austrian websites. In addition to these differences, these users appeared to be quite successful in translating their interests into a language the technology could "understand". The young woman interested in whether the sports she liked might positively contribute to living better with diabetes, when asked to describe her search, started by talking about the topics she was initially interested in:

U13f: Yes, I was interested in, well, how can I improve, what sports are appropriate. Whether the sports I'm doing right now, well, martial arts would not be appropriate. (laughs) That is something I found out. Then, then I looked what I should eat. This was, this was rather abstract, with carbohydrates and proteins. I thought, "This will be hard if I want to cook this," but finally I found a recipe. Then it came to mind, if I had diabetes, my children would probably get it as well. Then I had a look at how far it could be handed down. Type 2 specifically. (Q57, 26-40, university staff)

When talking about the way she actually searched for these issues, she automatically translated her interests into technology-compatible terms. A few sentences later she said:

U13f: (...) at first I put in "diabetes mellitus", then "diabetes type 2", then "diabetes and sports", then various types of sports, "diabetes and martial arts", then "diabetes and children" and "diabetes and inheritable", because I wanted to know if, if I can hand it down. (Q58, 26-40, university staff)

The quotation illustrates how she encoded her interests in sports and hereditary issues related to diabetes into the search strings "diabetes and martial arts" or "diabetes and inheritable". She commanded Google to look for and bring back information relevant to the search terms, and thus hopefully useful to her. As Google crawls and screens websites to identify pages dealing with particular topics, the input it needs is keywords. The participant thus knew how to translate her diffuse interests into precise search terms the technology could deal with. This may be seen as a common search routine most of the participants performed, often in an implicit way, without mentioning it or reflecting on why. The majority of the participants thus had no difficulties phrasing their interests in terms corresponding to Google's requirements. Particularly young people trying to find information to better cope with diabetes articulated quite elaborate techniques for selecting and combining search strings to get results meeting their highly individual

needs. They formulated short questions to reach discussion forums and self-help communities, for example.

Hence, Google may be seen as enabling certain moves, while denying others. The technical features of Google could be interpreted as accepting particular forms of input, such as keywords or short questions, and denying other forms, such as whole passages of text. Despite these requirements, users found individual ways to interact and experiment with the search engine to reach diabetes information meeting their needs. This indicates that browsing the web requires a set of implicit skills and experiences to succeed in interacting with the search tool. Only if people deviated from these standard search practices, however, did these implicit skills become explicit.

### *Following Google results from the top down*

After they performed a search with keywords, the question arises how users selected certain websites out of the multitude proposed to them. First of all, the position of the website in Google's search results was of crucial importance. No matter what search terms they employed, all users started by selecting one of the first few websites displayed in the organic search results (users only seldom clicked on paid advertising during the search experiments, which may be otherwise in "real" searches). Primarily clicking on one of the "top ten seats" (Introna and Nissenbaum 2000), users having searched for diabetes generally reached big, commercial health portals first, as I discuss in the following.

Reasons why people clicked on one of the first links varied, however. One participant, for example, said, "the farther you go towards the bottom, the less accordance there is with things I expect" (Q59, U5m, 19-25, student), meaning that the first few results tended to correspond better to his interests. The participants generally agreed that the first few hits were "definitely professional" (Q60, U25m, 41-60, IT consultant), as a participant predominantly interested in orthodox medical knowledge put it. Other participants added that they went through the result list from the top down for pragmatic reasons. A female user, for example, said that it was impossible to look at all websites anyway, and as she needed to start somewhere she simply started on top. While some people went through the list in a strictly linear way by clicking on every link in turn, others were more selective, skipping over links from time to time. Either way, the selection process generally happened quite intuitively and quickly, and involved a range of heterogeneous elements, as the following quotation illustrates. When asked how she selected websites out of the search results, one participant said:

U21f: I go from the top to the bottom. Although I, this goes very quickly, because I look quickly to get an overview, okay, zack zack zack, does it fit. And then, I do not, I do not click on every website, but simply, okay, I look, does it fit and

*I: And you do that on the basis of the text?*

U21f: Yes, the short extract that is there, but also on the basis of the web address. This is something I definitely consider.

*I: What does the address tell you?*

U21f: This is complicated, if it's not in front of you. This is like if you asked me about road signs. How does the road sign you see every day look, right? (Q61, 41-60, homemaker)

Using the colloquial phrase "zack zack zack", she underlines how quickly she went through the result list, following Google's order. She considered both the teaser text and the address of the website, and made an intuitive decision without thinking long about it. Although she was able to draw certain information intuitively out of the website address, it was impossible for her to explain what exactly this information was. Her example of road signs again underlines that browsing the web requires implicit skills and knowledge often not easy to explain.

Like her, other participants mentioned the importance of the piece of text and the URL provided by the search engine in selecting particular websites. Talking about her practices of filtering and selecting websites, one participant said that she looked whether "my keywords appear first of all, and then below there is generally the address, and if then, I don't know, if there is a children's homepage or something like that, or if you can see that it is something private, I don't look at those websites" (Q62, U29f, <18, schoolgirl).

Quite a few of participants explained that they principally screened the headlines and the teaser texts highlighting the search terms when going through the result list. They generally used the sample text from the website that the search engine provided to form a first impression of the whole website. By providing headlines and teaser texts highlighting keywords, the search engine may be seen as providing content-oriented descriptions of websites that appealed to users. Browsing web content according to keywords thus appeared to be a common search practice going beyond the actual choice of the terms, an aspect further discussed later.

Besides textual elements, the address of a website, which disclosed information about the identity of the provider, was described as relevant by some users. The young user above, who perceived herself as a skilled internet user, was able to draw information about the provider out of the site's domain name. She said that she generally did not like websites from commercial providers or sites specifically designed for children. In order to exclude these sites immediately, she screened the text and the address of the website to get an idea of the type of provider behind the website. Like her, a male student straightforwardly

referred to the domain name of a specific website and how it formed his impression of the quality of the site:

U4m: Well, I started with Netdoktor. I used it first, although it in fact came at number three, but (.) well, because of the name and the prestige I would attach to it. I used it for another disease once and it was quite good". (Q63, 19-25, student)

Being interested in classical medical knowledge, he chose the site because its address communicated an impression of professionalism, he says here. The student further mentions that he had had good experiences with the site in the past, which further strengthened his decision to visit this website first. Especially users interested in obtaining knowledge to empower them in medical practices, tended to pay attention to the addresses of websites when screening web content. Their belief in orthodox medicine, meaning approved medical knowledge, may thus be seen as mirrored in their web searches. In contrast, users trying to acquire knowledge helping them in day-to-day contexts were less interested in the addresses of websites, because they were open to a wider variety of medical information. Some users further added that, since they knew few websites in the medical realm anyway, the address would be of no use to them. One user even said that he went online to learn about new perspectives and therefore deliberately sought out unfamiliar websites.

### *Switching between websites*

The examples discussed show that Google was generally perceived as a convenient search tool. It gave users the opportunity to easily work through a multitude of information in a linear way. This suggests that the participants generally went back to Google when a website was not useful to them anymore, making the back button of the search engine an important feature. As the film material shows, they selected one of the first few sites, read through the site, and then went back to Google to choose the next link down. Google may thus be seen as helping users not to get lost in the multitude of information, because it acted as an initial point to which people could always go back in case of trouble. This widely shared search pattern may best be described as "going back and forth to Google" (Q64, U40m, 26-40, engineer), as a number of participants phrased it.

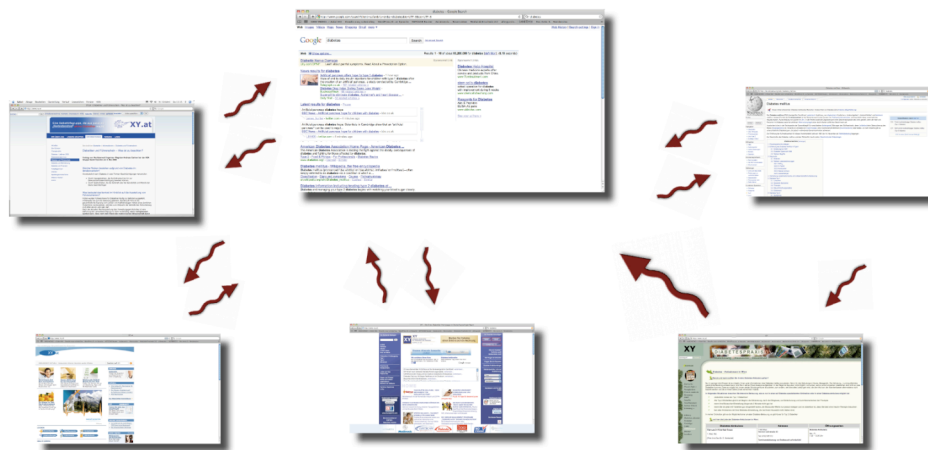


Figure 4: Illustration of Google as a home base.

Google could thus be interpreted as a kind of home base that the participants appreciated because it created a feeling of security. It established order in an unordered plethora of information. However, this home base should not be seen as stable throughout the whole search process. Rather, it was modified according to the participants' interests, and thus changed and developed over time. The home base figured as a stable location giving order to an unordered flood of information, while being elastic enough to adapt to users' preferences and needs. Google may thus be seen as providing users with the ability to browse the web according to their interests, while also giving them the idea of a reliable information structure. It provided agency and security simultaneously, which was widely appreciated by users.

In addition to Google, some people employed links repeatedly to move between websites. Especially when trying to find more detailed information, certain users perceived links as useful tools. People tended to use more links from websites they knew or particularly favored, because they trusted the providers of these sites, as the website providers themselves expected. One user further added that he appreciated links because they better enabled him to recognize the provider of a website, as the provider was usually described in the link list. However, in comparison to Google, links played a very subordinate role in users' search practices. No matter what issues users were interested in, they seldom followed the virtual pathways website providers had constructed for various reasons. A principal reason that participants regularly mentioned for not using links was that links would lead them away from their topics. As people tried to keep focus throughout their searches, links were largely perceived as risks for losing their way rather than as pointers to useful information. Talking about links and whether she used them to browse the web, one user, for example, said: "Yes, if they stay with the topic. If they digress too much, then it is too time-consuming for me, and I do not go on. If it's digressing too much." (Q65, U36f, 41-60, homemaker) This quotation may be seen as



typical of users' explanations for why they often rejected links. It also mirrors the attitude, shared by all participants, that browsing the web, particularly in regard to unpleasant topics such as medical issues, should be done in a quick and efficient way. Links were thus seen as chaotic and misleading. Associating them with "losing oneself" (Q66, U21f, 41-60, homemaker) in the flood of information, as another participant put it. Participants generally saw following links as abandoning the sense of control they associated with the Google home base.

This analysis has shown that searching the web for medical purposes may be seen as a multilayered sociotechnical practice shaped by medical preferences and interests, skill in using the technology, and technical limiting factors. Users may be seen as translating their thematic preferences, as well as their models of medicine and doctor-patient relations, into their searches by letting these issues guide their journeys. Once they had encoded their interests into keywords, the search engine enabled them to browse the web according to their preferred topics. In selecting websites, users primarily favoring orthodox medicine tended to pay more attention to the websites' domain names, which indicated the providers of the sites, than did users interested in practical information and patient support. Besides these preferences, a range of implicit skills for interacting with the technology were involved in the users' search practices. Finally, the search engine itself shaped users' searches through the algorithm it employed, although this generally went unnoticed by the users. It delivered its search results in a linear order easily followed by users, and figured as a kind of homebase users went back to in case of trouble. The consequences of this for which websites were actually used and which remained untouched will be discussed below.

### **8.3 Conclusion: Google as an "obligatory passage point"**

The above analysis has shown that website providers and users who participated in the study directed their actions towards each other in certain ways. Providers, especially of non-profit websites, offered links to other websites that might serve users. They tried to establish credible pathways to other websites, imagining that users would follow these virtual routes, and calling to mind for predictions that users would stroll through a decentralized web by following links (Berners-Lee 2000). In this context website providers perceived themselves as gatekeepers directing users to credible diabetes information. In addition, website providers observed users' search behavior in order to better attract their target groups. Accordingly, all website providers were aware that users primarily reached their sites via search engines. Consequently, they tried to gain a "top ten seat" (Introna and Nissenbaum 2000) in search results, in order to be found and recognized by users. As for users, they seldom employed links offered by website providers. Rather than following decentralized link networks, they primarily picked websites out of search engine results,

another result found in the literature (Jansen and Spink 2006). A central reason was that the search engine was seen as a kind of "home base", giving order to unordered information. Consequently, users primarily filtered and selected websites on the basis of textual elements provided by the search engine. They decided whether websites met their needs by looking through textual extracts of the websites as displayed in the search results, and at how their keywords were embedded. Certain users, particularly those with a leaning towards orthodox medical knowledge, also looked at the addresses of the websites to form impressions about the providers of the sites and their agendas.

The analysis has further shown that both providers and users acted in relation not only to their respective counterparts, but also to the technology, and most importantly to the search engine Google. For-profit website providers, in particular, adapted their linking strategies and meta keywords to Google's PageRank algorithm to obtain one of the "top ten seats" (Introna and Nissenbaum 2000). However, random links put on websites merely to enhance the site's position in search results sometimes offended users by leading them somewhere they did not want to be. Providers may thus be seen as partly losing track of the user by concentrating instead on the search engine. Users, for their part, widely employed Google to browse and order web information according to the issues and medical preferences they were interested in. Users trying to support themselves in their day-to-day routines, in particular, selected web sites on the basis of keywords and textual elements, largely losing sight of the website providers offering the information. This triggers profound consequences in terms of the way websites are employed and medical web information is evaluated and understood, as will be seen in the following chapters. Although generally using Google as a "black box", without knowing its complex inner dynamics and "politics" (Introna and Nissenbaum 2000), users usually followed Google's search results in a linear way, expecting to be directed to "good" medical websites. In contrast to the website providers, users employed Google as a directory leading them to the medical information meeting their needs mostly unreflectively, and simply for pragmatic reasons.

These results call to mind literature discussing search engines – and Google in particular – as central actors or "gatekeepers" (Diaz 2008) that regulate access to web information. Contrary to much of the literature, which conceptualizes search engines as if they were an external factor threatening the democratic potential of the web (Introna and Nissenbaum 2000), I conceptualize search engines as enacted in and stabilized by social practices. My analysis has shown that both website providers and users strongly direct their actions towards Google, and thus stabilize the search engine as an "obligatory passage point" (Callon 1986), as I have argued elsewhere (Mager 2009). This underlines arguments from ANT that power should be seen as stabilized by actor-networks. Google's power may be seen as a "network effect", to quote Law (1997). But why do both website providers and users stabilize the search engine as a powerful actor? Callon (1986) has argued that

“obligatory passage points” gain their powerful positions by translating others’ interests into their own. Similarly, Google may be seen as translating providers’ and users’ interests into its own, and thus supplying both providers’ and users’ wants. It helps website providers to gain visibility, and users to find, order, and select information according to their needs, as I discussed. The first segment of search results figures especially as an authoritative space where the battle for attention is fought today, where the day-to-day trading of medical web information is actually done. This is the space where providers usually succeed (or not) in making their voices heard, because users ordinarily pick up messages out of the babble there. Consequently, Google may be interpreted as enabling a space of encounter, where website providers and users meet each other to exchange medical web information.

But Google should not be seen as passively providing a meeting point to exchange medical web information, but rather as actively defining the rules applying to this space. It allows providers and users certain moves while denying others, and may thus be seen as changing a state of affairs. Google may be seen as a “full-blown actor” (Latour 2005), in ANT terminology. But how does Google “act”?

Google helps website providers to gain visibility, while crucially influencing their practices of configuring and positioning their websites. It has been shown that all website providers in the study employed a variety of strategies to gain visibility online. Commercial websites in particular aggressively tried to gain visibility by pleasing the technology, and most importantly Google. This triggers a Matthew effect (Merton 1968), making popular websites more popular, while marginalizing smaller websites, and requiring website providers to compete in the rankings to be found by users (a central precondition for sponsorship contracts). In this competition, links played a central role, because Google denied providers a direct means of gaining a preferred “seat” in search results (apart from payed links displayed as advertisements). In rewarding the quantity of links a website gets rather than the quality of links to be found on the site, Google triggers strategic linking practices, such as allocating links through “link exchanges”, as described above. This indicates that, with the omnipresence of Google, “information politics” (Rogers 2004) and market dynamics have clearly entered the medical realm. Pleasing the search engine algorithm has become a standard practice of medical websites trying to position their informational products well on the online market (and particularly of those that have the financial resources to do so).

That strategies of search engine optimization (SEO) indeed pay off, may be seen by considering users’ search practices. Users in the study generally went through Google’s result list from the top down, following the hierarchy Google proposed, as discussed above. Especially when using general search terms such as “diabetes” or “type 2 diabetes”, users primarily reached big, generally commercial medical websites containing

extensive text and links. Eight out of the ten people who searched for diabetes selected the same health portal out of the result list, making it a sort of “market leader” in the medical web space. In addition to health portals relying on professional SEO-strategies, smaller sites such as that of the patient who did extensive “link exchanges”, were displayed on top, at least in particular issue areas, as the image below illustrates:

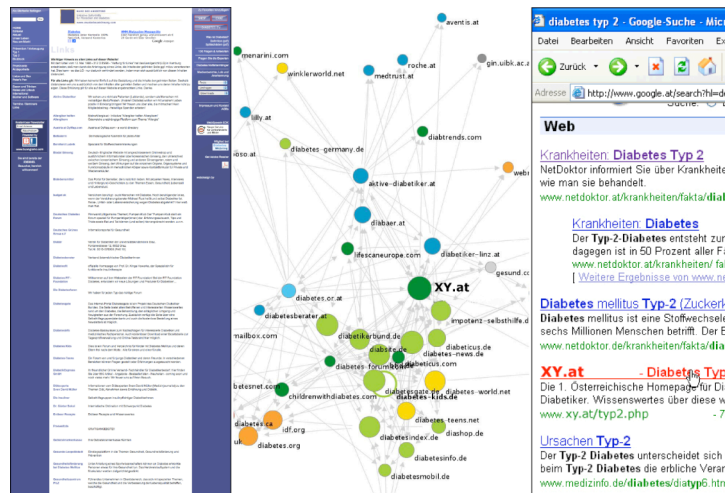


Figure 5: Strategy of gaining visibility through “link exchanges”. The image on the left illustrates the relatively long link list of the patient’s website, amassed through link exchanges. In the middle, this website is displayed as a well-connected node in hyperlink networks displaying the issue area of diabetes. On the left, the website is displayed as the fourth link in a user’s search for diabetes information – the user had employed the general search term “type 2 diabetes”.

As a consequence of the provider’s link exchanges, he had managed to become a well-interlinked hub in link networks and thus gained a prominent position in search engine results. Consequently, the majority of users who searched for diabetes came across his site, clicked on it, and employed it for some period of time.

This indicates that euphoric visions of the web democratizing medical knowledge seem to be rather naïve given the complex sociotechnical dynamics involved in the supply of medical web information. Instead, offline power relations – and particularly financial resources – which enable well-established institutions to attract more links than do unknown actors may be seen as defining which websites gain visibility and which do not. This is significant because most of the users in the study tended to read the first few websites much longer than the ones they visited later in their search processes, as may be seen from the film material showing users’ searches. Consequently, search engines, and Google in particular, need to be considered as central actors when thinking about the democratic ideal of the web as a health information source. Rather than the “collective intelligence of the web”, as Google advertises on its website, technical expertise and money assure the prominence of certain medical websites – mostly large commercial portals – on the provider side.

To fully understand the sociotechnical dynamics of the online health information market, further attention needs to be given to user practices. My analysis has shown that different users display different repertoires of search strategies and skills. Users who select very specific search terms and actively change and combine keywords – mainly experienced users – are much more likely to find more specialized websites, such as those from patient associations, that provide more specific diabetes information than general health portals. This particularly concerns websites that provide alternative medical information, which are perceived as somewhat “hidden” on the web in general, but which can be reached by users who actively search for alternative medicine, and thus who are interested in this particular type of medical knowledge. These sites are thus found primarily by members of their specific target group. Interviews with “real” patients suffering from chronic diseases such as diabetes further show that internet practices change over time, and that the longer a patient suffers from a disease, the more specific the information and websites for which she or he searches will become (Google still being central, however). This shows that practices both of providing and of using medical web information should be seen as changing over time. The dominance of Wikipedia in Google’s search results – and thus user practices – for example, only recently developed, underlining the flexibility of the sociotechnical dynamics at work in the medical context and beyond.

But Google should not only be seen as shaping providers’ and users’ practices by creating hierarchies between websites. Rather, more profound implications may be observed. Google translates link networks into PageRank-weighted lists, defining the position of each website in the search results (Brin and Page 1998), but also taking websites out of their link networks, thus contributing to a “disentangled web” (Elmer 2006). Hence, the multiple meanings website providers inscribe in their link connections lose importance in the context of search engines. That is why “link exchanges” that amass as many links as possible pay off in regard to search engines. Consequently, links lose importance on the user side, becoming increasingly perceived as “chaotic” and further stabilizing the search engines as an “obligatory passage point” (Callon 1986). On the user side, Google requires users to formulate their interests in terms the search engine will understand. Further, users’ strategies of sorting and selecting websites out of the plethora provided to them may be seen as adapting to the search engine, as websites are increasingly selected on the basis of textual elements instead of the actual providers. This indicates that search engines crucially shape medical web information, influencing not only what information is communicated between website providers and users, but also how it is communicated, as I discuss below.



## **9 How website providers and users communicate medical information via websites**

In this chapter I discuss how website providers and users exchange medical information via websites and what perceptions of each other accompany their exchanges. Concretely, I explore how website providers present and arrange their diabetes-related websites to appeal to users, and how users read through and select diabetes information meeting their needs. Central questions will be how website providers' and users' different medical agendas, mutual perceptions, and skills shape their practices, and how technical entities of various sorts mediate and contribute to their actions.

### **9.1 Website providers' strategies for configuring medical websites**

According to their motivations and models of health and illness, website providers translated their respective medical knowledge into information through configuring a medical website and formatting it in an appealing way. The goals website providers expressed for providing a website thus crucially shaped how they arranged the medical information on their sites. Despite their differences, all website providers shared basic practices of arranging a medical website, facilitated by the technological possibilities. These strategies included building a simple information architecture, formulating the content in a comprehensible way, and adapting the website to a specific target group, as I discuss below.

#### *Inviting users with a top-down information architecture*

First of all, website providers tried to appeal to users with a clear information architecture. All providers agreed that a website needs to have a plain structure to be easily navigated. When asked why he thought users employed the general health portal, the director mentioned the high quality and credibility of the information, established through a professional, partly medical, work force, and the strict "code of ethics", as mentioned earlier. Further, he added,

W3m: Yeah, and also because it's easy to navigate, I think. Well, we do not puzzle the user, and I think, because it is not a very modern, heavily designed portal, I think rather a very straightforward one, one can find one's way very well I think. (Q67, health portal)

Besides the information itself, the structure of the site was seen as central quality criterion. Like this interview partner, other website providers emphasized the importance of providing users with a simple information structure so as not to irritate them. But how did website providers imagine such an information structure?

At first sight, the websites included in the study had a very different look. According to their different agendas, approaches towards medicine, and technical and financial abilities, the website providers assembled their sites differently.



Figure 6: Anonymized representations of the five different websites included in the study, saved between 2005 and 2006.

After a more detailed analysis of the websites included in the study, however, it became apparent that all of them shared the same basic information architecture. They all welcomed the user on the homepage, which figured as an entry point to the site in one way or another. The homepage usually seemed to be the location where the user was supposed to start. Here, the provider, whether individual or institutional, and the sort of medical information the website offered, ranging from orthodox medical information to patient support, were presented, and an overview given of the various issues treated on the site. Depending on the website's agenda, its homepage might include a self-portrait, a short description of the site, or a menu of thematic categories and teaser stories to entice the user. The websites of the self-help association, the doctor's practice, and the pharmaceutical company described themselves particularly extensively on their entry pages. Because these providers used their sites as extensions of their offline services and as locations for self-promotion, the user was initially welcomed with the identity of the website providers. According to its overall agenda of helping diabetics to better cope with their health condition, the patient association, for example, stated on its homepage: "Welcome to XY. A self-help association that transforms passive diabetics into active ones" (Q68, website of the patient association). The diabetes doctor also presented herself with a picture and a statement saying that she aimed to accompany patients and develop therapies in a shared manner, corresponding to her model of medicine and doctor-patient relations. On the website of the pharmaceutical company, patients could read that the company had existed since the 1920s and that it had a long tradition of fighting diabetes with pharmaceutical research and products such as insulin and medical devices. The general health portal and the website of the patient, which were not



affiliated with other institutions, presented their identity only briefly with slogans: The health portal described itself as "The Independent Health Web for Austria" (Q69, website of the health portal), and the diabetic labeled his site "Initiative Immediate Aid for People with Diabetes" (Q70, website of the patient). That both the general health portal and the diabetic's site were legally run as companies, however, could only be read in the copyright sections of their sites.

In addition to their self-presentations, all websites used the homepage to offer a general overview of the issues treated on the sites, in the form of a task menu, as may also be seen in the illustration above. The diabetes association, for example, provided five categories: "About Us", "Self-Help Groups", "Diabetes Information", "Dates", and "Links". These categories mirrored the overall content the website provided. In the "About Us" section, detailed information about the association and its agenda could be found. In the section on "Self-Help Groups", the real-life groups and their thematic foci in the Federal States were presented. In the "Information" section, the user could find various diabetes information, including patient experiences; information on medical devices, diabetic feet, and other disease-related issues; institutional help on regulation for diabetics; summaries of lectures on specific diabetes topics; and discussions of health-political issues, particularly the advertising ban, as mentioned earlier. In the "Dates" section, upcoming events were announced. Following the association's strategy of gaining presence on the online health information market through networking, the section "Links" contained pointers to the association's social network, recommendations of other diabetes-related sites, and some links to companies that supported the site financially. Other websites similarly offered such thematic overviews, in more or less elaborate ways. The general practitioner offered the user three sections: The first section provided information on her practice, the second one offered extended orthodox medical information on diabetes and medication, and the third one assembled information on, help with, and links to medical devices and products from a professional's point of view. The pharmaceutical company also offered a directory of the main issues and sub-issues dealt with on the site, ranging from information on the company and its products to general information on diabetes. On each of the websites the user was expected to start on the entry page and delve into more detailed information from the top down.

In addition to a brief self-presentation in form of a slogan and an overview of the medical information provided on the site, the general health portal and the website of the diabetic provided additional features on their homepages. Besides offering a directory linking to orthodox medical information on all types of diseases (including diabetes), patient support, services such as a self-tests, and a news section, the homepage of the health portal displayed different types of boxes highlighting news stories related to health and lifestyle issues. The diabetic similarly provided teaser texts for news stories about celebrities suffering from diabetes, for example, and reports on medical products written

in an entertaining manner, as described earlier. Both the health portal and the diabetic's site provided more pictures on their homepages than did the other three sites, underlining their aim to provide appealing informational "products". While the pictures from the health portal seem to derive from commercial "image databases" providing images in stock, the pictures from the diabetic seem to be taken by the diabetic and individuals working for the platform. Additionally, both websites provided a discussion forum where patients exchange medical information and support with each other and a search box to browse the sites along keywords. This indicates that the look and content of a health-related website strongly depends on the budget available for building and maintaining the site, an issue further discussed below.

Despite these differences, all websites provided their information in a classical way by assembling it in a tree-like hierarchy with a trunk and several issues branching off. By following the tree structure from the top down, the user could reach more and more detailed information.



Figure 7: Illustration of the tree-like information structure of websites analyzed in this study.

This top-down information architecture was found on all websites included in the study in one way or another. Each site included a homepage and a body of information assembled in the tree-like information architecture according to its own medical approach. Depending on budget and technical skills, however, these "information trees" varied. Non-profit websites such as those of the doctor and the self-help group provided only this plain information structure. The other websites, all of which had a more or less explicitly commercial background, provided additional navigation elements. Besides the top-down menus, their homepages offered teaser texts to stories that could be clicked on directly. Some provided multiple navigation structures. Finally, the professional health portal also provided hyperlinks in the text enabling users to browse the text in a multi-directional way. These different features allowed users different scopes of agency in using the sites,

triggering consequences on the user side, as I discuss later. Each page usually contained a short piece of text with clear breaks and headlines. These pieces of text were often, but not always, framed by the logo and slogan of the site, emphasizing the site's provider. This seems to have become a standard practice, as the history of the diabetes association indicates. In 2006, when the study identified and saved all websites to be analyzed, the pages of this site were embellished only by the hedgehog that served as the mascot of the self-help group in both online and offline contexts. This, however, has changed since then, as may be seen below:

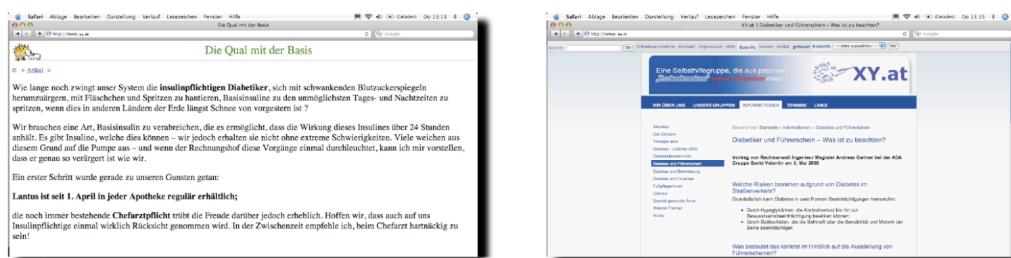


Figure 8: A page of the website of the patient association saved in 2006 on the left, and a page of the same website after its relaunch in 2009.

While previously only the hedgehog related to this particular self-help association was displayed on pages, full information about the group may now be found on each page of the website, as illustrated on the right. Again, this shift triggers consequences on the user side.

### *Tight entanglement of content and code*

This short excursion through the websites included in the study illustrates that, despite their differences, all website providers basically offered their information in a top-down information architecture. Because of this, each issue treated on the sites appeared to be embedded in and contextualized by the overall information structure. Website providers may thus be seen as tying together packages of information with an inner logic and coherence. But how do website providers do this, and what perceptions of users are embedded in their practices? In the interviews it became apparent that their packages of information were enabled by the harmony of content and code. For example, in talking about the early days of his website and how he configured the site with the help of a web designer, the diabetic offering patient support said:

W2m: I said, "There I'll put a directory of the categories, and there we'll put headlines and write stories. And there we'll put a button to go forward". And then it was, it also derived from collaboration (with the webmaster, A.M.), like, they know what to do. (Q71, patient)

This quotation illustrates that the information architecture provided on the website was influenced both by content and by code. Imagining how users would browse his site, the provider explained his vision to the web designer on the level of content. He explained that users were supposed to start on the homepage, which would offer a directory and teaser stories, and to delve into the site in a top-down manner by following links he provided. The purpose of the web designer then was to program this information structure into HTML. The informational structure had to be encoded in the technical fabric of the website, and the topical categories imagined by the provider had to be transformed in technical layers of the website. The overall appearance of web information may thus be seen as co-produced by content and code. The tight entanglement of content and code was also reflected in the close co-operation of providers and programmers of the websites. All website providers said that the collaboration between the people who wrote the content and the people who programmed the site was very important. When asked about the relation between people working on the content of the site and people working on the code, the director of the general health portal, for example, said:

W3m: Well it is like, it is of course very close, because they all sit in one office. So this is one advantage, that we do not outsource anything, (...). And because of this the teamwork is very close. (Q72, health portal)

This quotation underlines that the professional appearance of the portal was enabled by close cooperation between the people developing the content of the site and the technical work force. The better the interplay between the back end-and the front-end of the site, the better the content looks in the end, the director argued. This, however, required a budget that not all website providers had. Unlike commercial websites, and most particularly the health portal, providers of non-profit websites, such as the self-help group, did not have much money to maintain their sites. That is why they usually built their sites on their own or had them built by a web designer and then maintained them on their own. This of course shaped the structure and outlook of the sites. The doctor said in this regard:

W7f: And it is the old problem of laypeople, who program a site without professional help, it gets confusing pretty quickly and one constantly adds content without restructuring it completely. (Q73, doctor)

Further, these sites run the risk of being perceived as unprofessional in comparison to professionally maintained health portals, as I discuss later.

This shows that the different goals and financial resources of the different types of website providers influenced how the different websites appeared. The differences in budget and work force further explain why only the health portal provided additional features, such as hyperlinks in the text enabling users to browse the web in a multi-

directional way and a moderated discussion forum offering patients the opportunity to share their own expertise. Non-profit websites, in contrast, generally provided their content in a stable top-down information structure with static elements of text. This also applied to the pharmaceutical company, in a very different way, however. Since the site functioned primarily as a location for self-promotion, the company did not seek to provide fancy hypertext elements in the text or a discussion forum, but rather to present itself and some additional diabetes information in a classical way from the top down. This suggests that commercial medical websites have a certain advantage over competitors in the medical marketplace, not only because they are better able to invest in SEO-strategies, but also because they provide better-organized websites in comparison to non-profit sites such as self-help associations, as Oudshoorn and Somers (2006) also found in their study on patient associations providing websites.

### *Formulating content in a comprehensible way*

Besides information architecture, language was seen as an important issue to consider when trying to present an appealing medical website. All website providers in the study agreed that medical content should be provided in a comprehensible way online. When talking about medical information in general, website providers said that this type of information constantly runs the risk of becoming incomprehensible for patients. In this context the web was described as an alternative to classical health information sources, including doctors, which tend to provide medical information in a terminology hard for patients to understand:

W2m: Because previously you had to buy thick books about the topic, not readable for you, and when you had finished them you were still hopeless, because you did not understand the language. And today a lot of information is provided about each topic on the web, and it's also understandable for laypeople. Well, health-related information, right? And I appreciate it. (Q74, patient)

The diabetic who provided a website also pointed to the fact that the web figures as an information source that may provide medical information explicitly directed towards laypeople. During the interview, he regularly mentioned how he himself tried to provide his information in a language understandable for laypeople. One good example in this respect is the way he talked about medication on his site. In accordance with his goal of making a profit, he provided extensive information about medical devices and medication from the viewpoint of a concerned patient, as discussed earlier. Echoing the discourse of patient empowerment in the context of medical practices, he said:

W2m: We believe, and with me most medical professionals specializing in diabetes, and, and also self-help groups say that we would like people to know clearly what it is, and not only the Latin, medical term, but also the brand name. Because it does not make any sense, he

does not remember the name, he must know, for example, that insulin is called Lantus, and then he has to be able to go to the doctor and say, "I read something about the insulin Lantus". Or if it concerns insulin sensitizer, a new group of pharmaceuticals, brand new, he has to know this is called Actos, right? (...) And it does not make any sense to say Pioglitazon, right? I mean, clearly, the doctor knows it, but the patient cannot remember it. (Q75, patient)

Information about medication, usually seen as one of the central issues to negotiate with doctors, as argued earlier, is a good example of how website providers tried to appeal users with comprehensible content. Despite the advertising ban, the diabetic used his site to inform patients about medication, and explicitly mentioned the names of products. This was crucial to him because this was the information the patient would need to participate in medical decision-making, he said. The doctor also provided information about drugs, similarly arguing that the patient needs to be informed about medication in a way she or he can understand. Being a medical professional herself, she tried to keep her patients in mind when writing web information, so as not to get lost in technical terms or Latin, she further added. The PR manager of the pharmaceutical company also mentioned that medical information runs the risk of being "peppered with foreign words". In this context she explained how she tried to adapt her diabetes information to patients' needs:

W6f: Well, we sometimes run tests in the sense that we give the text to employees who have parents afflicted or the like to take it home and say: "Give it to your mother and let her read it and let's see what happens." Or we give it to self-help groups and say: "Look through it. Does anyone understand it?" Because if you're into the topic that much, one tends to get very complicated (laughs) (Q76, pharmaceutical company)

In this quotation, she underlines that expert medical information needs to be translated into patient-compatible speech, which she tries to achieve by testing the information with patients. In regard to medication, however, her hands were strictly tied by the advertising ban, she further said. This led to the paradoxical situation that legally the patient could only find technical information about medications, "and this does not help patients at all, because it's again written in a way that only doctors understand" (Q77, W6f, pharmaceutical company), she added. These quotations illustrate the website providers' basic awareness that medical knowledge needs to be translated into a language comprehensible to patients. According to their different identities, website providers achieved this goal differently, however. The director of the health portal, who provided medical information as a business, argued that the composition of his staff enabled him to accomplish the goal of providing evidence-based medical information in a comprehensible way. Medical professionals, writing the basic descriptions of the diseases, were supposed to guarantee the accuracy of the information, an aspect further discussed in the next chapter. The non-medical staff, mostly journalists, who arranged the overall content and wrote the main body of the site, including news stories, life-style issues, and the like,

were supposed to guarantee that the information was written in an appealing way. This combination of competences should enable him to provide “evidence-based medical information in a comprehensible way”, the core of his brand, the director argued. While providers such as the doctor, the PR manager of the pharmaceutical company, and the director of the portal talked explicitly about strategies for making sure that their information was comprehensible for users, patients had a certain advantage in this respect. In writing for their own community, they naturally used the language patients would need, both the self-help group and the individual diabetic agreed.

### *Visually formatting information to appeal target groups*

Finally, in addition to information architecture and language, design was regularly mentioned as important ingredient in composing an appealing package of information. All the website providers referred to their web design time and again when talking about how to appeal users. Particularly in this context, their specific target groups entered the scene. On a general level, all the website providers mentioned patients, and predominantly elderly people, as their primary target group. When asked if she had had a specific target group in mind when producing her website, the general practitioner, for example, answered:

W7f: That also was for elderly people. I thought the elderly would benefit from the design. Younger people who want to come to me don't really let an old-fashioned design frighten them off. (Q78, doctor)

She says that her primary target group determined her web design. The diabetic providing the commercial website similarly mentioned that he toned down flashing and blinking elements of the website so as not to disturb elderly users. Websites with institutions in the background further tried to visually represent their offline identities online. The diabetes association took the logo and design of the paper magazine they circulated amongst their members and applied them to its website. The doctor explained that she had developed her website in parallel to her practice:

W7f: And it was really co-developed. Well, the yellow of the homepage, the green, this grey-green that I consider really calming, they are on the wall in the room where I work. (Q79, doctor)

She designed her website according to the furnishings of her practice. Since she used her site partly as a location for self-promotion, her specific design was intended to help entice virtual users into her real practice. The pharmaceutical company, too, drew on offline marketing campaigns when designing its website. Further, the corporate design of the company defined how the website looked, the PR manager added. These examples show that the online and the offline worlds should not be seen as distinct domains, but rather

as tightly intermingled.

The director of the general health portal, on the contrary, had neither an offline institution to represent, nor a clearly defined target group right from the start. Consequently, the site was designed in a professional but quiet way, so as not to frighten off any target group, the director explained. Since it belonged to an international corporation, the portal was also bound to a corporate design to a certain degree, he said. Asked whether the website was created for a specific target group, he answered:

W3m: Yeah, well, it's like, for example, we have in mind, we know that we have more women than men, and we make an effort, also in the look and feel, in all of the information handling, to address women. Well, I, I make sure if there is a position to fill, because the technicians are mostly men, that we really employ women, because it is really important to have this point of view. (Q80, health portal)

Unlike the other website providers, who originally had specific target groups to serve, the director of the general health portal oriented his medical information towards user groups that formed over the course of time. Through regular customer surveys carried out on his site, as described above in the context of visibility strategies, the director of the health portal found out that more women than men visit the site. Accordingly, he adapted his site to particularly appeal to women, not least by deliberately employing women.

Unlike web design, images and multi-media applications were hardly mentioned when talking about visually formatting websites. The reason is that these features were seldom used on the diabetes-related sites analyzed in the study. The commercial diabetes site and the health portal displayed images linked to texts about diabetes news and lifestyle issues. The other sites, however, only displayed images to represent the doctor's practice, to present the diabetes association and its members, and, in case of the pharmaceutical company, to present medical devices and products. Despite these images, these websites primarily restricted themselves to text. Multi-media applications were seldom employed on any of the sites analyzed. This indicates that diabetes-related websites were generally text-heavy. One reason may be to avoid irritating elderly people with flashy pictures or multimedia applications, as mentioned earlier. Another reason may be that some providers, particularly of non-profit websites, had the goal of making their messages and services available in an authentic way, and may therefore not have been interested in enticing users with optical attractions. Accordingly, commercial websites with the goal of making a profit, and thus requiring a stable number of users, or "traffic" as the director of the health portal put it using the English term, would have more interest in inviting users in with attractive images and "eye candy". The issue of advertising, relevant particularly with regard to commercial sites, was hardly raised in this context. Only the director of the health portal mentioned that it was crucial to optically distinguish advertorial content from the other content of the site. The issue of advertising was primarily raised when talking



about credibility, as I discuss in the next chapter.

This analysis shows that all the website providers shared a basic set of strategies to assemble and present appealing packages of information. All of them arranged their content in a top-down information architecture, tried to formulate their content in a comprehensible way, and visually formatted their sites according to their target groups through a harmony of content-related decisions and technical possibilities. Their different agendas, models of medicine, and budgets, however, had an impact on the way providers actually implemented these criteria on their sites. Website providers from medical institutions emphasized offering their medical information in an authentic way. They tried to arrange this information in clear but stable top-down information structures and visually format it in ways corresponding to their offline identities, within their small budgets. The provider of the pharmaceutical company presented the company, its products, and some general diabetes information in ways similar to offline marketing campaigns. The providers of the general health portal and the semi-commercial diabetes site emphasized appealing to users much more heavily with good-looking packages of information. They spent quite some time and money to have their sites designed and maintained properly. They tried to appeal to users with a good informational product in terms of structure, language, and images. They further tried to adapt their content to actual user groups on the basis of statistics or surveys, in the case of the portal. Having no offline institutions behind them, they may be seen as aiming to build up their images and “labels” on both the front ends and the back ends of their sites.

Having analyzed how website providers envision and try to serve users, we can take up the next central question, that of how users actually find, browse through, and understand information on medical websites.

## **9.2 Users’ strategies for employing medical websites**

Users generally browsed the web with the help of search engines according to their thematic preferences and models of medicine and illness, as described earlier. They selected websites corresponding to their keywords and interests by going back and forth to Google. This implies that they seldom followed the top-down information architectures website providers had built, but instead followed the top-down information architecture proposed by Google. This indicates that users’ search routines crucially determined which websites they actually used, but also how they used and interacted with these sites and their information, as I discuss in the following.

According to their overall goals, different types of users employed different types of websites, as the film material capturing users’ searches shows. Users primarily interested

in finding knowledge enabling them to participate in doctor-patient relations tended to prefer websites providing orthodox medical information. These most often included general health portals and institutional websites such as doctors' or hospitals' sites, but also Wikipedia, all of which were widely seen as accurate health information sources. Users interested in knowledge enabling them to better cope with their health states in everyday life much more frequently used websites providing information from patients' viewpoints. These were predominantly sites from patient associations or individual patients, websites offering patient forums, sites dealing with nutritional and lifestyle issues, and industrial websites focusing on medical devices such as blood sugar measuring devices. Finally, users with a leaning towards alternative medicine also employed portals or sites offering information on naturopathy, homeopathy, medicinal plants, Bach flower remedies, and the like. But how did they actually navigate through and use these websites to find information meeting their needs?

### *Screening websites in a multi-directional way*

The film material makes it apparent that all users shared a basic method of using websites closely related to their search practices. Usually reaching a website via Google, they rarely entered through the homepage. Rather, they ended up on particular pages corresponding to their keywords. There, they started out by looking for the passages of text that included their keywords of interest. This practice of screening web information according to keywords, however, did not start on particular websites. Rather, it started with users' typing a keyword into the search engine and selecting websites by going back and forth to Google. This implies that websites were rarely used from the top down, but rather in a multi-directional way starting from whatever page users reached from the search engine:

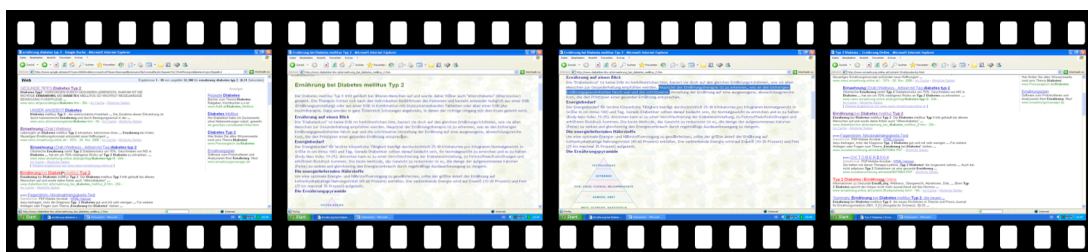


Figure 9: Illustration of a user's search showing that the user went from a Google result list to a page of a website, scrolled down a bit, and went back to Google to click on the next site, 2007.

If the website did not enable users to "quickly" find the information they wanted, they "immediately" left the site and went back to Google to try the next site, in the words of one participant. Asked how he employed medical websites in the search experiment, one user, for example, answered:

U9m: I guess the searchability is important first of all, right? Keywords, so, if you search and if you immediately find it – well, on this, for example, on the site XY, they deal with different diseases, and also symptoms and so on. (...), and you can really search well with keywords, you immediately find what you want. (Q81, 41-60, book seller)

Although asked about the use of medical websites, the participant starts by describing how he found the health portal XY with keywords, and only later explains that he also used keywords to navigate on the site to “immediately” reach the information he wanted.

The tight entanglement between searching for and searching within a website implies that the majority of the users perceived the structure of the information as a central feature of a website. They perceived a site as well-structured if it allowed them to promptly find the information corresponding to their keywords and needs. The middle-aged housewife, for example, described a good information architecture as follows:

U21f: Well, I say, if I immediately get where I want to be, yeah, well, that includes structure. Well, that the site is really well-thought-out and well-organized, yeah. (Q82, 41-60, homemaker)

Since they were constantly concerned with browsing and filtering information according to their needs, users appreciated an information structure facilitating this process. This particularly applied to users who were interested in specific issues, such as a particular medical device or Bach flower remedies. Further, users appreciated an information structure that enabled them not to get lost within the site, by providing a directory on each page, for example. A good information structure was thus expected to facilitate quickly sorting information according to users’ needs, and to provide orientation. This was central, as participants wanted to search for information in an efficient way without losing track or “wandering off” (Q83, U21f, 41-60, homemaker) in the web. Although this applied to web searches in general, it particularly applied to web searches on medical issues such as diabetes, since they were less enjoyable, one participant argued.

In striving for efficiency, people seldom read websites at length. Rather, at most they selected particular portions of text including their keywords and related information. One user, for example, described his reading practice as follows:

U40m: Keyword-oriented. Headlines, beginnings of sentences, looking whether it is an interesting paragraph and then going on to the next paragraph. I guess. I mean, one would have to confirm this with an eye scan (...) But I think that it’s like this. Because I definitely don’t read each word of the articles. Well, only if I zoom into an article, where I say, this is really interesting information now, then I read it word by word, no question. But in the course of screening, reading a longer article, only selectively for sure. (Q84, 21-40, engineer)

This illustrates that the information structure in terms of keywords and headlines was essential not only for browsing, but also for reading websites. Other participants similarly mentioned headlines and keywords as principal tools for screening medical information. They explained that texts should not be too long, and should be clearly divided into paragraphs with meaningful headlines. The overall structure of the site, as built into the technical infrastructure, turned out to be very important to users; since they generally entered a website not on the homepage, but on a particular sub-page, however, users appreciated if sites were readable in a multi-directional way:



Figure 10: The image above illustrates how users browsed through websites in a multi-directional way.

Hence, websites offering multiple menus, such as the one above, were appreciated very much. This site offered a classical menu, to be used from the top down, that appeared on each of the pages the users entered. Hence, each page could be used as a starting point to find more information (as the pages on the left side illustrate). Further, hyperlinks were embedded in the text, as may be seen on top, allowing users to construct their own information architectures. Users who enter the site on the homepage (large image), however, were presented with a plurality of possibilities for navigating the site including a search box enabling to browse the site along keywords. The flexibility of the site and the agency granted to users were praised by virtually all users. A number of users explicitly referred to hyperlinks as positive elements of websites. Wikipedia, in particular, was praised as offering a good hypertext structure. Some participants, however, mentioned drawbacks of hyperlinks embedded in the text. A young user, for example, said:

U29f: And that is why it was a little confusing to me, because there were too many different – well, in the text, if there was a word that was colorfully underlined, because you could actually click on it. It was foot, for example, and then you reached information about feet, but not related to diabetes. That is interlinked. (Q85, <18, schoolgirl)

This user describes her difficulties with hypertext by saying that she was reading a text on diabetes and then clicked on the hyperlinked word “foot” to reach further information, but that the information did not concern diabetes anymore. She was clearly irritated by the fact that the thematic context got lost when she followed the hypertext. This suggests that hypertext provides not only the opportunity, but also the duty, to construct one’s own path. It requires the user to integrate decontextualized information by recontextualizing it according to his or her own interests and body of knowledge. This underlines that searching for health information involves not only technical skills, but also cognitive abilities to recontextualize decontextualized pieces of information to create a coherent narrative. It demands not only internet skills, but also more profound knowledge, as I later discuss in detail (Chapter 10).

### *Appreciating comprehensible information*

In addition to information architecture, language was of crucial importance to users as well. The structure of the text and the language, however, turned out to be tightly interwoven in the process of examining a website. Referring to a particular website, a middle-aged user, for example, put it like this:

U21f: That was the last site I just explained. In fact, it was really well-structured and had all the information on one site, yeah. Well, including information like what it (diabetes, AM) actually is in a very detailed way, also for laypeople. Well, it was not medical jargon and so on, but really good for laypeople. And including treatment, arising problems, including nutrition, all of it. (Q86, 41-60, homemaker)

She appreciated this particular website because it was clearly arranged, because of its detailed information, and because of its comprehensible language. This indicates that evaluating a website is based on multiple criteria that intermingle in this process. When explicitly talking about language, all participants agreed that web information should be written in a language understandable for laypeople – “for people without medical training” (Q87, U13f, 26-40, university staff), as one participant put it. The participants perceived the language as particularly important in the medical context because they, like the website providers, generally saw medical knowledge as potentially incomprehensible. Some participants described a doctor using incomprehensible foreign words to underpin an argument. Foreign words turned out to play a particular role in this context. A number of users argued that medical websites should not be peppered with foreign words or written in medical jargon, because they were supposed to be an alternative to classical

information sources such as the doctor or a medical encyclopedia, as discussed earlier. Users particularly interested in orthodox medical knowledge, however, mentioned that medical terminology evoked professionalism, while colloquial language evoked non-professionalism, as one participant put it:

U40m: I would overlook an article much easier that looked as if someone were just chatting. Well, I would click it away faster or would not look at it at all, compared to one that evokes the feeling that someone has thought about it, based on the word order, the way it is presented. (Q88, 26-40, engineer)

This shows that the implicit model of medicine that users carried with them through the web crucially shaped how they interpreted diabetes websites. People with a leaning towards orthodox medical information tended to use more professional websites than people interested in experiential or alternative medical expertise, as argued earlier. Language in particular was seen as a relevant indicator in this respect. The quotation further illustrates that users did not use just one site, but rather multiple sites in parallel. The idea of quitting a site by “clicking it away” and jumping to the next one, usually the next one Google proposed, was a recurring pattern in the user interviews. This had a crucial impact on the way users evaluated medical web information, as I discuss in detail in the next chapter.

### *Reading websites visually*

In addition to language, the overall appearance of a website was seen as revealing information about the quality of the medical information it offered. Colors and background especially caught the users’ eyes immediately. All the users generally perceived medical websites as fairly similar. The sites visited were described as having white or clear colors, a discreet appearance, and a concentration of textual elements instead of pictures or sounds. To illustrate their thoughts, some participants compared these sites with websites from other areas. Against the background of other sites, such as newspapers, which were regularly mentioned, the users generally described health-related sites as cool and sterile. Except for one participant, who described this discreet type of design as boring, all participants agreed that it underlined the seriousness of the topic. Further, it evoked the professionalism important in the medical context. Some users further added that images, or rather the lack of images, were also seen as underlining the “objectivity” of a site. They described pictures of pathologies as evoking negative emotions and anxiety, and thus hardly helpful in this context. One participant referred to a picture of an abnormal foot of a diabetic to illustrate how pictures left her feeling disgusted. Other participants, however, said that images might be helpful in certain contexts. One user, who stumbled across the possibility of stomach downsizing to eat less, for example, said:

U36f: "(...) I reached something about stomach downsizing and there was a picture. That's something I find interesting, to imagine it. Clearly, who can imagine that, how to downsize a stomach, what does that actually look like?" (Q89, 41-60, homemaker).

Another participant similarly said that only a picture enabled him to understand how blood sugar measuring devices actually look and work.

Besides, the amount of advertising present on a site was regularly mentioned when people talked about the visual appearance of websites. In particular, websites that were overloaded with advertising were remembered negatively, as one participant argued, for example:

U40m: I also do not go into a store where you can only, I don't know, where you cannot see the door because it's covered with advertising all over, right? I cannot even enter it, right? (Q90, 26-40, engineer)

This participant perceived advertising as negative because it distracted him from the information he was actually looking for. The majority of the participants, however, said that they regarded websites containing numerous ads with skepticism because they had the impression that these sites had the primary goal of selling something, which negatively influenced their credibility, as I discuss in the next chapter. Some participants, however, accepted advertising in moderation, arguing that website providers had to maintain their sites through sponsorships to be able to offer medical information for free and this hinting at the economic dimension of this medical marketplace.

### *Losing sight of website providers*

The identity of website providers only played a subordinate role in users' practices of reading through and evaluating websites. The analysis of the film material made it apparent that the majority of the users rarely looked at a site's homepage or copyright section to figure out who the actual provider of the website was. Consequently, in the interviews the users only selectively remembered websites they had employed during their searches. The websites they remembered were predominantly those that had managed to become omnipresent in search engine results and thus market leaders, such as certain health portals. Further, websites from institutions people already knew from offline contexts, such as websites of hospitals and other popular medical institutions, were more easily remembered, particularly by participants who searched for orthodox medical information. Both their increased interest in the address of the websites when making a selection in Google results and their increased interest in website providers when surfing a website suggest that participants interested in becoming empowered in medical practices tended to pay more attention to the authority of the person or institution offering the information they used.

One reason why the actor providing the website only played a subordinate role in most of the users' practices was that the providers of websites often remained hidden to the users. Generally entering websites through the back door and landing on a sub-page proposed by Google, users regularly missed the entrance page presenting the provider of the site and her/ his institution. One user, for example, searched for sports related to diabetes. In addition to other search terms, she entered "diabetes" and "running" into the search engine. Among others, the search engine returned a website with the headline "we run away from diabetes" (second link on the illustration below). Since the site obviously met her interest, the user clicked on the link and arrived at the site of the diabetes association (discussed in the section on website providers' strategies). She browsed through the site by scrolling down and then went back to Google.

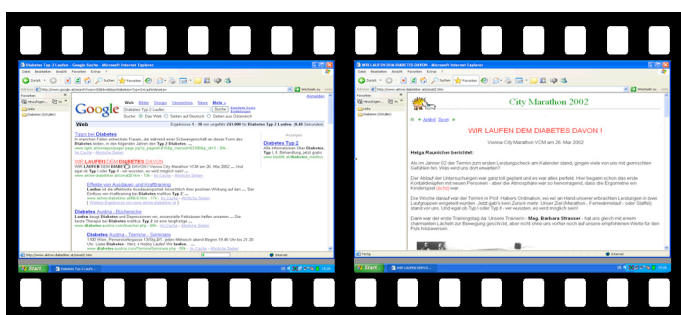


Figure 11: A user directed from Google to a page of the patient association that does not indicate who the provider of the site is, 2007.

This triggered the consequence that the user employed the websites without realizing who the provider of the information actually was. In the course of the interview she mentioned a number of websites to describe her search. She mentioned the look of the sites, and sometimes her perception of the type of website provider, in terms such as "some kind of self-help group", but did not name any of the sites. When asked if it was clear to her who the providers of these sites were, she answered:

U13f: No, not at all (...) I think, if you don't, if you don't know the address, well, the URL, then you don't know who it is.

*I: Do you have a look in the copyright section or, or do you leave the site, if you don't know who is running it, or do you use it nevertheless?*

U13f: Well, that does not really concern me. If it has the information I need, as I said, then it's all right. (Q91, 26-40, university staff)

The participant says that the providers of the websites were not visible to her. However, she further argues that this does not matter to her, as the relevance of the information is more important than knowing who the provider of a website is. She thus did not make the effort to figure out who the provider was by looking at the copyright section, for example. The new design of the website, however, would have clarified who the provider of the site was by providing the association's logo and information about the group in large letters



on each page. Whether the user would have appreciated the site with its new look more easily identifying its provider cannot be answered here.

Like this user, a number of other users straightforwardly said that it was not important to them to know who the providers of the sites they used actually were. Contrary to studies arguing that users employ “sub-optimal search techniques” because they do not check the sources of websites (Eysenbach and Köhler 2002), I rather suggest that users have developed alternative techniques of interpreting and evaluating a website on the basis of multiple criteria, including the relevance and architecture of the information and the site’s language and visual appearance, as well as by comparing it to other websites, as I discuss in the next chapter. Some of the participants, however, put their argument into perspective by saying that website providers were not important in this particular search, but would have been important in other contexts. People interested in becoming empowered in medical practices especially argued that they would be more likely to check the website provider if they were looking for a specific drug they “really” needed, or if they were taking the information to the doctor.

A couple of participants expressed strong ambivalence when talking about the importance of website providers in greater detail. Asked whether she remembered the source of the website she was talking about, one user who had searched for experiential medical information, for example, answered:

U9m: Well, there were other – the information about the disease, let’s say, was more important now than knowing where it comes from. But it would be, of course, it would also be important to check that, where it comes from. (Q92, 41-60, book seller)

Like the participant above, she first argues that the relevance of the information is more important to her than knowing who the provider is. In the second part of the quotation, however, she adds that it would “of course” be relevant to check the provider. This suggests that certain users felt a kind of obligation to check the source of a website, although it had no meaning to them in their actual practices. Talking about the importance of website providers, another participant revealed a similar discrepancy:

U21f: I did not look at that.

*I: You did not look at that at all.*

U21f: I did not look at that. That was not important for me.

*I: How do you think you gain confidence in a site, in its information?*

U21f: In the information? Well, that is a good question, yeah. How credible is it? How do I gain confidence? Yeah, it is also the name behind it. (Q93, 41-60, homemaker)

Although stating that the provider is not important to her, she clearly mentions the name behind the site as her first criterion when explicitly asked about trust in a website. This

confirms studies showing a certain discrepancy between users' narratives and their actual practices (Nettleton et al. 2005). It may, however, also be seen as reflecting the idea that the quality of online health information is bound to its provider, which is strongly pushed in medical practices and policy debates. When explicitly talking about trust, even users who neither looked for website providers when surfing a site nor perceived website providers as relevant criteria bought into the idea of quality as linked to providers of websites. The crucial question that arises, however, is not what strategies users did not employ to evaluate the credibility of health-related websites, but rather which strategies they actually employed, and why? This, however, goes beyond individual websites, as I discuss in the next chapter.

The above analysis shows that users shared a basic set of sociotechnical practices when navigating and reading health-related websites. They went through the sites in a multi-directional way, and appreciated comprehensible language and a simple web design. Differences may be identified according to the users' topical preferences and models of medicine. People predominantly interested in orthodox medical knowledge tended to prefer websites written in professional language and with a reduced web design, evoking accuracy. Further, they acknowledged providers of the websites more often than did the rest of the users, and better remembered the websites they visited. Users primarily interested in medical knowledge enabling them to act in everyday life situations tended to prefer non-professional websites written in colloquial language and with basic web designs, indicating that the information came from patients or patient organizations. They tended to ignore the providers of websites, having developed their own criteria of evaluation, including an information architecture that allowed them to easily find the information they wanted, and a rough categorization of information according to basic actor groups. The more specific their interests, the more specific the information they used, which may best be seen with people who searched for alternative medicine. Another reason that users partly lost sight of website providers was their overall search process. Website providers generally remained hidden to users because the users rarely entered websites through the front door, but more often through a back door, landing on a page that did not necessarily explain who the provider of the information was. This suggests a tension between website providers' and users' actions and narratives, which may partly be seen as triggered by the technology mediating between the two actor groups, as I discuss below.

### **9.3 Conclusion: Technology facilitating the tying and untying of coherent packages of information**

The above analysis shows that the ways the website providers and the users in the study interacted with the web – providers creating websites and users employing them – may be seen as reciprocal information practices. Website providers tried to appeal users with their medical information, and users tried to find information meeting their individual needs. According to their medical backgrounds, website providers presented their information and tried to make it easy to navigate with a clear, top-down information structure, more or less complex according to their budgets. Providers from the medical establishment in particular employed a range of strategies to present their information in language comprehensible for laypeople, not least by having them checked by laypeople. Further, website providers, most particularly of for-profit websites, tried to appeal to users with attractive web design and images enticing to particular target groups. Users, on the other hand, tried to find appealing medical information meeting their preferences. They navigated and screened websites according to keywords in a multi-directional way. Particularly users interested in finding medical and health-related knowledge to better cope with diabetes in everyday life situations appreciated simple language clearly directed towards laypeople, as well as a simple appearance and reduced advertising.

On a general level, website providers and users thus seem to have agreed on what constituted a good medical website. They agreed that, in addition to content, the structure, format, and design of a website were of crucial importance. Not only what was said, but also the way the information was organized and presented turned out to be relevant when producing and using a website. This corresponds well to Wynne's argument that, in addition to actual knowledge, the "social body language" (Wynne 1992) of the speaker is important in the acquisition of knowledge. In the digital age, however, new aspects are gaining importance in the trading of knowledge. Aspects such as the institutional affiliation of the actors, their actual behavior, and the way they organize their knowledge, Wynne (1992) subsumed under the term "social body language" are becoming increasingly mediated. The "social body language" of websites also includes elements such as the architecture, the design, and the format of the information, particularly in users' perceptions. Hence, the mediation of communication practices may be seen as implying a mediation and transformation of the "social body", as certain aspects, such as the affiliation of the speaker, lose importance, while others, such as the information architecture of a site, gain importance. And this mediation triggers crucial consequences in terms of the way information is evaluated by users, as I argue in the next chapter. This answers Michael's (2002) request that "complex media" should be taken into consideration when trying to understand how knowledge is communicated in the media-laden environments of present-day information societies. Considering complex media is particularly important when trying to understand epistemic consequences

involved in these communication practices, as will be seen.

Although the website providers and users in the study basically agreed that structure, language, and “social body language” (Wynne 1992) played a central role in communicating medical information online, crucial differences arose in the way these features were actually practiced by website providers and users, and in how the technology intervened. Website providers programmed their sites as coherent packages of information with the help of web designers. Technical features such as software packages, HTML code, metatext, and internal hyperlinks enabled them to build an information architecture easy to navigate from the top down. The logic built into this top-down information structure was that users would start from the entry page, where they would learn about the institution and medical information they were encountering. From there, users were supposed to delve into more and more detailed information by browsing the site from the top down. The information appeared to be provided in a tree-like structure, with a trunk and several issues branching off, corresponding to classical ways of providing knowledge I discussed earlier (Darwin 1859). In this view, each page was embedded in and shaped by the overall context. Further, the providers formatted and designed medical information according to their specific target groups with the help of technological components, and in some cases by observing user traffic. The technology may thus be seen as enabling them to offer their medical information in appealing packages, easy for interested users to absorb.

Users, in contrast, seldom recognized and remembered website providers or their institutional affiliations, instead generally losing sight of them. One reason is that the technology, and most particularly the search engine Google, which has become an “obligatory passage point” (Callon 1986), appeared to mediate between website providers and users. Users browsed the web according to keywords with the help of Google. Instead of entering a website via the entry page, as imagined by website providers, they usually entered through a back door, landing on a particular sub-page Google proposed. The search engine may thus be seen as taking pages out of their overall information packages. It may be interpreted as decontextualizing a particular piece of text from the context assembled by website providers. The search tool thus enabled users to unbundle coherent information packages that providers had tied and to take out pieces of information meeting their needs, while leaving the rest of the site untouched. This, however, implies that users did not follow the top-down information structures proposed by website providers, but rather tended to use websites in a multi-directional way. Whether a website was useful to them depended not only on the content provided, but much more importantly on whether it enabled them to “quickly” find the information they wanted at a particular point in time. It further implies that the participants sometimes used portions of text from websites without realizing who the providers actually were. They may be seen as picking messages out of the babble of voices without recognizing

the speakers. Having entered the sites through back doors, they often missed the entrance plate. However, this did not concern users much. On the contrary, the majority of users did not try to find out who the speakers of the messages were. The relevance of the information turned out to be much more important than who provided the information.

This analysis underlines that the technology, and most particularly search engines, may be seen as "acting" by mediating between website providers and users, while also transforming medical information on its way from website providers to users. The technology and the social practices surrounding it may be seen as "acting" in the sense of fragmenting information by taking websites out of their hyperlinked networks, and portions of content out of their overall websites. On their way from website providers to users, coherent information packages may be seen as getting untied, disconnected, and reassembled into lists of units of content corresponding to keywords, but not necessarily to each other. In this sense, the web may indeed be seen as a technology that contributes to processes of information fragmentation as envisioned by Lash, who describes "informationalized" societies as overwhelmed by "a mass of particulars without a universal" (Lash 2002: 144). Lash's argument serves to describe information transformations the web, and especially dominant actors such as search engines, trigger. By taking particular pages out of their contexts, search engines such as Google may be interpreted as transforming linear units of meaning into "abbreviated, non-linear units of information", as Lash (2002) puts it. Further, hypertext itself involves decontextualization, in that it passes on to the user the duty of integrating information from different contexts, as some users in the study said. In the medical context Nettleton and Burrows (2003) therefore speculate whether reflexive engagement with "informational knowledge" (Lash 2002) may be seen as more difficult than usually expected in accounts of late modernity, as I discussed in Chapter 2.

To empirically investigate this issue, I analyze how users interpret and translate the plethora of medical web information provided to them, somewhat fragmented and decontextualized, into coherent knowledge in the sense of a "capacity to act" (Stehr 2005), and how this relates to website providers' practices of making their respective medical websites credible and evoke trust on the user side. Further, I analyze the underlying epistemologies of website providers' and users' practices. This allows us to understand and discuss the practices and skills involved in communicating and obtaining medical knowledge via the web that may help to prevent present-day societies from turning into "disinformed information societies" overburdened with "out-of-control information", as Lash puts it in his rather dystopian vision.



## **10 Website providers' and users' epistemologies as embedded in their sociotechnical practices**

The central aim of this thesis is to gain insights into the way medical knowledge is communicated via the web and what epistemic consequences this triggers. So far, much has been said about online health information and the way it is provided, distributed, and used in sociotechnical practices. I have discussed how different types of website providers configure and position their medical websites to attract users, how different users browse through, filter, and select medical information out of the plethora offered to them, and how users employ websites in the context of their overall search practices. I have further shown that technology, and search engines in particular, may be seen as mediating between website providers' and users' practices, contributing to information hierarchies, market dynamics, and tendencies of information fragmentation.

The final question to be answered is what underlying epistemologies accompany website providers' and users' sociotechnical practices. How do website providers and users interpret and make sense of medical web information in the context of their reciprocal online practices? And how does the technology shape providers' practices of translating medical knowledge into web information and users' practices of translating medical web information into knowledge? To answer these questions, a concept of knowledge, or rather knowledge interpretation, is needed. Following Stehr (2005, 2003), I argued above that information requires interpretation to become knowledge. Contributions from critical PUS (Wynne 1992, Busby et al. 1997, Lambert and Rose 1996) show that laypeople interpret scientific, and most particularly medical, knowledge by embedding it in their own social contexts and bodies of knowledge. They develop comprehensive accounts of knowledge they perceive as relevant to their personal situations, and thus figure as epistemic actors in their own rights, as I argued.

Further, Wynne (1992) shows that not only knowledge itself, but also elements such as the institutional affiliation, the actual behavior, and the credibility of the speakers, or their "social body language", are relevant in face-to-face communications between scientists and the public. Hence, trust relations between the speakers and the recipients turn out to be central in these acts of communication. But how are trust and credibility negotiated in mediated acts of communication, where the "social body" of a speaker is mediated, as I showed in the previous chapter? How do website providers try to evoke trust on the user side, and how do users evaluate the credibility of medical web information? What role do the institutions and "social body language" of website providers play in these evaluations, and what other aspects turn out to be important? And how does technology contribute to website providers' and users' credibility strategies? Those are the questions to be answered first in this chapter. Secondly, I elaborate on what epistemologies are

embedded in website providers' and users' practices and narratives. How do website providers and users conceptualize online health information in the context of their reciprocal practices? Finally, I show that the technology and its dominant features not only shapes how medical web information is communicated between website providers and users, but also how web information is interpreted and conceived. This allows us to understand the abilities and skills required to communicate medical knowledge via the web.

Before presenting this final analysis, however, I make a short detour to consider Ludwik Fleck (1981 [1935]) and his concepts of "thought style" and "thought collective". Both website providers and users should not be seen as homogeneous actor groups, but rather as consisting of heterogeneous actors with different agendas and medical backgrounds. These differences crucially shape how they offer and acquire medical web information on and across websites. I thus suggest that they will have an even bigger influence on the ways providers try to make their websites credible and the ways users interpret and evaluate medical web information. Fleck's theoretical considerations help to understand these differences, as I discuss below.

### *Website providers' and users' practices as epistemic practices*

Epistemological questions centering on knowledge, truth, and belief go back to Greek philosophers such as Aristotle, Plato and Socrates. The idea that knowledge, and cognition more specifically, should be considered as a social practice, however, came later. Ludwik Fleck may be seen as one of the first philosophers of science to observe empirically how scientific facts are constructed. In the 1930s, long before Latour and his colleagues, Fleck argued that scientific knowledge, along with other types of knowledge, is shaped in social practices. Fleck, a natural scientist, discussed how scientific knowledge is configured in social groups that share a particular "thought style". In Fleck's terms, a thought style is "the readiness for directed perception, with corresponding mental and objective assimilation of what has been perceived so perceived" (Fleck 1981 [1935]: 159). In his view, the thought style present at a particular time and in a particular social group shapes how individuals interpret and make sense of the world. Their way of thinking shapes their cognition, to put it briefly. According to Fleck, these thought styles emerge in communities such as the scientific community, in specific disciplines such as biology, and also in non-scientific social groups such as political parties or religious groups. These social groups are considered "thought collectives" in Fleck's terminology: "What links the individuals of thought collectives together is the thought style they share" (Fleck 1981 [1935]: 159).

Drawing on Fleck, I argue that different types of website providers and users may be seen as belonging to different, sometimes multiple, thought collectives sharing different



medical thought styles. I previously discussed how different website providers and users in the study articulated different motivations for using the web for medical purposes. These different motivations may be seen as closely related to different medical thought styles. I roughly characterize them as a scientific thought style, a thought style of experiential medical knowledge, and a thought style of alternative medicine. All interview partners aligned with one or more of these thought styles in more or less explicit ways. Further, all interview partners talked about the economic dimension of the web as a health information source, a dimension closely related to their respective practices. This economic thought style may be seen as lying across the various medical thought styles, as I discuss below.

All the website providers in the study may be seen as belonging to different "thought collectives" related to their offline institutions and medical backgrounds. The doctor and the director of the health portal were trained as medical doctors, and may thus be seen as sharing a scientific, medical thought style. Further, the PR manager of the pharmaceutical company may be seen as sharing a scientific thought style because of her occupation: she represented a company doing scientific research on diabetes and developing insulin and other medical devices. Accordingly, these providers primarily offered professional medical knowledge, or "evidence-based medicine", as the director of the health portal put it, through their websites, and held rather skeptical attitudes towards alternative medicine, as previous discussions have shown.

In contrast, the chairman and the webmaster of the patient association, as well as the individual patient, may be seen as members of the patient community in more or less institutionalized ways. They provided medical knowledge from the perspective of a concerned person, such as knowledge that would help patients in day-to-day contexts and would enable them to act as "reflexive selves", in Giddens's (1991) terms. Because of their closeness to the medical establishment, however, the information provided on their sites generally stayed within the orthodox medical framework. This indicates that patients, both individual and organized, also shared a scientific medical thought style to a certain degree, although not formally part of the scientific thought collective. This applies even more to users who relied primarily on "medical facts", thus aligning with the scientific thought style, as I discuss below. The thought style of alternative medicine, however, appeared to be underrepresented on the provider side, as no proponent of alternative medicine was included in the study. Thus, only traces of alternative medical knowledge were found on the websites, such as short reviews of homeopathy in the context of diabetes, for example. This example shows that website providers should not be seen as always sharing only one medical thought style. Rather, it shows that traces of different thought styles may sometimes be found on their sites and in their narratives.

This applies to users to an even greater extent. Their search practices and narratives show traces of different thought styles. One reason is that the users included in the study were not formally part of any of the three thought collectives mentioned above. In comparison to website providers, who were more or less institutionalized members of medical thought collectives, users may be seen as merely aligning with these thought collectives. They may be seen as “exoteric members”, in Fleck’s (1981 [1935]) terms. According to Fleck, an exoteric member of a thought collective is someone who shares the thought style without actually being member of the thought collective. He gives the example of an individual who shares a particular religious dogma without being a member of the church. Similarly, users who primarily rely on “medical facts” or “alternative medicine” may be seen as aligning with different medical thought styles without being trained as doctors or homeopaths, for example. Even the patient status was somewhat hypothetical in the context of the search experiments carried out in the study, as the users were given a fictive scenario. That they searched for medical “definitions” of diabetes, for practical “tips”, or for “alternative treatments”, however, indicates that traces of the scientific, the experiential, and the alternative thought styles may be found in their practices and related conceptions. Many users displayed traces of multiple thought styles in searching for medical facts and definitions at first, and for experiential knowledge enabling them to take action later on. Similarly, alternative medicine was generally seen as complementing orthodox medicine rather than replacing it. Like website providers, users may thus be seen as sharing multiple thought styles, partly combining them, but also partly letting them remain side by side in their narratives.

In addition, an economic dimension may be identified in providers’ and users’ practices and narratives, running across the medical thought styles mentioned. Website providers with commercial agendas in particular may be seen as members not only of medical thought collectives, but also of the economic thought collective. While the PR manager of the pharmaceutical company and the director of the health portal may be seen as sharing the scientific and economic thought styles, the individual patient who provided a website may be seen as a hybrid between the experiential and commercial thought styles. But interview partners from non-commercial websites may also be seen as aligning with the market paradigm to a certain degree, in that they used the web to recruit patients or self-help group members. Users, for their part, also noticed and discussed the commercial content they were confronted with on their journeys through diabetes-related web information, mostly in the form of advertising. Contrary to providers’ highly differentiated views of the commercial dimension of medical web information, users articulated that they generally oppose paid content and advertising, both on websites and in search results. They may thus be seen as widely neglecting providers’ commercial thought styles, at least on a conscious level.

The central question for the purpose of this chapter is how providers' and users' different medical thought styles shape how they interpret medical web information and its credibility. How do different types of website providers try to evoke trust on the user side, and how do different users interpret and evaluate medical web information according to their thought styles? How does technology contribute to these practices? And what underlying epistemologies are embedded in providers' and users' practices and narratives? In the following, I describe website providers' and users' epistemic practices as shaped in a complex interplay of thought styles, skills, and technical entities. I start by discussing the credibility strategies and underlying epistemologies of website providers and users in turn. I conclude by juxtaposing providers' and users' epistemic practices and showing that the web may be seen as contributing to an epistemological shift from an actor-centred towards an issue-centred epistemology.

### **10.1 Website providers' credibility strategies**

All website providers shared a basic understanding that valuable medical web information is structured information with a coherent inner logic. When configuring their websites they translated their medical knowledge into coherent packages of information to appeal to users. Since their aim was to provide users with their respective medical knowledge, but also to promote their brands, institutions, services, and products in one way or another, the offline identities of website providers became central in their credibility strategies. In accordance with the goal of making their voices heard, website providers primarily let their identities and thought styles speak for the quality of the information provided. Website providers basically conceptualized their offline identities and consequent credibility as guaranteeing the credibility of the medical information they provided.

Depending on the thought styles of these institutions and persons, the narratives articulated in this context, however, strongly differed between different types of website providers. When asked how he tried to evoke trust on the user side, the individual patient offering the diabetes site answered:

W2m: And I also have an advantage, since everyone knows that I am a diabetic myself and therefore it is in my own best interest only to offer credible information, and also, obviously, not having disappointed anyone yet, my credibility is huge of course. Because they say: "Hey, he has it. He has to cope with it, he copes with it and thus won't tell us nonsense."  
(Q94, patient)

The diabetic clearly links the credibility of his web information to his personal affliction. He describes his patient status as making him an authentic and trustworthy person, one

who therefore offers credible information. He may be seen as conceptualizing himself as part of the patient community and thereby taking on the thought style of experiential knowledge. His extensive presentation of himself on his homepage, with stories and pictures, may therefore be seen as a credibility strategy. That he also used the website to earn money and make a living remained unmentioned when he talked about the credibility of his web information, an aspect I further discuss below. The strategy of emphasizing one's own identity to evoke credibility on the user side may be seen as particularly applying to website providers such as medical institutions and patient associations. This explains why both the doctor and the self-help group welcomed the user on their homepages and provided extensive information about their offline institutions. While patients and patient organizations may be seen as aligning with the thought style of experiential knowledge, the doctor gravitated more towards the scientific thought style. She offered information from the perspective of a medical professional and let the user know that very explicitly on her homepage. The medical information provided on her site may be clearly seen as scientific medical knowledge offered by a medical professional.

But it is not only non-profit websites that use their identity to evoke trust in the user. Similarly, the PR manager of the pharmaceutical company presented the company and its long history of "fighting diabetes" to make its medical devices and products credible. The fact that the company already had a long tradition of doing research and developing drugs was supposed to convince the user of its seriousness. Here, the seriousness of the company was intended to guarantee the information provided on the site, at least in regard to the pharmaceutical products. The provider aligned the company and its web information with a scientific thought style, which was further strengthened by the site's plain white design, often linked to science, as mentioned earlier. However, website providers from pharmaceutical companies seem to be well aware that the commercial impetus of their sites may also jeopardize the credibility status of the medical information they provide. Further, the advertising ban puts strong restrictions on them in terms of advertising drugs, as discussed earlier. That is why pharmaceutical companies occasionally run health portals in a largely anonymous way, appearing only as sponsor of the site, as the PR manager explained. This enables them to advertise their products between the lines without offending users with their commercial thought style. That this strategy indeed works will be further discussed when I present users' evaluation strategies. Instead of emphasizing their identities to users, the providers relegate that information to the copyright section, where users seldom go. The strategy of hiding the economic thought style in certain cases, however, also underlines that website providers strongly based their credibility strategies on the providers' offline institutions and companies and their credibility status.

In addition to website providers with strong pre-existing offline identities, however, there also exist websites that may be seen as having co-evolved with the technology, such as the general health portal. Lacking an identity that can be easily transferred to the web and used for credibility strategies, these sites have to create their identities and credibility status online. One central strategy that came to light in the study was to use the identities of the site's partners and the authors writing the content of the site to evoke trust. Talking about the credibility of medical web information, the director of the health portal said:

W3m: Well, in the end it is a matter of belief, well, I, I really think at the end of the day, what counts, maybe, is if there is a name and a face connected to it. (Q95, health portal)

By the "name" behind the website, however, he does not mean himself, although he ran the site as a company. Rather, he means the medical professionals who wrote detailed descriptions of the various diseases the site dealt with, or "fact sheets", as he called them, he explained a few sentences later:

W3m: Well, I think if there is an article and the professor XY is mentioned, then someone has been designated. Someone has been made responsible. (Q96, health portal)

In this quotation, the credibility of his website is linked to the authority of his writers. The website is seen as offering credible medical information because it has been assembled and formulated by medical professionals capable of taking responsibility for the correctness of the information because of their training as medical professionals and their adherence to the scientific thought style. Similarly, co-operation with partners from the medical establishment, such as the "Austrian Diabetes Association", whose logos and links were put on the website, was seen as a strategy that "additionally evokes trust of course" (Q97, W3m, health portal). The health portal's credibility strategy may thus be seen as based on the director's strong emphasis on "evidence-based medicine" throughout the interview, which reflected his scientific medical thought style.

But the offline identities and related thought styles of website providers were not only communicated through explicit presentation of the primary agenda, institution, or authors of the website; they were also inscribed in the look of the site, or its "social body language" (Wynne 1992), as discussed in the previous chapter. In particular, the director of the health portal, the diabetic, and the PR manger of the pharmaceutical company argued that a professional design would evoke seriousness. Providers of non-profit websites, however, suggested that overemphasizing the appearance of a website could signal that customers were to be enticed by any means, which they perceived as inappropriate, particularly in the medical realm. Talking about criteria of credibility, the doctor, for example, said:

W7f: In the medical context, first of all where the information comes from of course. Then simply the visual appearance, how loud it screams, how blatant it is, how much it cries, 'Buy me! Use me! Apply me!' (Q98, doctor)

In addition to the provider of the site, the doctor mentions the visual appearance of the site, indicating that she sees the practice of enticing users with design as harmful to her credibility. In accordance with her primary goal of communicating orthodox medical knowledge in an authentic way, she preferred an appealing but simple web design, she added. Further content-related links to appreciated diabetes websites were used to evoke trust on the user side, as argued earlier. This indicates that the market mechanisms of the web were also conceptualized according to the providers' different goals and thought styles. This was also important when talking about the advertising strategies providers used to increase their credibility.

### *A transparent "market model"*

According to their different identities, website providers perceived the relation between advertising and the credibility of their content differently. The doctor and the diabetes-association, in particular, clearly avoided sponsorship on a large scale, perceiving it as contradicting their primary agendas and related thought styles. The chairman of the diabetes association expressed it like this:

W1m: And, actually, I never want to be suspected of looking for sponsorship. I mean, there are plenty of companies inundating us: We should play this and that game and get sponsorship money. I don't want that. I don't want to say, "Please" and "Thank you" to anyone. I also do want to say: "This is bullshit, this drug, and the other one is better". That is something I cannot do if I take sponsorship money. (Q99, patient association)

This quotation illustrates that sponsorship was associated with losing independence. The chairman claims that he regularly turns down requests for sponsorship contracts in order to stay independent and able to freely express his opinion. Sponsorship relations on a large scale would put him under pressure to censor certain information on medical products made by companies financing the site. This would constrain his credibility in the long run, both online and offline, two tightly intertwined realms. The doctor similarly argued against advertising and sponsored links on her site, so as not to endanger her credibility both on- and offline. This shows that website providers from classical medical institutions related advertising and sponsorship to non-credibility and biased content, a perception widely shared by users, as I discuss.

Website providers offering medical information for financial purposes, however, expressed a slightly different opinion. Clearly speaking between the lines from a commercial thought style, the director of the general health portal agreed that advertising could evoke non-

credibility of content. Since he used advertising to keep the website and company financially successful, however, he further described a strategy of displaying advertising on the site while keeping its credibility intact. Talking about credibility, he said that it was central

W3m: (...) that you clearly distinguish advertising from editorial content. Actually, you'd think that this would be a matter of course, and that this would actually be in the media laws, but the practice always is, well, it was, for I would say 10 years there was a huge erosion in this area, a mixture of promotion and editorial content. (Q100, health portal)

He alludes to the market mechanisms involved in providing information on the web, but also acknowledges the importance of making a clear distinction between content and promotion to remain credible. Concerning his own site, he went on to emphasize strongly the necessity to sharply distinguish editorial content from paid content by visually setting advertising apart from the rest of the information. This policy was also made transparent on the side by a "code of conduct" he placed in the site's copyright section. This strategy may be seen as reflecting his primary aim of providing an informational product corresponding to his "evidence-based medicine" thought style. It illustrates that he shared both a scientific and a commercial thought style, which he had to co-ordinate using strategies such as this one.

Similarly, the diabetic trying to make money with his website had to find ways of co-ordinating his thought style of experiential knowledge and his commercial agenda. Compared to the health portal, however, his strategy was fundamentally different. Since he wrote stories about medical products he tested, for example, and linked to the companies developing the products, content and promotion appeared to strongly intermingle on his site. Instead of fearing a loss of credibility, however, the diabetic argued that this strategy fit his primary aim of providing information on medical products and drugs, because it provided essential information for patients who wanted to participate in health-care decisions, as discussed earlier. Accordingly, the promotion inherent in the information would not reduce the credibility of the content, which was primarily based on his patient status. This underlines how website providers' thought styles were inscribed in the look of their websites and introduced to users both explicitly and implicitly through their designs and advertising policies.

## **10.2 Website providers' actor-centred epistemology**

Despite their different thought styles, all website providers in the study shared an underlying epistemology closely related to their sociotechnical practices. All website providers translated their medical knowledge into coherent packages of information to appeal to users. They built a top-down information architecture into their sites, welcoming

the user on the homepage and usually introducing him or her to the provider. Technical components such as software packages, HTML text, meta tags, and hyperlinks may be seen as enabling website providers to translate their medical knowledge into packages of information on the online health information market. Accordingly, they conceptualized their websites as discrete entities, each with an inner logic and clear boundaries with other websites. Their identities and related thought styles were seen as guaranteeing the credibility of the information.

The centrality of their own identities in website providers' credibility strategies may be seen as embodying a particular epistemology I label *actor-centered epistemology*. The credibility of medical web information was seen as inextricably connected to and interwoven with the identity of the actor providing it. This explains the importance of the homepage, which often figured as a location of self-representation amongst the providers. Moreover, website providers evaluated other medical web information on the basis of the concepts behind their own sites. When asked how she generally perceived the quality of health information available on the web, the general practitioner answered:

W7f: Well, not so bad as is often said. I think it is fairly apparent how good the information is. Also, because of these standard websites that have been established, XY and YZ and these sites" (Q101, doctor).

Talking about the way she perceives the quality of medical web information as such, she immediately mentions websites by name. This indicates that she had a clear understanding of the other websites in the medical field, and particularly in the context of diabetes. Similarly, other website providers referred to particular websites when talking about online health information in general. They all articulated an awareness of specific websites in the field of diabetes, and had opinions of them. In particular, website providers from self-help groups, who were focused on supporting patients, knew all the other institutions and persons acting in the field of diabetes well. They sometimes worked together, and helped each other on various occasions when they shared an agenda. Consequently, the providers from self-help groups frequently mentioned other self-help groups, medical institutions, doctors, and other actors working in the field of diabetes throughout the interviews. The general practitioner similarly mentioned particular websites she appreciated and recommended to patients, both on- and offline. The self-help association and the general practitioner usually interlinked their sites with other sites they worked with, knew, and particularly appreciated, as discussed earlier. They mainly linked to the homepages of these sites, which welcomed the user and presented the identity of the website provider. This allowed them to interconnect web content, while keeping the boundaries between websites and between their identities visible and secure. It further indicates that website providers saw websites as enclosed entities interrelated with, but also having clear boundaries with, other websites. This illustrates the website



providers' actor-centered epistemology, which conceptualized online health information as an assemblage of information packages inextricably linked to the providers of the information and their identities.

Commercial website providers were also aware of websites operating in their own field. Instead of talking about institutions they appreciated or worked with, however, they rather pointed to websites they perceived as competitors. When asked about the quality of online health information, the director of such a site answered:

W2f: Well, for me there are hardly any relevant portals. If you ask me now I would say there is the VW portal, really okay; there is the WX portal, wellness-like, okay; (..) there is the XY portal, I can't say anything, seems to be all right, the medical content was not current; there is the YZ portal, they stole content from us from time to time, I say off the record, right? (Q102, doctor)

He clearly answers the question by naming one website after the other, and the quality he attaches to them, indicating that the intense competition on the online health information market requires him to observe competitors. The diabetic offering the commercial site said that he regularly checked other websites providing diabetes-related content to see "how you can sharpen up your own content a bit" (Q103, W2m, patient). Copying and pasting content from other websites into one's own website, as depicted by the director of the health portal, may happen easily in this context.

The actor-centred information epistemology was also reflected in the way providers talked about their own web searches for health and medical issues. Asked how she personally surfed the web when trying to find medical information, the PR manager of the pharmaceutical company answered:

W6f: Hm. How do I do that? Well, I start out by putting the disease in (into the search engine AM), and then, kind of funny, I always go to university sites. Well, for example, the University Clinic XY or something like that. They often have good sites, so I primarily go there. (...). Well, I think, okay, if the University Clinic XY, the senior physician or the professor, has published that, there I go. (Q104, pharmaceutical company)

Like users, she says that she usually starts out by putting the name of the disease into the search engine. Unlike users, however, she explicitly refers to a particular website from the University XY she trusts on the basis of the provider's identity and status. She perceives the website as credible because it is written by medical professionals, underlining her orthodox medical thought style once again. This indicates that website providers employed the credibility concept of their own sites to evaluate medical web information in general. According to their own awareness of relevant actors in the field and their own backgrounds, they employed epistemic practices favoring the identity of

the speaker. The director of the general health-portal described his epistemic practice as follows:

W3m: Well, I once looked into the issue of Alzheimer's Disease or something like that, I came across an American website and there I read: "Sponsored by XY" – and you had to look closely, and finally you found the copyright section and then you realized it actually was the website of XY. And this is a huge difference. Well, this is important to me if I want to check that. (Q105, health portal)

Again, the quality of the information is clearly linked to the provider of the website and his or her financing policy. Since his own site had a clear advertising policy, the director expected other medical websites to disclose their sponsorship guidelines. Referring to courses he had given for doctors on what to consider when employing the web to search for medical purposes, he said:

W3m: (...) and I always tell them at first: Have a look whether you can find who the provider actually is and whether he tells why he offers a site. What are his interests? What is his business model? Does he have advertising guidelines that say that he strictly distinguishes advertising from editorial content?" (Q106, health portal).

This quotation nicely sums up website providers' actor-centered epistemology, clearly putting the provider at the center when evaluating the credibility of online health information.

In this actor-centered logic, quality labels categorizing entire websites as credible or not make sense in principle. Consequently, some website providers argued in favor of standardized quality criteria such as HON. Particularly the director of the general health portal, who had acquired the HON label himself, described quality labels as a good way to increase the credibility of medical web information. Website providers representing offline identities were much less convinced of such labels, however. The general practitioner, for example, said:

W7f: I think the silly thing is that there is no, there is not one that is approved. Well, that would be a great thing to have something like that on the level of universities or something. (Q107, W7f, doctor)

She expresses skepticism towards quality labels by mentioning the multitude of such labels in existence. Instead of universities, the PR manager mentioned health political actors as adequate authorities to approve labels. This suggests that multiple authorities would come into consideration in such an undertaking. The providers of the self-help group further said that they perceived other criteria, most importantly the identity of website providers, as more important than a label put in the corner of a homepage. This indicates that providers of websites that had co-evolved with the web, such as general

health portals, particularly favored quality labels to assure the credibility of their information. In contrast to websites relying on their offline identities, these sites had no prior offline identity to guarantee the value of their information, and therefore needed a quality label to raise their credibility.

Analysis of website providers' credibility strategies has shown that website providers primarily rely on their offline institutions and authority to evoke credibility and trust in the user. This, however, strongly contradicts users' strategies of evaluating credibility, which are tightly intertwined with their interactions with the technology. Their practices may be seen as implying a very different epistemology, as I discuss in the following.

### **10.3 Users' credibility strategies**

Users' strategies of evaluating medical web information and its credibility may be seen as closely related to their sociotechnical practices. Users browse the web according to their respective interests and models of medicine. Instead of website providers and their institutional affiliations, users in the study kept their own preferences and related thought styles in tight focus when assembling and evaluating medical information. Hence, one strategy of evaluating medical web information that users described was to check whether the information they found met their respective interests and needs. One participant, for example, who had primarily searched for experiential knowledge enabling her to take action in day-to-day contexts, described the importance of her own interests when evaluating a medical website this way:

*I: How do you think you evaluate a website?*

U13f: Well, what should I say to that? (laughs) (.) In general, or a particular site?

*I: As you like. If you want to explain it with a particular one you could do that, or in general.*

U13f: Well, actually, if I find the information that I need there. If I find it there, then I read through it; if not, I close it again. (Q108, 26-40, University staff)

This quotation indicates that the fit of the information provided on a website to the user's interest at a particular point in time was her very first criterion when evaluating a medical website and its usefulness. Having put the keywords "diabetes" and "martial arts" into the search engine, she filtered and assembled the multiple types of medical information provided according to her specific interests. A young user similarly said that she continually clicked information away that did not meet her interests. Having found information about the way diabetes may affect little children, she said that she immediately dismissed it as not relating to her personal situation. Like users interested in experiential knowledge, users who searched for "medical facts" or "alternative

treatments" filtered, assembled, and evaluated multiple types of diabetes information according to their specific interests and thought styles. Talking about the way he evaluated different information found online, one participant with a scientific thought style said that he preferred "pure information meant for doctors" (Q109, U18m, 41-60, employee), instead of experiential knowledge he described as "general information" (Q110, U18m, 4160, employee). Accordingly, he selected information on medication and therapies, and clicked away practical tips on sports and nutrition. For their part, users with an alternative thought style selected and used information deriving from homeopathy or traditional Chinese medicine. But how did users decide whether a particular piece of information fit to their thought styles?

In the course of constantly filtering and evaluating medical information according to their interests and needs, users generally lost sight of the providers of the information and their institutional affiliations. This was further exaggerated by the fact that users went back and forth to Google and employed websites in ways embedded in their overall search practices, as discussed earlier. Further, users did not pay much attention to the actual providers of websites. Although medical institutions such as well-known hospitals were favored by users with a scientific thought style, and popular health portals had managed to become market leaders, the majority of website providers remained unrecognized by users.

Instead, users roughly categorized websites by different types of providers on the basis of the design of each website and the language it used – the mediated "social body", as I called it earlier. According to their respective thought styles, this "feeling" for a website, as users put it, helped to evaluate the information. One participant with a leaning towards a scientific thought style described it like this: "That was some self-help association. I mean, it should be right, but, well, it is not 100% sure that it is right, what is written there" (Q111, U18m, 41-60, employee). He roughly categorizes the site as "some self-help association" and evaluates the information as "not 100% right" according to his thought style. Primarily relying on "medical facts", he expresses skepticism towards experiential knowledge provided by patients, since it is not approved by medical authorities. Users primarily interested in practical tips, however, generally dismissed scientific medical information as not helping to cope better with diabetes in day-to-day contexts. In this context, users often mentioned that language or "medical jargon" helped them to identify whether the information they found met their respective thought styles or not. Similarly, users with a thought style of alternative medicine recognized information offered by an alternative provider on the basis of the language used, but also on the basis of design elements and the like.

This indicates that users interested in facts and definitions tended to be more interested in the actor providing the information – at least to the extent necessary for a rough

categorization – than users interested in experiential knowledge or alternative medicine, who relied on the mediated “social body” of websites much more. However, here it is important to note that certain users preferred scientific medical information at first, to question doctors, for example, and experiential or alternative knowledge at a later stage of their search, to potentially help them in day-to-day contexts. This indicates that tensions and even contradictions ran through users’ descriptions of their evaluation strategies. While certain users generally neglected to pay attention to website providers, they did mention the source of the information when explicitly asked about their strategies of evaluating a website, as discussed in the last chapter. This indicates that evaluation strategies may be seen as highly intuitive processes that are difficult to explicate. All together, these examples show that users evaluated medical web information on the basis of their own models of medicine. Like website providers, they interpreted medical information within the framework of their own thought styles, but not necessarily on the basis of website providers’ identities. But what alternative strategies did users employ to evaluate the credibility of medical web information?

In contrast to the providers’ epistemology, users employed a much more relational evaluation practice. They went back and forth to Google, assembling and evaluating medical web information according to their respective interests. In this process, they did not employ single websites, but rather multiple ones, either in parallel or quickly one after the other. Constantly switching between websites and pieces of information, all bound to the same keywords, allowed them to compare different information from multiple sources. Hence, users evaluated the credibility of a piece of information by comparing it to other information found on the web. Accordingly, the credibility of medical web information was not seen as bound to a particular website, but rather as something to be identified and developed in the course of the search process. One participant described her practice as follows:

U36f: If I only have one site, I might possibly know, okay that is right for me, but mostly I can, it is much easier if there are more sites.

*I: The information recurs when reading, I assume?*

U36f: Yeah, but that doesn’t matter, because then you understand it, right. And if you know, okay, the message is like this, then I know that it’s right. Then I can remain on the site that I accept according to my feeling. (Q112, 41-60, homemaker)

This quotation indicates that it was not the identity of the provider, but rather the fit of the information with other information found online, that was central. She evaluated the credibility of a particular piece of information by comparing it to other information. The credibility of information may thus be seen as crystallizing throughout the search process in the users’ practices. This user’s practice of evaluating medical web information turned out to be a highly intuitive process shaped by her thought style and her interaction with

the technology, that entailed the recurrence of certain information because she was using multiple websites in conjunction with each other. Asked about the quality of the information he found in his search, one participant similarly answered:

*I: Do you have the feeling that this was high-quality information?*

U25m: Right, yes.

*I: Why do you think that?*

U25m: Well, because of the consistency of different sources. A source of advice from Austria, a source of advice from Germany, research from America, and the information on sports and nutrition has to be right because it is written everywhere. (Q113, 41-60, IT consultant)

The participant says that he evaluates the credibility of information by comparing various sources of information with each other. Referring to the example of physical training and nutrition, he explains that he perceives this type of information as right because it is written "everywhere". During his search, the relation between diabetes, physical training, and nutrition crystallized as essential information because it recurred on various websites. Credibility was thus seen as emerging in the course of time through comparisons of different sources of information with each other. This practice may be seen as spilling over from offline contexts.

Particularly in the medical field, comparing information from different sources may be seen as a common evaluation routine. Information from a doctor may be compared with a second opinion from another doctor, and with information found in encyclopedias such as the *Pschyrembel* or in newspaper articles. The practice of comparing various sources of information with each other may thus be seen as transferred into online contexts. In contrast to offline practices, however, the practice of switching between sources online happens much more quickly, and partly unconsciously. Google offers access to a multitude of sources at once, usually through back doors. In their search practices, users thus lost track of the actual providers of information, sticking instead to the practice of comparison. This indicates that the offline practice was not only transferred to the web, but also transformed by becoming embedded in online practices. While users generally perceived recurring information as becoming more and more "right", the recurrence of information may also have derived from copying and pasting, and similar activities of website providers. The director of the general health portal explicitly described a particular website as having "stolen" content from his site, as mentioned earlier. This indicates that epistemic practices incorporated from offline contexts may help to evaluate the plethora of medical information available online, but also require scrutiny in light of the new mechanisms evolving in a technology such as the web.

Google may be seen as a kind of "group practice" enabling an easy comparison between different information sources. However, some participants perceived the "group practice" itself as the provider guaranteeing the credibility of the information by ranking "the best" websites on top. They trusted Google to link them to credible information, rather than website providers and their link lists. All these examples show that users developed their own strategies of evaluating credibility in the context of their search practices. However, they also show that a range of skills and knowledge about the technology is needed in these practices.

The comparison of pieces of web information with each other did not always lead to the "essence of information" (Q114, U9m, 41-60, book seller), as one participant put it, but sometimes to contradictions. One participant who searched for orthodox medicine, for example, said that he stumbled across contradictory information. When asked how he dealt with this information, he answered:

U40m: Well, well, I know that there will be inconsistency, right? Because everyone uploads his version somehow, and this, this is a signal to check it critically again. (Q115, 26-40, engineer)

Checking the information critically could mean different things to him, he further explained. It could mean checking the information by comparing it to other online sources, or it could mean checking the information against offline sources such as an encyclopedia or a doctor. In particular, users who tried to find information to challenge medical authorities mentioned that they would take the online information to the doctor to check its accuracy anyway. This underlines that the practice of using the web for medical purposes should not be seen as replacing traditional medical practices. Rather, users' online practices should be seen as embedded in and intertwined with a network of other information sources and the medical establishment. In cases where doctors refuse to discuss knowledge patients have gathered from various sources, and from the web in particular, patients may increasingly separate their information practices from the medical establishment, a possibility further discussed in the conclusion.

### *Neglecting the "market model"*

The "social body language" (Wynne 1992) of websites, and particularly the amount of advertising, was relevant when evaluating the credibility of information, in ways reflecting users' models of medicine and doctor-patient relations. While simple web design and clear colors were associated with professionalism, advertising was linked to biased information, particularly by users trying to find information outside the orthodox medical framework. A participant who searched for alternative medicine said:

U21f: If there is (.) lots of advertising next to the information, which seems not credible or reliable to me, and it goes through the whole site, then I leave the site. Then the underlying information is just, also just biased from my point of view. (Q116, 41-60, homemaker)

This quotation shows that users associated websites containing extensive advertising and sponsorships with non-credibility, in the sense of filtered or biased information. They expressed skepticism because they saw these sites as having the primary goal of selling something. This participant further added that her evaluation of a site's look and the amount of advertising on it was a rather intuitive process: "This is a matter of feeling also, if something is very striking and blatant and the like, then I'm skeptic, yeah" (Q117, U21f, 41-60, homemaker).

This shows that commercial websites, that tried to entice users with striking slogans, as well as "blatant" content and web design, were generally opposed by our interview partners because they evoked non-credibility in their perceptions. The video recordings of users' searches, however, show that many users nevertheless employed commercial portals financed by pharmaceutical companies. The reason for this was that users appreciated the "professional" web design and did not recognize what companies provided these sites. Strategies of enticing users with expensive web design while advertising medical products and drugs between the lines may thus be seen as indeed working on many users. This became particularly clear when we watched the videos of the search experiments with the users themselves after their searches. In this situation, one user discovered a website's identity while watching her search and was strongly disappointed that she had been "trapped" by the pharmaceutical company, as she put it. This indicates a certain discrepancy between users' practices and their narratives, as observed in other studies (Nettleton et al. 2005). It further indicates, however, that a range of skills and knowledge about the sociotechnical dynamics behind this medical marketplace was needed to actually reach the information users wanted to find. Recognizing such dynamics may also mean accepting circumstances that other users strongly avoided. One participant, for example, mentioned that he accepted advertising in moderate doses. As an explanation, he said he appreciated that website providers had to maintain their sites through sponsorships to be able to offer cost-free health information, as argued earlier.

#### **10.4 Users' issue-centered epistemology**

Like website providers' credibility strategies, users' strategies may be seen as embodying a certain epistemology closely related to their practices. Unlike website providers, who conceptualized online health information as an assemblage of packaged information linked to its providers, users conceptualized medical web information primarily as a "flood of information" (Q118, U9m, 41-60, book seller), as a number of participants put it,



generally disconnected from its providers. The majority of the participants said that the web provided a plethora of information related to diabetes, in fact much more than they needed. One participant, for example, said that it would have been enough information if she had read a single website to its full extent. However, as she was provided with a multitude of web sources, she felt a kind of obligation to browse at least parts of other sites as well. While the majority appreciated the diversity and plurality of different types of information, some users felt overburdened by the mass of health information. Whether users appreciated the plethora of information or felt overburdened by it partly related to their skills of integrating and recontextualizing bits and pieces of fragmented information. In constantly browsing, filtering, and interpreting web information according to their interests and needs, users unpacked packaged information, decontextualized it, and then reassembled and recontextualized it with the help of search engines. But how did users actually recontextualize bits and pieces of medical web information and distill knowledge out of them?

Corresponding to the argument of Stehr and Grundmann (2005) that information always needs interpretation, users saw online health information as useless in its unprocessed state. One participant said that one had to “filter out the valuable information, let’s put it like that” (Q119, U9m, 41-60, book seller), so as not to get swamped by the information. Another participant phrased it like this: “Well, you have to search in a targeted way. Otherwise you’ll find everything, which means nothing” (Q120, U4m, 19-25, student). Both quotations show that the web was perceived as a pool of information requiring selection. In contrast to website providers, who saw online health information as a variety of coherent packages, users perceived the web as an assemblage of bits and pieces of information in need of structure and sense.

Provided with medical information deriving from different sources, and partly decontextualized and fragmented, users had to integrate and recontextualize this information according to their own bodies of knowledge and thought styles. A number of participants referred to the process of selecting and sense-making as a “puzzle”. One participant put it like this:

U9m: One has to, altogether, I think, one has to filter one’s information, one has to piece together the information valuable for oneself – what is relevant to me, what do I search now. (...) If you search for specific information on a particular issue, then you find several sites, and those are mostly overlapping, then you can filter out what you need. (Q121, U9m, 41-60, book seller)

This quotation shows that instead of following website providers’ information structures, users assembled and combined information from different websites, constructing their own narratives according to their personal interests and thought styles. Users saw themselves as having the authority to construct their own stories when browsing through

the flood of information. Hence, rather than website providers and their credibility status deriving from offline identities, users had their own interests and needs in tight focus. Knowledge was developed by interpreting and assembling medical information according to the users' specific interests and needs. In this context, the quality and validity of the information was primarily seen as emerging through repetition and non-contradiction in the process of assembling a coherent story. Thus, users' practices may be seen as embodying an *issue-centred information epistemology*.

The flexibility of the web in enabling users to construct their own stories may also be seen as reinforcing users' medical thought styles and worldviews. One participant put it like this: "This relates to discussions on modernity and post-modernity very well, that you construct your own world" (Q122, 19-25, U4m, student). Drawing on the notion of post-modernity, he indicates that, instead of the provider, the user should be seen as the one ordering and constructing the world of information today. Lyotard and Baudrillard – considered as post-modern thinkers – argue that "grand narratives" (Lyotard 1979) may increasingly be seen as replaced by "versions" of truth and reality, undermining modern confidence in (scientific) truth. They see ongoing trends towards information fragmentation neither as a source of disinformation, as Lash (2002) suggested, nor as demanding knowledge politics, as Stehr (2005) argued in the scientific context. On the contrary, these authors embrace information fragmentation, because it offers individuals the opportunity to construct their own realities or versions of truth. This recalls Weinberger's (2007) argument that control over information will increasingly pass from website providers to users in online environments. While Weinberger particularly focuses on Web 2.0 applications, the above user's narrative indicates that simply browsing the web according to one's own interests may be seen as an information practice putting the user at the centre. Instead of the provider, the user is increasingly in control of the information architecture of the web, constructing his or her own narrative and coherence. This implies that users in the study rarely took away coherent packages of information linked to a particular actor, but rather created their own stories and packages of information. In this practice, they develop new ways of sense-making, largely bypassing website providers and their identities, involving new skills and abilities. Users' practices in interpreting online health information and creating knowledge out of it may thus be seen as embodying a much more issue-centred epistemology.

While the majority of the users in the study assembled and constructed their own knowledge only mentally, some users also materially created their own "medical lexicon". One third of the participants created a Word file with diabetes information they wanted to keep. They did so by assembling, combining, and integrating information they appreciated, producing their own packages of information about diabetes. Participants who tried to find information enabling them to better cope with diabetes in everyday life in particular collected and preserved information by copying and pasting it into a text file.

One user interested in experiential knowledge (U21f, 41-60 homemaker), for example, picked out pieces of information from various websites, re-shuffled them, and created her own information package corresponding to her interests. Her package finally contained practical medical information about diabetes, a "10 point program" listing what to consider when suffering from diabetes, and a range of specific information such as recipes. While some participants put the address of the source website next to each piece of information they copied, most of the participants did not note their sources. In addition to Word files and printouts, some participants bookmarked various websites or pages they particularly appreciated. This practice may be seen as preserving the provider of the information, because it saves and categorizes information in a way inextricably linked to its providers (whether of interest to the users or not). Concrete packages of information users had gathered from the web would help them to better cope with their health condition if they "really" suffered from it, one participant argued. Some participants further added that they would take these packages of information to the doctor, either mentally or literally in form of printouts, once again underlining the tight entanglement of users' online activities and offline medical practices.

In the users' issue-centred epistemology, quality labels categorizing websites as discrete entities that are either credible or not does not make much sense. Consequently, no user mentioned standardized quality criteria as helpful in evaluating the credibility of medical web information. Since they usually entered websites through "back doors", the quality labels generally remained hidden to the users. The more crucial aspect, however, is that quality labels did not fit the users' epistemic practices. In the users' perception, credibility was not bound to particular websites and their providers, but rather crystallized throughout their search practices.

This indicates that attention needs to be shifted from top-down methods of governing online health information and "educating" users towards the abilities and skills required to obtain medical information from the web and distill knowledge out of it. Following literature from critical PUS, I have shown that users interpret medical web information by embedding it in their own bodies of knowledge and thought styles. In these practices, trust and credibility are newly negotiated, not least because the "social body language" (Wynne 1992) of the speakers gets mediated in online contexts. While institutional affiliation and actual behaviour were central in face-to-face interactions, design elements, language, and the architecture of information turned out often to be more relevant online than the actual providers of the information and their (offline) identities. Users in the study developed new strategies for deciding whether information met their interests and thought styles and evaluating its credibility. Routinized strategies of comparing different pieces of information with each other to identify which are credible may be helpful evaluation strategies. However, relying too heavily on practices of comparing information may also pose a risk of being misled by the copy-and-paste measures of website

providers. "One has to be aware, of course, of the fact that a lot is faked, copied, and made up on the internet" (Q123, U9m, 41-60, book seller), as one user put it. Finally, users had to develop the ability to re-integrate fragmented information and distill knowledge out of it. In this sense, the flexibility of web information and technical entities such as search engines and hypertext may be seen as providing users not only with the opportunity to assemble medical web information according to their interests and thought styles, but also with the duty to make sense out of it. Understanding the abilities and skills users require to obtain medical knowledge from the web, and how to convey those skills in online and offline contexts, thus seem to be central, as I further discuss in my conclusions.

To fully understand how users make sense of medical web information, however, one needs to understand not only social practices, but also the role technical entities play in those practices. *Search engines in particular should be seen not only as political actors* that trigger information hierarchies and market mechanisms, *but also as epistemic actors* crucially contributing to the shape medical web information takes and the wider consequences this may trigger, as I further discuss below. When asked whether he remembered what websites he had used in the search experiment, one participant, for example, answered: "Well, I would rather remember the search terms that brought me there" (Q124, U40m, 26-40, engineer). This underlines the central importance of search engines in users' epistemic practices. I thus finally discuss how technology may be seen as contributing to a shift from an actor-centred towards an issue-centred epistemology.

## **10.5 Conclusion: Technology's contribution to an epistemological shift**

In the previous sections, I have shown that website providers' and users' epistemic practices may be seen as shaped in a complex network of individual thought styles, abilities, and skills, as well as technical entities that also contribute to and shape underlying epistemologies. I argued that thought styles strongly shape how website providers try to evoke trust in the user, and how users interpret and evaluate medical web information and its credibility. Website providers' offline identities and related thought styles may be seen as being inscribed on their sites, primarily through their presentation of themselves on their homepages, but also through the vocabulary they use, as well as their design and advertising schemes. Practices of hiding commercial thought styles further underline the importance of identity in website providers' credibility strategies. Users' evaluation practices were also shaped by their respective thought styles. Users interpreted the information they come across in the context of their topical preferences and models of medicine, which carried traces of the scientific, the experiential, or the alternative medical thought style. While users interested in "medical facts" focused somewhat on the actual providers of information, the majority of users,

especially those interested in experiential and alternative medicine, focused much more on the issues discussed and the vocabulary used on the websites when deciding whether a piece of information fit their respective thought styles. The commercial thought style on the part of website providers was widely ignored by users.

Despite their different thought styles, all website providers and users in the study shared particular epistemologies closely related to their sociotechnical practices, as I further argued. But how did the technology shape these epistemologies? In the following, I examine website providers' and users' epistemic practices by focusing on the way the technology contributed to divergent epistemologies. I argue that the web and its specificities may be seen as triggering a shift from an actor-centred towards an issue-centred epistemology.

Website providers encoded their medical knowledge in coherent packages of information with the help of software packages and HTML code. They provided their institutions on homepages imagined to welcome the user. Accordingly, they saw the credibility of medical web information as inextricably linked to the providers of sites, and their offline identities as speaking for their information. On the basis of their own sociotechnical practices, website providers conceptualized online health information as assemblages of packaged information linked to its providers and their credibility status, I labeled actor-centred epistemology. This perception was further strengthened by the fact that providers knew other institutions in the field – either as collaborators or as competitors – and linked their sites to them partly on the basis of the providers and their credibility. Website providers' interactions with the technology may thus be seen as partly shaping their rather traditional concept of credibility or "source positivism" (Haider and Sundin 2010).

Users, in contrast, employed a very different epistemology, which recalled discussions of the diversification and fragmentation of knowledge characterizing late modernity (Lash 2002, Nettleton and Burrows 2003). Their strategies of sense-making were clearly linked to practices of assembling and integrating medical web information, partly fragmented and decontextualized, according to their own interests and thought styles. In users' practices and interpretations, a certain shift from an actor-centred towards an issue-centred epistemology may be observed. Instead of the actor, users' interests and issues were at the centre of attention, since users perceived online health information as a "flood of information" partly disconnected from its providers. In the course of constantly assembling and recontextualizing bits and pieces of information according to issues of interest, trust and credibility were newly negotiated in users' practices. Rather than the actors behind the information, the fit of the information to users' interests and to other pieces of information turned out to be important. In users' perceptions, credibility was not something a website had or did not, a "yes-or-no kind of attribute" as Adams et al. (2006) call it, but rather something crystallizing in the course of the search. This was

partly triggered by users' interactions with technology, search engines in particular. First, search engines enabled them to browse, select, and interpret medical web information according to issues rather than actors. Because of the way websites were displayed in search results, users tended to lose sight of website providers, because headlines and pieces of text including their keywords were more relevant to them. Further, providers often remained hidden to them, because they entered websites through a back door rather than the front door, as argued in the last chapter. Further, the search engine enabled a quick comparison between different pieces of information all dealing with the same keywords, as users constantly switched between websites all bound to the keyword, but not necessarily, in users' perceptions, to the provider. Finally, the "social body" of website providers may be seen as mediated, enabling users to evaluate the design elements and language of websites, rather than their sources as imagined by providers.

*The web may thus be seen as contributing to the shift from an actor-centred towards an issue-centred epistemology on the user side, a shift linked to tendencies of information fragmentation (Lash 2002). And this concerns not only users, but also providers of websites. While the website providers included in this study turned out to be "experts" in the sense of knowing institutions and actors in the field of diabetes (facilitating their actor-centred epistemology), they may be seen as regular users in issue areas other than diabetes. Consequently, website providers are likely to display a more issue-oriented epistemology when acting as users searching for topics new and unfamiliar to them. Practices of not checking website providers and their credibility status should thus not be seen as "sub-optimal", as they sometimes are in academic and public discourses (Eysenbach and Köhler 2002, European Commission 2002). Rather, these practices show that the whole concept of trust in and credibility of medical information may be seen as changing through the technical mediation of medical knowledge. Contrary to Lash, who posits that our society may turn into a "disinformed information society", the analysis of users' epistemic practices shows that users developed a range of strategies of re-assembling and recontextualizing information. Using their own bodies of knowledge and thought styles, they assemble and translate fragmented information into coherent narratives again. Drawing on experiences from offline contexts and experimenting with the technology, they develop practices of sense-making corresponding to the technology's way of functioning.*

Weinberger's (2007) argument that control over web information is increasingly passing from the provider of the information to the user may thus be seen as applying not only to Web 2.0 applications, but also to classical web searching practices – at least to a certain extent, as technical entities such as search engines may also be seen as shaping users' online behavior, as I showed. With the passing of at least some control over web information to the user, however, users are not only provided with the opportunity to assemble information according to their needs, but also given the duty to make sense of

largely fragmented and decontextualized web information. New developments such as the semantic web, which is supposed to facilitate searching the web according to ones' own issues and interests, may be seen as further strengthening these tendencies. It is thus high time for website providers to start thinking about what consequences users' epistemic practices trigger and adapting their sites accordingly. Techniques such as catering to search engines in order to be found by users will not suffice. Rather, a more profound understanding of users' knowledge practices and how technology contributes to them is needed, as I discuss in the conclusion.

But did control over knowledge ever lie in the hands of writers or providers of information? What about acts of contextualizing and recontextualizing knowledge in the course of citation practices? Taking a particular quotation out of its context and re-assembling it as part of one's own body of knowledge may be seen at the core of scientific knowledge practices, as Latour (1987) argues. Discussing the writer's control over the scientific text, Latour says: "Although Schally is able to control most of what he writes in his papers, he has only weak control over what others do" (Latour 1987: 39). In this quotation, Latour refers to the transformations scientific knowledge undergoes when it is adopted and cited by other authors. The original argument may be strengthened, weakened, or otherwise transformed when reintegrated in a new article: "(...) the fate of what we say and make is in later users' hands", Latour (1987: 29) thus concludes. The example of citations in academic work suggests that control over the text never lay exclusively in the writer's hands. Rather, readers have always been part of the construction of knowledge by taking up particular parts of an overall argument and recombining them with other work to develop and strengthen their own arguments.

The example of citations underlines that epistemic practices observed in online contexts should not be seen as entirely new, but rather as partly deriving from classical knowledge practices. These practices may, however, be seen as transforming online. Practices of comparing knowledge from different sources, for example, may be seen as a classical practice of evaluating medical knowledge. The fact that the source of the information is increasingly lost from sight, however, may be seen as partly triggered by the technology, as I argued. Similarly, practices of decontextualizing and recontextualizing knowledge transform in online contexts. While citing practices may be seen as highly conscious acts, not least because of regulations specifying that the author of the cited text should be mentioned by name, online practices usually happen much more intuitively, in everyday contexts without regulation or governance. Further, technology, and particularly entities such as search engines, may be seen as inviting users to switch quickly between different types of medical information almost unconsciously. Finally, the technology enables users to assemble their own worlds of information, and allows them to create their own "versions" of reality by facilitating a flexible handling of information.

The shift from an actor- to an issue-centred epistemology may thus be seen as triggered by the distance the technology creates between website providers and users. The highly technically mediated act of communication involves a range of technical actors and sociotechnical dynamics that neither website providers nor users can fully control. On the contrary, technical entities, and most particularly search engines, may be seen as full-blown actors shaping not only how medical knowledge is traded via the web, but also how it is evaluated and conceived in online contexts. New technologies such as the web may thus be seen as transforming knowledge practices, and this should be considered when speculating about the empowering potential of the web in all its different facets. Whether they want to become empowered with respect to medical professionals by posing critical questions, and ideally become a collaborating partner with the doctor, or whether they want to act as self-responsible patients in everyday contexts according to the notion of a "reflexive self" (Giddens 1991), users have to obtain coherent medical knowledge rather than fragmented bits of information.

This indicates that the focus of attention needs to be shifted from standardized quality criteria based on "source positivism" (Haider and Sundin 2010) towards the knowledge practices emerging in user communities. Quality labels "approving" medical websites as credible or not will hardly help to assist users in obtaining medical web information, as imagined by policy makers. First of all, users rarely stumble across quality labels put somewhere in the corner of a homepage, because of their sociotechnical practices. Further, users do not seek medically "approved" information, but rather information corresponding to their respective thought styles, ranging from scientific, to experiential, to alternative medical knowledge. Finally, and most importantly, quality labels fundamentally contradict users' epistemic practices.

While quality labels would make sense in an actor-centred epistemology, where the identity of the speaker is central to credibility strategies, they appear to be rather ineffective in users' issue-centred epistemology, where website providers and their quality status are hardly worthy of attention. This suggests that efforts to govern online health information and educate users from the top down are unlikely to work. I argue that users' own evaluation practices and thought styles need to be put at the centre of attention. This allows us to discern knowledge work and skills involved in practices of using the web as a source of knowledge, in the sense of a "capacity to act" (Stehr 2005), rather than as a messy information source. Only when we have achieved a better understanding of the skills and knowledge work involved in practices of obtaining information from the web and translating it into valuable knowledge can we start thinking about strategies of assisting patients to acquire medical knowledge within their own epistemic frameworks. How these skills may be cultivated and strengthened within the medical field, and how this concerns the role of medical professionals who currently display a reluctant attitude towards "informed patients", will be further discussed in my conclusions.



## **11 Conclusions: From “educating” users towards engaging with “informed patients”**

In the previous chapters I explored practices of communicating medical knowledge via the web inspired by actor-network theory. In the first empirical chapter (Chapter 7), I showed that both website providers and users often draw on the rhetoric of patient empowerment – in all its different forms – when talking about motivations for using the web for medical purposes. After that, I analyzed how medical knowledge is communicated between website providers and users, and how technology and its features mediate between the two actor groups. First, I discussed how website providers and users find each other in the online medical marketplace, and concluded that Google offers an “obligatory passage point” (Callon 1986) where medical web information are primarily exchanged today (Chapter 8). Second, I showed how medical information is communicated via websites, and how technology contributes to practices of tying up coherent packages of information on the provider side and untying this packaged information on the user side (Chapter 9). Finally, I explored website providers’ and users’ credibility strategies, and suggested that the web may shape not only website providers’ and users’ practices, but also, to a certain degree, their epistemologies (Chapter 10).

This analysis revealed that technically mediated acts of communicating medical knowledge online may be seen as a multi-layered sociotechnical practices. Both the supply and acquisition of medical knowledge via the web are shaped in a *heterogeneous network of social actors*, each with different practices and medical “thought styles” (Fleck 1981 [1935]), *as well as technical entities*, most particularly search engines and the algorithms they employ. Different medical backgrounds and thought styles have a crucial impact on website providers’ and users’ information practices and their credibility strategies. This suggests that different conceptualizations of medicine, health, and the body, as well as conditions such as time, money, and internet skills, shape how website providers and users engage with the web. Practices of providing and acquiring medical knowledge online should thus be seen as *highly individual practices*. What counts as *valuable medical information* is unique to the individual and her or his experiences, body of knowledge, and technical skills.

Further, this analysis revealed that technology and its features crucially participate in and shape website providers’ and users’ practices, with epistemic implications. My thesis suggests that new technologies such as the web may indeed be seen as *contributing to tendencies of information fragmentation* and decontextualization as discussed in the literature (Lash 2002, Nettleton and Burrows 2003). However, the analysis further showed that new epistemic practices have co-evolved with the introduction of the web. In mediated acts of communication between website providers and users, *categories such as trust and credibility are newly negotiated*, and epistemic practices transformed, in ways

tightly intertwined with the technology and its features. Classical evaluation criteria such as the providers' affiliations and their "social body language" (Wynne 1992) are transformed in online practices. Moreover, *new strategies of sense-making* emerge on the user side because users' interactions with technology trigger a shift from an actor-centred towards an issue-centred epistemology. But what are implications of these results in the societal debates I brought up at the beginning of this thesis?

In this concluding chapter, I discuss consequences of my analysis, focusing on three aspects that need further reflection. First, I argue that complex sociotechnical practices and dominant actors stabilized in these practices – Google in particular – trigger "*information politics*", *hierarchies*, and *inequalities* challenging visions of the web as democratizing medical knowledge. Second, I subsume that emerging epistemic practices involve complex *knowledge work and a set of new skills*. Hence patients empower themselves with the help of technology rather than becoming empowered through technology. Third, I argue for moving beyond top-down regulations of online health information and ambitions of "educating" users from a superior position. I suggest instead conceptualizing users as epistemic actors in their own right, and *engaging with "informed patients"*, particularly on the part of medical professionals.

## **11.1 The emergence of “information politics” and inequalities**

*In the first conclusion, I argue that “information politics”, hierarchies, and inequalities emerge from sociotechnical practices and market dynamics on the web, challenging visions of the web as democratizing medical knowledge. The results of this thesis show that search engines and the social practices surrounding them trigger hierarchies between more and less visible medical information, partly overlapping traditional knowledge hierarchies. Rather than conceptualizing dominant actors such as Google as external factors threatening the democratic potential of the web, as is often done, I show that Google has become stabilized as an “obligatory passage point” in social practices by supplying wants. Consequently, I suggest opening up the black box of search engines, but also – and more importantly – scrutinizing routinized online practices and their consequences on both the provider and the user side.*

From its early days, the web and its network structure have been linked to democratic values such as broadening access to the production and use of knowledge and providing information in a decentralized way (Berners-Lee 2000, Kahn and Kellner 2004). In the medical context, the web has widely been embraced as giving voice to multiple types of actors, ranging from medical experts to non-experts, and providing different kinds of medical information side by side (Hardey 1999), as I discussed. The web has been euphorically envisioned as strengthening the democratic ideal by giving voice to previously marginalized actors, patients in particular (Anderson et al. 2003). Insights from this thesis challenge this euphoric viewpoint. My analysis shows that sociotechnical practices of communicating medical knowledge via the web trigger a range of information hierarchies and market dynamics that need further consideration, as I argue in this first conclusion.

In an environment where attention is a scarce commodity, not all types of websites and medical information have equal presence. While the web may indeed be seen as giving voice to all types of actors (with access to the internet and the required expertise), not all voices are heard equally. Rather, voices that adapt better to the technology and its current way of functioning are much more present and more easily accessible than voices simply trying to communicate their medical information with no technical boost. Adapting to the technology, however, requires technical expertise, financial resources, and a work force that, for the most part, only commercial actors such as big health portals can afford. Further, the web should not be seen as entirely removed from the offline environment. Rather, offline power relations may be translated into the online environment, strengthening popular medical institutions – and orthodox medicine in general – while silencing actors offering medical knowledge less accepted by the majority of the population, such as alternative medicine. The local medical context may thus be seen as shaping the online supply and consumption of medical information, confirming arguments

of “media convergence” that claim conventional institutions are foregrounded on the web (Seale 2005, Nettleton et al. 2005). Rather than a “bottom-up medium” (Anderson et al. 2003) that gives an equal voice to all types of medical actors and institutions, this thesis suggests conceptualizing the web and the social practices surrounding it as a medical marketplace shaped by information hierarchies and power relations between big, often commercial websites on one hand, and marginalized voices, including patient organizations and alternative medicine, on the other.

One central reason for this is that both website providers and users enact and stabilize the search engine Google as an “obligatory passage point” (Callon 1986) in their practices of providing and acquiring medical knowledge via the web, as I discussed elsewhere (Mager 2009). This thesis suggests that we should go beyond criticizing search engines as potentially malevolent “information gatekeepers” (Diaz 2008), threatening the democratic potential of the web as if they were external factors. Rather, it calls for the recognition that powerful actors and the information hierarchies they spawn are configured in social practices. Dominant actors such as Google may be seen as “network effects” (Law 1997) in ANT terminology. Website providers adapt their online practices to the search engine to communicate their medical knowledge and to be found by users. Users, in turn, employ the search engine because it enables them to browse, order, and assemble medical web information according to their highly individual interests and needs. *Both website providers and users may thus be seen as actively stabilizing Google as an “obligatory passage point”* because it supplies their wants. Drawbacks resulting from Google’s dominant position are often not recognized in these practices. These may be seen by looking more closely, however, as I did in this thesis.

Because Google is stabilized as a central location where medical information is traded today, hierarchies between more and less visible medical websites develop. The search engine may be seen as triggering “information politics” (Rogers 2004), such as strategic linking practices and search engine optimization measures on the provider side, particularly amongst website providers with a commercial agenda and in need of user traffic. Accordingly, large commercial sites such as general health portals are much more successful in gaining one of the “top ten seats” (Introna and Nissenbaum 2000) in search results, and become *market leaders*, as this study shows. Smaller, non-profit websites remain marginalized in comparison. Alternative medicine, widely perceived as “hidden” by users, serves as paradigmatic example of offline dynamics being reenacted in search engine results. What types of medical information are actually picked up from the medical marketplace, however, depends on the way users engage with the technology. The majority of users employ Google as neutral technical tool, or black box, following their information rankings in a generally unreflective way. Users, and particularly those employing unspecific search terms, thus often end up on sites that are market leaders, mostly provided by commercial actors. Users engaging and experimenting with the

technology by choosing and combining search terms more actively – mainly experienced internet users – reach comparatively more specific medical information better meeting their interests and thought styles. Inequalities thus arise through individuals' handling of technology, and search engines in particular. This indicates that ranking instruments – whether Google or other search tools that may gain importance in the future – need to be considered as central actors when trying to understand how medical knowledge is provided, distributed, and acquired online.

Just as using a medical encyclopedia involves a range of skills, engaging with the web as health information source involves certain experiences and implicit knowledge - not least about technical tools that have largely taken over the role of selecting and filtering medical information for the user. In comparison to the encyclopedia, however, the web is a much more complex source of medical information, supplied with content by different types of actors following different agendas and strategies of presenting and positioning their information on the web. Search tools such as Google embody complex algorithms widely remaining black boxed to the majority of the users. Further, corporations such as Google are discussed as following a "service-for-profile" business model (Elmer 2004, Rogers 2009), making user data a valuable product. What consequences this triggers for users in the long run cannot be answered in this thesis, but deserves further attention in future research. This indicates that the digital divide, at least in Western information societies, should not only be seen as an issue of having access to the technology or not. Rather, the issue increasingly is the ability to understand and engage with the technology and the "information politics" involved in the supply and distribution of medical web information. This applies to more and less experienced internet users, both of whom were included in this study, but especially to inexperienced users, such as elderly patients who only sporadically use the web to search for medical information.

Consequently, the focus of attention needs to be shifted from the web and its democratic potential towards the sociotechnical relations that trigger hierarchies, market dynamics, and inequalities. Rather than simply better adapting to the technology, I invite website providers and users to critically examine and question information practices and the consequences these trigger. Website providers need to understand that being hit by users via search engines does not necessarily mean that their institutions and offline services are recognized or remembered, a central motivation for website providers to build a medical website at all. Hence, a better understanding of users' complex information practices and needs is required on the provider side, to enable them to better adapt their information practices to users' practices rather than to search engines and their algorithms. Users, on the other hand, are advised to consider whether routinely going back and forth to Google and using the search engine as their home base is likely leading them to medical information meeting their highly specific needs. I invite them to develop a more critical stance towards search engines and take a look behind the strategic

practices of gaining visibility employed by websites that usually gain a “top ten seat” (Introna and Nissenbaum 2000) in search results. Further, users might consider how to access more specialized information by developing alternative search strategies and seeking out additional sources of medical information, such as patient community-based platforms specializing in particular diseases, that are often marginalized in search engine results.

I therefore ask that the black box of search engines may be opened, and its contents critically and publicly discussed. Awareness needs to be raised that the machines that have partly taken over duties of ordering and filtering information for us are not neutral tools, but trigger market dynamics and hierarchies. Furthermore – and even more importantly – I argue for reconsidering routinized information practices. I suggest a critical debate on the role highly commercial search engines play in contemporary knowledge practices and the way both website providers and users – that is, all of us – contribute to this circumstance by stabilizing them as “obligatory passage points” (Callon 1986), often unconsciously. The societal challenge of the future will lie not in providing more information, but rather in finding ways of organizing, distributing, and acquiring medical web information in a more decentralized and individualized way – particularly in a delicate issue area such as the medical one. A starting point may be to acknowledge the sociotechnical dynamics involved in practices of providing and acquiring medical knowledge online. Following Seale (2005) and Nettleton et al. (2005), I argue that more critical research is needed, both to investigate the strategies and “politics” different website providers employ to gain visibility on the online medical marketplace, and to make them an issue of public debate. On the user side, I suggest acknowledging that acquiring medical knowledge via the web is not a passive act of receiving information. Instead it may be seen as an act requiring a range of abilities, experiences, and implicit knowledge to engage with the technology and its sociotechnical dynamics to find information corresponding to highly individual needs. I therefore argue that these skills need further consideration in scientific research and public debates. That these skills go far beyond technical skills will be subsumed in the second conclusion.

## 11.2 Empowerment involves knowledge work

*In the second conclusion, I argue for abandoning the idea of the web as a "tool for patient empowerment", as discussed in academic and public discourses. Instead, I suggest focusing on the range of skills and abilities required to use the web for medical purposes. In addition to internet skills, a network of epistemic practices and profound knowledge work is involved in obtaining medical knowledge from the web. Technical entities such as search engines influence not only how medical web information is hierarchized, but also how it takes shape, triggering tendencies of information fragmentation and new practices of sense-making. I therefore conclude that, rather than becoming empowered through the web, users have to empower themselves with the web.*

In many academic and policy discussions, the web is euphorically described as turning patients into empowered or "informed patients", perceived as actively taking over responsibility for health issues and taking part in medical decision-making (Hardey 1999, Anderson et al. 2003, Broom 2005a, 2005b, European Commission 2002). The web is seen as a sort of empowering tool creating self-responsible patients, echoing Giddens's (1991) notion of the "reflexive self", as I discussed. The vision of "informed patients" has diffused into and gained ground in society. The majority of the interview partners in this study drew on the rhetoric of patient empowerment when talking about reasons why they turned to the web for medical purposes (which does not necessarily mean that they indeed act as empowered patients in doctor-patient relations and beyond, as this was not observed in this thesis). In these debates, the web is widely interpreted as a powerful source of knowledge, in Stehr's (2005) sense of a "capacity to act".

This thesis, however, shows that a range of skills and abilities are involved in individual practices of translating the plethora of medical web information into coherent knowledge that can indeed figure as a "capacity to act" (Stehr 2005) and thus strengthen patients in doctor-patient relations and everyday contexts. In addition to the handling of the technology, profound knowledge work is involved in practices of obtaining medical knowledge serving the individual's needs. The web and the social practices surrounding it may be seen as contributing to processes of "information fragmentation" (Lash 2002, Nettleton 2004), as I discussed. In this context, technical entities, and search engines in particular, may be seen not only as "political actors" (Introna and Nissenbaum 2000) triggering information hierarchies and inequalities, but also as *epistemic actors* influencing the shape medical web information takes. Website providers translate their medical knowledge into packages of information in attempts to serve users with coherent medical information. Search engine algorithms and users' practices of going back and forth to Google may be seen as taking websites out of their link networks and individual pages out of their overall contexts. Consequently, users are not provided with packaged information, as imagined by website providers, but rather with bits and pieces of medical

information deriving from different websites and medical contexts.

"Informational knowledge" (Lash 2002) and its acquisition via the web may thus indeed be seen as "making a reflexive engagement with information more difficult than is supposed in many accounts on reflexive modernization" as Nettleton and Burrows (2003) suggested. This thesis has shown that individuals have developed complex practices and strategies to interpret, evaluate, and make sense of medical web information corresponding to their individual backgrounds and thought styles. Drawing on contributions from the field of critical PUS (Wynne 1986, Michael 1992), I therefore conceptualize users as epistemic actors in their own right. These new strategies of evaluating and making sense of medical knowledge, however, evolve in mediated acts of communication rather than in face-to-face interactions. Consequently *categories such as trust and credibility are newly negotiated in mediated interactions* between website providers and users. Because of the mediation of the "social body" of website providers, elements such as the design, language, and architecture of medical web information may be seen as more important to users than the providers' affiliation and credibility status. This result may be seen as partly triggered in this study by the hypothetical character of the search experiments and the fact that users had to search for a medical condition they had no prior experience with. However, similar results are found in studies carrying out interviews with "real" patients (Henwood et al. 2003). Further, alternative strategies of sense-making emerge in the context of users' issue-centred epistemology. Users piece together bits and pieces of information from various sources and compare them with each other, rather than evaluating the provider's credibility, as my analysis, along with work from Adams et al. (2006) and Höcher (2008), shows. In these practices, credibility may be seen as a relational concept crystallizing through users' searches, rather than a "yes-or-no kind of attribute" (Adams et al. 2006), as I concluded.

Newly emerging evaluation strategies and knowledge work on the user side trigger a range of implications for both website providers and users. On the provider side, they indicate that a better understanding of users' knowledge practices and needs has to be developed. Website providers have to understand how users actually search for and evaluate medical web information and distill knowledge out of it. They need to acknowledge that users usually enter their websites via search engines and thus not on the homepage, imagined as the entry point by website providers, but rather on a different page corresponding to the users' search terms. Further, they have to understand that users untie their packaged information, re-combine parts of that information with information from other sites, and thus end up with their own packages of medical information not necessarily corresponding to website providers' expectations. Consequently, providers might start reconsidering their information practices and developing new ways of presenting and ordering their information to be used in a more flexible, multi-directional way. Rather than conceptualizing whole websites as packaged



information, for example, they might think of each page as a package of information in itself. This would facilitate users' practices of combining information from various pages dealing with the same issues but not necessarily in the same medical contexts. Further, alternative strategies of attracting users may be found, bypassing search engines and the epistemic implications they trigger, as argued earlier.

On the user side, this thesis suggests that new epistemic practices require new skills and abilities. Users have to recognize that features such as the information architecture, design, and language of medical web information – the mediated “social body” of website providers – may be signs of professionalism, but may equally be the results of budget and expertise. They have to realize that well-designed websites with a good look and feel may in fact be commercial sites sponsored by the pharmaceutical industry, while smaller sites with a less fancy design may be more authentic and credible in comparison. Further, evaluation practices such as identifying recurring medical information as “right” should be reconsidered in a medium where copying and pasting has become commonplace. Finally, cognitive abilities of interpreting and integrating fragmented information are needed to provide context where context lacks. Browsing the web not only requires mastering search engines and questioning the market dynamics they trigger, but also actively combining heterogeneous information to create a coherent narrative corresponding to the users' thought styles and needs. Information from different medical contexts needs to be harmonized, and contradictions dissolved. In this process, heterogeneous pieces of medical web information are integrated and provided with context by relating them with each other and with the users' own experiences and bodies of knowledge. In these highly intuitive practices, web information may be seen as being translated into coherent knowledge, as I discussed. More than any other medium, the web may be seen as requiring an active agent capable of interpreting information and distilling knowledge out of it, rather than a passive recipient. Given the complex network of technical skills, knowledge work, and cognitive abilities needed to obtain knowledge from the web, euphoric visions of the web as a tool for patient empowerment seem rather naïve. Instead, *“informed patients” need to empower themselves with the help of the technology, rather than being empowered by the technology.*

In a wider societal context, this means that access to medical knowledge is not enough to empower patients in any sense. Rather, internet skills and cognitive abilities that may support patients to obtain medical knowledge from the web need to be cultivated on a societal level, to prevent patients from ending up with messy information, fragmented and decontextualized. New skills are necessary to avoid present-day knowledge societies turn into “disinformed information societies”, as Lash (2002) postulates in his rather dystopian vision. Empirical results from this thesis may be taken as a starting point to develop a more fine-grained understanding of information practices and strategies website providers and users develop and which skills and abilities are needed in these

practices. Website providers' and users' information practices and related conceptions of each other reveal tensions and misunderstandings that might be dealt with productively in the future. Further, my analysis shows that the reasons for these misunderstandings are partly rooted in the way the web and its specificities mediates between and contributes to website providers' and users' practices. Hence, not only website providers and users, but also technical entities such as Google – or other actors that may be dominantly stabilized in the future – need to be taken into consideration when trying to understand and strengthen skills required in practices of providing and acquiring medical knowledge via the web.

### **11.3 Engaging with “informed patients”**

*In the third and final conclusion, I argue that the knowledge work and skills involved in acquiring medical knowledge from the web should be seen not as distinct from, but rather as tightly intertwined with, broader offline medical contexts. I call for a reconsideration of top-down regulations of online health information and desires of “educating” users from a superior position. Instead, I suggest engaging with “informed patients” and their medical web information. Particularly medical professionals are invited to accept patients as epistemic actors in their own right. They may use patients’ information practices as a window into patients’ own knowledge cultures and concerns helping to establish trust relations, rather than resisting web information for fear of losing their knowledge monopoly. I thus argue for engaging with informed patients, their problems, and their knowledge, and acting accordingly, instead of trying to educate and discipline them with quick, standardized solutions.*

Contrary to euphoric visions of the web as an empowerment tool for patients, members of the medical establishment display a rather reluctant attitude towards the web as a health information source, according to the majority of the interview partners in this study. This result confirms studies showing that the medical establishment widely adheres to a risk discourse in discussing the web, warning of misinformation and harm – not least because doctors are frightened of losing their own knowledge monopoly (Henwood et al. 2003, Broom 2005a, 2005b). Even doctors with a positive attitude towards online health information and “informed patients” interpret patient empowerment in a narrow sense, as this study shows, in agreement with Broom (2005a). One reason is their narrow concept of what constitutes valuable medical web information. On the basis of their scientific thought style, medical professionals favor medical web information deriving from medical “experts”. Consequently, medical professionals and policy makers argue for standardized quality criteria and labels for medical websites, in order to “educate” users and direct them to the “right” medical information as defined by experts (Eysenbach and Köhler 2002, European Commission 2002), as I discussed.

Governing online health information and its users from the top down, however, is likely to fail, as it neglects and even contradicts epistemic practices users perform. This thesis shows that users do not always look for standardized medical web information, but also for experiential knowledge and alternative medicine, according to their respective thought styles. Especially the web is often deliberately accessed to find alternatives to standardized medical knowledge. Hence, standardized quality criteria and labels supposed to direct users to the “right” medical web information as defined by “evidence-based medicine” may help users only to a very limited extent. Instead, we need to better understand users’ information practices, and ask why they often do not pay attention to website providers or their credibility status, let alone quality labels. I suggest

reconsidering the characterization of users' search techniques as "sub-optimal" (Eysenbach and Köhler 2002) if they do not correspond to experts' ideas, and instead paying more attention to the alternative evaluation strategies users do employ. Awareness needs to be raised of the complex network of thought styles, experiences, and skills involved in practices of obtaining medical knowledge from the web, and of how to assist users within their own knowledge cultures. Rather than educating users with quick, standardized solutions, I ask that we – and most particularly doctors – acknowledge users as epistemic actors in their own right, following arguments from the field of critical PUS. The whole idea of patient empowerment will remain futile if doctors refuse to accept "informed patients" as epistemic actors with their own knowledge acquired from multiple information sources, increasingly the web.

Users carry printouts, notes, and critical questions from the web into medical practices (sometimes in an effort to relieve doctors of their workloads), and expect to be helped with the multitude of information therein, partly fragmented and contradictory, as users' narratives indicate and patient accounts from the broader research project confirm<sup>19</sup>. Turning them down and rejecting their information will either mean that patients quit the doctor-patient relationship and look for more open doctors, or that patients perform their online activities secretly and do not share them with their doctors anymore. To prevent these rather problematic developments, the knowledge work patients perform online needs to be integrated into broader medical contexts, the doctor-patient relationship in particular. Practices of interpreting and integrating medical web information and distilling knowledge out of it should not be seen as finished when users turn off their computers. On the contrary, online knowledge practices are embedded in and tightly intertwined with offline contexts. Patients do not employ only the web to obtain medical knowledge. Rather, they employ multiple sources, such as print media, television, social networks – and, most particularly, they go to the doctor to obtain medical knowledge and advice. Indeed, a number of patients still prefer to rely on doctors and refuse to take on the active patient role, as studies indicate (Henwood et al. 2003). Becoming informed may thus be seen as a complex practice shaped in a network of different actors and information sources, both online and offline. The networked search for knowledge intensifies when patients suffer from a chronic disease, as interviews with diabetics have shown. "Informed patients" thus constantly have to balance information deriving from multiple sources, integrate it into their own bodies of knowledge, and co-ordinate it with advice they get from doctors.

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<sup>19</sup> In the project "Virtually Informed", 33 patients with chronic diseases, diabetes among them, were interviewed about their use of the Internet in regard to their health conditions, supplementing the findings of this thesis, as explained earlier.

Consequently, I argue for *engaging with informed patients rather than trying to discipline and educate them from a superior position* with quality criteria that do not necessarily help them or serve their highly specific needs. Ways of assisting patients within their own information practices and knowledge cultures have to be found. This, however, requires a fundamental reordering of medical practices and a rethinking of doctors' roles therein. In a market paradigm where patients are increasingly supposed to actively manage their health state, take preventive action, and make "informed choices" (Giddens 1991), the role of doctors also has to change. Demanding that patients participate in and take over partial control of medical decision requires doctors to let go some of their control over patients and start conceptualizing them as epistemic actors to be taken seriously. Medical professionals are invited to start taking users' own epistemic practices of assembling and balancing heterogeneous medical knowledge along their respective thought styles seriously. Patients' information practices may be seen as a rich resource where doctors can learn about patients' problems, perceptions, and concerns. Online printouts, assemblages of web information created by patients – such as those developed in the search experiments – and patients' experiences with online health information may be seen as windows into patients' own knowledge cultures. They can provide an opportunity to learn about patients' thought styles and better understand patients' own approaches to health, illness, and their bodies. A step towards patients and their knowledge derived from multiple sources, including the web, may help to prevent tensions between doctors and "informed patients" from growing and hopes for shared decision-making from becoming seriously endangered. Only a mutual learning process between doctors and patients has the potential to indeed challenge paternalistic medical care and take a step towards a partnership model of doctor-patient relations.

In present-day knowledge societies where patient empowerment is discussed virtually everywhere but negatively sanctioned in medical practices, "informed patients" will not simply stop going online to search for medical and health-related information. Rather, they are likely to proceed with their online activities, but to keep them secret or bring them into the medical encounter only implicitly, as indicated in this thesis. In such an environment, the web and the epistemic practices co-evolving with it may indeed become harmful as they turn into a parallel universe left to its own resources. I thus conclude that it is time for medical professionals to reconsider widespread fears of the web as a threat to medical autonomy, and start thinking about ways of using the web and patients' knowledge practices to regain patients' trust. Rather than opposing "informed patients", doctors should take patients and their knowledge practices seriously and start to engage with patients' own bodies of knowledge and perspectives in medical practices. Hence, knowledge work is required not only on the part of patients, but also on the part of medical professionals, who might reconsider their own knowledge cultures and underlying thought styles and develop a more open perspective. Medical professionals are invited to jump on the bandwagon, accept the web and knowledge practices surrounding it, and use

it to establish a true dialogue with their patients to prevent trust relations from crumbling further.

This, however, requires a health care system that gives medical professionals the freedom to engage with "informed patients". Critical research is needed investigating not only doctors' resistance to informed patients, but also how local health care systems and their way of functioning might contribute to their attitudes. Awareness needs to be raised that ICT, and the web in particular, may not serve a quick solution to the socio-political problems health care faces in local and European contexts – as sometimes imagined in public discourses (Felt et al. 2009b). Instead, they may be seen as posing new challenges for patients, doctors, and health care policy that, most likely, may only be met with long-term measures, rather than quick, standardized solutions.

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## 13 Annex

### 13.1 Original quotations

Q1:

W4m: Im Zeitalter von, wo man wirklich eigentlich sagen sollte, ein Patient sollte mündig sein, nur dann ist er ein guter Partner zum Arzt. Weil es ist nicht so: „Bitte Herr Doktor, heilen Sie mich.“ Das funktioniert eigentlich nicht richtig. Man muss selber was tun, und der Arzt ist der Manager und Berater. Ja? Aber ich muss mit dem diskutieren können und sagen: „Hören Sie, ich hab das auch gehört. Passt das für mich nicht auch? (patient association)

Q2:

U40m: Aber Tatsache ist, dass das nicht alles für voll zu nehmen ist, was die Ärzte erzählen. Also, macht's definitiv Sinn, da Vergleiche von, entweder eben aus der Literatur oder aus den Foren, da, wenn da einer sagt, ja, das ist was, das bringt überhaupt nichts, also, das hat ihm überhaupt nichts gebracht, und das kommt zwanzig Mal, dann ist das was, das man, wenn das als Vorschlag kommt, natürlich ganz genau hinterfragen muss. (...) Und dann kommt durchaus heraus, ob er (Anm: der Doktor) das argumentieren kann oder nicht. Oder der sagt von vornherein, ah, Sie wissen da, verstehen da eh nichts, dann geht man zu einem anderen. Also, da geht's durchaus um das Abklären der Kompetenz, wollen wir's einmal so nennen. (26-40, engineer)

Q3:

U21f: Ich hab mir einiges abgespeichert, und ich weiß, also, ich würd jetzt dann weiter vorgehen, dass ich mir das nehm, dass ich einmal ausprobieren würd. Also, ich würd mir einen Ernährungsplan zusammenstellen und fühl mich in manchen Sachen bestätigt, weil ich das sowieso schon mach, würd mehr Bewegung machen usw., also, würd mir einen Plan zusammenstellen und wüsste jederzeit, wenn Fragen aufkommen oder irgendwas, ich könnt jederzeit nachschauen und fragen. (41-60, homemaker)

Q4:

W3m: Jemand der keine Informationen hat, der traut sich meistens gar nicht fragen, sondern es braucht einen gewissen Grundstock an Informationen, um dann auch beim Arzt weiter vertieft zu fragen. Also das ist irgendwie so dieser Grundzugang und die Philosophie dahinter ist, dass man sagt: Sprache und Kommunikation ist einfach ein wesentlicher Teil dessen, was in der Medizin passiert. (health portal)

Q5:

W2m: Du musst was wissen über die Krankheit, sonst kannst damit nicht umgehen und wirst sehr schnell Schiffbruch erleiden. Meine persönliche Therapeutin, die Professor X vom AKH sagt immer, das ist so wie Autofahren. Wenn du Autofahren willst, musst du einen Führerschein machen. Wenn du keinen machst, wirst du über kurz oder lang in einem Baum landen (.) oder in einem anderen Fahrzeug, ja? Nun ist zwar Diabetes kein Auto das man gerne fahren will, man bekommt's sozusagen (.) umgeschnallt ohne, ohne dass man's will. Nichtsdestotrotz muss man, muss man damit fahren lernen. Und das war etwas, was ich durch die Schulung bei ihr (.) gelernt hab, und mir, und aus dem heraus hat sich dann auch logischerweise entwickelt das, na wenn's ich weiß und ich

kann damit umgehen, so möchte ich zwar nicht jetzt den Professor ersetzen und die Schulung, aber ich möchte meine (.) Kollegen und Kolleginnen sozusagen mit Wissen vollstopfen. Weil je mehr die wissen, umso besser sind sie drauf. (patient)

Q6:

W2m: dicke schmöker (patient)

Q7:

W4m: Da brauchen sie sich nicht bei uns irgendwie deklarieren: Ich bin Diabetiker. Manche fürchten sich ja davor, dass das bekannt wird. (patient association)

Q8:

U9m: Meine ersten Eindrücke sind eigentlich, (.) es gibt doch umfassende, also, doch eine ganze Reihe von Internetseiten, die sich damit beschäftigen, was mich sehr positiv überrascht hat. (41-60, book seller)

Q9:

U9m: (...) wie immer im internet. (41-60, book seller)

Q10:

W6f: Es gibt qualitative Medien oder qualitative Seiten, und es gibt Schrott. Und nachdem es ein freies Medium ist, ich seh's wirklich wie den Medienmarkt. Wird al-, es wird immer alles geben. Und jeder muss für sich entscheiden: investier ich meine Zeit, dass ich den Schrott lese oder investier ich meine Zeit, dass ich eine qualitative Seite lese? (pharmaceutical company)

Q11:

W2m: Weil wenn du so ein Medium baust, dann willst du kommunizieren. (patient)

Q12:

W6f: Also das Internet, da muss man bei der Wahrheit bleiben, das existiert, weil es Geld schafft. Da verdient Google, da verdienen alle die, die ihre Banners hineinstellen. Das würde alles nicht funktionieren, wenn da nicht extrem viel Geld fließt. (...) Also das ist schon auch die Realität. Ich kenne wenige, die aus reiner Nächstenliebe hier [beide lachen] informative Texte hineinstellen. Außer vielleicht die, die Kirche. Und selbst die wird ja wahrscheinlich da einen Spendenaufruf hineinstellen dazu. (Q11, pharmaceutical company)

Q13:

U9m: Was ich halt wichtig finde ist, man sollte halt auch (.) dem User immer vor Augen führen, dass – und das ist mir auch immer bewusst – dass ein Arztbesuch halt nicht unumgänglich ist, ja, durch das, also, dass man nicht durchs Internet eine Prognose, eine 100%ige bekommt und auch eine 100%ig Behandlung, ja. Das sollt immer ein Doktor durchführen. (41-60, book seller)

Q14:

W1m: Oder Sie kommen und sagen: „Ich hab Schwangerschaftsdiabetes. Was muss ich denn jetzt machen?“ Na da muss ich 2 Sachen sagen. Erstens, mit der Feuerwehr zu, es gibt drei Spezialisten die ich empfehl in Wien. Es gibt nicht mehr. Wo ich weiß, dass dann wirklich ein Erfolg



ist. Denn das Kind ist in Gefahr. Also musst du etwas machen. Und zweitens, dann vergiss es bitte nicht nach 5, 6 Jahren wirst du auch Diabetiker. Und diese 2 Meldungen, erstens „Feuerwehr - Kind ist in Gefahr“ und wohin, und zweitens, was mach ich in den nächsten 5, 6 Jahren, damit ich also eher frühzeitig - das ist eine lange Entwicklung, das Diabetes - also sehr frühzeitig in dieser Entwicklung gebremst wird oder sie weiter wegschiebt. Diese beiden Meldungen muss ich vermitteln. (patient association)

Q15:

W1m: Und wir wollen mindestens so viel von der Pharmaindustrie erzählt kriegen wie wir im Internet sowieso nachlesen. (patient association).

Q16:

W7f: (...) einen gewissen Informationslevel, wo man dann besser miteinander reden kann. (doctor)

Q17:

W7f: (...) wenn er dann trotzdem ganz dringend auf Alternativseiten ausweicht und (..) versucht mit irgendwelchen Heilkräutertees Diabetes zu heilen, ist es letztlich dann doch seine Sache, na?. (doctor)

Q18:

W4m: (...) einer der Leitsätze ist: „Wir wollen an dem Diabetes nichts verdienen. Also an unserer Krankheit nichts verdienen. (patient association)

Q19:

W6f: Der Konzern steht dazu, dass wir ein Forschungsunternehmen sind und den Patienten auch Zugang zu den Entwicklungen bieten möchten. Weil grad bei Diabetes oder bei Typ-1-Diabetes als Krankheit die man erwirbt und nicht, die man sich nicht aussuchen kann, ist halt eine un-, bis dato unheilbare Krankheit, und das große Ziel der Novo nordisk ist ja, den Diabetes irgendwann mal heilen zu können. Und natürlich wollen wir dem Patienten auch die Möglichkeit geben, ein bisschen auch recherchieren zu können, wie weit ist denn das Unternehmen mit seinem großen hehren Ziel für die Zukunft. (pharmaceutical company)

Q20:

W6f: Ja. Also es geht nicht, dass wir's nicht haben. Ich glaub das wäre imagemäßig wär das extrem schlecht, überhaupt keine Seite anbieten zu können. (pharmaceutical company)

Q21:

W7f: Naja, es war sicher gekoppelt an den Entschluss überhaupt eine Ordination aufzumachen. (doctor)

Q22

W7f: (...) da ist eine Ordination, die arbeitet schwerpunktmäßig mit Diabetes, und man muss sich nicht fürchten. (doctor)

Q23:

W3m: Das Thema war immer, dass man medizinisch relevante Informationen, die aus ärztlichem Know-how kommen, in einer für [räuspert sich], möglichst jeden, jede Frau, verständlichen Form aufbereitet und ins Netz stellt. (health portal)

Q24:

W3m: (...) weil der Betrieb so eines Portals ist ja eine sehr eine kostenintensive Geschichte. (health portal)

Q25:

W2m: (...) wir haben früher PR und Journalismus auf ganz anderen Ebenen gemacht, und haben dann quasi aus dieser, meiner Betroffenheit die Firma komplett gewitcht.

I: Interessant, ja.

W2m: Ja, und haben gesagt (.), ich hab gesagt, also Printmedien wollt ich nie machen, weil ich immer gesagt hab, diese Kosten, das geht sich nicht aus, und die ganze Distribution und Retouren und ich weiß nicht was alles. Aber Internet hab ich als Perspektive sofort gesehen, weil ich gesagt hab, da druckt sich jeder aus was er will. Ich hab nix mit der Auslieferung zu tun, hab daher keine, relativ geringe Kosten, und die müssten eigentlich (.) durch Sponsorship hereinzubekommen sein. Also ich hab es sehr wohl (.) auch ökonomisch auf gesunden Beinen sehr schnell gesehen. Weil ich gesagt hab, einerseits der Diabetiker muss es natürlich gratis bekommen, weil der hat sowieso erhöhte Lebensaufwandskosten (...) okay, von mir die Infos muss er gratis kriegen, und das muss letztlich die fina-, die Industrie finanzieren. So dass da eine, das auf einer gesunden Basis steht, die (.) ja, die einen Nutzen bringt für alle Beteiligten. Gesagt, getan. (patient)

Q26:

U18m: Ich verlasse mich da auf die Schulmedizin, weil die haben ja das festgestellt, und ja, ich denke mit einer Ernährungsumstellung und einer, und ausreichendem Sport kann man das in den Griff bekommen. (41-60, employee)

Q27:

U18m: Also man muss das, man muss sich das immer vor Augen führen, das schreiben Leut wie du und ich, die, der kann hineinschreiben, was er will. Das heißt ja nicht, dass es richtig ist. (41-60, employee).

Q28:

U25m: (...) man liest was und ist versucht, das auf sich zu beziehen. (.) Und dann ist es aber mit hoher Wahrscheinlichkeit nicht so. (41-60, IT consultant)

Q29:

U4m: (...) vom Allgemeinen ins Spezielle (...) (19-25, student)

Q30:

U36f: Nein, also es würd mich prinzipiell einmal interessieren, (...), was kann ich tun. Ohne jetzt mich [hustet], ohne jetzt ständig zum Arzt rennen zu müssen, ohne mich zuzuschütten

mit Medikamenten. Also ich würd einmal versuchen herauszufinden, was kann ich einmal tun und wie sinnvoll ist es. (41-60, homemaker)

Q31:

U36f: (...) nicht als Opfer, sondern was kann ich tun, die Verantwortung also einfach übernehmen. (41-60, homemaker)

Q32:

U9m: Und dann halt eine Reihe von Maßnahmen, die man (.), was eigentlich eh auf dieser Seite steht, so Schritte, was können sie selbst tun. Und das hab ich mir einfach jetzt durchdacht und überlegt, wie man da weiter vorgehen kann. (.) Also, krankheitsbewusster zu leben und einfach niedrigen Blut-, höheren Blutzucker zu erkennen, einmal zu versuchen, was sind dafür Anzeichen, was ist da ausschlaggebend dafür, dass man das einmal erkennt. (.) Dann auch natürlich hab ich dann in weiterer Folge geschaut, wie kann man den Blutzucker messen. (...) Und dann natürlich, was mir auch sehr wichtig war, ist einmal, was für Notfälle können jetzt auftreten bei dem Ganzen, also, diese Überzuckerung, ne. Und da hilft nur Insulin oder der Notarzt, und bei Unterzuckerung Traubenzucker und Fruchtgetränke. (41-60, book seller)

Q33:

U21f: Und weil ich ja von der Ecke komm Homöopathie, TCM usw., hab ich da auch hineingeschaut. Und da gibt's immens viel. Also, es ist genauso, ich sag, ich bin also nicht angewiesen auf Medikamente, sondern ich kann auch homöopathisch und TCM-mäßig, was also chinesische Kräuterkunde usw. etwas tun. Also, muss sagen, fühl mich sehr versorgt davon, ja. Also, wirklich so, dass ich sag, ich kann's, ich bin kein Opfer und ich sag, wah, ich hab jetzt Diabetes, sondern, also, dass ich sagen kann, ich hab Diabetes und nicht ich bin Diabetiker. Also, ich muss mich nicht identifizieren damit, sondern ich kann wirklich sagen, ich kann was tun, ja, ich kann's in die Hand nehmen. (.) Und ich fühl mich, also, da überhaupt nicht alleingelassen damit, sondern ich kann sagen, pah, toll, ja. (41-60, homemaker)

Q34:

U36f: Ich steh auf dem Standpunkt: wir sind Menschen, wir kommen aus der Natur, wir sollten auch Natur zu uns nehmen. Also pass-, würden Süßstoffe für mich nicht passen. (41-60, homemaker)

Q35:

U35m: Also, ich würd mir einmal einige Wochen hindurch jeden Tag so und so viel Stutenmilch geben und würd schauen, was geschieht da. Dann würd ich mit Schwarzkümmelöl arbeiten, dann würd ich mit Kräutertees arbeiten und mit allem Möglichen. Also, ich würde diese effektiven Sachen, Salbe, ich weiß gar nicht, also, ich sag Ihnen ganz ehrlich, ich würde diese Salbe, die mir der Arzt verschrieben hat, zumindest einmal einige Wochen lang oder Monate lang nicht verwenden. Ich würde versuchen einmal psychische Faktoren auszuschalten, wenn das irgendwie geht – weniger Stress und diese ganzen Dinge. (41-60, self-employed)

Q36:

W2m: Das ist ja auch unter den Selbsthilfegruppen, jetzt gibt es natürlich Austausch. Vor Internet genauso wie jetzt nach Internet, und du fängst einfach an einmal jetzt dann zu schauen,

was gibt's im Internet jetzt außer mir? Das hat sich ja, vieles hat sich parallel entwickelt. (...) Und wir haben gesagt: „Hängen wir uns einfach zusammen, weil wenn einer uns findet, und dann hast die Seite Links, na dann sucht er vielleicht weiter, ja? Oder umgekehrt bei Euch.“ Das ist also so eine gegenseitige (.)

I: Also man gibt dann einen Link und kriegt dafür einen, das ist so die Praxis?

W2m: Ja, ja. Das ist quasi ein, ein, ein, ein bargeldloser Austausch, der am Anfang sicher nützlich ist. (patient)

Q37:

W4m: Naja, die Links sind eingeteilt einmal in, in Organisationen wie zum Beispiel so Freundschafts-, mit denen wir zusammenarbeiten, zum Beispiel da in Graz da der, der Wagner mit den, mit seinen Kindern, ja, und ähnliche. Dann Homepages die, die mir irgendwie so mal schon aufgefallen sind, weil sie sehr gute Informationen bieten. Oder auch zum Beispiel die Homepage von der Dr. X, die Ärztin, ja, die eine super Homepage hat, wo wirklich viel erklärt wird (...) So was nehmen wir natürlich gerne auf. Das ist einmal die eine Reihe. Dann gibt's natürlich auch wie gesagt diese Firmen, und ja, das ist es eigentlich. (patient association)

Q38:

W4m: Na sicher. (...) Ich will ja nicht irgendwie unsere mündigen Patienten quasi mit, mit Scharlatanerie irgendwie in Verbindung bringen. Das lehne ich ab. Das mache ich nicht. (patient association)

Q39:

W3m: Links nach draußen waren also von der Tradition her eigentlich immer kaum zu finden. Das ist halt die Philosophie, möglichst den User in der Website zu halten also großes horizontales Portal. (health portal)

Q40:

W3m: (...) ich finde's dann immer ganz nett, wenn jemand kommt und sagt: „machen wir doch einen Linkexchange“, und der hat 5.000 unique clients im Monat und ich hab 500.000. [I lacht] Das, das geht nicht zusammen. Das geht nicht, ja? Das wär widersinnig einfach. (health portal)

Q41:

W1m: Indem sie beim Google Diabetes einklopfen (patient association)

Q42:

W4m: (...) also ich hab ja hin und wieder mal hineingeschaut und Diabetes eingegeben. Es kommt unter den ersten, weiß ich, 15 bis 20 kommt's auf jeden Fall. (patient association)

Q43:

W3m: Also Google gibt eben aufgrund von, aufgrund der Quantität und Qualität der Verlinkung auf deine Seite ein Page Rank. Und dann gibt's noch die Verknüpfung mit dem Stichwort, mit dem Keyword, schaut Google eben, geht in den Text, Textsensitivity. (health portal)

Q44:

W2m: Und dann kommt halt dazu, dass durch die lange Zeit, die wir drin sind, es (.) unglaublich viele Verlinkungen gibt (.) oder Hinweise oder auch gute Benotungen unserer, unserer Seite, (...) (patient)

Q45:

W3m: (...) wir müssen's hauptsächlich über die Inhalte machen (health portal)

Q46:

W2m: Was der Webmaster auch noch gemacht hat, was wir nie hätten können, (.) ist dieses Festlegen der sogenannten Metatags und der Platzierung in Suchmaschinen.

I: Was sind Metatags?

W2m: Das sind die Worte, die Schlagworte unter denen man ein Thema sucht. Oder wo man dann, wenn ich jetzt sag „Blutdruck“ beispielsweise, hat zunächst nix mit Diabetes zu tun, aber eigentlich schon, im Hintergrund, wenn man's weiß. Jetzt wenn man da Blutdruck eingibt, wird natürlich jetzt in einer Suchmaschine vorkommen irgendwas was Blutdruck auf der Seite, (.) also [www.blutdruck.at](http://www.blutdruck.at) würde kommen als erstes, vermutlich. Aber wenn du gut, wenn du das auch hast, dann kommst du auch irgendwann vor, weil's eben ein Metatag ist, ja? Und das haben wir glaub ich sehr gut, sehr gut auch bestimmt was das sein soll. (patient)

Q47:

W3m: dass wir natürlich unsere Hausaufgaben machen (health portal)

Q48:

W4m: (...) es ist ja nicht so, dass wir davon leben und dass unbedingt mein Geschäftserfolg davon abhängt, wie viel Leute sich wirklich das anschauen und dann bei mir kaufen, ja? Wir sind ja eine Selbsthilfegruppe, die (.) eigentlich kein Geld einnimmt u-, und damit bieten wir eine Information an, aber wir drängen sie niemandem auf [lacht]. (patient association)

Q49:

W7f: Sehr häufig mein Name, deshalb ist das XY.at sicher als Domain eine gute Idee gewesen. Ganz häufig werd einfach ich gesucht, na? Das sind ganz oft Leute die mich von der Ambulanz kennen, vom Spital oder vom Wienerberg, und da schaut man: wo ist sie denn jetzt? Und, ja. Und dann eben Diabetes-spezifische Schlagwörter. Ist ganz häufig.

I: Also das ist schon was, was Sie im Gedächtnis behalten, dass das auch aufgefunden werden kann und so.

W7f: Das schaut man sich regelmäßig an, ja. Also regelmäßig, immer wieder mal. (doctor)

Q50:

W3m: Also der Standard hat 1,2 Millionen unique clients, wir haben 488.000, und die kommen einfach größtenteils, weil sie diese Begriffe eingeben und weil's uns schon so lange gibt, weil viele Websites auf uns linken, Googlereferenzierung, und ein Teil hat das gebookmarkt. Also ich

würd sagen, so 1/4 ungefähr hat das gebookmarkt und schaut immer wieder nach. (health portal)

Q51:

W3m: (...) die Abhängigkeit von Suchmaschinen, die ist jetzt nicht super. (health portal)

Q52:

U9m: Na ja, das liegt am Zeitgeist. [lacht] Also, es gibt ja schon Ausdrücke wie ich google dich oder so was. Also, ja, man kann's wirklich, also, Google ist halt die Suchmaschine schlechthin. Also, wer im Internet sucht, ich weiß nicht, ich kenn, glaub ich, 90% meiner Bekannten und Leute, die ich kenne, die googlen alles. (41-60, book seller)

Q53:

U18m: abgelenkt (41-60, employee)

Q54:

U20m: Was da im Hintergrund passiert, interessiert mich nicht wirklich (investment advisor)

Q55:

U13f: Na da hab ich mir verschiedene Seiten angeschaut, mal geschaut, was Google so ausspuckt. (26-40, University staff)

Q56:

U9m: Informationsflut (41-60, book seller)

Q57:

U13f: Ja, mich hat interessiert, also wie, wie man das verbessern kann, also welcher Sport da geeignet ist. Ob ich mit dem Sport, den ich jetzt mache, also so Kampfsport wäre glaube ich nicht geeignet [beide lachen]. Da bin ich draufgekommen. Dann, dann hab ich geschaut, was man essen kann. Das war auch, das war eher so theoretisch, mit Kohlenhydraten, Eiweißstoffen. [Ich habe mir gedacht,] das wird schwierig, wenn man da was kochen will, aber zum Schluss hab ich dann ein Rezept gefunden. (.) Dann ist mir eingefallen, also wenn ich Diabetes hätte, dann würden es wahrscheinlich meine Kinder kriegen. (..) Dann habe ich [eben] geschaut, inwieweit das vererbbar ist. Der Typ 2 jetzt. (26-40, University staff)

Q58:

U13f: Nein, zuerst hab ich „Diabetes Meditus“ angegeben, dann „Diabetes Typ 2“, dann „Diabetes & Sport“, dann verschiedene Sportarten, „Diabetes & Kampfsport“, dann „Diabetes & Kinder“ und (.) „Diabetes & vererbbar“, weil ich eben schauen wollt, ob i..., ob ich das dann vererben kann. (26-40, University staff)

Q59:

U5m: (...) dass umso weiter nach hinten dass ich komm, umso weniger trifft's das, was ich mir erwartet hab. (19-25, student)

Q60:

U25m: definitiv professionell (41-60, IT consultant)

Q61:

U21f: Nein, geh ich von vorn nach hinten. Wobei ich das sehr, das geht sehr schnell, weil ich einfach schnell überblicksmäßig schau, okay, zack, zack, zack, passt das. Und dann... Ich geh nicht jedes, ich klick nicht jedes an, sondern einfach, okay, ich schau, passt das für mich und (.)

I: Und das machen Sie anhand dieses Texts?

U21f: Ja. Dieses kurzen Auszugs [gleichzeitig I], der da ist, und auch anhand der Internetadresse, die schau ich mir auch an. Also, die schau ich mir auf jeden Fall an.

I: Schauen Sie da...? Ja. [gleichzeitig] Was sagt Ihnen die?

U21f: (.) Das ist interessant, wenn sie nicht vor einem ist, dann danach, ja [gleichzeitig I], das ist so ungefähr wie wenn's Verkehrszeichen fragt. Wie schaut das Verkehrszeichen aus, das man jeden Tag sieht, gell. (.) (41-60, homemaker)

Q62:

U29f: (...) ob meine Wörter einmal vorkommen und unten steht ja schon öfters die Adresse oder so, und wenn da dann irgendwie, weiß nicht, so eine Kinderhomepage oder so was, oder wenn man sieht, dass es so was Privates ist, schau ich da nicht so drauf. (<18, schoolgirl)

Q63:

U4m: Also, von NetDoktor.at habe ich angefangen. Die da, gut, als erster, (.) verwende ich als erster, eigentlich als dritter rausgekommen ist, aber (.) also vom Namen her und vom Prestige, die ich da irgendwie dem beimessen würde. Ich hab's einmal schon verwendet für eine andere Krankheit, und es war recht gut. (19-25, student)

Q64:

U40m: vor und zurück zu Google (24-60, engineer)

Q65:

U36f: Ja. Wenn Sie, wenn Sie beim Thema bleiben. Wenn Sie zu sehr dann abschweifen, dann ist mir das zu zeitaufwändig, dann ist mir das zu, dann geh ich da nicht weiter. (.) Wenn es dann zu sehr abschweift. (41-60, homemaker)

Q66:

U21f: sich verlieren (41-60, homemaker)

Q67:

W3m: Ja, und weil man sich auch glaub ich bei uns sehr gut zurecht findet. Also weil wir den User nicht verwirren, sondern glaub ich, weil's kein sehr modern designtes Portal ist, ich glaub eher ein sehr klares und man findet sich glaub ich gut zurecht. (health portal)

Q68:

Herzlich willkommen bei XY. Eine Selbsthilfegruppe, die aus passiven "Zuckerkranken" active Diabetiker macht! (website of the patient association)

Q69:

Das unabhängige Gesundheitsweb für Österreich (website of the health portal)

Q70:

Initiative Soforthilfe für Menschen mit Diabetes (website of the patient)

Q71:

W2m: Hab gesagt, „da mach ich jetzt ein, quasi ein Inhaltsverzeichnis von den Rubriken, und dann machen wir da Schlagzeilen und reißen Geschichten an. Und da machen wir einen Button hinein, da geht's weiter“. Und hinten hin muss, also es war dann, das war dann auch der, der Zusammenschluss, die wissen schon wie das geht. (patient)

Q72:

W3m: Also es ist so, dass die, die (.) sehr, es ist natürlich sehr intensiv, weil die sitzen in einem Büro. Also das ist schon mal der Vorteil, dass wir nix ausgelagert haben, sondern wir haben eben so 2,7 Headcount, ich weiß nicht ob ich das so ausdrücken darf in dieser Sprache, in der Technik, ja? Und von da her ist das Zusammenspiel ein sehr enges, (...) (health portal)

Q73:

W7f: Und es ist halt das alte Problem vom Laien, der eine Seite programmiert ohne professionelle Hilfe, dass es sehr schnell unübersichtlich wird und er immer wieder Inhalte dazuhängt. Und nicht komplett neu strukturiert. (doctor)

Q74:

W2m: Weil vorher hast dir riesige, für dich nicht lesbar Schmöcker kaufen müssen zum Thema; bis du da durch warst, bist eh schon verzweifelt, weil du die Sprache nicht verstanden hast. Und heute wird doch viel auch für den Laien verständliche Info zu egal welchem Thema angeboten im Netz. Also Gesundheitsinfo, ja? Und ich halte das für gut. (patient)

Q75:

W2m: Wir glauben, oder ich glaub, und mit mir auch eigentlich die meisten (.) Diabetologen und, und auch Selbsthilfegruppen-Menschen sagen, wir wollen, dass die Leut sehr wohl ganz genau wissen, was das ist, und nicht nur mit dem lateinischen, medizinischen Namen, sondern auch mit dem Markennamen. Weil das hat keinen Sinn, wenn der sich den, ich mein den Namen nicht merkt, sondern der muss wissen, Beispiel: Insulin heißt Lantus, dann muss er zu seinem Doktor gehen können und sagen können: "Ich hab da jetzt was gelesen über Insulin Lantus." Oder wenn's geht um Insulin Sensitiser, neue Wirkstoffklasse, ganz neu, der muss wissen, das heißt Actos. Ja? (...) Und da hat's keinen Sinn, jetzt zu sagen, das heißt (.) Pioglytazon, ja? Ich mein, klar, der Arzt weiß eh, aber der Patient merkt sich's nicht. (patient)

Q76:

W6f: Also wir machen dann auch manchmal so Tests, dass wir es Mitarbeitern mit nach Haus geben, die, die Eltern haben die betroffen sind und so, und sagen: „Ich geb's mal der Mama mit und lass sie lesen und, und schau mal was passiert.“ Oder wir geben's den Selbsthilfegruppen und sagen: „Schaut's Ihr mal drüber. Versteht das irgendwer?“ Weil wenn man selber im Thema so stark drinnen ist, neigt man dazu, sehr kompliziert zu werden [I lacht]. (pharmaceutical company)

Q77:

W6f: Und die hilft den Patienten ja überhaupt nicht weiter, weil das ja wieder so geschrieben



ist, dass es wieder nur ein Arzt versteht. (pharmaceutical company)

Q78:

W7f: Das war schon auch für Ältere. Ich hab mir gedacht, die Älteren profitieren vom Design. Jüngere die zu mir kommen wollen, lassen sich von einem altmodischen Design nicht wirklich abschrecken. (doctor)

Q79:

W7f: Und es war wirklich miteinander entwickelt. Also die, das Gelb von der Homepage, das Grün, dieses Grau-Grün, das ich einfach extrem beruhigend empfind, ist bei mir an der Wand in meinem Zimmer in dem ich arbeite. (doctor)

Q80:

W3m: Ja, also, es ist so, dass wir zum Beispiel im Kopf haben, dass wir wissen, dass wir mehr Frauen haben als Männer und dass wir uns schon bemühen, auch in der Anmutung, im ganzen Informationsumgang, Frauen anzusprechen. Also ich, ich sorg ja dafür, wenn Stellen nachzubesetzen sind, weil die Techniker meistens Männer sind, dass wir wirklich Frauen einstellen, weil (.) das einfach wichtig ist, dass man diese Denke auch hat. (health portal)

Q81:

U9m: (.) ich mein, der Suchfaktor ist einmal sehr wichtig, ned. Schlagworte, also, wenn man sucht und die findet, dann kommt man direkt, also, auf dieser, z.B. auf dieser Seite XY, die haben ja verschiedenste Krankheiten und, also, so Symptome usw. Wenn das einmal, und da kann man sehr gut mit Schlagwort suchen (.) und findet man auch gleich direkt hin. (41-60, book seller)

Q82:

U21f: Also, wenn ich sag, ich komm sofort dorthin, wo ich hin will, ja, also, das ist alles, gehört alles zur Übersicht. Also, dass sie wirklich gut durchdacht und gut organisiert ist, die Seite, ja. (41-60, homemaker)

Q83:

U21f: verfransen (41-60, homemaker)

Q84:

U40m: Schlagwortemäßig. Überschriften, Anfang des Satzes, schauen, ob das ein interessanter Absatz ist und weiter zum nächsten Absatz. Glaube ich. Ich meine, das müsste man jetzt erhärten mit einer wirklichen Augenabtastung (...) Aber ich glaube, dass es so ist. Weil ich les definitiv nicht jedes Wort von den Artikeln. Also, erst wenn ich dann zoom auf einen Absatz, wo ich sag, das ist jetzt eine interessante Information, dann les ich mir den sicher Wort für Wort durch, keine Frage. Aber beim Durchschauen, Durchlesen so eines längeren Artikels, sicher punktuell. (26-40, engineer)

Q85:

U29f: Und, deshalb war's für mich ein bisschen unübersichtlich, weil zu viele verschiedene, also, im Text, wenn da irgendein Wort war, war das dann immer so bunt unterlegt und so, weil man da eigentlich auch draufdrücken könnte, obwohl es nur, weiß nicht, so Fuß war oder so, und dann ist

man halt auf Informationen über Füße gekommen und so und nicht nur mit Diabetes in Zusammenhang. Das hat sich halt dann gleich so verlinkt oder so. (<18, schoolgirl)

Q86:

U21f: Das war die letzte Seite, die ich jetzt gerade beschrieben hab. Und zwar, die sehr übersichtlich war und wirklich alle Informationen auf einer Seite hatte, ja. Also, inklusive Information, was ist es überhaupt und da sehr ins Detail gegangen ist, und zwar auch für Laien. Also, da war kein Fachchinesisch, und so weiter sondern wirklich für Laien sehr gut. Und inklusive Problembehandlung, auftauchende Probleme, inklusive Ernährung, alles. (41-60, homemaker)

Q87:

U13f: (...) für Leute, die jetzt kein Medizinstudium haben. (26-40, University staff)

Q88:

U40m: Ich würde über einen Artikel, der (.), dem man ansieht, dass da einer so bloß aus dem Nähkästchen plaudert, leichter hinwegsehen. Also, den klick ich sicher schneller weg oder fass ich gar nicht zuerst ins Aug, wie einer, der, wo man das Gefühl hat einfach vom Satzbau, von der Art, wie das präsentiert wird, da hat sich einer Gedanken gemacht, das ist ein Referat. (26-40, engineer)

Q89:

U3f: (...) auf irgendwas bin ich gekommen zu Magenverkleinerung, da war ein Bild dabei. Das find ich natürlich auch interessant, dass man sich das vorstellen kann. Klar, wer kann sich vorstellen, wie verkleinert man einen Magen, wie schaut das überhaupt aus. (41-60, homemaker)

Q90:

U40m: (...) weil ich geh ja auch nicht in ein Geschäft, wo ich nur, ich weiß nicht, wo man die Tür nicht sieht, weil lauter Werbung pickt, ja. Das werd ich gar nicht erst betreten können, ne. (26-40, engineer)

Q91:

U13f: Nein, überhaupt nicht. (...) na ich glaub, wenn man die Ad..., wenn man die Adresse, also den, den URL nicht kennt, dann weiß man nicht, wer das ist.

I: Schauen Sie dann ins Impressum oder, oder benutzen Sie die Seite dann nicht, wenn Sie, wenn Sie nicht wissen, wer sie betreibt, oder benutzen Sie's trotzdem?

U13f: Das ist mir eigentlich egal, wenn die Information drinsteht, wie gesagt, die ich brauche, dann ist das okay. (26-40, University staff)

Q92:

U9m: Naja, da waren mir anderen, da war mir jetzt die Information über die Krankheit, sagen wir jetzt, wichtiger, als jetzt zu wissen, woher das kommt. Ist natürlich sicher, wäre sicher auch eine wichtige Sache, dass man das abcheckt, woher das kommt (...). (E9) . (41-60, book seller)

Q93:

U21f: Ich hab nicht drauf geschaut.

I: Sie haben gar nicht drauf geschaut?

U21f: Ich hab gar nicht drauf geschaut. Das ist für mich nicht wichtig. (.)

I: Wie, denken Sie, bauen Sie Ihr Vertrauen zu einer Seite auf oder zu der Information?

U21f: (.) Zu der Information? Ah, das ist eine gute Frage, ja. (.) Wie integer das ist. Wie bau ich mein Vertrauen auf? (.) Ja, es ist der Name auch, der dahinter steht. ( 41-60, homemaker)

Q94:

W2m: Und ich hab halt wieder den Vorteil, nachdem alle wissen, dass ich auch ein Diabetiker bin, und ja im ureigensten Interesse (.) nur (.) versuche, seriöse Nachrichten weiterzugeben, und das auch nicht, da auch offensichtlich noch niemand wirklich enttäuscht hab, ja, (.) daher ist meine Credibility natürlich riesig groß. Weil die sagen: „Hey, er hat's. Der muss selber damit, der geht selber damit um, dann wird er uns keinen, keinen Blödsinn erzählen. (patient)

Q95:

W3m: Aber es ist dann doch ein matter of belief, also ich, ich glaub wirklich, ich glaub am Ende des Tages, was noch vielleicht gut ist, wenn ein Name und ein Gesicht dahinter steht. (health portal)

Q96:

W3m: Also ich glaub, wenn jetzt auf dem Artikel oben der Professor soundso ist, dann wurde einer namhaft gemacht. Es wurde einer verantwortlich gemacht. (health portal)

Q97:

W3m: (...) dann zusätzlich noch mal für Vertrauen sorgt natürlich auch. (health portal)

Q98:

W7f: Im Medizinbereich, na sicher als erstes woher sie kommt. Dann ganz einfach die optische Aufmachung, wie schreierisch ist es, wie marktschreierisch ist es, wie sehr schreit's nach „Kauf mich! Verwend mich! Wend mich an! (doctor)

Q99:

W1m: Und ich will eigentlich nie in den Geruch kommen, dass ich Sponsoring suche. Ich mein da gibt's jetzt Agenturen noch und noch, die bestürmen uns: Wir sollen dort und dort mitspielen, da kriegen wir Sponsergelder. Ich will es nicht. Ich sage niemandem Bittschön und Dankschön. Ich will auch sagen können: „Das ist ein Dreck, dieses Medikament, und dafür, das andere ist besser.“ Das kann ich nicht wenn ich Sponserbeiträge nehme. (patient association)

Q100:

W3m: (...) dass man die Werbung deutlich trennt von, vom redaktionellen Bereich? Da sollte man meinen, dass es ja eine Selbstverständlichkeit ist, und dass es eigentlich schon aus dem Mediengesetz sich heraus ergibt, aber es ist, die Praxis ist immer die, also es war ja eigentlich seit, seit ich würd sagen 10 Jahren eine gewaltige Erosion eigentlich in dem Bereich, eine Vermischung zwischen Promotion und Redaktion. (health portal)

Q101:

W7f: Also nicht so schlecht wie es oft gemacht wird. Ich denk mir, dass es schon ziemlich

klar ersichtlich ist wie gut eine Information ist. Auch durch diese Standardseiten die sich da etabliert haben, das Netdoktor.at und .de (.) (doctor)

Q102:

W2m: Also ich, für mich gibt's kaum relevante Portale. Also wenn Sie mich jetzt fragen, würd ich sagen: es gibt das VW portal, sehr in Ordnung; es gibt das WX portal, wellnessmäßig okay; (..)es gibt XY [wieder] Abnehmprogramm, kann ich nicht beurteilen, scheint ganz nett zu sein, medizinische Contents waren nicht aktualisiert; es gibt YZ, haben immer wieder Sachen von uns geklaut, sag ich jetzt off record, bitte das dann zu löschen, ja? (health portal)

Q103:

W2m: (...) wie kannst du die Schraube noch ein bisschen weiter drehen. (patient)

Q104:

W6f: Hm, wie mach ich das? Also ich geb's ganz normal als Krankheit ein, wenn irgendwas ist, und dann su-, witzigerweise, ich geh immer auf Universitätsseiten. Also z.B. Uniklinik XY oder so irgendwie. Also die haben oft gute Seiten auch, da geh ich primär hin. (...) Also da denk mir, okay, wenn die Uniklinik XY das, der Oberarzt oder der Dozent veröffentlicht hat, da geh ich hinein. (pharmaceutical company)

Q105:

W3m: (...) also ich bin einmal, hab einmal recherchiert zum Thema Alzheimer oder so irgendwas, bin auf eine amerikanische Seite gestoßen, und da ist eben draufgestanden: (.) sponsored by XY, und dann hast lang gesucht. Irgendwann mal hast dann doch das Impressum gefunden, und dann ist man eben draufgekommen, es ist die Website von XY. Und das macht ja wohl einen gewaltigen Unterschied. (.) Also das, das ist für mich wichtig, wenn ich das prüfen möchte. (health portal)

Q106:

W3m: (...) und ich sag ihnen auch immer als erstes, dass man schaut, findet man wer eigentlich der Anbieter ist, und sagt mir der überhaupt was, warum er das eigentlich macht, was seine Interessen sind, was ist sein Businessmodell, hat er Werberichtlinien, die besagen, dass er die Werbung deutlich trennt von, vom redaktionellen Bereich? (health portal)

Q107:

W7f: Ich denk mir, das Blöde ist, es gibt kein, es gibt nicht eines, das jetzt anerkannt wär. Also das wär eine tolle Sache auf universitärem Niveau, dass irgendwer, oder dass man da was hätte. (doctor)

Q108:

I: Wie glauben Sie, beurteilen Sie eine Seite?

U13f: Ja, was soll ich drauf jetzt sagen? [lacht] Wie a..., allgemein oder eine bestimmte?

I: Wie Sie wollen, also wenn Sie es an einer bestimmten erklären wollen, können Sie das tun oder, oder allgemein.

U13f: Also, na ja, eigentlich daran, ob ich das finde, was ich brauche. Und wenn ich das finde, dann, dann les ich's mir durch, wenn nicht, mach ich's wieder zu. (26-40, University staff)

Q109:

U18m: (...) reine Informationen für den Arzt (41-60, employee)

Q110:

U18m: allgemeine Informationen (41-60, employee)

Q111:

U18m: Das war irgendein Selbsthilfverein. (.) Ich mein, wird schon stimmen, ja, aber es ist halt (.) nicht hundertprozentig gesagt, dass das stimmt, was da drinnen steht. (41-60, employee)

Q112:

U36f: Wenn ich nur eine Seite hab, kann ich, kann ich untere Umständen wissen, okay, das, das ist für mich richtig, aber meistens kann ich, kann ich, ist es viel einfacher wenn es mehrere Seiten gibt.

I: Wiederholt sich dann wahrscheinlich halt öfter, oder, halt beim Lesen?

U36f: „Ja, aber das macht nix, weil das, das, das erfasst man dann ja. Und wenn man weiß, okay, die Aussage ist so, dann weiß ich das stimmt. Dann kann ich auf der Seite bleiben, die ich gefühlsmäßig (.) für mich angenommen hab.“ (41-60, homemaker)

Q113:

I: Sie haben das Gefühl, das ist (.) hochwertige Information gewesen?

U25m: Richtig, ja.

I: Woran würden Sie das festmachen?

E25: (.) Naja, (.) an der Gleichheit verschiedener Quellen. Eine Ratgeberquelle Österreich, eine Ratgeberquelle Deutschland, eine Studie aus Amerika, und das mit Bewegung und Ernährung, dass das stimmen muss, das steht überall drin. (41-60, IT consultant)

Q114:

U9m: Kern der Information (41-60, book seller)

Q115:

U40m: Na, na ja gut, es ist mir bewusst, dass es Widersprüche geben muss, nicht? Weil ja jeder seine Version irgendwo hinstellt, und das, das wär halt ein Zeichnen dafür, dass man dann da noch einmal kritisch nachfragen muss. (26-40, engineer)

Q116:

U21f: Wenn da sehr viel (.) Werbung ist und zwar zu Information so, die für mich nicht glaubhaft oder integer ist, denk ich mir, und das sich durch die ganze Seite durchzieht, dann lass ich die Seite, ja. Dann ist die Information, die dahinter steht auch nur, meiner Meinung nach, gefiltert. (41-60, homemaker)

Q117:

U21f: Das ist eine Gefühlssache teilweise auch, wenn etwas so plakativ und schreiend ist und so, dann bin ich da eher skeptisch, ja. (41-60, homemaker)

Q118:

U9m: Informationsfülle (41-60, book seller)

Q119:

U9m: (...) rausfiltern, das Brauchbare, sag ich mal (41-60, book seller)

Q120:

U4m: Also, man muss gezielt suchen. (.) Sonst findet man (.) alles, das heißt, nichts. (19-25, student)

Q121:

U9m: Aber man muss sich das Ganze insgesamt, glaub ich, dann, seine Informationen muss man raus lesen und sich das praktisch zusammenpuzzeln für einen selber - was ist einem jetzt wichtig, was sucht man jetzt. (...) Wenn man dann zu einem Thema das speziell immer sucht, dann kommen mehrere Seiten, und das kann man dann, und die sind eh meistens überlappend und da kann man sich das dann herausfiltern das Ganze. (41-60, book seller)

Q122:

U4m: (...) das kommt sehr gut in die Diskussion über Moderne und Postmoderne, dass man sich selbst seine Welt erschafft (.) (19-25, student)

Q123:

U9m: Man muss sich immer halt natürlich auch bewusst sein, dass im Internet viel gefälscht, kopiert und gelogen wird. (41-60, book seller)

Q124:

U40m: Also ich würde mir eher merken, welche Schlagworte waren's die mich dorthin gebracht haben. (26-40, engineer).

## 13.2 List of figures

Figure 1: Hyperlink network displaying lay-oriented diabetes sites, created in 2005, and one of five diabetes-related websites analyzed in detail, saved in 2006.

Figure 2: Illustration of a web search on diabetes carried out in 2006.

Figure 3: Network map displaying Austrian diabetes self-help sites heavily interlinked with German sites, 2006.

Figure 4: Illustration of Google as a home base.

Figure 5: Strategy of gaining visibility through "link exchanges".

Figure 6: Anonymized representations of the five different websites included in the study, saved between 2005 and 2006.

Figure 7: Illustration of the tree-like information structure of websites analyzed in this study.

Figure 8: A page of the website of the patient association saved in 2006 and a page of the same website after its relaunch in 2009.

Figure 9: Illustration of a user's search showing that the user went from a Google result list to a page of the website of the patient association, scrolled down a bit, and went back to Google to click on the next site, 2007.

Figure 10: The image illustrates how users browsed through websites in a multi-directional way.

Figure 11: A user directed from Google to a page of the patient association that does not indicate who the provider of the site is, 2007.





## Zusammenfassung

Diese Dissertation verortet sich an der Schnittstelle von *Wissenschaftsforschung, Medizinsoziologie und Internetforschung*. Ausgehend von Diskursen rund um den „informierten Patienten“ im Kontext breiterer techno-wissenschaftlicher Entwicklungen beschäftigt sich die Arbeit mit dem Internet als Quelle für Gesundheitsinformationen. Das Ziel dieser Arbeit ist es, eine kritische Perspektive auf diese Thematik zu werfen und damit euphorische Visionen vom Netz als Werkzeug zum „Patienten Empowerment“ zu hinterfragen. Dazu fokussiere ich auf die Kommunikation von medizinischem Wissen über das Internet und welche Rolle die Technologie in dieser Kommunikation spielt. Eingebettet in Diskurse rund um die „Wissens-“ und „Informationsgesellschaft“ fasse ich das *Internet als Medium, das zur Diversifizierung und „Informationalisierung“ von medizinischem Wissen beiträgt*. In Anlehnung an kritische Arbeiten aus dem Feld der Internetforschung konzeptualisiere ich technische Entitäten wie Links und Suchmaschinen als zentrale Akteure in der Kommunikation von Wissen über das Netz. Daraus ergibt sich die Fragestellung dieser Arbeit:

*Wie wird medizinisches Wissen über das Netz kommuniziert und welche epistemologischen Konsequenzen ergeben sich daraus?*

Mit Hilfe des analytischen Zugangs der *Actor-Network Theory* und einem *Mix an Methoden* konzeptualisiert und analysiert die Arbeit Praxen des Anbietens und Nutzens von medizinischem Wissen über das Netz als soziotechnische Praxen<sup>20</sup>. Konkret wurde untersucht, wie unterschiedliche Typen von AnbieterInnen medizinische Webseiten strukturieren, am Netz positionieren und für NutzerInnen vertrauenswürdig gestalten, und wie unterschiedliche NutzerInnen nach medizinischen Informationen suchen, Webseiten auswählen und nutzen, und wie sie die Qualität und Glaubwürdigkeit von online Gesundheitsinformationen einschätzen.

Diese Analyse zeigt, dass sowohl Praxen des Anbietens, als auch Praxen des Nutzens von medizinischem Wissen über das Netz höchst individuelle Informationspraxen darstellen. Welche Medizininformationen angeboten, genutzt und für glaubwürdig befunden werden, hängt von *individuellen Hintergründen und medizinischen „Denkstilen“ des Individuums* ab. Darüber hinaus zeigt die Analyse, dass die Technologie – und insbesondere Suchmaschinen – die Kommunikation zwischen AnbieterInnen und NutzerInnen formt und prägt. Sowohl AnbieterInnen, als auch NutzerInnen *orientieren sich* nicht allein an ihrem jeweiligen Gegenüber, sondern auch *an technischen Entitäten, insbesondere der*

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<sup>20</sup> Das Datenmaterial dieser Arbeit stammt aus dem Forschungsprojekt „Virtuell Informiert. Das Internet im Medizinischen Feld“ (Institut für Wissenschaftsforschung).

*Suchmaschine Google*. Dabei werden Interpretationsmuster und Bewertungskriterien von medizinischem Wissen entlang der Technologie neu verhandelt, und epistemologische Praxen verändern sich.

Dies führt mich zu der Schlussfolgerung, dass die Mediatisierung oder „Informationalisierung“ von medizinischem Wissen durch das Internet *neue Wissenspraxen hervor bringt, die neue Fähigkeiten erfordern*. Die Stabilisierung von Google als „obligatory passage point“ führt zu *Informationshierarchien und Marktmechanismen*, die durch technisches Know-How und Wissen über Suchmaschinen umgangen werden können. Über das Handling der Technologie hinaus, erfordert die Aneignung von medizinischem Wissen über das Netz *kognitive Fähigkeiten und Wissensarbeit*. Online Gesundheitsinformationen – z.T. fragmentiert und dekontextualisiert – werden entlang individueller Bedürfnisse und medizinischer Denkstile kombiniert, re-kontextualisiert und in Wissen transformiert. Dies relativiert Visionen des Netzes als „empowerment tool“ und zeigt, dass sich *PatientInnen mit Hilfe der Technologie selbst „empowern“ müssen*. Es legt weiters nahe, „informierte PatientInnen“ in dieser Wissensarbeit zu unterstützen. Anstelle von standardisierten Qualitätskriterien für Medizinwebseiten, schlage ich vor, individuelle Informationspraxen und dazugehörige Wissensarbeit ins Zentrum zu rücken. Insbesondere ÄrztInnen sind aufgefordert, das Netz nicht als Gefahr zu begreifen, sondern auf Netzinformationen und Wissensbestände ihrer PatientInnen einzugehen. Diese könnten als Fenster in die Welt von PatientInnen und deren Bedürfnisse begriffen und genutzt werden, um ein neues Vertrauensverhältnis zwischen ÄrztInnen und PatientInnen aufzubauen.

## Curriculum Vitae Astrid Mager

### Education/ Career

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Since 2007	Co-organizer and member of the doctoral network „Internet Research“ at the Graduiertenzentrum, Faculty of Social Sciences, URL: <a href="http://www.univie.ac.at/internetforschung/">http://www.univie.ac.at/internetforschung/</a>
Since 2005	Doctoral Student for Dr.phil. (Sociology), University of Vienna
Since 2005	Lecturer at the Department of Social Studies of Science
10 2008 - 12 2009	Lecturer at the Department of Nursing Science
02 2004 - 09 2008	Contract Researcher at the Department of Social Studies of Science, research projects (project lead: Univ.-Prof.Dr. Ulrike Felt):  „Virtually Informed. The Internet in the Medical Field“ (FWF)  „Challenges of Biomedicine – Socio-Cultural Contexts, European Governance and Bioethics“ (EU)  „Let’s talk about GOLD: Analysing the Interactions between Genome-Research(ers) and the Public as a Learning Process“ (bm:bwk; GEN-AU)
9 2002 - 7 2003	University of Jussieu/ École des Mines/ EHESS, Paris: Science and Technology Studies
1996 - 2002	University of Vienna: Studies of Sociology and Communication Science with a focus on Science and Technology Studies
1995	Matura in Linz

### Publications

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Mager, Astrid (2009): Mediated Health. Sociotechnical practices of providing and using online health information, *New Media & Society* 11/7: 1123-1142

Felt, Ulrike, Lisa Gugglberger, Astrid Mager (2009): Shaping the future e-patient: The citizen-patient in public discourse on e-health, *Science Studies* 22/1: 24-43

Felt, Ulrike, Maximilian Fochler, Astrid Mager, Peter Winkler (2008): Visions and versions of governing biomedicine: narratives on power structures, decision-making, and public participation in the field of biomedical technologies in the Austrian context, *Social Studies of Science* 38/2: 233-257

Felt, Ulrike, Lisa Gugglberger, Bernhard Höcher, Astrid Mager, Sonja Österreicher (2008): Virtuell informiert? Möglichkeiten und Herausforderungen für die Medizin im Internetzeitalter, *Project Report*

Mager Astrid (2002): „Ewige Jugend“ – „Menschliche Ersatzteile“ – „Zuwenig Verkehrstote“. Organ transplantation in the context of Austrian media discourses, *Diploma Thesis*