

Search Engines Matter: From Educating Users Towards Engaging with Online Health Information Practices

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Abstract

While the Internet is often discussed as empowering or endangering patients due to broadening access to medical and health-related information, little is known about the way patients actually get informed about medical conditions and how the technology shapes their practices. This article draws on 40 user observations and 40 qualitative interviews to explore how users employ the web to obtain knowledge about a chronic disease in the Austrian context. Following concepts from the field of Science and Technology Studies (STS) it explores how users' individual medical preferences and search engines' mechanisms of pre-filtering information co-shape online health information practices. The analysis demonstrates that search engines are not passive intermediaries, but rather actively shape how users browse through, select and evaluate health information in the context of their own bodies of knowledge. Accordingly, new skills are required on the part of users, but also on the part of medical professionals and policy makers. Both policy makers and doctors should engage with users' highly individual search practices and establish more dialogue-oriented and technology-focused health policy measures, rather than trying to educate users with standardized quality criteria for websites not responding to users' online routines and needs.

KEYWORDS: online health information, reliability, user study, STS, search engine, health policy

Author Notes: This research was supported by the Austrian Science Fund (project "Virtually Informed", P18006) and HUMlab. I would like to thank Ulrike Felt (project leader), Lisa Gugglberger, Bernhard Höcher, Paul Ringler, and Sonja Österreicher for having collaborated with me on the project, and Patrik Svensson for the HUMlab postdoctoral fellowship (2010-2012). Further, I would like to thank Max Fochler, Bernhard Höcher, René König, and three anonymous reviewers for valuable comments on earlier drafts of the article, and Mike Frangos for editing the English.

Introduction

According to recent surveys, more than 80 percent of Internet users, both in Europe and the United States, have searched for a health-related issue online (Andreassen, Sørensen, and Kummervold 2007; Fox 2011). With the increasing availability and use of medical information on the Internet, it has become a central object of discussion in academic, public, and policy discourses (Felt, Gugglberger, and Mager 2009). The Internet has often been described in medical sociology as an empowerment tool that turns patients into “informed patients” who actively take health matters into their own hands (Hardey 1999; Anderson, Rainey, and Eysenbach 2003; Broom 2005; Barker 2008; Timmermans and Oh 2010). As a result, a new model of doctor–patient relationship was supposed to emerge where patients and doctors made decisions in a shared manner (Anderson, Rainey, and Eysenbach 2003).

More critical research, however, has raised concerns about the empowering potential of the Web. Henwood et al. (2003) have found that patients often experience a hard time discussing treatments with their doctors and reaching a cooperative decision. Broom (2005) has claimed that doctors perceive the Internet as contesting their profession, and Internet-informed patients as challenging their expert status. Gage and Panagakos (2011) have described doctors explicitly telling patients not to go online, particularly during an acute crisis such as a cancer diagnosis of their child. One reason for doctors’ reluctant behavior towards “informed patients” is that they doubt the quality and reliability of medical information on the Internet against the backdrop of their own expert knowledge, and that they interpret the Web as endangering patients.

As a solution to the problem, medical professionals have suggested standardized quality criteria and labels for medical websites such as “Health on the Net” (HON) or DISCERN (Khazaa et al. 2012). The Health on the Net Foundation, a Swiss NGO chiefly comprising medical professionals, offers the HON code of conduct, a “multi-stakeholder consensus on standards to protect citizens from misleading health information” (<http://www.hon.ch>). It is intended to provide authority to websites according to standardized criteria, while denying it to others. The user is to be guided to the “right” information as defined by medical experts. The British quality indicator, DISCERN, similarly aims to help users identify high-quality health information based on “good evidence” (<http://www.discern.org.uk>). EU policymakers have picked up and integrated these quality labels, as well as the accompanying concept of good evidence, to assist users in evaluating medical information on the Web: “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 quote exemplifies policymakers’ attempts to govern medical information on the Internet, and educate users in how to use the Web to obtain medical knowledge from a superior, top-down position. Following traditional models of credibility (Wathen and Burkell 2002), the source of the information, the website’s provider, and its reliability status are considered central in these measurements of medical information on the Internet. Within the broader context of evidence-based medicine (Timmermans and Berg 2003) quality labels such as HON or DISCERN may therefore be seen as reinforcing boundaries between expert and lay knowledge, as is argued by Adams and Bal (2009).

These top-down initiatives, however, hardly work out in practice, as a number of studies have shown (Eysenbach and Köhler 2002; Nettleton, Burrows, and O’Malley 2005; Adams, de Bont, and Berg 2006; Höcher 2008). Instead of following the pathways suggested by standardized quality criteria, users find their own ways through the Web and develop alternative practices of evaluating health information online. Adams, de Bont, and Berg (2006) further argue that users’ search strategies appear tightly intertwined with the technology and the way it provides health information. Accordingly, Wyatt, Harris, and Wathen (2008) call for attention to be paid not only to humans, but also to non-humans (i.e., machines) and their role in “mediating” health information when trying to understand how users engage with various information and communication technologies (ICTs) to obtain medical knowledge. Building on this line of work, this article investigates how users search for, filter, and evaluate medical information on the Internet, in the context of their highly individual medical “thought styles” (Fleck 1981 [1935]), and how search engines and their method of algorithmic “software sorting” (Graham 2005) shape their practices. This analysis makes us understand that tools like search engines play an important role in users’ highly individual knowledge practices, requiring new skills and awareness on the part of users, but also on the part of doctors and policymakers. Rather than educating users from a superior standpoint, health policymakers and doctors are advised to engage with users’ online health information practices and the role played by search engines, as will be discussed in this article’s conclusion.

Critical Public Understanding of Science

Contrary to the vision of medical experts, users rarely check website providers or pay attention to quality labels such as HON or DISCERN when browsing the Web (Eysenbach and Köhler 2002; Nettleton, Burrows, and O’Malley 2005; Adams, de Bont, and Berg 2006). Studies carried out in the medical field

therefore argue that users have sub-optimal search techniques (Eysenbach and Köhler 2002), mirroring the desire of experts to educate and govern users from the top down. Social science research, by contrast, shows that users develop alternative strategies of evaluating medical information on the Internet that are closely related to their own desires and needs. Instead of looking for pre-defined reliable information, users piece together information from different websites, creating answers to their questions (Adams, de Bont, and Berg 2006; Höcher 2008). In this process they tend to compare information from different websites, rather than enquiring about website providers (Adams, de Bont, and Berg 2006). Nettleton, Burrows, and O'Malley (2005, 983) describe a similar strategy which they term "going with the majority view": people keep finding the same information repeated and therefore trust it. These scholars argue that more insight is needed in how users engage with and make sense of health information online. Reliability is not a "yes-or-no kind of attribute" (Adams, de Bont, and Berg 2006, 109), as widely imagined by policymakers and doctors, but "the reliability of information for the patient becomes intertwined in the search process," as they conclude (111).

These results correspond to research from the field of critical public understanding of science (critical PUS), which has a long tradition of criticizing top-down initiatives for educating lay people in science and technology. Critical PUS research holds that lay people have elaborate techniques for making sense of scientific knowledge that bears on their personal situation (Wynne 1992; Michael 1992)—this applies particularly to patients who are searching for knowledge concerning their own medical conditions (Lambert and Rose 1996; Busby, Williams, and Rogers 1997). Lambert and Rose (1996, 71) conceptualize patients as "health workers actively seeking to understand and make sense of science they see as relevant." This line of work allows for interpretation of the acquisition of medical knowledge as a highly individual social practice. Further, trust in scientists and their "social body language" (Wynne 1992, 297) have turned out to be relevant in face-to-face interactions. According to Wynne, social body language encompasses categories such as institutional affiliation, the scientists' actual behavior, and the way they organize knowledge. But how do lay people acquire and interpret medical information that is not communicated in face-to-face interactions, but rather mediated by complex technologies such as the Web? To answer this question we focus on users' individual "thought styles" (Fleck 1981 [1935]) and search engines' standardized methods of "software sorting" (Graham 2005).

“Thought Styles” and “Software Sorting”

According to research in the tradition of critical PUS, users should not be seen as a homogeneous group, as they often are in medical and policy discourses, but rather as individuals with heterogeneous interests and bodies of knowledge. Since users' health searches are guided by finding answers to specific questions (Adams, de Bont, and Berg 2006), the different interests, desires, and medical backgrounds of users need to be taken seriously. Moreover, online health information practices should be seen as tightly interwoven with users' offline health experiences (Kivits 2009). To consider how users' individual backgrounds influence their online practices, Fleck's (1981 [1935]) notion of “thought style” serves as a valuable theoretical concept. Fleck coined the term to grasp how individuals interpret and make sense of the world in the context of their own world-views. Thought styles emerge in communities such as the scientific community, in specific disciplines such as biology, but 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” (159). Even though most of the participants included in the present study were not formally part of a particular thought collective (such as the community of medical professionals), traces of different thought styles may be seen in their narratives and search behavior. They may be considered as “exoteric members” in Fleck's terminology: someone who shares the thought style without actually being a member of the thought collective (e.g., an individual who adheres to a particular religious dogma without being a member of that church). The particular thought styles that users aligned with—and how these shaped user practice in searching for and evaluating medical information online—is the first question we address in the following analysis.

The second question we will answer concerns the role played by technology in users' individual search behavior, and how it affects users' online health information practices. Besides individual thought styles, technology needs to be considered since “the starting point—portal, domain name, search engine, home page of a user tool—cannot be separated from the progression of a search, for the former is determinant of the latter” (Adams, de Bont, and Berg 2006, 70). In the exploration we will focus particularly on search engines and the “software sorting” they perform.

Graham (2005) introduces the term “software-sorting” to capture and describe the crucial role played by code in providing and denying access to all sorts of critical goods in contemporary society. Regarding the Web, search engines (and Google in particular) have become central tools in providing and denying access to information, both in the medical realm and beyond (Jansen and

Spink 2006). Due to its dominant position in users' online practices, Google is described as a gatekeeper to Web information since it directs users to certain websites and not to others (Diaz 2008).¹ Google's founders, Sergey Brin and Larry Page (1998), have described how Google's PageRank algorithm provides a mathematical way of ordering and ranking search results, since it uses the number and quality of links received by a website as an indicator of the value of that website. Hyperlinks can be considered as "votes" for a website, in a way that resembles the concept of recognition or citation (Brin and Page 1998; Mayer 2009). Search engine critics, however, have pointed to the information hierarchies and biases maintained by search engines because they systematically give prominence to bigger, well-connected websites at the expense of smaller ones (Introna and Nissenbaum 2000; Hindman, Tsioutsoulis, and Johnson 2003). Introna and Nissenbaum (2000) have thus concluded that search engines run counter to the democratic ideal of the Web. More recently, the trend for search engines to collect vast amounts of user data to personalize and customize search results has come under scrutiny. Besides the original index based on publicly available information—websites and link connections—search engines such as Google have created a second index based on proprietary information extracted from users' search histories, as described by Stalder and Mayer (2009). This index is used primarily to target sponsored links to users' locations and preferences (and thereby create huge advertising revenues), but increasingly also to personalize so-called "organic" search results. This circumstance raises concerns in terms of user surveillance, commercial exploitation of user data, and filtering processes based on (partly distorted) user profiles (Röhle 2009; Stalder and Mayer 2009; Fuchs 2011).

In the medical context, search algorithms are described as contributing to hierarchies of big, well-connected websites and smaller, marginalized ones. Seale (2005) finds that Web-savvy mainstream websites, such as those of major cancer charities, succeed better in gaining presence in search engine rankings, arguably at the expense of counter-cultural voices. Nettleton, Burrows, and O'Malley (2005) similarly conclude that conventional institutions and medical material is foregrounded in search engine results. Mager (2010) argues that search algorithms trigger commercialization processes of medical information online because big websites with a good PageRank are often commercial websites (such as health portals), which can afford search engine optimization strategies on a grand scale, and which can also afford to buy sponsored search results that are displayed alongside the organic ones. The above-cited research shows that search engines should not be seen as passively delivering health information to the user, but rather as actively influencing how health and medical information is sorted,

¹ More recently, social networking platforms, and Facebook in particular, have also been described as gatekeepers, since users increasingly enter and experience the Web through these services.

ordered into a hierarchy, and displayed to users. Instead of “silent intermediaries,” search engines may be seen as “full-blown mediators” in Latour’s (2005, 58f) terms: “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.”

Accordingly, ICTs are described as important mediators in health communication because they actively participate in and shape processes of health communication (Wyatt, Harris, and Wathen 2008; Mager 2009; 2010). Wyatt, Harris, and Wathen (2008) use the term “info(r)mediator” to refer to the complex configurations of people and technology involved in the communication and uptake of health information via ICTs. How Google—and the “software-sorting” it performs—mediates and shapes users’ online health information practices in the context of their individual “thought styles” is discussed in the following analysis.

Empirical Study and Methods

The empirical basis for the following analysis stems from an Austrian research project that investigated the Internet as a health information source from different angles (2005–2009, Department of Social Studies of Science, University of Vienna). For the purposes of this article, user observations and qualitative interviews conducted between 2006 and 2007 will be analyzed. Forty users were recruited via bulk mail, who varied in gender, age, educational background, Internet skills, and medical preferences, in order to represent the variety of different users searching for medical information online. Half of the participants were male, and participants’ educational backgrounds ranged from basic school qualifications to university degree. The youngest participant was a 16-year-old schoolgirl, and the oldest participant was a retired doctor over 60 years old. Some had better Internet skills than others (e.g., an IT technician compared with an elderly employee), and all expressed different medical interests. This will be discussed in relation to their “thought styles” in the following analysis.

Each participant was individually invited to our department and presented with a fictional scenario stating that they had just come from the doctor with a diagnosis of one of four chronic diseases: diabetes, asthma, eczema, or rheumatism (10 participants each). All the participants had used the Internet before, but no participant had any personal experience of the disease they were randomly assigned with (if that was the case we exchanged the disease). The participants were additionally provided with some information that a doctor would provide about the disease. The participants were then asked to use the Web

to search for information relevant to them in this particular situation. To avoid imposing a particular browser, website, or search engine on the participants that they would not otherwise use, two different browsers were available on the laptop used for the user observations. Each of the browsers opened with a blank page to provide users with a free choice of how to start their searches. Search histories and cookies storing user data were deleted after each search to prevent users from choosing websites others had used before, and also to prevent search engines from personalizing search results on the basis of previous searches (factors such as the location captured by the IP address of the computer or language were still used by the search engine to localize search results). The participants' online searches were saved with the commercial software "My Screen Recorder,"² which captured the desktop activity and stored it as a video file.

Previous research has shown that how users conduct Web searches on a medical topic, and how they remember and describe the searches afterwards may not necessarily correspond (Eysenbach and Köhler 2002; Nettleton, Burrows, and O'Malley 2005). The method of user observations we employed enabled us to observe how users actually searched for a chronic health condition, and how technology (and search engines in particular) influenced their strategies, which is hard to grasp solely through interviews. Further, we assumed that researching a topic on the Internet requires skills and implicit knowledge that is hard to explain: the searches thus allowed users to experience a health-related Web search before talking about it. At the same time, the user observations also carry certain limitations in their setup. First of all, the idea of performing a long Web search after receiving a (fictional) medical diagnosis was imposed on the participants by giving them about one hour of search time. Secondly, the information given to the participants—such as the orthodox medical term for the disease, possible influencing factors such as lifestyles, and suggested medication—may have partly determined the search that followed. Finally, the participants neither experienced an encounter with the doctor themselves, nor felt the disease symptoms, nor a state of crisis. Hence, elements such as urgency, specificity, and embodied symptoms involved in "real" health searches were lacking, which may have influenced not only participants' search strategies, but also their practices of interpreting the health information they found online.

We therefore conducted qualitative semi-structured interviews with the 40 participants immediately after the user observations to gain a better understanding of their own perceptions of the search, and the way they evaluated and made sense of the information they found. The participants were asked how they started their search, what kind of information they looked for, if they were satisfied with the information they found, how they navigated through the Web, how they

² <http://www.deskshare.com/screen-recorder.aspx>.

selected websites, how they evaluated and interpreted the information, and what role website providers played in these practices. In these interviews, the hypothetical search situation was compared to real health searches to contextualize the material gained in the user observations and to prevent excessively biased results. Finally, 10 users were presented with their own searches (captured in the video file) and invited to comment on them to get an idea of how they themselves perceived their searches. The interview material was fully transcribed, coded using the qualitative research software ATLAS.ti,³ and analyzed along the central research questions following a Grounded Theory approach (Glaser and Strauss 1968).

Thought Styles, Keywords, and Evaluation Practices

We started the interviews by asking participants about the type of information they had looked for. Some participants answered by mentioning specific information they found in relation to the health conditions they searched for. Most participants, however, described the information they were interested in by referring to their own model of medicine or “thought style” (Fleck 1981 [1935]). A middle-aged employee stated clearly that he searched for medical “facts” because “I rely on orthodox medicine.”⁴ Like him, approximately half of the participants argued that they looked for facts, such as the cause of the disease or orthodox treatments, to interrogate the doctor and participate in medical decisions, mirroring the model of shared decision-making discussed earlier (Anderson, Rainey, and Eysenbach 2003). Information about medication was also relevant to these participants, as drugs in particular were seen as an issue that required negotiation with the doctor. Throughout the interviews the participants regularly fell back to their “orthodox medical thought style,” when speaking about the quality of the information, for example.

The other half of the participants, most particularly women, were more interested in finding medical and health-related information to help them in their day-to-day routines, reflecting the idea of the “informed patient” who takes health matters into their own hands (Hardey 1999; Broom 2005; Barker 2008). Rather than standardized medical solutions, these users were interested in information that enabled them to act in terms of measuring and controlling blood sugar levels, or handling an asthmatic attack, for example. Accordingly, they primarily tried to learn about experiences and stories from other patients, reflecting an “experiential

³ <http://www.atlasti.com/>.

⁴ All interviews were conducted in German; the quotes presented in the empirical analysis have been translated into English by the author.

medical thought style.” Of this latter group, a quarter of the participants additionally said they tried to find information about alternative medicine such as homeopathy or traditional Chinese medicine. A self-employed participant (having searched for information about eczema) straightforwardly described what he had looked for: “Yes, against my own backdrop I immediately searched for natural remedies in relation to eczema, of course.” Later in the interview he mentioned how he would have made use of the information he found online:

“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 (...) Well, honestly I would not take the salve the doctor prescribed at least for a couple of weeks or a month.”

This quotation clearly shows that our participants’ online practices appeared to be tightly interwoven with offline medical experiences, confirming Kivits’ (2009) research. A holistic perception of the body, health, and illness—an “alternative medical thought style”—clearly influenced what kind of information users looked for online. But how do different thought styles shape users’ practices and interactions with the technology?

To find information that met their highly individual “models of medicine,” most participants immediately turned to search engines. Thirty-five out of 40 participants opened Google straightforwardly, confirming Google’s important gatekeeper role (Diaz 2008).⁵ Users with an orthodox medical thought style encoded their interests in formal medical search strings such as “type 2 diabetes” or “eczema and causes,” while users with an experiential or alternative medical thought style searched for terms like “avoid asthma attack,” “diabetes recipes,” “eczema and cleaner wrasse,” or “rheumatism and radon galleries,” which are supposed to have therapeutic effects. This exemplifies that users had learned to express their interests in a language the technology would “understand.” The keywords, in turn, allowed users to organize Web information according to their preferences and browse websites accordingly. In the process of filtering and assembling heterogeneous information through use of keywords, users first checked whether the information they found met their respective interests, confirming previous studies (Nettleton, Burrows, and O’Malley 2005; Adams, de

⁵ Three participants could not immediately find Google, since they typed Goggl or Googl instead (the reason was that the browser of their home computers had Google as its starting page, as they said in the interviews). One participant started his search with Wikipedia, another one with a general health portal she knew from a previous health search. Some participants tried other search engines, such as Yahoo!, Alta Vista, or the Austrian search engine Astronaut, in order to compare these results with Google results at the end.

Bont, and Berg 2006; Höcher 2008). Instead of evaluating websites as relevant or irrelevant per se, they rather interpreted the medical information in relation to their own thought styles, resembling case studies from the literature on critical PUS (Lambert and Rose 1996; Busby, Williams, and Rogers 1997). Having been asked how she evaluated medical websites, a young university employee, who searched for experiential knowledge, answered immediately:

“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.”

One participant argued that he would evaluate information from self-help groups as not “100 percent right” in the context of his own “orthodox medical thought style.” Contrary to assumptions made in the realm of medical professionals and policymakers (European Commission 2002; Eysenbach and Köhler 2002; Khazaal et al. 2012), the provider of the information and its institutional affiliation were not highly important in evaluating the relevance of websites, concurring with other studies (Adams, de Bont, and Berg 2006; Höcher 2008). Further, none of the participants used or mentioned standardized quality criteria such as HON or DISCERN. Rather, the “feeling” for a website and its language helped users to evaluate the information in the context of their own bodies of knowledge. One young participant stated:

“If I would have the choice between two websites and I would not want to read through all the information to see what content is more appealing, then I would take the one with the better design to be honest.”

This indicates that the technical mediation of the information involved a transformation of the “social body” (Wynne 1992) as certain aspects (such as the author’s institutional affiliation) lost importance, while others gained importance, such as the information architecture and design of the website, and the amount of advertising present.

Talking about providers and users of medical information on the Internet, a student said this would relate to “discussions on modernity and post-modernity very well, that you construct your own world.” Post-modern thinkers, such as Lyotard (1979), have argued that “grand narratives” are increasingly replaced by “versions” of truth and reality, undermining modern confidence in (scientific) truth. Drawing on the notion of post-modernity, the participant indicated that, instead of the provider, the user should be seen as the one ordering and constructing the world of information today. The control of information in online environments may be seen as passing from website providers to users, as Weinberger (2007) argues. In this process, technology, and the search engine

Google in particular, plays an important role, as we will see in the following section.

Software Sorting, Information Hierarchies, and Transformations

According to its PageRank algorithm (Brin and Page 1998; Mayer 2009), Google assembles and displays websites corresponding to users' keywords in a linear order. The more links a website receives from other websites (i.e., the more it is referenced by others), the higher the website is displayed in the result list (among other factors such as clicks from users, which have gained importance in recent years due to the "second index"; Stalder and Mayer 2009). Consequently, not all websites gained equal positions in our participants' search results—rather, big, well-connected, often optimized websites, such as popular medical institutions or commercial health portals offering orthodox medical information, gained one of the "top ten seats" (Introna and Nissenbaum 2000) in participants' searches. Websites from self-help associations that provided more experiential information or information about alternative medicine were ranked lower (Seale 2005; Nettleton, Burrows, and O'Malley 2005; Mager 2010). Since users primarily worked down the result lists by returning repeatedly to that listing, the hierarchy presented by Google was of crucial importance in determining which websites were reached by users. This aspect was addressed explicitly in the interviews. A bookseller, having searched for alternative medicine in the context of asthma, stated:

"Well, the first impression I got was that the websites were predominantly doctor-centered, with incredibly much orthodox medicine. The first things I found were hardcore orthodox medical practitioners anatomically explaining the progression of the disease, and also the medication and so on (...) It almost seemed to me as bashing alternative medicine."

A university employee had a similar experience when searching for information about eczema. She explained why she thought alternative medicine was less prominent online:

"Because orthodox medicine is well established. Because it simply exists longer and because there is, let's say, 90 percent orthodox medicine and 10 percent alternative medicine. It is thus not surprising that a preponderance of orthodox medicine is created online as well."

These quotes illustrate that not only users' individual thought styles, but also standardized ways of pre-filtering, and the "software sorting" performed by the search engine, shaped what information users ended up with.⁶ Technologies such as Google may hence be seen as contributing to information hierarchies, which partly overlap with offline power relations as shown by studies on the representation of health information in search engine results (Seale 2005; Nettleton, Burrows, and O'Malley 2005). Even though the PageRank algorithm has changed over the last few years, and more social media platforms (particularly the user-generated encyclopedia Wikipedia) are now present among the top Google results,⁷ offline power relations are still reified in search results according to a recent study on the representation of human genome research in search engine results and classical media (Gerhards and Schäfer 2011). How the increasing personalization of search results influences real-world searches needs to be addressed in future research, since the majority of users do not delete search histories and cookies (as we did in the observations), and would hence be served with more customized search results and sponsored links (especially when logged into Google email accounts or other Google services which provide additional information that is used to personalize search results).

Besides the order in which health information was presented, Google crucially influenced how the information was formatted and presented to users and, in turn, how users interacted with and evaluated the information they found. By using the quantity of links (and not the quality) to measure a website's importance, Google presented "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). Moreover, the search engine took particular subpages out of their overall context by directing users to (keyword rich) subpages, rather than to homepages that explained the overall aim and structure of a website. Users consequently rarely entered websites via the homepage, therefore often missing the identity of the website provider (which is often presented on the homepage)—yet another reason why users did not pay much attention to website providers or quality labels.

On being asked whether she remembered a particular website she was talking about in the interview, a female risk manager answered that she

⁶ Interestingly, the different health conditions triggered pretty similar search engine results, since general health portals like Netdoktor.at or Netdoktor.de showed up at the top of all Google search results, particularly when generic search terms such as "eczema" or "asthma" were chosen. Slight differences appeared, however, when users went further down in the search results or chose more specific search terms, reflecting the range of websites that exist in different issue areas; for example more diabetes self-help websites than asthma self-help websites (mirroring Austria's lively diabetes self-help scene, both online and offline).

⁷ Wikipedia now often reaches top positions in Google's search results due to the huge amounts of text and links it contains and the broad range of topics it covers.

“[couldn’t] really tell which link it actually was” because “one rather remembers that one has put a combination of keywords into Google and that the site appeared on the third position.” This shows that Google should not merely be seen as an entry point to the Web, but rather as critically influencing how users interact with and perceive health information online. Going back and forth to Google, users ended up with bits and pieces of information from different websites instead of more coherent, discursive knowledge presented on any one website. Enabling users to order Web information according to their interests and keywords, search engines may therefore be seen as facilitating the unbundling of coherent pieces of information packaged by website providers and the extraction of information that meets user needs, while leaving the rest of the site untouched. Search engines such as Google may hence be considered as contributing to “informational knowledge” (Lash 2002)—knowledge which is disembedded, de-contextualized, and partly meaningless. “Unlike discourse or discursive analysis, [informational knowledge] does not subsume particulars under universals. It is instead a mass of particulars without a universal” (Lash 2002, 144).

Accordingly, our study participants had to constantly interpret, integrate, and re-configure fragmented bits and pieces of information and create their own narratives and linearity according to their individual medical thought styles. “Well, you have to search in a targeted way. Otherwise you’ll find everything, which means nothing,” as a student expressed pointedly. In this process users developed more relational concepts of reliability based on comparison, rather than on website providers and their quality status, as suggested by medical professionals and policymakers. In response to the question why he thought a particular piece of information he found was reliable, one user, having searched for “medical facts,” answered:

“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.”

During his search, the relation between diabetes, physical training, and nutrition crystallized as essential information because it recurred on various websites, confirming the research mentioned above (Nettleton, Burrows, and O’Malley 2005; Adams, de Bont, and Berg 2006; Höcher 2008). These strategies, however, should not be considered as “sub-optimal,” as they sometimes are in medical research (Eysenbach and Köhler 2002), but rather as tightly intertwined with users’ search practices and the dominant role played by search engines. Instead of following the information structure provided by website providers, users followed the information structure presented by Google, which channeled

users away from homepages and towards fragmented pieces of information, which were often disconnected from website providers. Accordingly, some users created their own packages of information in the form of a Word file that contained information from different websites, all corresponding to their individual needs. One participant, having searched for diabetes, finally argued that this information would help her to better cope with diabetes if she were really to suffer from that health condition. Another participant who placed reliance on orthodox medicine said that he would take the information to the doctor to check its accuracy, underlining the tight entanglement of users' online activities, thought styles, and offline medical practices.

The dominant role played by search engines in user practices, and the reordering of information they performed, requires new skills on the part of users. Experienced Internet users (mostly younger ones) displayed quite elaborate techniques for selecting and combining keywords to reach health information that met their highly individual thought styles. For example, they formulated short questions to reach discussion forums and self-help communities. Less experienced (often elderly) users were more reluctant to change keywords and had trouble finding certain information—alternative medicine in particular, which they described as “hidden” in the interviews. Hence, a certain knowledge about and experience with search engines is needed to challenge the biases and information hierarchies constructed by these new gatekeepers, as well as the search engine optimization strategies increasingly employed by providers of online health information (Mager 2010). Besides technical know-how and skepticism towards dominant tools such as Google, more profound skills such as the ability to combine and integrate heterogeneous health information in the context of users' own knowledge—often described as “media literacy” or “information literacy” in debates on media education⁸—are necessary. More than any other medium, the Web may be seen as requiring an active agent who is capable of interpreting heterogeneous information and creating knowledge out of it, rather than a passive recipient. This applies even more to Web 2.0 technologies such as blogs, wikis, and podcasts, which are increasingly used for medical purposes (Adams 2010), and which provide users with even more technical flexibility. A follow-up study would be helpful to better understand whether and how social media platforms such as Wikipedia, Twitter, or Facebook affect search engine results, and how users respond to these developments in the medical field.⁹

⁸ For a more detailed discussion, see Koltay (2011).

⁹ Research by the author on the representation of the biofuel controversy in search engine results shows that more Wikipedia sites, Facebook groups, and blogs are now present among the 10–30 Google results than they were in 2006–2007. The overall picture of information hierarchies and biases presented in this article, however, has not fundamentally changed since then.

Discussion: Search Engines Matter

The above analysis has shown that users' online health information practices are co-shaped by users' individual "thought styles" (Fleck 1981 [1935]) and search engines' standardized ways of "software-sorting" (Graham 2005). The participants in our study pieced together and integrated health information they found online according to their various interests, mirroring their orthodox, experiential, or alternative medical thought styles. Moreover, search technologies, and Google in particular, mattered since they played a central role in users' practices. Rather than passively transmitting information, they actively mediated (Wyatt, Harris, and Wathen 2008) and shaped what information users ended up with, and how they interacted with and evaluated bits and pieces of information they found on various websites. The way search engines order, filter, and transform Web information therefore needs to be taken seriously when trying to understand how users obtain medical knowledge from the Web, and what skills are required in these practices.

Just as using a medical encyclopedia involves a range of skills, employing the Web as a health information source involves certain abilities such as using search engines, critically assessing the vast number of search results, and integrating heterogeneous information according to one's own body of knowledge.¹⁰ Quality criteria and labels for websites such as HON or DISCERN can thus only help to a very limited extent. First, our users did not all try to find approved orthodox or "evidence-based" medical knowledge, as is often assumed. Rather, half of our users went online to become informed about alternatives to orthodox medicine, such as self-help possibilities and alternative treatments. Second, technology, and search engines in particular, partly hindered search and evaluation practices based on website providers and their reliability status (as imagined in various health experts' visions: European Commission 2002; Eysenbach and Köhler 2002; Khazaal et al. 2012).

Categories such as trust and reliability were re-negotiated in online environments, not least because the authors' "social body" (Wynne 1992) became transformed on the Web. While institutional affiliation and actual behaviour are central in face-to-face interactions, design elements, language, and information architecture turned out to be more relevant online than the providers of the information. A central reason is that website providers were often hidden to users, since search engines channeled users away from homepages and towards sub-pages that did not necessarily state the identity of the website's provider, or whether a quality label was present on the website. As a consequence, trust and

¹⁰ Not to mention questioning the privacy issues and economic implications posed by search engines, which go beyond the scope of this article.

reliability developed in users' practices of comparison, rather than being an implicitly "yes-or-no kind of attribute" as argued by Adams, de Bont, and Berg (2006).

Consequently, new ways of engaging with users and their highly individual practices need to be found, rather than educating users from a superior position with standardized quality criteria that do not correspond to users' practices and needs. Attention should shift from quality labels and criteria based on "source positivism" (Haider and Sundin 2010) towards users' own search and evaluation practices. The introduction by the HON foundation of a downloadable toolbar, enabling users to see in the browser window whether a website is certified or not, may be a first step in the direction of acknowledging users' online practices and the important role played by search engines. Besides such small-scale adaptations, however, more large-scale reconsiderations of how to assist users within their heterogeneous online practices are required.

Conclusion

Policymakers and medical professionals are advised to critically examine top-down initiatives of governing online medical information and to develop more technology-focused and dialogue-oriented measures. Health policymakers are invited to pay attention to user practices and to take search engines into account when trying to reach an effective policy for assisting users in how to acquire medical knowledge from the Web. Emphasis should be placed on the considerable impact the Web and its central gatekeepers (like Google or other ranking instruments that may gain importance in the future) have on knowledge practices. A critical debate on search tools and their underlying mechanisms is needed to raise awareness about the biases these tools construct in the medical field (e.g., serving big institutions and orthodox medicine first), the process of information fragmentation supported by search engines, and what new forms of information literacy are needed to address these challenges in the sensitive area of health and illness. A serious discussion of "critical health literacy" (Chinn 2011) that actually responds to user practice and needs may be initiated only by understanding the tools that pre-filter health information for the user, and how these tools influence the way trust and reliability are reconfigured online.

Health professionals are invited to reconsider widespread fears of the Web as a threat to medical autonomy, and start thinking about ways of using new technologies to start a true dialogue with patients. Online printouts, assemblages of Web information created by patients—such as those developed in our user observations—and patient experiences with the Web may be seen as windows into patients' own knowledge cultures. They can provide insights into patients'

own approaches to health, illness, and the body. A more dialogue-oriented approach, however, would require a healthcare system that gave doctors enough time and freedom to engage with patients' health information practices and Internet routines. Critical research is needed to investigate not only doctors' resistance to "informed patients," but also how local healthcare systems and EU health policy contribute to doctors' attitudes and, most importantly, how to adjust this policy. ICTs, and the Web in particular, should not be interpreted as an easy solution to the socio-political problems faced by healthcare in local and European contexts—as they sometimes are in policy discourses (Felt, Gugglberger, and Mager 2009). Instead, they should rather be recognized as posing new challenges not only for patients but also for doctors and healthcare policy, which can only be met with long-term measures, rather than quick, standardized solutions.

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