

# **Under Construction**

**Reviewing and Producing  
Information Reliability on the web**

## **Werk in uitvoering**

Over het ontwikkelen en beoordelen van  
informatiebetrouwbaarheid op het web

**Samantha Ashley Adams**

# Colophon

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### **Thesis**

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**Samantha Ashley Adams**

born in Winston-Salem, North Carolina, USA

# Doctoral Committee

Promotor: Prof.dr. M. Berg

Other members: Prof.dr. M. Trappenburg  
Prof.dr. J. van der Lei  
Prof.dr. N. Oudshoorn

Copromotor: Dr. A.A. de Bont

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# ***Introduction***

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**Person 1: The internet, huh? Well, I'd like to know what there is to help me determine the reliability of information in newspapers and books?**

**Person 2: Exactly. What about medicine ads on television and in magazines?**

**Person 3: Forget all of those – what guarantees the reliability of words that come from my doctor's mouth?** (Notes from an informal discussion, 2002)

In their every-day, common-sense reflections, the discussants quoted above hit on the central points that underlie this thesis – points that sometimes seem to have eluded many during the past few years. First of all, the issue of information reliability is *not* specific to internet-based technologies and second, the reliability of any information, but especially medical information, cannot be couched in *de facto*, black and white terms, regardless of medium and/or message. As the public face of “the Internet,” the world wide web is the most recent of many aids that have evolved through the years to assist human interaction (Langford, 2000) and serves, in this respect, merely to provide a new spin on debates (e.g.: about the reliability of information) that, in many cases, have existed since antiquity. Therefore, one can ask, if the web as a medium is non-differentiable from any other media and the issues of information reliability are not special to it, then why is this work written as representative of 5.5 years of academic research into understanding the problematic of finding reliable medical and health information on the web?

DiMaggio et al (2001) suggest that there is a uniqueness of internet-based technologies that lies in the integration of all the different communication media and numerous types of content into a single medium. Indeed, the world wide web and its accompanying debates about the reliability of information are situated at a complex intersection of hybrid combinations of media, but also of actors, spaces and standards for/practices of information review, to name just a few. DiMaggio et al make a common sociological argument in their suggestion that the current rapid growth and change of internet technologies provide unique opportunities for studying these early stages of diffusion and institutionalization, before everything is decided and settled. They further argue that the choices that are made during this time will shape not only the technology, but also the normative structures around it, many of which have, until now, been based on *assumptions* about users and use, rather than actual understandings of these.<sup>1</sup> Markham's (2003) work aligns with this latter position, further arguing that researchers, especially, contribute to how understandings of internet technologies and their users (as well as accompanying policies, procedures and laws) are shaped, directed, discussed and perceived. Together, different authors writing about emergent opportunities for research point to methodological, philosophical, political and ethical reasons for studying internet technologies and any of their accompanying controversies. We must seek to understand how internet

technologies become incorporated in existing information-seeking activities and other communication behaviors (ranging from the individual to the institution and beyond) and now have unique opportunities and methods for doing so.

In this respect, the question is not so much *if* we should study emergent hybrid technologies, or revitalized debates in their alternative contexts, but *how* we should study them.<sup>2</sup> How must a researcher structure any study such that it avoids the paradoxical situation that the very nature of the fact that it is being studied at all suggests something new, special or different? (Henwood et al, 2002) The answer to this question can be divided into three parts. The first part of the answer has already been mentioned – use of the technology must be studied in a larger social, informational and technological context that extends beyond one single medium. In this respect, the world wide web becomes just one of many other media interfaces available to individuals. By not focusing only on the technology or the information it contains, one allows room for what Brown and Duguid call the “fuzzy stuff that lies around the edges” (2000, p. 1): contexts of use, backgrounds, histories, shared knowledge, social resources, and so forth. In seeking to study “use of the web,” rather than just “the web,” one component of this study places web use by individuals in the context of their personal use of other media and their specific searches for health information in the context of daily information gathering on the whole, thus expanding the focus beyond a single technological mechanism to include the context in which it is used and the human actors who are using it.

A second part of the answer is found in discussions about how to study the technology itself. Sassen (2004) discusses the importance of avoiding two analytical flaws: confining interpretations of the technology strictly to a reading of technological capabilities and relying on analytic categorizations that were developed under other spatial and historical conditions. Countering the latter analytic flaw, while difficult, is made easier by the underlying philosophy of studying open controversies. Outcomes of existing controversies regarding, for example, how to present medical or health-related information (from whom and to whom) on the web are uncertain and still being shaped. The decisions that are made now are not without consequence, as these will further shape how internet technologies and the information they contain are directed, used and perceived in the future. According to Langford (2000), the challenge lies in the relative positioning of debate and development. We can study these debates and developments in order to gain an understanding of how a particular piece of information is placed on the web under a label of reliability – and how these labels of reliability can differ. It is first necessary to get inside “reliability”: At what stage do we find this claim? Who is producing the claim and striving to transform it into a fact, and how? (Latour, 1987)

Countering the flaw mentioned in Sassen's first point indicates a necessary understanding of the web as, at once, both human/social and technical. It cannot be addressed, discussed, studied or understood as a technical assemblage standing alone for individuals to use, but rather, it must be also be addressed, discussed, studied and understood from the perspective of the complex heterogeneous network of persons and materials that contributes to and supports it. For example, consider domain endings (such as .com, .org, .gov, and .edu, or country endings: .uk, .nl), which are now taken for granted components of the internet – necessary to a url, they signify the general categorization of a site and, often, the country of origin. These domain endings, which now contribute to how individuals understand and interpret the web, have a long history of development, coupled with structured rules for creating, assigning and applying them. ICANN, the Internet Corporation for Assigned Names and Numbers<sup>3</sup>, a private sector, non-profit corporation created in 1998, coordinates the management of the technical elements of domain names by overseeing the distribution of unique technical identifiers used in the Internet's operations, as well as the delegation of top-level domains. With respect to the issue of reliability and health information, the organization is responsible for assigning (or denying assignment of) specific domains, such as the "health" domain proposed by the World Health Organization (see below, and chapters one and four). ICANN is illustrative of the regulatory challenges of the internet and demonstrates how governments and international treaty organizations must work with businesses, organizations, and skilled individuals involved in building and sustaining the global internet.<sup>4</sup>

This approach to studying the internet suggests the importance of understanding the work practices that contribute to both the technical and social substantiation of websites and other internet-based initiatives. The bulk of this study, therefore, has been devoted to understanding the routine, daily work (Suchman, 1995, 2000) that is carried out by individuals and organizations to create and sustain different types of web-tools for finding and assessing web-based medical or health-related information. Technical features of the medium are not obscured from view, but instead are considered as part of broader contexts of social life. (Slevin, 2000) In this sense, attention must also be given, for example, to normative consequences that accompany the selection of information. Including one piece of information for a given tool means excluding another. The actors who create tools and label information as reliable also decide which topics receive attention and which do not, thereby defining roles, relations, power and capacities.<sup>5</sup>

The final part of the answer of how to study the internet is that there is a need to be reflexive about how internet-based technologies are discussed. Prevalent conceptualizations and available discourses carry the potential to highlight certain aspects while rendering others invisible. (Suchman, 2000) Researchers must be wary of terms that carry

technological determinism (such as Markoff's [2000] reference in the popular press to a "fast changing genie" that is "altering the world") and must also be careful in utilizing metaphors of popular discourse (for example, references to the internet as an "information superhighway" or "great frontier").<sup>6</sup> The Association of Internet Researchers (AoIR), an inter-disciplinary body of self-identified researchers of various techniques, technologies and social issues related in some way to this particular network that connects computers, have discussed at length the language for talking about, and the grammar for writing about, these inter-related research subjects.<sup>7</sup>

For this reason, it is important to give a moment's attention to how different aspects are discussed in this thesis. In many circles, the internet is (mis-)understood, often interpreted and referred to as a source, rather than as a medium. The word internet, referring to a technical connection between computers, is also often used interchangeably and synonymously with the world wide web (www or, in this thesis, just "the web"), although they are actually two different things. The latter, which is defined by the particular protocol to which it adheres (http), is a little over ten years old and currently the most used interface for accessing the former, which has a traceable history dating at least 40 years.<sup>8</sup> With the exception of Ch 1, where I employ a modicum of poetic license to refer to the interface, the term internet is used in this thesis only when referring to the technical components of the network (protocols, codes, computer structures, etc.) or in consistent referral to the research (and/or discourse) of others.

Discourse about the internet has introduced new words and concepts into our vocabularies<sup>9</sup> and has opened issues of spelling and capitalization. Researchers must learn to read and use unfamiliar names, acronyms and unconventional spellings. (Markham, 2002) In this thesis, internet and web are not capitalized<sup>10</sup> except where capitalization is used, as in the opening paragraph, between quotes for the purpose of capturing the popular manner of discussing these as technological entities that stand alone. Empirically, I endeavor to remain true to the names of sites and initiatives as they present themselves, allowing for the unconventional uses (or non-uses) of capital letters, rather than correcting these for reasons of readability or grammatical propriety. Different chapters shall also indicate the difficulty of discussing the non-professionally trained seeker and user of web-based medical or health-related information (e.g. chapters four and six) and the tendency of other authors to interchange (or use circularly) the terms reliability, trustworthiness, quality and accuracy (e.g.: chapter one). Finally, the popular trend of inserting an "e-" or "cyber" as prefixes to words such as health, medicine, space, etc., is avoided where possible, as this terminology sets the technology apart and otherwise undermines the suggestions that the internet is integrated into an evolutionary line of communication media, is embedded in everyday life, and should be studied as such.<sup>11</sup>

## ■ RESEARCH QUESTIONS

By beginning with current debates about the reliability of web-based medical and health information, this study is empirically led. Reliability is not a given, and what constitutes a reliable piece of information (or medium for communicating that piece of information) is not pre-defined. Likewise, the relevant actors, the best or most important tools, correct (or even actual) use of the web, information, or tools, and in what (types of) spaces, and necessary skills associated with this use, are also not pre-defined. Further still, they are understood to be heterogeneous and still fluctuating (and therefore, worthy objects of study). As such, questions regarding these different aspects necessarily formed the rudimentary questions that I sought to answer with this study:

- Which concepts of reliability are ascribed in the technologies developed to control the medical information on the internet and to facilitate users in identifying relevant sites?
- Which borders are constructed to separate sites that are marked as reliable from sites that are marked as unreliable and what spaces are formed as a result?
- How do these technologies re-constitute, configure or construct users?
- How do patients select, qualify and use health information and web-based tools?

These particular research questions are contextualized and interpreted primarily from within the context of political theory and theories stemming from studies of science, technology and society, but I also draw on insights from concurrently developing fields, such as internet and new media studies and studies of consumer health informatics. The research study assembled here indicates recognition that the renewed debate about the reliability of web-based medical information brings with it longer-term, broader debates about rights to authorship, effective population-based patient education, trust in authority, making sense of illness, the promises of technology, empowerment and reflexive identity, and what constitutes “evidence,” “best practice,” or even “expertise.” Although this is a non-exhaustive list, it helps to reflect how complex and intertwined the methodological, philosophical, political and ethical components of “singled out” debates with respect to internet technologies actually are.

## ■ WHAT IS BEING DONE TO GUARANTEE THE RELIABILITY OF MEDICAL INFORMATION?

Having established the whys and hows of studying the web, its use in context and its open controversies, we can now turn our attention to the controversy that is highlighted

in this thesis. As I discuss in detail in chapters one and three, early discussions about the web suggested the arrival of a revolution in publishing – the speed of the publishing process would increase, new (types of) authors would emerge and everyone with an internet connection would have instant access to the world wide web and its various types of information. Anyone could publish anything from anywhere and anyone else could access it from anywhere else at anytime. While this was heralded as the advent of increased choice, such an open publishing environment quickly led to concerns about the un-regulated nature of the available information. The consequences of the variable nature of “anything, anywhere” have become especially obvious in more or less controlled information fields such as health care, legal practice and finance, where the risks of misinformation or malpractice for health, safety and pocketbook are considered to be especially high. (Coiera, 1996; Hersch et al, 1998; Stanford et al, 2002) In the absence of formal quality control, it was argued in medical and medical informatics literature, internet users were in “grave danger” of falling prey to unreliable information.

The suggested unreliability of this information could take any of several different forms: misinformation such as mistakes, overload of (irrelevant) information, intentionally misleading or fraudulent information, the availability of information and products related to alternative medicines, country-specific treatment information, undisclosed hidden financial or political interests that blended into how information is presented, and so on. (Eng and Gustafston, 1999; Crocco et al, 2002; Davies et al, 2002) Use of the internet by non-medically trained individuals was interpreted largely as typing a keyword or search term into a search engine such as Google, which simultaneously made ungrounded assumptions about use and highlighted concerns about the efficacy of search engines in returning relevant results and in not discriminating on basis of quality. (Cain and Mittman, 1999; Cooke, 1999; Berland et al, 2001)

Warning of the risks to health and well-being that such unreliable health information presented to “vulnerable” web users, various authors suggested that these users needed assistance in learning how to search for, sort through and assess the available information. (Eysenbach and Diepgen, 1998; Jadad and Gagliardi, 1998; Eysenbach, 1999; Kasirer, 2000; Rigby et al, 2001; Wilson, 2002). The forms of assistance that these different authors proposed were as numerous and varied as the forms of unreliable information that could be found on the web. Suggestions ranged from selective subject gateways (or portals), where resources were selected and tagged with descriptions, and other lists of approved/endorsed websites, to an auditing mechanism emerging from the medical community (Belcher et al, 2000; Pautler et al, 2001), a special url with a “.health” domain name afforded to sites approved by the World Health Organization (Risk and Dzenowagis, 2001) and varied combinations of voluntary ethical codes, content auditing procedures,

filtering and labeling of sites, all of which could be signified with special quality icons, or trust marks. (Eysenbach, 2000a, 2000b, 2001; Nater and Boyer, 2000) More recently, special downloadable browsers were also created as supplements to existing initiatives (HON and MedCIRCLE, discussed below) in order to allow patients to set their own criteria for searches within databases of already reviewed sites. A central tenet of all of these initiatives was the need to combine the given technique with broad-scale programs for patient education.

This line of discourse and the resulting initiatives do not form a uniform approach to medical information on the web. Although some authors would have us believe that these initiatives are necessary to combat a spreading epidemic of misinformation (Eysenbach, 2002), Coiera (1998) preemptively called this idea into question by reminding the medical community that retrieval of medical information from non-medical sources was neither new, nor internet specific. As Schroeder also points out, "Snake oil salesmen have been with us always, now they attract their customers through modems and animated GIFs, instead of brightly painted horse-drawn wagons." (in: Rice and Katz, 2001, foreword, p. x) Furthermore, Risk and Dzenowagis (2001) saw the "burgeoning output of codes" that resulted from efforts to create quality standards as equally problematic to the reliability issue itself.

Ferguson (2002, 2004 [with Frydman]) argues that many clinicians have underestimated the benefits and overestimated the risks of internet-based information and technologies and has gone so far as to question the discussion about the reliability of information on the web as an overreaction. He further argues that there is not enough convincing evidence to conclude that information is inadequate, incomplete or scary. In a similar vein, Craigie et al (2002) shift attention away from the web as the root of the problem by questioning whether it is more disconcerting that individual experts disagree with internet or that several experts disagree with each other. However, responses to these types of arguments have included, among other things, the publication of documented cases of harm and the establishment of a database of adverse events related to decisions based on poor information. (Eysenbach and Kohler, 2002a and Kiley, 2002)

## ■ THE CASE STUDIES

Although there are, internationally, almost 100 initiatives that can be categorized as "striving toward more reliable health information for lay users,"<sup>12</sup> I originally selected the following initiatives on the basis of their name and longevity: Healthfinder, the national gateway provided by the US Department of Health and Human Services and the Code of

Conduct and accompanying hyperlinked icon (HONcode) created by the Geneva-based Health on the Net Foundation (HON). At the beginning of this study, each of these existed online for at least 4 years, which was considered to be 'old' for the web. Also, these two names circulated prominently in the literature about reliability and each served as a model-type for newly developing initiatives. At each of these institutions, I conducted interviews and observations and participated in team meetings. At HON, I was also trained to carry out review activities.

As a contrast, I also selected two initiatives that were under development at that time: the European collaboration MedCERTAIN, because of its similarity in type and relative position to the Health on the Net and Gezondheidskiosk ("health kiosk"), the portal proposed by the Dutch Ministry of Health, Welfare and Sport (MinVWS), because of its relevance to Dutch setting and suggested similarity to healthfinder. Due to circumstances in the course of the project, data collection was limited for MedCERTAIN and Gezondheidskiosk. Where possible or necessary, these changes are addressed in the individual chapters of this thesis. For MedCERTAIN, which underwent a transformation in collaboration and style, emerging in 2002 as MedCIRCLE, I rely on interviews with the principle investigator and analyses of the respective home pages for these two initiatives. The portal Gezondheidskiosk was removed from the web not long after its launch and was recently replaced by a new initiative, kiesBeter ("better choice"), for which I participate in two different think tanks (quality assurance and content). Data regarding these two portals is taken from e-mails and press releases about both, as well as notes from think tank meetings for kiesBeter.

Supplementary data in the form of interviews and individual website analyses was collected for the following: the US-based Quackwatch, the Dutch-based QMIC seal (proposed and implemented by the Dutch Research and Development Organization TNO), and the US website Medline*plus* (and one of its GoLocal spin-off sites), provided by the National Library of Medicine. This data enabled me to position these as critical cases against the standing case studies. In addition to the descriptions given below, the nature of research conducted for each of the initiatives is explained in the chapters where they are discussed and is further reflected upon in the conclusion.<sup>13</sup>

<http://www.healthfinder.gov>

*Healthfinder.gov* is a gateway, or web-portal, that was created by the Office of Disease Prevention and Health Promotion within the US Department of Health and Human Services in 1997 and revamped in 2001. The government agency transferred existing, free, easy to read information from the longer standing National Health Information Clearing-



house into web-friendly formats and also provided links to other government agencies, non-profit organizations, support groups, libraries and research institutions, where individuals could get more information (online or off) about a given condition. Healthfinder is discussed in chapters one, two and four.

<http://www.hon.ch>

*Health on the Net* was created in 1995 as a direct result of concerns about the reliability of web-based health information. It provides a variety of tools to help both patients and professionals find and use information. My research focused on two of those tools: the HONcode, an ethical code consisting of eight principles (see Appendix), with an accompanying hyperlinked icon and the downloadable browser that enables the incorporation of patient preferences into searches carried out within HON's database. HON's initiatives are discussed in all chapters.

<http://www.medcertain.org> and <http://www.medcircle.org>

*MedCERTAIN* was developed in 2000 as a collaborative effort that proposed expanding third-party review of sites on the basis of ethical codes to include review based on content auditing. It proposed three-tiered assignment of seals to indicate levels of review, as well as attaching metadata to individual websites. It was followed by *MedCIRCLE* in 2002, which abandons the idea of seals to indicate quality review, but uses metadata to label sites. Ideally, individuals who download the MedCIRCLE browser can search for information on sites that have been labeled using specialized meta-data terminology. MedCERTAIN is discussed in chapter one and MedCIRCLE is discussed in chapter four.

<http://www.kiesbeter.nl>

*Gezondheidskiosk.nl*, the Dutch-language health portal provided by the Ministry of Health, Welfare and Sport went public in 2000 and was online (although not fully developed) for approximately one year. *KiesBeter.nl* was launched at the beginning of 2005 and began with information about health services and a separate section containing topical content was launched in November 2005. There are plans to expand kiesBeter to include a call-center and kiosk, mirroring the model provided by NHS Direct in the UK. *Gezondheidskiosk* is mentioned in chapter one and *kiesBeter* is mentioned in chapter three, but not explicitly analyzed due to the limited nature of the data.

<http://www.quackwatch.org>

*Quackwatch.org* is the web name given to a longer standing initiative run by Dr. Stephen Barrett to combat fraudulent information in health care. The organization publishes “reports” on its home page that break down and attempt to refute the argumentation of medical claims that are considered dangerous or fraudulent. The site warns users of links that they should avoid and recommends useful pages. Quackwatch is mentioned in chapter one and discussed in chapter two.

<http://www.qmic.nl>

*TNO*, a Dutch Research and Development Organization launched the *QMIC* trust mark for Dutch websites in 2002. The design of this trust mark follows the three-tiered MedCERTAIN model. QMIC is mentioned in chapters one, three and six.

<http://www.medlineplus.gov>

*Medlineplus*, a second US federal health portal, has been online since 1997. It contains information created and/or reviewed by the National Institutes of Health. Since 2003, the National Library of Medicine has been working to create daughter portal sites that provide information about health services on a local (state-based) level and link to medical content on *Medlineplus*. *Medlineplus* is mentioned in chapter one and discussed in chapters three and four.

## ■ THE STRUCTURE OF THIS THESIS

This thesis is divisible into three parts consisting of two chapters each. The first two chapters break open claims to reliability, the second set of chapters focuses on work carried out to produce and sustain the initiatives behind these claims, and the last two chapters examine reliability from the perspectives of users and understandings of use. Because I seek to understand what it means for information to carry a label of reliability, I do not assign *a priori* assumptions or definitions to that which I wish to explain (Law, 1992), but instead explore the concept as part of a trajectory that is still being socially produced, and the outcome of which is still uncertain. Each chapter singles out, and seeks to counter, one of the predominant assumptions, definitions or questions found in existing literature.

*Chapter one* begins by addressing the tendency of authors to compare the web to other (more) dominant media, such as the printed word and television, and to privilege the

latter (especially printed works) over the former with respect to reliability.<sup>14</sup> Although the book is now exemplified as a bastion of good quality information, histories of printed media paint a different picture.<sup>15</sup> Thus, while I agree that it is possible to compare media, I do not agree that we can do this in a manner that ignores said histories. We cannot compare the web with the book of today, but instead must draw a comparison between the web and the book in its developmental stages. Returning to the past enables us to see strains of similar ideas. This does not mean that they are always the same, and the point of the chapter is not so much to make a direct comparison, but rather to search for echoes of similarity and thereby draw upon history to introduce theoretical points of departure. (Timmermans and Berg, 2003) Using both empirical data from the aforementioned organizations and drawing on literature about other initiatives not included in this study, I look at the large number of actors, issues, materials and elements that are involved not only in discussing how to handle the issue of reliability, but also in actively creating initiatives that attempt to do so. What patterns of discourse are reproduced? What social and political choices are determining which notions of reliability will emerge?

*Chapter two* examines three examples in order to point to different notions of reliability that co-exist. Within medical and informatics literature there has been a dominant overtone of the need to search for overlap between existing approaches and streamline them into one universal norm. Reliability is broadly taken to be rather strictly defined, with well-known and relatively uncontested criteria in most scientific research. However, while use of this word perhaps implies a shared understanding, it can actually embody different things. Differences are not avoidable, nor do they just happen to exist; instead, they can be viewed as effects – as achieved or constructed. (Law, 1992; Aanestad, 2003) Defining reliability means carving out spaces and drawing boundaries – and such boundaries are drawn differently for different types of initiatives. For each example in this chapter (healthfinder, HON and Quackwatch), I extend an analysis of the public presentation of the initiative by examining its home page on the web. What components of information are disclaimed? How are sites selected by organizations and how do organizations utilize spatialities to draw boundaries around information?

The second set of chapters recognizes that all of these initiatives need networks in and through which they sustain their existence. (Latour, 1991, 1999) The socio-technical aspects of tools are hardly addressed in most existing studies, which focus rather on differences between information sources or the efficacy of a given type of tool. Therefore, in both of these chapters, I examine the initiatives from the production perspective – focusing on the actual work carried out by governments, medical professionals, etc, not only in reviewing information, but also in enrolling the public in activities related to assessing web-based information.

*Chapter three* goes behind the scenes of the initiatives to look at practices behind reviewing information. Hine (2001) argues that research has largely neglected attempts to understand how site developers think about sites – there exists a knowledge gap with respect to what they aim to achieve and whom they aim to reach. The same can be said for existing studies of reliability initiatives. Most of the existing literature on the topic focuses on which criteria compose the various selection policies of those initiatives – that is, how reliability is defined on paper. I argue that it is necessary to look beyond the individual criteria to how they are applied in practice. Moving beyond the work of Hine, I suggest that the subject of study can be disaggregated further, not looking at whole pages or initiatives, but focusing on one underlying component – the practice(s) of information review. Drawing on ethnographic work at HON and supplementary data gathered from NLM about *Medlineplus* and *GoLocal*, I examine practices of applying black and white rules to gray areas of information. What are the local understandings or assumptions that make the production of a reliability initiative meaningful? How does the application of rules in practice go beyond merely checking information to reinforce existing distinctions (such as those between lay and expert, global and local, non-profit and commercial, etc.) that current medical sociology and informatics literature otherwise suggests have been broken down by the availability of web-based medical information?

*Chapter four* looks at a different type of work that is carried out by individual organizations. Routine, daily work, such as the review practices examined in chapter three, is necessary to sustain an initiative and its claims to reliability. Additionally, organizations must also work to build the networks within and through which they carry out this review work. Concurrent with reviewing and posting information on the web, organizations also carry out different forms of promotional work to enroll individuals to help share the burden of “checking” information. The web is, in this sense, contextualized in a discourse of social responsibility and community values, simplifying the realities of practice in search of the ideal or perfect end user.<sup>16</sup> As in chapter two, I once again look at the public face of the initiatives, examining how these organizations present themselves. Drawing on examples from all of the initiatives under study, I question how the word “reliability” is used as a tactic of the work employed to enroll users in different ways. How is use re-defined and what skills are necessary for engaging in this alternative definition of use?

The final two chapters return to ideas about use, examining these as they are more commonly discussed in the literature about reliability – in the form of visits to websites and clicks on seals. I again look at prescriptions for use, but shift my attention from the production side of the initiatives to the use side. I juxtapose prescriptions for use with actual searching practices and point to omitted understandings of use.

*Chapter five* reports the results of an ethnographic study of how Dutch patients search for and assess health-related information on the internet. It is important to approach the web as one among many media that form both an individual's information "landscape" (Henwood, et al, 2003; Doupi, 2005; Hargittai, *in press*) and communication processes (Kling and Star, 1998). No matter how strong the reliability claim of a given initiative is, its impact and value will depend upon how it aligns with user perceptions, existing practices and the social context in which it is used. (Coiera, 1998; Doupi and van der Lei 1999; Suchman, et al, 1999) For this reason, the study reported in this chapter set out to understand what Dutch patients were searching for, when they turned to the web, how they started and developed searches on the web and how they assessed the reliability of the medical and health information they found during their searches. Going against the grain of more dominant discourse, the intent was not to be normative in judging search practices, indicating failures and the need for re-training individuals in how to search. Rather, I sought to understand the various behaviors of individuals. How do individuals use the web, both in general and specifically for health-related purposes? What was the relationship between online and offline information-seeking activities? What makes information reliable for the patient?

*Chapter six* returns to data about work practices in order to turn existing argumentation about the effectiveness of initiatives on its head and to look at alternative understandings of users and use. Hargittai (2004b) argues that it is becoming increasingly important to specify what is meant by internet "use." While it is true that use can be used and understood in diverse ways, we must be careful about assigning an *a priori* definition to use. If use is defined too strictly, we run the risk of assigning normative judgments to use that differs from our expectations, or, of focusing on the wrong set of users. Drawing on data from research at HON, I examine their work as having a pedagogical purpose, not only for lay end-users of the web, but also for the site providers who are seeking HON certification. Although the importance of considering site providers has been mentioned in passing (Doupi and van der Lei, 1999; Risk and Dzenowagis, 2001; and Terry, 2002), little research attention has been further devoted to understanding the position of site providers as users of initiatives. How does tweaking a small technical mechanism, in this case, a line of code that makes an icon clickable and links it to something (somewhere) else on the web, change the popular understanding of who the user is? How is use re-constructed, or perhaps mis-constructed, rendering invisible other possible users and uses of that icon?

I conclude with a general discussion of the practical and theoretical consequences of the conclusions drawn in this thesis for our understanding of network technologies with respect to health care. Additionally, I reflect upon the methodologies employed here and argue that studying the internet *necessitates* a piecemeal, ad hoc use of methodologies and theories.

## ■ NOTES

<sup>1</sup> See also Hargittai (2004a) on this point.

<sup>2</sup> See also Jones (1999) and Howard and Jones (2004) for more on the importance of studying network technologies.

<sup>3</sup> The web address for ICANN: <http://www.icann.org>.

<sup>4</sup> For a review of the work and struggles of ICANN more generally, see Kleinwächter (2000) and Klein (2002), and for information on the .health domain specifically, see Brown (2002).

<sup>5</sup> See Aanestad (2003) for an analogous point.

<sup>6</sup> See also Hesse (1996) and Erickson (2002) for discussions about how the internet is discussed.

<sup>7</sup> These exchanges can be found in the archived discussions of the AoIR listserv, online at: <http://listserv.aoir.org/pipermail/air-l-aoir.org/>.

<sup>8</sup> See Hafner and Lyon (1996), Abbate (1999) and Beckett (2000) for a general review of internet history, Randall (1997) for a discussion of how gopher was replaced by the web and Berners-Lee and Fischetti (2000) for an inside view of the ideology behind and history of the development of the web.

<sup>9</sup> In this case, one can think of technical terms such as, "url" and "http protocol", and also terms such as Eschenfelder's (2003) "click-and-mortar" that answers the tendency to differentiate between new online companies and old "brick and mortar" companies by indicating the online-offline-hybrid work practices of many companies.

<sup>10</sup> See Jones (2004) and the AoIR discussion list (see note 7 above) for a discussion of the difference between "Internet" and "internet."

<sup>11</sup> See Howard (2004) for a discussion about the word "embeddedness."

<sup>12</sup> See Jadad and Gagliardi (1998), Risk and Dzenowagis (2001), Commission of the European Communities (2002) and Gagliardi and Jadad (2002) for a review of initiatives various (types of) initiatives.

<sup>13</sup> Chapter 4 also contains an at-a-glance overview of the primary initiatives discussed in this thesis. Because the ".health" domain is discussed in Chapter 4, the at-a-glance includes information about WHO, which is not included here due to lack of empirical study during this project.

<sup>14</sup> See, as just one example, Bader and Braude (1998), who discuss the rigors of review for books and journals and compare this to the "anyone can be a guru" nature of the web.

<sup>15</sup> Chapter one specifically uses the history traced by Adrian Johns (1998), but similar arguments are also developed in the collection of essays edited by Nunberg (1996). In the latter, see especially the work of Hesse (1996).

<sup>16</sup> See also Klecun-Dabrowska and Cornford (2000) and Henwood et al (2002, 2003) for similar criticisms of discourse around telemedicine technologies and the internet.

# ***Chapter One***

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## **The nature of the Net: Constructing reliability of health information on the web**

Adams, S.A. and M. Berg. 2004.

The nature of the net: constructing reliability of health information on the web.

*IT and People* 17 (2). Pages 150-170.





**“If an early modern reader picked up a printed book – *De Natura Libri*, perhaps – then he or she could not be immediately certain that it was what it claimed to be, and its proper use might not be so self-evident. ...illicit uses of the press threatened the credibility of all printed products. More broadly, ideas about the correct ways to make and use books varied markedly from place to place and time to time.”**

– A. Johns, *The Nature of the Book* (1998)

The world wide web, now approaching ten years as a public medium, has seen so many fluctuations that a four year existence has been said to indicate the seniority of a website (Lundberg, 1999). Accompanying the innumerable changes of the previous years is a wealth of literature regarding the presence and potential staying power of health care information on the world wide web. Acknowledging possibilities related to the availability of such information results in both enthusiasm and skepticism – existing information is considered to be able either to help those searching for health care information by empowering them with knowledge, or to hurt them by subjecting them to fraud and “quackery” (Eysenbach & Diepgen, 1998; Gottlieb, 2000; Kiley, 2000). In 1995, individuals, governments, professional groups and non-profit organizations in both Europe and the United States began calling for action to ensure the reliability of information on the web. These players sought the establishment, by an authoritative institution, of mechanisms that would enable those who were accessing this type of information to assess the quality of what they found. Furthermore, they hoped for tools that would also enable users to apply the information they found. Eight years and at least 98 instruments later (Gagliardi & Jadad, 2002), the discussion about reliability problems continues.

The “Internet” is often referred to as “revolutionary” and “unprecedented” in its potential role in society, a stance that is no different in medical literature. With respect to the “quality” of information, the pages of the web are often compared, or rather, contrasted, with newspapers, journals, and books, with especially the latter frequently being depicted as bastions of trustworthiness in contrast to the renegade nature of the web. This is a familiar dichotomy: “scientific” publications, such as books (and journal articles), because they are time-tested and peer-reviewed, are typified as exemplary of “reliable,” “usable” information, whereas the Internet, which is still new and frequently changing, is presented as a chaotic assemblage of questionable material. In medical literature, for example, Eysenbach and Diepgen (1998) list “why Internet information is different from printed information,” citing characteristics such as lack of quality control, anonymity, and unclear markers to indicate for whom a document is published. Additionally, they compare the “quality control” in “traditional” publishing with current internet publishing, criticizing the latter process for what is missing, vis-à-vis what is present in the former. The result of

this line of argumentation is a contrast between a new, unstable medium and one that already has a stronghold, one that has been “black-boxed”.<sup>1</sup>

Studies of Science and Technology have revealed that reopening of the history of a fact or an object can sometimes be surprising in that we come to see that certain components, which would now be considered obvious (sometimes to the point of being taken for granted), were not so obvious in the making. The opening quotation from Adrian Johns’ The Nature of the Book alludes to this very idea with regard to the book as a reliable source of information. A familiar Latourian argument is that we do not want to analyze the *final* state of things (for purposes of this paper, the reliability of printed texts or the unequivocalness of authorship), but we must return to a point before that state of being – we must reopen its history. He states, “I want to situate myself at the stage *before* we can clearly delineate subject and objects, goals and functions, form and matter... Full-fledged human subjects and respectable objects out there in the world cannot be my starting point; they may be my point of arrival.” (Latour, 1999, p. 182, original emphasis) In the same vein, Madeleine Akrich (1992), in discussing descriptions of technical objects and the role of mediators, differentiates situations where technologies are stabilized and those where they are not. “The situation is quite different when we are confronted with stabilized technologies that have been ‘black-boxed.’ Here the innovator is no longer present, and study of the ordinary user is not very useful because he or she has already taken on board the prescriptions implied in interaction with the machine. ... Alternatively, we may study disputes, look at what happens when devices go wrong, or follow the device as it moves into countries that are culturally or historically different from its place of origin.” (p. 211)

The work of Adrian Johns aligns with these and other works in Science and Technology Studies. As is further explained in the following section, this work revisits previous chronicles of the history of the book in order to re-open the history of printing, print culture and printed works. Johns asserts the need for understanding the complex processes involved in producing and using books in society: “In the first place, a large number of people, machines and materials must converge and act together for it to come into existence at all. How exactly they do so will inevitably affect its finished character in a number of ways. In that sense a book is the material embodiment of, if not a consensus, then at least a collective consent.” (p. 3)

In contending that the identity of the book can be understood in terms of intricate processes, Johns leads the reader to question his/her own understanding of the book – what it is, where it came from, and why it seems so secure. To fully appreciate the significance, he states, echoing ideas from the above statement from Akrich, there are two options –

looking at different places at the same time (cultural differences) or looking at one place during different times (historical differences) – and he opts for the latter. By opening many of the black-boxed components of print (reliability, for one; the idea of the “print culture” for another), Johns demonstrates that quality and reliability of information were not unproblematic concepts. Furthermore, much like now, the actual meaning of words such as quality and reliability was not clear – they were defined differently in different times and places and there was often disagreement about the definitions. Additionally, reaching the point where they became obviously connected with the book, to the point of being taken for granted even, ultimately took several centuries. His print history of the 16th century reveals important parallels, such that we already see that concerns over reliability of information are neither new nor specifically connected to the technology of the internet.

In this paper, we juxtapose this history of the book with the current discussions on the reliability of lay health information on the internet.<sup>2</sup> Our purpose in doing so is to open up the notion of ‘reliability’ that underlies these discussions. In revisiting the history of the book, we are confronted with striking parallels that we can draw upon to better understand how *reliability* currently is constructed and why it is seen as so crucial. Importantly, we do not suggest strong parallels in the developmental trajectories that the book and the internet take, nor do we suggest that the history of the book has any predictive value for the future developments around the web. All we suggest is that drawing these parallels may enrich our understanding of current developments – by confronting us, through contrast, with what we take for granted.

Our aim is not so much to show *that* reliability is constructed – that would not be a very surprising message. Of course it takes much work, resources and time to build up the working routines, institutions, artifacts and cultural expectations that all come together in the term ‘reliability’. What is more interesting is *how* reliability is constructed: what actors are involved, what drives them, what issues are at stake? Finally, our core aim is to investigate *what* reliability is constructed. The most important, yet the hardest, part to grasp is that the very concept of ‘reliability’ can take many different (and highly consequential) shapes.

## ■ OPENING THE BLACK BOX OF THE “RELIABLE BOOK”

The commercialization of print, through the use of the printing press, has often been referred to as revolutionary because it supposedly enabled, as never before, the transcendence of context. Dispersal of printed reproductions of works would enhance communi-

cation – connecting the producer with others in distant places (multiple copies could be distributed among many different regions) and removing certain temporal constraints in the exchange of information – one did not have to be present at the revelation of a work, but could read a copy of it later. More importantly, Westman (1980) acknowledges that the conditions for collecting, storing, promoting and reviewing information began to change, with implications for the relationships between producers of information, consumers and middlemen.

Johns' summary of the contemporary approach to printed materials, reveals that, in modern definitions of print, reliability is so deeply ingrained that the two are intertwined in a tautology: we know that printed pieces are reliable because they are printed.<sup>3</sup> He then calls this idea into question by tracing a history that begins in the late 16<sup>th</sup>/early 17<sup>th</sup> centuries, in various parts of Europe.<sup>4</sup> Tycho Brahe, Galileo Galilei and their contemporaries were producing printed versions of the results of their 'scientific' work, and distributing them "as gifts to patrons at courts and universities." (p. 14)<sup>5</sup> As Westman (1980) points out, publication at that time was also different from our current understanding of the concept – and even then, it was changing.

Reference to courts and universities gives us cause to consider their role in the printing of books at that time and to think about the changes that were occurring in who was printing, what they were printing, how they were printing and the regulation of this printing. Prior to the printing press, the control over printing was largely in the hands of the church and/or state.<sup>6</sup> Levinson (see note 2) argues that both the church and the state had their own ideologies of what should be printed – based either on conceptions of what should *not* be printed (of what should be kept from the public) or of the fate of texts (how to preserve them, where and when to disperse them, etc). If we consider printing in the period before the printing press, we see, for example that the primary agenda of those producing scribal reproductions of scripture was to reproduce, ideally without distortion, and to preserve ancient texts. In so doing, these texts remained primarily in the hands of the church, enabling the church to remain in control not only over the quality of texts, but also over what ideas were brought to the public. Even after the printing press and the beginning of mass productions of the bible, Levinson argues, the church continued to exercise this control in order to stifle opinions that were in contrasts to its teachings. One example of this would be the First Index of prohibited books, which was issued by the Congregation of the Inquisition in 1557. In 1571, this became a continuously revised list that served either to prohibit books completely, or to control revision of certain material before the books were returned to circulation. (Goodman and Russell, 1991)

At the time of the printing press, the royal courts were already playing an important role. Although the court was not considered to be a “scientific” establishment (existing rather to represent royal power), endorsement by the court was crucial for aspiring scientists and philosophers. (Biagioli, 1990) Patrons of the court were influential on the politics of the state, and subsequent control over dispersal of printed presentations enabled the strategies of both the patrons and the rulers. “The tendency of governments to reign by reining in decentralizing media was already apparent in the attempts of monarchs to control the first printers.” (Levinson, p. 86) Controlling the flow of information to the public was essential, in Levinson’s terms, to ensuring the power of the monarch.

Regardless of developments for tighter control, en masse publication was accompanied by new problems, most noticeably increased possibilities for errors and increasing cases of piracy and imitation. Johns writes that the early printers identified scribal reproductions (supposedly precisely preserving ancient texts) as corrupt and full of errors (such as spelling). They further used this point to argue that it was the press that actually enabled preservation. However, he notes the contrary in demonstrating that these problems presented even in the case of reproductions of the bible, despite close monitoring by the church and even later under the tight control of the state: “There were, it has been estimated, some twenty-four thousand variations in the text of the King James bible between its first printing<sup>7</sup> and the 1830s.”

In England, Francis Bacon expressed his opinion that the press was “a device discovered by chance and by disorganized artisans.” (Johns, p. 50) And, he felt, it encouraged dangerous ambitions. He was displeased by the devolution of content control to actors “independent of the state’s bureaucracy.” (p.50) That is, “...he certainly did not recommend unrestricted publication of knowledge, urging rather its retention within a tiny community of royal licentiates.” (p. 49-50) Bacon was known, and saw himself, primarily as a statesman and royal counselor and he used this position to champion his own cause – natural philosophy. In regard to printing, he saw outsiders as dangerous and attacked the rights of those not in courtly circles to profess knowledge. Therefore, Bacon advocated the implementation by the state of an administrative mechanism that would best serve to advance the interests of state officials. However, other individuals and small groups were also attempting to create their own methods for addressing the same issues that Bacon raised when expressing his vision of official licensing by the court and centralized (elite) approval of all publications. These individuals and groups were not always in accordance with one another, resulting in a stream of new, slightly different methods, each considered to be the “unified answer,” at least in the opinion of those providing it.

What is noticeable in looking at how changes in publication practices led to concerns about rightful control is that the idea of authorship became important. Who had written a piece? Was the work really the production of the name that was attached to it? Before the press, authorship was a relatively minor issue, but once the church and courts were no longer the only locales for the production of “knowledge,” as it were, the name attached to a publication was crucial. Establishing one’s name as an author – of having the authority to distribute a work in print (or as Bacon had said, the “right to profess knowledge” [Johns, p. 50]) – was therefore important and authors assumed the task of simultaneously forging the reliability of their personal names and that of their work. Authorship in that time period entailed the anxieties of gaining and holding attention and out-competing rivals for a new market of reward and prestige. (Westman, 1980) Authors could play upon these concerns regarding authorship to levy criticisms against their opponents. Rather than replying to the content of a criticism, characteristics of the criticizing author were called into question. Especially in cases where criticism was offered anonymously, the resulting lack of a name was an important factor in questioning credibility.

“Licensing” was increasingly supported as the answer to regulating works and ensuring credibility, but even this licensing was variable. Johns traces a period of just over a century, in which some form of licensing was in force for almost the entire time, even though there were some periods when licenses were ineffective. Such a licensing system generally required that any text to be published must be read and approved beforehand by one of a small number of authorized officials. Licensers were expected to be knowledgeable in fields over which they were to hold jurisdiction, but they had to develop individual manners for reading in order to stay within the parameters of existing protocols. “In theory, [licensers] had at first been ecclesiastical officers appointed by the church. Before the Civil War, however, a remarkable variety of individuals, clerical and lay, felt authorized to sign imprimaturs.” (Johns, p. 239)

Because the notion of licenser as a figure of credit within a particular province prevailed, Johns asserts, licensers could not be seen as holding a neutral position: “Licensing was another connected response to a print culture characterized by endemic distrust. It was machinery for producing credit. Books bearing a license, defenders of the practice often claimed, were ‘distinguish’d like Money by a Royal Stamp.’ Would-be readers would know before purchasing it that a licensed book was no counterfeit and, moreover, ‘that there is no Poison in the Composition.’” (p. 263) A license was interpreted as a badge of distinction or “a public demarcation of knowledge from error.” (p. 263)

Licensing, even though it changed over time, gradually developed into a complex regulatory system, upon which authors increasingly became dependent. The relationship

between authors and those affording the licenses was crucial and the process was often used to suppress any text of which the state disapproved. In each city the regimes were different, and a work had to be licensed where it was published. Galileo's work is perhaps infamous for the "failure" of the licensing process. Galileo published a piece in support of Copernican postulations regarding the Earth's revolution around the sun – an opinion refuted by the church. Even though the piece in question was certified by five different licensing groups and in both cities of its release (Florence and Rome), its release was considered scandalous. Levinson (1999) discusses how the church "bullied" Galileo into recanting this position, which he did in Rome, although in other cities his original work continued to be publicly distributed. "Orders were given for the suspension of sales and confiscation of stock; it was too late, all copies were in circulation." (Goodman and Russell, 1991: p. 112)

In 1662, after the deaths of Galileo, Tycho and Bacon, much of the work to solidify the reliability of printed work, in England at least, continued through the Royal Society of London. Despite its higher profile role, and the changes that resulted from its "aggressive intervention" into scientific publishing (p. 44), Johns refers to the Royal Society's achievements as, "consequently but *one element in a continuing history* of attempts to discipline print and render it a sound platform..." (p. 49, emphasis added) He further demonstrates that once the control over printing diffused from the church or the state, there was no way to return it to them. "Courtly aspirations notwithstanding, in England there would always be other printers, booksellers, writers, and readers at work. The fact was that book dispersal did not operate entirely through diplomatic and courtly channels. There was a national and international book trade and before long even books directed at restricted audiences ... participated in it." (Johns, p. 51)

We halt the historical scenario at this point, as it has already set the stage for thinking about reliability issues in relationship to the internet. In re-visiting accounts of the history of the book, we see that reliability and truthfulness of works are not implicit in print. We have not discussed this history in order to make any detailed *historical* claims. Rather, we see this analysis as a useful tool to examine the issue of reliability work in relation to the internet. It enables us to formulate new questions in the midst of the web's continual development, while there are still many options for how the trajectory that arrives at "reliable" information will evolve.

## ■ THE OPEN CONTROVERSY: “RELIABILITY” AND THE INTERNET

Early on, the “everyone is a publisher” idea that was coupled with the world wide web was considered to be an asset and the internet was extolled for all the revolutionary changes it would bring in the nature of health care delivery. There was much published speculation about the advent of a communications revolution, the possible “death” of academic journals, the breaking down of geographical borders and the subsequent ease of transferring expertise in real time across great distances. The web and internet technologies were considered to be unprecedented for all the different types of changes they would bring.

The most significant concern at that time regarded a potential overabundance of information, but it was expected that the “nature of science” and the “nature of the internet” would correct for this – sub-standard information would be indicated as poor and would be pulled from the pages of the web. However, opinions changed as the authors voicing these concerns began to realize that the internet was gradually growing out of the domains of academia. (Pluscauskas, 1996) Publishing was indeed changing and opinions regarding internet potential rather quickly dissolved from excitement into unease as the realization set in that the “nature of the web” and the “nature of science” did *not* correct for the problem of placing medical information on the web for public consumption without peer review. Medical informatics experts meeting in Geneva in 1995 raised concerns about the abundance of information that could be accessed and the lack of any guarantee that this information could be trusted for accuracy.<sup>8</sup>

The types of publication changes that subsequently have taken place during the last decade with respect to the internet are leading not only to redefinitions of what it is to publish, to be an author, to be a reader, or to play a mediating role, but also to the search for and creation of mechanisms for the distribution of reliable information to the public. And thus, just as the early modern reader questioned sources of information, so too does the present day user of health care websites. Or, at least he or she should be questioning the available information, according to current health professionals. (Eysenbach, 2000b)

A 2002 communication from the Commission of the European Communities categorizes the existing international reliability initiatives into 5 incremental levels, beginning with simple codes of conduct, and proceeding to the self applied code of conduct or quality label, user guidance tools, filtering tools, and third party quality and accreditation labels. Such a list already begins to black box components of the technological developments at hand. It is important for our understanding of the reliability problematic that we approach it from a prior time period. We must question how such a list came to be



– an exercise in revisiting how publication again changes, the locations where the major players have assembled during the last eight years, and the work being done to regulate publication, as well as attempting to understand the role of the gate-keeping ideology in shaping the initiatives that they develop.

At the time of the 1995 conference in Geneva, the world wide web had been available for public use for just over two years.<sup>9</sup> A range of different types of authors, primarily from the US and Europe, were placing various types and levels of information on the pages of their websites. Concurrent with the changes in publication types and sources was an increase in consumer warnings instructing users to be wary of the information found on the existing websites of the time, which possibly came not from medical professionals, but rather from big businesses. (Keating, 1997)<sup>10</sup> Increasing scrutiny of medical websites was reflected in concerns expressed in medical circles about the “everyone is an author” (or editor or publisher) phenomenon. In contrast to the concern about commercial enterprise, which was considered to be intentional non-disclosure, the prevalent theme of this discourse was concern about unintentional omissions that came through ignorance and bias. (Wyatt, 1997) More concern derived from existing ambiguity about who was doing what, how and from where – on both the production side and the reception side – and even more concern about how to adequately measure this. And notably, there was consternation about the conspicuous absence of health care professionals on many levels.

Significant challenges facing those seeking to counter the problem of proposed unreliability of information were those of jurisdiction and enforcement. How far was the reach of any individual or body working to improve the quality of information and how effective would any effort be? In the United States, the statement was made within the federal government<sup>11</sup> that it was time to bring the internet back into the proper hands – yet, whose hands this might be and how this was to be accomplished was unclear. Equally puzzling was the question from whom, precisely, did the internet need to be “regained”?

Authorship and publication consequently became topics that were also wide open. Sechrest (2000), in addressing doctors about e-Health, discussed the presence of patients in internet space, in absence of professionals there to meet them, and the subsequent “vacuum” that resulted from this imbalance. He further discussed how “non-traditional” players were filling the gap that the professionals had left. Who were these purported non-traditional players that were filling the open space and how were they answering patients’ requests for information? The answer to this is variable – as is stated above, there were all types of new authors – and for many, there was a general feeling that the

exponential increase of medical websites by unknown sources was a problem that was quickly growing beyond any or all control.

The aforementioned 1995 conference in Geneva provided a venue for discussion of these issues and participants questioned how to reach global agreement on evaluation, how to maintain a server with which real, accurate and up-to-date data could constantly be delivered, and how to keep control over medical information in the hands of the professionals. Participants resolved to coordinate an international effort (assembling representatives from what they identified as the three main world areas – the United States, the European Union and Asia) and to create a Foundation, now known as Health on the Net (HON), which would be centrally located in Geneva, in close proximity to the academic hospital. The Foundation sought to create and maintain a server with real, accurate and up-to-date information.

Following the conference, HON became much more than just a catalogue of sites. It responded to the above “authorship” problem by proposing that anyone responsible for a web page containing medical information follow a specific set of ethical guidelines (the HON Code).<sup>12</sup> Sites that agreed to adhere to these principles and were approved of during a HON review were then enabled with a hyper-linked icon, which was to be placed on the website. Users could click on this icon to travel to the HON site, for the purpose of either verifying proper use of the icon or attaining additional information about the organization providing the website.<sup>13</sup>

Criticisms that were levied against HON and similar organizations contributing to what Ahmad Risk and Joan Dzenowagis (2001) from the World Health Organization identified as “the burgeoning output of codes of conduct from numerous organizations trying to address quality of health information” were three-fold. Firstly, there was the concern that codes alone were unenforceable and that breaking them was inconsequential. (Rigby & Forsstrom, 2000; Meric et al, 2002; Wilson, 2002) Secondly, there was concern that codes in combination with, for example, icons, though somewhat more complex were still equally ineffective, as they were of little meaning to users. Thirdly, questions abounded (and still regularly surface) regarding the quality and reliability of the practices behind the initiatives themselves. (Gagliardi & Jadad, 2002; Stanberry, 2002)

Eysenbach (2000b) published an opinion piece on the home page of his own Journal of Medical Internet Research. In this piece, he identified four pillars that he believes support “quality management of health information on the Internet”: educating consumers, encouraging self-regulation, evaluating information by third parties and enforcement in cases of fraudulent or positively harmful information. Under the second of these pillars,

Eysenbach extended this criticism by stating that the efforts of specific initiatives were “problematic, perhaps even counter-productive,” and suggested the need for a more sophisticated system.

In this editorial, Eysenbach introduced the MedCERTAIN initiative, a third-party rating system that is funded by the EU under the “Action plan on promoting safer use of the Internet by combating illegal and harmful content on global networks.”<sup>14</sup> He described the project as one that “follows up the idea that the quality of health information and interactive applications can not and should not be controlled by a central body or authority, but instead information and applications must be evaluated and labeled in a decentralized and distributed way.” Eysenbach defined labeling as the provision of meta-information, which provides additional description or evaluation for existing information. MedCERTAIN planned to use PICS (Platform for Internet Content Selection) – a technical development from the W3 Consortium. Individuals, organizations, and associations, among others could digitally label (rate, evaluate<sup>15</sup>, peer-review, give quality seals to...) online published health information using labels consisting of a standard computer-readable vocabulary (meta-information). Eysenbach also identified different levels of certification that MedCERTAIN would give, “ranging from simple quality seals indicating the ‘good standing’ of the site to “gold” quality seals indicating that the site has been peer-reviewed externally.”

Concurrent with these two European level developments, individual countries also have implemented various initiatives, many citing the need for own-language initiatives. One example is a collaborative effort from Spanish health care professionals led to the development of a nationally recognized seal (the Seal of Calidad<sup>16</sup>) to place on Spanish-language websites. Another example is in the Netherlands, where the Ministry of Health established a national health information portal ([www.gezondheidskiosk.nl](http://www.gezondheidskiosk.nl)) and TNO (a Dutch Research and Development organization) created a recognizable trust mark (QMIC) for Dutch-language websites.

The Dutch Ministry of Health’s Gezondheidskiosk is exemplary of a different approach to the reliability question – assembling a portal site for approved information. One of the longest standing national health portals is [healthfinder.gov](http://healthfinder.gov), developed in 1996 by the US Department of Health and Human Services, out of an existing service from the Office of Disease Prevention and Health Promotion (ODPHP). The ODPHP had been active since 1979 in assembling information to which they could refer the public. They used existing guidelines for selecting information as a basis for judging quality and reliability. Coupling these with the newly formulated HON standards, and in collaboration with other divisions within the Department of Health, the [healthfinder.gov](http://healthfinder.gov) steering committee created

a new web-based selection policy. However, this effort was not in absence of difficulties, attributed to internal disagreement about what should and should not be included. It is important that the healthfinder.gov portal was never intended as a primary end-result; rather, it was established as part of larger educational programs administered by the Department of Health and Human Services. Those involved in setting up the portal saw it then as a chance to take advantage of the new internet technologies as one more medium to reach their intended public.

Although healthfinder.gov was the official US government portal, it was not the only federal initiative that was developing. Just as experts were discovering that they were unable to control who was providing information in the domain of health care, they also discovered that they could not control who was retrieving it from websites. The National Library of Medicine discovered that it was not only scientists, students and doctors who were using its Medline database of articles (freely available through their website since 1997) but also that many lay persons were searching the website for health care information. Through continued study of web logs in combination with focus group research and evaluation, the library modified the services it offered, leading for example to the creation of *medlineplus* and other public-oriented web-based resources starting in 1998.

Although there was much speculation early on about the possible adverse effects of the internet on public health, leading to the creation of the aforementioned initiatives, there were few actual anecdotes providing a foundation for these concerns. That is, until 1997, when the first concrete adverse effects of the internet's "open market" evidenced in an article in the *New England Journal of Medicine* and received international attention. "Poison on Line" discussed the case of a patient that was hospitalized after drinking essential oil of wormwood that he had purchased online. (Weisbord, 1997) It was unclear what information the patient had received when purchasing the product – was the mistake his own, or had the oil been sold as an ingestible potion? This was the first widely publicized case to lend support to concerns that had been voiced in the previous two years about the ability to receive via mail-order products from the web that crossed national borders.<sup>17</sup>

During this time period, the first studies regarding quality of information were also carried out, with the results being published in major medical journals. There were three studies in particular that were noted and widely discussed within the professional community. Impicciatore, et al (1997), searched the web for sites with information regarding manag- ing fever in children. They expected some inconsistency because of lack of consensus within professional communities. Out of the sites they studied, the authors judged only one as dangerous and concluded that the problem of inconsistent information was not

web specific and that more research was needed. In the same vein, McClung, et al (1998) searched the web to see how official AAP position papers were presented to the lay public. They found many informational errors on sites provided by universities and medical institutions, citing the problem as one of lack of peer review and oversight of submissions. They were concerned about the equal presentation of good and bad information. Sandvik (1999) published another similar study wherein he expressed concern about the fact that the information most often missing from sites (whether containing correct or incorrect information) was that of the author and source – this was especially true of sites that he identified as “commercial” sites.

These events and studies contributed to increasing concern that the *threat* of bad information alone would sabotage the purposes of good information providers, by creating a general loss of confidence among the public. (Mitchell, 1999) Once again, there was a call for action among the professional community to evaluate the problem, propose solutions and attempt to design better mechanisms that would respond to consumer needs and be more effectively implemented on the web. (Eysenbach & Diepgen, 1998; Mandl, et al, 1998; Eysenbach, et al, 1999; Mitchell, 1999; Ostrom, 1999) However, the issue became one of more than just monitoring – how to enforce any initiative across nation-state borders remains an unanswered question.

Risk and Dzenowagis contributed to the discussion by addressing the need for *global* leadership. “The author believes that there is a need for clear leadership on a global scale to achieve the yet-unfulfilled promise of information and communication technologies of better health for all,” identifying the potential role of the WHO in this process. “In line with the WHO’s global role in setting norms and standards and assisting member states to implement these norms and standards, the organization has a crucial role to play in developing norms and standards for Internet health information quality.” One proposed solution stemming from this discussion is the creation of a “.health” domain that can only be used by those with express permission. Permission would of course come from the World Health Organization after careful review of sites.

## ■ DISCUSSION

The above fragments of these two histories are extracted with the intent of illustrating the importance of breaking away from a frame of reference that contrasts a black-boxed technology with one that is still open. By reopening its history, we are forced to abandon the current understanding of the book as a homogeneous object with which we daily engage. From there we can use the book as a frame of reference for the internet – not so much

to demonstrate what the internet is missing, or how it is different, as others have done, but to extract the components that are crucial to understanding how initiatives develop and take shape. What leads to the categorizations in the communication to the European Union and the creation of lists of initiatives lasting longer than four years, and so forth?

Just as the emergence of the printing press raised anxieties about the unrestrained diffusion of incontrollable writings, the rise of the internet raises concerns about the dangers of uncontrolled and unreliable health information. The types of localized work by individuals or small groups that are described in both the history of the book and the network initiatives discussed here are often referred to as “gate-keeping.” Institutions filter information by deciding what to release to the public (and from which source), based on particular ideologies. These ideologies are variable across time, place, types of institutions and actors involved, and singular ideologies are themselves malleable. Yet, Levinson identifies one characteristic common to all. “The logic of gate-keeping, whether by Church, national states, or the media themselves – is that information is like a food or drug, which, apropos the Pure Food and Drug Act of the United States and similar laws in most countries, requires inspection or certification before it can be made available to the public. To offer information unvetted is, on this reasoning, to risk poisoning the public, as it could be from spoiled food or bogus medication.” (p.125) Levinson then emphasizes that this mentality is never abandoned, but rather that it changes in regard to new media, new opportunities, new actors and new types of regimes.

Although Borowitz and Wyatt (1998) discussed the absence of a governing body or authority that serves a gate-keeping function for web publications, we actually see that, just as it was voiced with the book, the same gate-keeping argumentation is being made by those who favor the filtering of internet information and are working to create initiatives to execute this task. As with the church and the state, the strong urge to develop some form of gate-keeping for health information is undoubtedly also due to a fear within health professions to lose their grip on their ‘public’. Discussing the ‘imbalance’ in cyberspace, and the danger that ‘non-traditional players fill up the vacuum left by professionals’, for example, clearly plays upon the classic positioning of the profession fighting off attempts to intrude upon its sphere of professional jurisdiction. (Abbott, 1998)

Driven by different yet deeply historically anchored motivations, then, we see a plethora of actors and institutions aiming to reinvent the classical licensing mechanisms for the internet era. As in the history of the book, the reliability of the content of a web site is to be established through an independent, third party. Drawing upon mechanisms that are already historically available would lead one to expect that the construction of a similar mechanism for health information in the internet era might be a relatively unequivocal

affair. And indeed, many initiatives refer to the preferred example of scientific publishing, with its 'objective' form of licensing based upon blind refereeing, journals run by established scientists, and so forth. Yet in the case of the book, the high reputation of the licensing official or body was to ensure a strengthening of the position of the book and its author. This historically specific form of 'licensing' was tied to both the desire of established bodies (be it the state, government, or later scientific communities) to control the content of published work *and* to the desire of potential authors to solidify their name and work through the licenser's stamp. In the case of web-based health information, however, those establishing themselves as potential licensors *cannot* be said to be already 'established' institutional bodies. In addition, web-authors use a wide array of other marketing and web-design tools to enhance the visibility of and trust in their websites. (See, for example, Brown and Duguid, 2000; Introna and Nissenbaum, 2000 and Sechrest, 2000.)

Establishing one's role as 'licenser', then, is difficult work. Every project is centered on building an extensive network of persons and computer programs, of collaborative groups and guidelines. Healthfinder.gov's steering committee is comprised of representatives from a number of government agencies. HON has an international advisory board and site reviewers from different countries, enabling the review of pages in a diversity of languages. Development and expansion of these networks leads to changes – changes in composition of the claim to reliability and changes in the physical design of the technique(s) that represent this claim on the internet.<sup>18</sup> Over the last eight years, Health on the Net has expanded from a database to a code of conduct with a hyperlink seal, to current developments underway regarding natural language search capabilities. In addition, their definition of what makes a reliable site has been modified more than once (the addition of two principles in the code of conduct, more elaborate descriptions of the policing process and responsibilities included therein, expanded guidelines for information providers, and a deepened understanding of user behavior, expectations, needs, etc.). By the time a project is presented, it is not just a website, a seal, a database, or a set of published guidelines – it is a conglomeration of definitions, actions, technical elements, etc., which all have resulted from real-time, hands on work done by the individuals involved.<sup>19</sup> 'Reliable health information' is what emerges from that work: sites with HON's hyperlink seal, or a network of sites all linked to healthfinder.gov.

As was stated earlier, in constructing these reliability networks, these initiatives draw upon traditional scientific publishing as the paradigmatic example that should be 'reinvented' in the health information domain. Yet what is interesting is that there are many important differences between the individual initiatives. Diverse proposed "singular reliabilities" are emerging, each one different, each one proposing their own definition of

'the problem' of health information reliability. Since each proposed problem definition or technical solution is 'packaged' with a specific initiative and a specific licensing apparatus, the question of *what* 'reliability' we will see emerge is very much tied to the question of *which* licensor will prevail. There are several, related differentiations here that are of interest.<sup>20</sup>

First of all, much like in Johns' examples of the differences between streets and neighborhoods of London, the influence of the *local* cannot be ignored. With the internet, the role of the local is still very much of consequence, although it may take the form of a geographical region, a bundle of dispersed institutions linked by some ideology, or a particular web-domain, rather than a street. We are reminded that, although popular thought tends to categorize it as such, the internet was not the first technology to be labeled as a "border breaker." Further still, we are reminded that this label is not necessarily correct, internet technologies can be viewed not only as not breaking borders, but also as actually creating new (types of) borders. Finally, as we have discussed elsewhere, with reliability work, there is also the active creation of new specific bordered spaces.<sup>21</sup>

Regardless of how far the boundaries of an initiative currently extend, in how many circles it is recognized, or how large of a network it has built, the project is still centered in a specific location. Although many of the initiatives are collaborative efforts in geographically separated regions, there are identifiable, pocketed locations where the physical work of reviewing sites or updating portals is carried out. When we take a closer look at current initiatives, we see the local elements that are embedded in each. Furthermore, we see how these elements, in turn, return in the specific definition of 'reliability' construed by these initiatives.<sup>22</sup>

We see this in the case of new national initiatives, but also in more "international" or "collaborative" efforts, such as HON and MedCERTAIN. Although considered by many to be a "European" initiative, and itself claiming to be an "international" initiative, the Health on the Net organization still holds very closely to its Geneva roots. Geneva, as the home of CERN, gives special significance to internet-related work because of its centrality in the developmental history of the web itself. More important still, HON is of the opinion that an organization carrying out this type of reliability work must be international, non-profit and neutral in order to successfully function as a symbol of reliability for health internet users.<sup>23</sup> Its location in Geneva, the home of politically neutral inter-governmental and non-governmental organizations (itself located in the neutral territory of Switzerland), is crucial to building that outward image into its initiative. All this is physically illustrated in the organization's web address, which keeps a Swiss domain ending, rather than a ".org" or other ending.



For others, this attempt at 'universality' carries a much too strong, *local* tone. From a US perspective, this strong 'Switzerland' heritage makes HON too European indeed. To the US, it would be unthinkable that a Swiss organization would perform such an important "gate-keeper" function for their citizens; similarly, MedCERTAIN is obviously too 'European' for many. Vice versa, European countries do not want simply to follow US-led initiatives – and 'language issues' are in this case truly secondary issues.

Similarly, the locality of national initiatives comes clearly to the fore in their struggles about including non-national links. In the Netherlands, the national health information portal refers only to Dutch language sites from the participating organizations (physicians and pharmacists organizations, Dutch Quality Institute, and so forth). Doing so, of course, severely limits its relevance to a population whose web-users are very often well versed in (reading) English. After all, the amount of health information on the web in Dutch is negligible to all the English language information that is available (and browsers can often even automatically translate to Dutch, if desired). In the US, healthfinder.gov primarily endorses US government links or links that have already been endorsed by US government bodies. There as well, there are no links to information outside the US. There are many Spanish websites – but all of them are of US-based health care organizations or institutions, often simply direct translations of the English resources.

In addition to these struggles about the locality and universality of the licenser, and its concurrent consequences for the kinds of reliability that are established, the very *problem* that the licenser is focused on addressing varies. Not all initiatives were established with the same intent of responding to a perceived "threat of bad information," although many were. Healthfinder.gov, for example, was considered to be an aid for patients who were unfamiliar with the internet – a starting point to help them begin a search. It is also part of a larger public education program. One can also consider the National Library of Medicine, which was establishing a scientific database for a specific community (and not specifically looking to address issues of reliability) and only later realized that other communities (some of whom were looking for "reliable" information) were using it as well.

Related to this previous point, different groups envisioned projects that utilized various components of internet technology. Early on, healthfinder.gov merely converted existing paper-based information into easy-to-access web pages, whereas Quackwatch (see note 17) assumed a double task of converting existing resources into a website and assembling a new index of recommended (or non-recommended) sites. HON wanted to design a more 'open' technology, utilizing a specific mechanism of flexible design (an electronic 'seal') that could be adjusted in response to alterations in other web technologies. Other

initiatives, such as MedCERTAIN, the QMIC and the Seal of Calidad, further built upon these ideas, adding different technical and conceptual layers.

Finally, just how the line is drawn between 'reliable' and 'non-reliable' can also be due to other reasons than a site's national background, its government endorsement, or its vision of patients as in need of either 'protection' or 'information'. Differences also proliferate within medicine as well as within its potential 'users'. What counts as 'reliable' for a strong Evidence Based Medicine believer, for example, might be far too limited for a more pragmatically inclined medical specialist or GP. What is posited as 'well-established' information on the benefits of wine or the use of antibiotics in France, to use a common example, would abhor most Dutch physicians.<sup>24</sup> Likewise, it is evident that what would count as 'reliable' or not will differ considerably, according to an individual user/patient's beliefs. A national portal would lead to general, basic information, whereas the criteria of an independent initiative, or perhaps even for a third party rating system, would be too restrictive. A fanatic chiropractic patient would appreciate healthfinder.gov much more than Quackwatch, but would be ultimately disappointed with both.

## ■ CONCLUSION

Born from anxieties not unlike those calling for the 'regulation' of the printing press several centuries ago, many initiatives have been developed during the last decade to 'regulate' health information on the internet. The discussion about health information reliability lends much attention to finding the one notion of reliability that answers the threat of misinformation on the web and then establishing the ultimate gate-keeping method. This notion is one mirrored on the "ideal" image of scientific publishing, and the apparatus that ensures its objectivity and trustworthiness.

Yet as we have argued, this ideal-typed historical example is not easily transportable to the Internet of today. In addition to the impossible extent of the task of reviewing all relevant web sites, the historical positioning of the 'author' versus the 'licenser' is different. Furthermore, the existing categorical definitions for these respective roles are not always applicable, as the persons attempting to fill them continues to change.

Creating 'reliability', then, has become a difficult process of reinvention, involving much work – now, as much as it did several centuries ago. In addition, the different initiatives produce different reliabilities. We see differences in technical modes of operation: basically, two main competing forms (although within both types there is variation): the indicatory label and the separate domain of a web portal. Also, we see different notions

about what consumers need or require, and we see struggles and differences between locales that are remarkably resonant with the competition and differences between the Florence and London licensing bodies. Finally, we pointed at the differences within the medical content of the site: how alternative medicines were evaluated, for example, or which side of a current medical debate would be taken. Although those working to create reliability persist in the attempt to reach universality, each initiative remains tied to specific characteristics attributable to its respective local context.

For many reliability-seekers, this variety is offensive. It shows, after all, the *failure* to match the health information reliability quest to the scientific publishing example, and it stands in the way of an unequivocal defense-line against 'bad' information (or a rallying point for 'useful' information, depending on one's philosophy!). For us, however, this variety, although still limited *because* of this very attempt to 'unify', is the only desirable situation imaginable. A deep fault of many current approaches is this underlying, sometimes implicit, ideal of the *one* system for 'reliable health information'. Of course, all systems (quite openly) cover only a small fragment of what they would like to cover, but there is a clear desire to overcome that limitation – if not practically (providing a comprehensive response and reviewing all the existing medical websites), then conceptually (i.e., in defining the 'best' system to ensure reliability).

Yet one comprehensive reliability model to which all sites and licensors must adhere is not only inherently doomed to fail, but it is also deeply undesirable. The diversity of options that the internet offers is indeed exactly one of the components of its "nature" that has helped to create much enthusiasm, if not pure hype, about both its existence in general and its potential uses specifically within health care. A singular gate-keeping regime, if even possible to set firmly in place, would run the risk of stifling this, while not necessarily "solving" the suggested problems related to reliability. Thinking more in terms of feasibility than of medical ideal types, we can see that the co-existence of different systems actually serves as an avenue to reach different audiences, with different needs, and for that reason can be considered to be an asset, rather than a detriment.

## ■ NOTES

<sup>1</sup> For discussions about the concept of black boxing, see Latour and Woolgar (1986), Latour (1987, 1999).

<sup>2</sup> Levinson (2001) has already made a partial comparison of media when interpreting the works of Marshall McLuhan in terms of the internet. Within medical literature, two historical comparisons have been made. Both return to the introduction of a specific technology into society (and consequently, into medical care), thereby referring to the controversies that arose around these technologies. Spielberg (1998) compares the introduction of e-mail in current medical consultations to the introduction of the telephone in medical practice just over a century ago. She addresses parallels in legal and ethical issues that are/

were raised, such as questions about privacy, the increasingly vulnerable position of the physician, the level of care and “proper” examinations and about the possibility of miscommunication. Although Spielberg shows how the telephone was accepted and used comparably much faster and on a much wider scale than e-mail has been to date, she uses the analogy to enrich understanding of the changing expectations, standards and potential liabilities that accompany the use new communication media in health care practice. Rigby et al, (2001) compare use of healthcare related software, telemedicine and websites to the employment of experimental pharmaceuticals in health care just 40 years ago. The authors analogize current concerns about the dangers of unregulated information to a statement made by the UK Secretary of State for Health to the British House of Commons in 1963, in the wake of the Thalidomide scare, about marketing products that were neither properly tested, nor independently controlled for safety and efficacy, as well as about the associated risks for the public.

<sup>3</sup> It is important to be reflexive about our use of particular sources. Johns introduces his work by demonstrating how the “reliability” of his own printed book, for example, is indeed now by and large unquestioned. That is, there is no reason to doubt his identification, the quality of the content, and so on, because these are essentially a “given.” Why can we accept Johns’ standpoint or the theories of Latour and Akkrich? How would we feel about utilizing these works if they were pulled from the web? What is the inscription contained in the book as a technologically produced object, whereby we trust it without question and base our reasoning upon the information it contains?

<sup>4</sup> It is acknowledged that what one author typifies in one place is not necessarily applicable to other regions at that same point in history. Especially within Europe, the differences within and between locations during this period of history were great. As Eisenstein asserts, “Quattrocento Florence, in any case, is scarcely typical of other Italian centers (such as Bologna), let alone of regions beyond the Alps. But then *no* region is typical. There is no ‘typical’ book dealer, scribe or even manuscript. Even if we set aside problems presented by secular book producers and markets as hopelessly complex and consider only the needs of churchmen on the eve of printing, we are still faced by a remarkable diversity of procedures.” (1983: p. 9)

<sup>5</sup> See also Biagioli (1990) for information about Galileo’s patronage at the courts.

<sup>6</sup> Although the concept of separation of church and state was prevalent in early Medieval Europe, historical accounts reflect that the two institutions are not easily separable into two isolated entities. Especially with the rise of monarchies and the creation of the “modern government”, the intricate relationship between the two and their intertwined power becomes increasingly evident. Many authors handle the two in a linear manner, with the church preceding the state in influence, but this representation is not always accurate – as the respective roles differed throughout the European countries and a specific point of time of change of influence could not be identified. When not referring to the work of a specific author, this piece attempts not to differentiate the two, but rather to handle them in conjunction with one another.

<sup>7</sup> The first version was published in 1611.

<sup>8</sup> The transcript of the session referred to in this article is available at: <http://www.hon.ch/Conf/Info/sessions2.html>.

<sup>9</sup> For historical information about the Internet, see, Hafner and Lyon (1996), Randall (1997), Berners-Lee and Fischetti (1999) and the W3C homepage (<http://www.w3.org/History.html>).

<sup>10</sup> This was later exemplified in the case of drkoop.com. In 2001, the former US Surgeon General’s then four-year old site was the second-most visited health site on the internet. (Mabin, 2000) However, criticisms of the site increased because the sources for information provided on the site were not clearly disclosed. Funding from larger companies was necessary to the existence of the site, but it was alleged that advertisements were presented as educational, rather than promotional, information. (Cho, 2000) Widely publicized criticisms caused other institutions, such as the National Library of Medicine to withdraw their support of Dr Koop’s site. In 2002, banner ads on the site were clearly labeled as sponsored information.

However, the home page also stated that the site was no longer affiliated with the former Surgeon General. See: <http://www.drkoop.com>.

<sup>11</sup> C. Baur, personal communication.

<sup>12</sup> In the course of the next five years, others also attempted to establish guidelines for practice, even collaborating with one another to ensure that different codes corresponded with each other in their fundamental principles. The Internet Healthcare Coalition (IHC), a group of individuals in the medical community, held a summit in Washington, DC in February, 2000 that resulted in a code of ethics for websites that later became known as the Washington Code of eHealth Ethics and is used to facilitate the efforts of several of the organizations that are discussed in this section. Other examples include the Health Summit Working Group (HSWG) from Miritek systems, which published seven major criteria for assessing information quality, and Hi-ethics, a collaboration of organizations and companies providing medical services via the internet that met and developed ethical guidelines (based on the URAC accreditation codes) for health services that also included information guidelines (Fried et al, 2000). The American Medical Association also published a set of guidelines for its websites (Winker et al, 2000).

<sup>13</sup> For extensive explanation of the HON Code and hyperlink set-up, see: <http://www.hon.ch/HONcode/audience.html>.

<sup>14</sup> MedCERTAIN was in a three-year experimental phase that lasted until February 2002, when it entered a second phase and became known as MedCIRCLE. (see: <http://www.medcertain.org> and <http://www.medcircle.org>)

<sup>15</sup> Guidelines for evaluating as were listed on the MedCERTAIN site are taken from the Washington Code of eHealth Ethics. See note 12.

<sup>16</sup> <http://www.accessible.org/wmc/wmc-1.htm>

<sup>17</sup> Concerns about illegitimate medical claims were not new. In the United States, organizations such as the LeHigh Valley Committee Against Health Fraud, which at this point had been active for 25 years, began to include web-based claims in their focus on fraud. This group established a website under the name Quackwatch (<http://www.quackwatch.org>) and expanded into "a worldwide of volunteers and expert advisors" to investigate questionable claims. They sought to improve the quality of health information on the web and attack misleading advertising on websites. Among target sites were chiropractic, nutritional, dental and homeopathy sites.

<sup>18</sup> See Pinch and Bijker (1987).

<sup>19</sup> For a discussion of such 'reliability' work, see e.g. Timmermans and Berg (1997) and Bowker and Star (1999).

<sup>20</sup> See Adams and DeBont (2003) for a discussion about different constructions of reliability in three of the initiatives discussed in this paper.

<sup>21</sup> See Adams and DeBont (2003) and previous note.

<sup>22</sup> For more on this, see other works in STS. For example, Shapin (1995), in discussing the analogous idea of credibility in relation to scientific claims asserts, "All propositions have to win credibility and credibility is the outcome of contingent social and cultural practices." (p.257) See also Shapin and Schaffer (1985), Latour (1987) and Berg, et al (2000).

<sup>23</sup> C. Boyer, personal communication.

<sup>24</sup> See Payer (1989) for a rich discussion on the manifold cultural differences that inhabit biomedicine between countries. See also, Berg and Mol (1998).



## ***Chapter Two***

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### **Notions of reliability: Considering the importance of difference in guiding patients to health care web sites**

Adams, S.A. and A.A. de Bont. 2003.

Notions of reliability: considering the importance of difference in guiding patients to health care web sites.

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As health care web sites have increased in prevalence, so have accompanying questions regarding how individuals and organizations can guarantee the reliability of these sites. These questions have arisen in medical and academic literature alike and are debated in policy circles on both national and international levels. Complicating these debates is the desire to attempt to align standards across nation-state borders. As of yet, no single concept has emerged as a standard for identifying reliable sites, nor for ensuring that a certain site remains reliable after it is so identified. Rather, a variety of types of measures promising to lead patients toward reliable sites has emerged.

Analyzing three of the more prominent approaches to guarding health care information demonstrates three different notions of 'reliability'. The differences contained in these constructions of reliability are important to analyze, because this helps us to improve our understanding of what is at stake in creating a 'reliable' web site, portal or information guide. In this paper, thus, rather than seeing these differences as problems to be solved (by finding an optimal, 'universal' solution), we will argue instead that they can be potential assets for users.

Understanding reliability issues generally requires addressing, in its entirety, the exchange that takes place when users employ the internet to pull information from, or submit information to, one or more websites. One must examine how reliability is ensured at different stages of this bi-directional flow of information, or for different actors utilizing the internet. This paper examines three examples of mechanisms that primarily address the information that is provided from sites to users, and that are aimed primarily at assisting patients or laypersons (rather than professionals) during their search for health care information resources.<sup>1</sup> For each example, analysis is extended on the basis of how reliable sites are selected by an organization, as well as by how each organization utilizes network space.

## ■ EXAMPLE ONE: HEALTHFINDER

Several institutions and governments have undertaken to create health portals, which do not offer direct medical information, but rather provide links to resources on other sites that are considered reliable by the supporting organization. In the United States, the national health portal, healthfinder<sup>2</sup>, was first launched in 1997 and redesigned in 2001. The site is a federal collaboration: provided by the Department of Health and Human Services, coordinated by the Office of Disease Prevention and Health Promotion and advocated by the Surgeon General. Developments surrounding healthfinder are impor-

tant from a global perspective because it is a primary resource that other governments have used as a model for setting up their own health portals.

Labeled as a “gateway,” healthfinder provides a spectrum of links to government run or government approved sites, under the slogan, “Your guide to reliable health information.” Information categories are wide ranging, covering many traditional and alternative medical topics. These resources are not limited to encyclopedic information, but also offer news, decision support, counseling information, and specialized resources aimed at children, in addition to links to libraries, universities, journals and online databases.

### *Reliability*

How sites are selected and approved for inclusion on the portal is delineated in the “Content Selection Policies and Procedures,” which consists of six sections on the current site.<sup>3</sup> The first section of the explanation states, “The goal of the web site is to improve consumer access to selected health information from government agencies, their many partner organizations and other reliable sources that serve the public interest.” An important question that arises is how the department has actually determined reliability, especially given that the disclaimer in the last section of the selection policy absolves the site from any direct responsibility for the quality (accuracy of information, for example) of the respective sites, by stating that, “Also, healthfinder does not control the *content* of the Internet sites or organizations listed.” (Emphasis added.)<sup>4</sup>

Surfing thoroughly through these links provides insight for understanding the implicit definition of reliability suggested by the national health portal. First and foremost, the links lead only to US-based resources, and often to government, government related or government supported organizations. Secondly, selection of these is made on basis of name recognition and reputation. The burden of proof is laid upon organizations – if they can establish that they are credible and consistent, a link to the organization may be established on the healthfinder site. By not checking content, the idea of reliability of information becomes disjointed from the information itself and is connected, rather, only with the source from which it comes. These first two points become more explicit when one looks at the second-language resources that are also offered on the site. Most of the resources are also offered in Spanish, but the information resources offered are Spanish translations provided by the same institute that provides that information in English.

A third point about sources considered to be reliable is related to the topics that are presented on the site. In addition to information about standard medical concerns and practices, there are also numerous resources about alternative medicine, acupuncture,

chiropractic, etc. This is worthy of note because these are topics that are considered to be illegitimate by some individuals offering guidelines and resources for reliable information on the web, as will be discussed below.

By attributing reliability to institutions and assembling sites in this manner, the umbrella site that results is actually the creation of a bordered space wherein links are made only to the sites of those organizations that are already bound by standing regulations. These regulations can derive from federal or state laws, or from internal policies of the individual institution, and subsequently, they affect institutional practices. On the basis of reputation, an institution is then entrusted to apply the same regulation standards to both on- and offline behavior. It is this use of *institutional reliability* for judgment that differentiates healthfinder from the other examples.

### *Spatial Configuration*

One of the often-touted advantages of the internet is its ability to expose users to resources all over the world. Thus, it is interesting that, in this case, "reliability" is essentially confined to geographical borders, even though the technology is not. The critic will argue that a state cannot maintain a quality control on sites provided by organizations in other states, which is true. However, in this case, the government is not merely trying to control quality on sites. Instead, a federal collaboration is providing users with sites labeled as reliable because of the organization behind them, and these provided sites remain restricted to those within US geographical borders.

Spielberg (1998) expresses concern over the ease with which the web allows users to cascade so quickly and easily through cyberspace because it can be unclear when certain borders, such as those between sites which are approved and those which are not, is crossed: "The 'linking' of one web site to another has engendered the concept of a 'web.' However, providing links to other sites may imply an endorsement of the service, information, or products found linked on the site. This is problematic, particularly because the content of a web site can be constantly altered or updated, making monitoring of its contents very difficult." (p. 1358) Spielberg reiterates the point that previously supported information may have changed since the link was created or last updated, reflecting the dynamics of the web and indicating one difficulty in identifying a site as reliable.

Through drawing these boundaries, the mechanism implemented by the state is the domestication of a defined space, where the portal becomes a 'safe haven.' That is, the gateway leads to an area where everything the user sees or with which s/he must interact can be trusted, even though this space is still hyper-linked to other parts of the web. This

approach is a logical concept, if one compares this to the physical nature of nation-state borders. The government attempts to create one specific space where the reliability is implicit in the construction. In this respect, the state remains able to “patrol” its own “borders.” Yet, Spielberg’s questions regarding crossing these borders remain, especially given that borders on the internet are rarely easily defined and visible. By venturing in different directions beyond this region of space, information seekers search through sites that are less regulated, leaving the issue of reliability as an open question in many regards.

## ■ EXAMPLE TWO: QUACKWATCH

The above sections suggest that individuals and institutions are not always in agreement about what content can be considered reliable. In stark contrast to the US national health portal, is another US-based site, Quackwatch<sup>5</sup>, operated by Dr. Stephen Barrett. Quackwatch began in 1969 under the name Lehigh Valley Committee Against Health Fraud. The name change accompanied expansion into a worldwide network that focused on both on- and offline information in 1997. Among the list of activities included in the organization’s mission statement are: investigating questionable claims, improving quality of health information on the Internet and attacking misleading advertising on the Internet. On the web site, Dr. Barrett has openly posted both compliments and criticisms that he has received about the site.<sup>6</sup> One pervasive theme of the criticisms is that Dr. Barrett dismisses as “quackery” any type of health care practice that does not follow western medicine.

### *Reliability*

By comparing healthfinder and Quackwatch, one sees that there is a difference of opinion about what topics in the material can even be considered as reliable. The latter dissuades visitors from entrusting some of the very sites that the US government recommends – mostly, those that deal with alternative medicines. For example, both sites recommend the American Cancer Society’s site, but whereas the US portal has included the site as a trustworthy source of information for alternative medicine about cancer, the Quackwatch site recommends it in conjunction with the following caveat: “Warning: Much of the information the ACS site has about ‘alternative’ methods is either misleading or written so blandly that it provides little guidance.”<sup>7</sup>

Whereas healthfinder recognizes that there is an interest in varied practices, and therefore undertakes at least to lead visitors to sites of reputable institutions that provide information about such practices, Quackwatch discourages the interest itself. In this way,

the difference in defining reliability becomes important. As opposed to healthfinder's method of using institutions that are known to be reliable, without specifically controlling content, Quackwatch instead targets and uses content as the measure of reliability. The Quackwatch site both recommends visitation and discourages visitation to various sites, based on the information that the respective sites contain. However, in so doing, judgments of good and bad are made on the basis of a strictly defined value system with a particular agenda. That is, the action of labeling reliable sites in this manner reinforces the familiar rhetoric defending rational western medicine. What is or is not included on the site, or better yet, what is included as reliable and what is marked as quackery is decided on the basis of very tightly drawn boundaries. Adhering to such a strict division makes reliability of medical information a black and white issue, an oversimplification of the reality that even within biomedicine, there are many gray areas, where boundaries are not so strictly defined.

### *Spatial Configuration*

Quackwatch and healthfinder are similar in that they assemble a variety of links and reports that are accessible from a centralized home site. Differences between the two lie in scope. Quackwatch does not remain confined to the physical borders of the political state where it is located, nor is this the intent. Likewise, it is not restricted to organizations that are, in one way or another, closely linked to the government. The individuals working on this project with Dr. Barrett review a diversity of sites from a multitude of sources and physical locations. The site also embraces a broader range of topics and gives other types of consumer advice.

Additionally, Quackwatch is also translated into German, Spanish, French and Portuguese, each with a physician who is a native speaker of the language as the contact person. The site states that the organization, which identifies itself as a worldwide network, is interested in growing by setting up smaller versions of the site in other languages. With Quackwatch, as with healthfinder, one sees that a bordered zone is created and patrolled. In contrast to healthfinder's safe zone, enclosed by state borders, Quackwatch aggressively creates restricted areas on the basis of topics that patients and others should avoid. The links on the site act as detour signs to maneuver information seekers away from these threatening areas.

## ■ EXAMPLE THREE: HEALTH ON THE NET

Dr. Barrett and his colleagues are joined by many non-profit organizations in their concern about issues such as content, advertising practices, privacy issues and ethical practice (among many others) in this open space. Organizations such as the Health on the Net Foundation, Hi-Ethics, the Internet Healthcare Coalition, the Health Summit Working Group and the American Medical Association<sup>8</sup> have established their own, different, published guidelines for the ethical or reliable provision of health care information. These groups have highlighted areas of importance that providers should heed when creating sites and users should look for when surfing for information.<sup>9</sup>

Because the Swiss-based Health on the Net Foundation (HON) has created a hyper-linked seal to accompany and complement its ethical guidelines (the Code of Conduct, or HON-code), HON's approach is discussed as the third example. When visiting the HON site, one finds, in addition to background information, user and membership information and policing information, explanations (in more than 20 languages) of the "eight ethical management principles" intended for use by developers of health care sites on the web. Additionally, the site fully details the organization's four-step process for resolving complaint cases and explains how broken standards are handled and how compliance with the HONcode is assured.

### *Reliability*

In contrast to the "hand-picked" nature of sites on healthfinder, HON does not choose sites. Site administrators must take the initiative to request membership and accreditation. This process begins when a site agrees to adhere to HON's eight ethical principles and is then followed by the HON review and approval process. The eight principles, as listed, are: authority, complementarity, confidentiality, attribution, justifiability, transparency of authorship, transparency of sponsorship, and honesty in advertising/editorial policy.<sup>10</sup> Of the eight, seven are concerned with the flow of information from the site to the user, and one (confidentiality), with protection of the information that flows from the user to the site.

The HON seal is an identifier for those sites that have agreed to adhere to HON's principles, and that have been reviewed and approved by HON. The seal is a mechanism of the technology, a hyper-linked icon, that provides a cross-check system between HON and member sites. Web end-users are expected to verify honest display of the seal by a site in one of three ways: by placing the mouse over the seal on a given site and checking the site's registration number; by clicking the icon, a hyperlink, back to HON's information

about the site in question; or by visiting the HON site and submitting answers to a list of questions about a site in order to receive either verification of compliance or an assessment of the areas where the site breaks from HON principles.

HON issues two disclaimers about the seal and principles. Firstly, HON states that just because a site doesn't display the logo doesn't mean that it is of poor quality. (For example, both healthfinder and Quackwatch are registered with HON, and HON recommends both as good starting points on the web, but while the former cites the Code of Conduct as one standard of measure for site evaluation, only the latter openly displays the HON seal on the opening homepage of its website.<sup>11</sup>) Secondly, the organization states that it does not "seek to rate the medical accuracy, validity, or appropriateness of the information itself."<sup>12</sup> This second statement clarifies that, although the organization also claims to control for information content, it also disclaims any responsibility for that content. Instead, it is the provider who is kept in check.

A reliable site agrees with the aforementioned eight ethical management principles, and participates in a virtual community watch program. Such a site not only checks itself by adhering to the aforementioned ethical guidelines (understanding that it can undergo a random spot-check at any time), but it also reports violations of the code by others, keeping the entire self-regulation process in check. These guidelines and accordant checks of sites comprise an established *process* and participants in this process are expected to protect it at all times.

### *Spatial Configuration*

The placement of the seal on a page is also a strategy for raising awareness about the need to distinguish between different forms of content. HON's provision of the Code and the hyperlink intends to encourage users to be skeptical about sites that they visit – to evaluate the source and purpose of information being offered by a site. The icon is grounded in a policy that allows it to flux dynamically with changes in the web. The foundation has devoted much time to working out the intricacies of making the logo work, for example, technically updating it to reduce the potential for unauthorized duplication. As web technologies further develop, so do the technical intricacies of the seal, indicating that the employed technique uses one small component of the technology to contribute to indicating the reliability of a larger part. The logo reflects flexibility employed by the organization in responding to the dynamics of the web.

In contrast to the creation of smaller regions of space that evidences with healthfinder and Quackwatch, the HON seal utilizes the space of the network itself. The icon tran-

scends different regions of space on the internet, and does not remain within the Swiss, or even European, domain. Furthermore, within the network, the seal maintains and indicates its own specific set of standards. The creation of a new set of guidelines eludes the issue of aligning existing statutes and practices across nation-state borders.

## ■ DISCUSSION

Healthfinder, Quackwatch, and Health on the Net are only three examples chosen from a long list in order to demonstrate different constructions of the same concept. Although more examples (and from different types of sources) could be utilized, through these examples one already sees three different constructions of reliability: institutional, content, and procedural reliability. These differences are not coincidental, but rather, they are implicitly linked to the varying purposes of the different institutions. Why, then, are they interesting?

Many authors focus on differences in order to strengthen arguments that favor universal standards. These authors see difference as a problem and argue that employing such a universal standard will enable us to avoid this “problem” of difference. We argue, however, that eliminating difference is neither a feasible nor necessary path to take. We suggest that differences should not be erased, but rather, explicated. Deepening our understanding of differences between organizations that attempt to identify reliable sites can be used to direct us to the next steps for guaranteeing (forms of) reliability of health care information on the web.

Analyzing these attempts along the two lines above already reveals crucial differences in notions of reliability. Not only do these definitions not easily align, but they are also often in conflict with one another. Such contradictions evidence when Quackwatch and healthfinder are juxtaposed. If a choice for the best possible approach (or for the best elements of different approaches) must be made in order to standardize contradictory approaches, how is such a choice made? Whose standards of good and bad are used? What criteria are used to choose the “most acceptable” construction of reliability? These questions present real challenges – the same challenges that arise when attempting to provide a definition of reliability.

Making any choice also means accepting the trade-offs. What is lost in the trade-off with those that are now excluded? What consequences result for the respective organizations? It is unlikely that a government site, such as healthfinder, can afford to make the staunch statements that Quackwatch does. Similarly, an international effort such as HON



cannot achieve the type of national recognition that a single government sponsored site undoubtedly will have. The issues become politicized and the question seems unsolvable, if not in principle, then in practice.

Arguments about reliability are closely coupled with those of building trust. The work of Nissenbaum (1999) is important here. Her work questions the ability of security mechanisms to secure trust online, and provides helpful insights for deepening our own understanding of the issues raised in this article. Although she primarily examines more technical security mechanisms, her arguments can also be applied to the examples given above.

Nissenbaum identifies conditions for and obstacles to trust and eventually asserts that current methods to secure trust online are simultaneously incomplete and over-bearing. With this statement, she suggests that mechanisms promise more security than they actually offer. This would imply that no single reliability indicator can cover the expanse of the internet, nor can it fully cover even the space within which it functions. At the same time, she argues, while restricting interaction can ensure more safety in utilization, it also greatly limits the choices and possibilities available to the user. "The tradeoff is clear: a more free-wheeling, open, permissive online world is likely to be the less safe. Proponents of security would limit the range of interactivity, increase surveillance and transparency – all in the name of trust." These same arguments are applied to these examples, in order to further analyze ideas surrounding reliability and to understand the importance of difference.

### *Localized Security*

Reliability zones on the internet are attempts to define specific regions of space. Regardless of the form, in the end, the resulting spatiality is relatively confined. Thus, any mechanism that is implemented, through the demands of localization, will never be a comprehensive tool for guaranteeing reliability. Leading users to safe areas, detouring them around dangerous ones, or even giving them markers as they traverse conflicting areas, first requires that all of these locales be constructed. Part and parcel to this effort is simultaneously creating one's own image as a trustworthy source.

This building process demands an enormous deal of work: HON must review applicant sites and oversee the policing procedure, the US site reviewers must constantly seek and control new sites, and Dr. Barrett must continue to expand his network. Furthermore, each organization must ensure that the content of included hyper-linked sites remains at the same level as when they were originally reviewed. The degree of work involved in the creation either of bordered zones or demarcating signposts, and in the presentation of one-

self as an authority of these areas, demands the use of different instruments. Because the instruments used to define each type of spatiality also confine that space, reliability can only be guaranteed within small niches on the internet. Niches take on different forms and extend in different directions – they can conflict, but they can also overlap. Understanding spatial distribution on the internet can be difficult, but nonetheless, spaces can be isolated, as associated with a particular point of origin (portal, hyper-link icon) demonstrating that the functionality of each space remains contingent upon the restrictions imposed during the process of localizing that area. Furthermore, any collection of sites, regardless of how comprehensive it tries to be, will confront the problem of only having local effectiveness.

### *Normative Consequences*

Nissenbaum's argument suggests that a consequence of being confined by borders is that they also become confining. That is, that the exclusion that accompanies the definition of borders also leads to the restriction of choice. Staying within these zones to guarantee reliability also means subjecting oneself to the available choices, as well as to the principles that are used in the process of reviewing and selecting the sites that comprise these choices. Nissenbaum uses this as the second half of her paradox: simultaneously incomplete, yet overbearing. For example, healthfinder provides its users with only American/government associated sources, while Quackwatch limits choices based on the rationale that "non-regular" medicine equals unreliable "quackery."

However, we can also look at it in another way. Alone, each institution/organization maintains its own approach, which can be limited. Together, however, these three examples offer users a choice in whose advice they will follow. A user interested in avoiding an encounter with alternative options can choose also to stay within the parameters of Western medicine by following the strict norms of good and bad as exercised by Quackwatch. The user that relies on the tried and true – the established organization – or the user who wants to restrict the amount of information and sees limiting sources to American institutions as an acceptable manner can choose healthfinder. HON's seal is ideal for a patient that wants to surf freely, or from various starting points, but still appreciates an indication that the site is in some way being held responsible for the information it provides. A particular spatiality can work differently for different user-sets.

Examining these differences leads us to see that they are not problems that need to be replaced with a single solution, but rather that they can be assets if allowed to stand. The web is renowned for the diversity of options and ease of access to these options that it provides to its users. In creating effective mechanisms for indicating reliable sites, one cannot forsake the position of the user. Actually, there is a broad array of different us-

ers, with very different information needs and desires, which suggests the need for *different* options. Therefore, striving toward one single approach to guaranteeing reliability is not only an implausible strategy, but it is less effective than the combination of existing mechanisms. Choosing only one type of reliability indicator would not do justice to the plurality of users (nor to the single user with various needs) who are searching the web for medical information and services. For existing mechanisms to be effective, more time and effort should be invested in informing users about the choices available to them (and the trade-offs involved with these choices), so that they can analyze these options and decide for themselves. More importantly, rather than continuing to problematize the existence of differences, we should make them more explicit and start to consider them as a fitting way to handle “reliability” in a world of multiple perspectives and multiple preferences.

## NOTES

<sup>1</sup> Because these distinctions are not always entirely clear-cut, the organizations and said resources that comprise the given examples can be partly geared toward taming the flow of information from the users back to sites, and/or toward assisting the efforts of professionals as users in utilizing sites. Those components, though acknowledged, are not addressed here.

<sup>2</sup> United States Department of Health and Human Services. healthfinder. See: <http://www.healthfinder.gov>.

<sup>3</sup> The authors acknowledge that by the time of publication of this article, subsequent changes regarding the content of sites may have taken place.

<sup>4</sup> Both of the notes in this paragraph are drawn from the United States Department of Health and Human Services healthfinder content selection policies and procedures, which are available at: <http://www.healthfinder.gov/aboutus/selectionpolicy.htm>.

<sup>5</sup> Quackwatch home page. See: <http://www.quackwatch.org>.

<sup>6</sup> Comments from Quackwatch visitors. See: <http://www.quackwatch.org/00AboutQuackwatch/comments.html>.

<sup>7</sup> Quackwatch. A special message for cancer patients seeking “alternative” treatments. Available at: <http://www.quackwatch.org/00AboutQuackwatch/altseek.html>.

<sup>8</sup> Web pages for all of these organizations are listed under their names in the references list, with the exception of HON, for which links are given throughout the thesis and the AMA, which is listed under Winker et al (2000).

<sup>9</sup> Because of the length and complexity of each set of guidelines, they will not be extensively reviewed here. (For further details, one can obtain the guidelines by visiting the individual sites of each organization.)

<sup>10</sup> For a comprehensive explanation of both the selection process and these eight terms, refer to the home site of the Health on the Net Foundation: <http://www.hon.ch>. (See Appendix.)

<sup>11</sup> The HON seal is placed under the “about us” section of the healthfinder website, which is evident only to those users who actively seek background information about the site.

<sup>12</sup> Health on the Net Foundation. Responsible self-regulation. See: <http://www.hon.ch/HONcode/method.html>.



## ***Chapter Three***

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### **Practicing reliability and the case of the 'iffy': Reconstructing traditional boundaries in the gray areas of information review**

Adams, S.A. and R. Bal. *Forthcoming*.

Practicing reliability and the case of the iffiness.

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**“The next step is to decide which quality criteria we want to use to select sites for the new portal. I’ve done a review of the literature and there are currently at least 122 individual criteria from which we can choose. Obviously we cannot choose all of them, but what should we choose?”<sup>1</sup>**

Medical and consumer health informatics literature devote considerable attention to the increasing availability of medical information on the world wide web. As with most areas of internet discourse, this literature simultaneously constructs the internet as a medium that empowers its users by giving them access to more (types of) information, enabling them to make better informed decisions, as well as one that endangers its users by subjecting them to too much irrelevant information and information of questionable quality. One prevalent argument in this discussion is that the medical and informatics communities can combat problems related to surplus and quality by controlling the provision of health related information and helping patients<sup>2</sup> find reliable resources on the web. Various medical, political and independent organizations have undertaken to create user-friendly tools for finding reliable information and, as such, have been faced with the challenge of (re-) defining what it means for information to be reliable. This definition work has raised the question of whether transferring existing criteria to online information is sufficient or if it is necessary to create new quality criteria with web-specific needs in mind. Additionally, it raises questions of who should be reviewing information, what rules must be followed during such assessments, and how compliance is physically signified on the web.

Underlying the creation of these criteria and techniques is the suggestion that once a definitive list of quality criteria is produced, with specific guidelines for how to review on the basis of these quality criteria, the bulk of the work is done and the list must merely “be applied” during the review of information. As such, these tools and their accompanying criteria have seen much review in current literature (Jadad and Gagliardi, 1998; Risk and Dzenowagis, 2001; Gagliardi and Jadad, 2002; Wilson, 2002; Bernstam et al, 2005), with a practical focus directed toward the *choice* of criteria to fit a given technique, as is demonstrated in the opening quote. Aside from isolated criticisms about how criteria potentially influence information review, little attention has been given to the actual work involved in the review process that follows the selection of criteria. This work is crucial because compliance with a given guideline or criterion is not automatic and the guideline alone cannot indicate when it is or is not applicable. (Garfinkel, 1967; Wittgenstein, 1967; Lynch, 1992) Compliance with a guideline is determined during the practice of review – a practice that is not straight-forward, but rather a process through which the site reviewer engages with a site and weighs the balance between types of information presented on a site. In the application of such criteria and guidelines to assess informa-

tion on websites, reliability is further defined in practice. As such, of further interest is how the application of rules to sustain the technique also reconstructs and reproduces not only the reliable, but also its opposite – what is not reliable.<sup>3</sup>

Although claims that patients can be led to “de facto” reliable information can be questioned (Adams, de Bont and Berg, 2006), it is nonetheless interesting to look at how organizations come to produce these claims. If we consider codes of conduct and selection criteria to be analogous to rules, we can see them as bureaucratic instruments and artifacts to be studied. (Garfinkel, 1967; Timmermans and Berg, 1997; Berg et al, 2000) In this paper we question how reliability is practiced in the process of reviewing medical websites by studying how codes of conduct and selection criteria are applied to information. We approach quality criteria as a reflection of the localized circumstances in which a (bureaucratic) technique (for our purposes, the given initiatives) is embedded: what is realistic in terms of reviewing sites, appropriate with regard to the group targeted by the initiative, within the geographical breadth of initiative, etc.

We begin by situating this work within two contexts: the debate about empowering patients and prior research on rule-following. Using two case studies – the Health on the Net Foundation’s (HON) Code of Conduct and web portals provided by the US National Library of Medicine – we explicate the gray areas of review and deepen our understanding of how localized definitions of reliability are built through the practices of applying criteria. Following Singleton’s argumentation about the New Public Health in the UK (Singleton, 2005), we look at how these practices reinforce distinctions (such as those between lay and expert, global and local, non-profit and commercial, etc.) that current medical sociology and informatics literature suggests have been broken down by internet technologies and the availability of web-based medical information. What individual criteria must comprise the guidelines specific to a given technique? How do organizations adapt and change these general quality criteria when applying them to specific cases? How do practices employed in applying guidelines for judging information continuously co-produce the reliable and the unreliable? And, in so doing, how do these practices also reinforce the boundaries that current literature suggests are being broken down?

## ■ FOLLOWING GUIDELINES TOWARD EMPOWERMENT?

In medical sociology lay web use is generally inscribed in notions of the informed patient. (Kivits, 2004) “Online information seekers” are often depicted as critical and active participants in their own health care process. The “empowerment” of patients through



increased potential for access to medical information coming from outside of the health care arena has led to arguments that the boundary between lay and expert is breaking down. (Hardey, 1999, 2001) Familiar arguments suggest that through the use of technology, training and skill development, lay persons can become experts, enabling patients to be more assertive in managing their own care and changing the nature of relationships between professionals and lay citizens. However, many have argued that the concept of the “informed patient” is empirically difficult to sustain. Research participants do not conform to this depiction. (Lupton, 1997) Reasons vary, but include constraints related to information literacy and barriers within the medical encounter, as well as restrictions related to the dominance of biomedical discourse. (Henwood et al, 2002, 2003; Fox et al, 2005)

In medical informatics literature, the suggestion is not that lay information seekers are constrained in conforming to this image, but rather, the stronger assertion that they are actually *prevented* from being empowered because of the large amount of information and the questionable quality of much of that information. Warning of the dangers that unreliable health information presents to vulnerable web users, authors suggest that these users will need assistance in learning how to sort through the available information. (Eysenbach and Diepgen, 1998; Jadad and Gagliardi, 1998; Eysenbach, 1999; Wilson, 2002). The rhetoric contained in warnings about health information has been strong: the derogatory notion “poison online” was used to refer to the availability of information and products related to alternative medicines (Weisbord et al, 1997), while hidden financial interests that blended into how information is presented were brought to the fore in criticisms of DrKoop.com<sup>4</sup> (Cho, 2000). Lack of quality control and an open publishing environment were used to suggest that there was great potential for “evil uses” of the medium. (Appleby, 1999) A more general pronouncement was made by Dr Gunther Eysenbach<sup>5</sup> in his reference to the information “jungle” (1999) and subsequent discussion of the important emergence of infodemiology – the epidemiology of misinformation (2002). In Eysenbach’s opinion (2000a), patients could only be empowered through rating and education, and it was the physician’s duty to lead them through the aforementioned “jungle”.

In discourses about health information, the patient is simultaneously an active, certain, demanding consumer of health information, and an uncertain, unskilled, passive reader incapable of distinguishing reliable, relevant information from misinformation such as mistakes, irrelevant information, fraud and “quackery.” The suggestion about web-based information and its users is twofold: that “good” (valid, reliable, accurate) information can be distinguished from “bad” (not valid in individual situations, not thoroughly reviewed, not in keeping with evidence-based standards) and that specially created user tools can

lead individuals to “good” information, rendering “bad” information avoidable. As such, the empowered patient does not merely emerge through access to the web and the availability of health-related information, but rather, is actively constructed through education and guidance to the “right” sources of information.<sup>6</sup>

This discussion about reliability also suggests that other boundaries around information are broken down: national or geographical boundaries, the boundary between evidence-based medicine and complementary and alternative medicine (CAM), the boundary between “objective, scientific fact” and advertising or subjective experiences, the boundaries around authorship and publishing, and the boundaries between quality components (e.g.: the validity or accuracy of a given claim). Kivits (2004) discusses that when medical or health-related information is discussed in relation to the internet, an issue of power (keeping medical knowledge in the realm of the professional) is a primary factor. This is reinforced in suggestions that search assistance provided to web users should comprise a combination of a stronger role of physicians, strengthened public health education programs and initiatives, and the creation and implementation of professionally approved guidelines. (Eysenbach, 2000a)

## ■ GUIDELINES ALONE ARE NOT ENOUGH

Not enough attention has been given to the background work of applying said guidelines to differentiate between types of information and assign a label of reliability. How do guidelines give form to review practices? Garfinkel’s (1967) research experiments showed that rules and the practices in which they are put to use do not completely cover each other. In one of his experiments, sociology students were asked to code clinical careers in a psychiatric hospital. Despite the strict rules for coding that were intended to guide the process, there were always specific cases that demanded supplementary decision tools and solutions, which the students thought up in an ad hoc manner. Garfinkel concluded that: “...*ad hoc* considerations are essential features of coding procedures. *Ad hocing* is required if the researcher is to grasp the relevance of the instructions to the particular and actual situation they are intended to analyze (...) *ad hocing* practices are used in order to recognize what the instructions are definitely talking about.” (Garfinkel, 1967: 22 original emphasis) Garfinkel further concluded that coding is confined neither to external rules, nor to ad hoc solutions, but is an exchange between the two, through which rules and practices constitute one another. Without rules, we would not be able to code and yet, the rules alone are not enough, as ad hoc solutions are necessary to the completion of the task and arrival at a final product.

An analogous argument is made by Dodier (1998) regarding how doctors use codified rules to deliver judgments on specific individuals. He argues that the use of rules depends on how doctors frame individuals. He discusses how two frames, the administrative and the clinical, are used in conjunction. In the administrative frame, all people of the same formal category are treated the same way according to that category. This frame uses a pre-defined list of items for judging individuals and leads to strict judgments. In the clinical frame, points of reference for a given individual are no longer connected to general categories, but to personal norms and the doctor must leave room for individuals, unpredictability and particularities. He argues that judgment does not consist of applying rules, but rather of putting them in relation with one another, and that following a rule actually means placing it within several points of reference. Merging the two frames creates complex ensembles where a concern for strict rules coexists with flexibility.

Whereas both Garfinkel and Dodier rightly point to the under-determinate character of rules, they seem to miss one important aspect of the use of bureaucratic techniques – these also serve for external accountability of the practices in which those techniques are performed. Power's (1997) discussion of auditing practices stresses that only considering the use of ad hocing is not enough, because there is more behind the process than just the need to make adjustments. Auditable performance suggests that the design of performance measures and the development of audit practices are mutually constitutive. The process known as auditing works because it creates an environment of auditable performance; it provides a dominant reference point for organizational activity and serves to construct concepts of performance in its own image. Moreover, an audit must also be auditable in its own right – how performance measures are applied in practice must be (able to be) accounted for, which creates friction with respect to ad hocing, as these practices must be checked and accounted for, as well.

In order to study how those frictions are dealt with in the case of practicing reliability, we can turn to Singleton's work, which argues that suggested tensions and broken boundaries, such as those between centralized medical expertise and distributed lay expertise, are reconciled in practice through the employment of categories that allow information to be reviewed in the first place. As bureaucratic techniques such as codes of conduct are employed for classification purposes, the reliability of information is defined through the combination of written guidelines and the practices of applying those guidelines, both of which re-validate existing forms of information review and privilege medical science. The under-determinate character, then, makes clear that there is more going on than just ad hocing in the application, although this takes on an entirely different meaning than Power intends. Practices that engage in the definition work of differentiating between the reliable and the unreliable are used to (re-)produce *conventional normativities*.

(Singleton, 2005) In other words, combining strict rules with flexible ad hoc decisions is important because, in the process of deciding how to apply principles and selection criteria to individual sites, reviewers bind practices for reviewing information by prescribing specific behaviors for different actors. Furthermore, through these practices, traditional boundaries are reconstructed and stabilized.

In the following sections we turn to two case studies that exemplify the application of guidelines in practice. The first case, the Health on the Net, exists because of concerns about reliability and affords its seal to sites that adhere to ethical principles. The second, the US National Library of Medicine, currently provides a national portal to information on more than 700 topics and is developing state-based portals linked to the national portal. We examine how the principles and practices are explained on paper and how reviewers apply these to web-based health information.

## ■ APPLYING CODES AND GUIDELINES: CASE 1

The Geneva-based HON was created in 1995 as a response to concerns about the quality of medical information on the web. The identity of HON as an institution is inextricably intertwined with its reliability definition work. Although it is European based, it seeks to serve a global user group of patients, professionals and site/information providers with its Code of Conduct (see Appendix) and hyperlinked icon. HON reviews sites on the basis of eight principles dealing with ethical aspects of providing a site, but does not (officially) judge the medical content itself. When a site is compliant with seven of the eight principles, it is given the technical code for a hyper-linked seal that is then posted on the site to denote compliance. The hyperlink in the seal enables users to review a certificate from HON giving the review dates for that site. HON argues that the Code of Conduct is a standard for creating reliable sites because it creates transparency. It enables site visitors to see the “inner workings” of a site: Who is running the site, what type of financial support the site receives, what type of information, if any, is collected about site visitors, how the site protects the privacy of its user-group, etc. More importantly, for HON, it is imperative that the information required by the eight components of the code is just as obvious to the site visitor as is the primary medical/health information that is found there.

Data were collected during ethnographic research at HON in 2002 and 2003 and derive mostly from observations made during an experimental exercise. Although reviewers generally review sites alone, only discussing review when there is a question about a site, for research purposes they were asked to engage as a team in an exercise that would make review practices visible. Three reviewers were asked to assess individually the same

four sites (one new applicant site and three sites eligible for periodic review) together with the researcher. After reviewing sites individually, the reviewers discussed questions that arose during the review and how these were addressed.

As reviewers systematically apply the principles (generally, in numerical order), the first differentiations the HON reviewers make are simple and straightforward – derived directly from the principles. Following these differentiations is much like following a dichotomous branching decision tree. *Principle one* (“authority”) states firstly that medical advice is provided by a trained and qualified professional and secondly that if the host is not medically trained, this is clearly stated. In the dichotomizing think process of the reviewer, the person behind the site is a medical professional, or not. If the site provider is medically trained, the person has provided specific information regarding his/her training, degree and specialty (compliant with principle one), or not (non-compliant). If the site provider is not medically trained, the person has clearly stated that s/he has no medical training (compliant with principle one), or not (non-compliant). The reviewers then look for the presence of overt statements, precisely phrased, that are not completely incorporated in the public definition of the principle. This is an additional working definition that is implicit in the rule and that is explained to new reviewers during the training process.

- Reviewer 2: He says that he is devoting the site to a relative and you can deduce that he is probably not a medical practitioner, but he still needs to state that he is an individual with *no medical training* – to clearly state that he is not a medical professional. He has either written or gathered all of the information on his website, but he is not a medical professional and that needs to be clearly stated.
- Reviewer 3: But, look then let’s return to the first site, for example – it says that this person is a health professional, but it doesn’t say specifically MD or whatever.
- Reviewer 2: Yes, but that is also not enough. (sites one and three – original emphasis)

Even though *principle two* (“complementarity”) stands alone from *principle three* (“confidentiality”), site providers tend to interpret compliance with the latter as dependent upon compliance with the former. The implication of this interpretation is that many site providers do not understand how principle three applies to their respective sites. The principle only states that the site must respect confidentiality and be in compliance with the privacy laws of its state. An individual “just relating personal experience,” or a site that does not contain medical records, often assumes from this that the nature of site activity makes it automatically compliant with the principle. However, again, compliance is reached only with the presence of direct statements regarding if (and how) information is collected, stored and used.

As the reviewers progress through the list of principles, the decision tree becomes increasingly complex and this complexity is generally related to the very first distinction that is made between the trained medical professional (further sub-divided into physician, specialist, nurse, etc.) and the lay-person. *Principle four* (“attribution”), for example, refers to referencing claims with source and date, but the presence of a reference and date is not enough. HON checks links and reviews information, ensuring that the link correctly supports the claim that is made. If the site provider is not a medical professional, the reviewers pay special attention to the content of the linked source – checking that it has not been misinterpreted by lay persons or otherwise misused because of hidden interests. If the site provider has a medical background, the reviewers are more flexible when reviewing this principle.

- Reviewer: OK, we have an article here, with this person, we have information about her training. She’s probably a medical writer. We have a date. And now I want to find information about the advisory board. This is a difficult site. . . What I am trying to find is the author – it is one of the most important things. . . What was troubling me earlier was that I couldn’t find the medical title of the writer but since it comes from a newspaper then it is assumable just to think that it comes from a medical writer. It could be improved by them saying that the people who gather the information are journalists experienced in the field of medical writing, but I’m not going to send a mail saying we couldn’t find the information when the information is more or less here. Regarding the references, we don’t need to see every reference clearly – since this is general information, we have to give some confidence to the professional who has done the article. (site two)

During the exercise, reviewers encountered sites that provided conflicting information, for example, about contact persons (“authorship,” *principle six*) or the nature of sponsorship (*principle seven*). Sites cannot always be judged on the basis of web content alone, even though the principles suggest otherwise. Often, extra information is necessary for HON to assess compliance. Also, as review progresses, it is increasingly difficult to deal with each principle individually. In the following example, the reviewer is checking one principle, but sees clearly in how information is presented that the site is not compliant with another – *principle eight* (“Honesty in advertising and editorial policy”). The unclear blending of types of information, and the subject matter itself give cause to alter the nature of individual principle review, by instead making judgments about the site as a whole – how it is set-up and what claims are presented.

- Reviewer: He seems to have a reference for everything, but look at this one – he begins discussing a financial interest in supplements, “with you, your family and your insurer, but. . .” Now, this seems like advertising.
- SA: It is sort of mixed in. It only has this box around it.
- Reviewer: Yeah, just mixed in with everything else. . . Yes. It clearly seems like advertising, because it goes to an outside site and it says, “Supplements for You.”

- SA: Is it properly marked?
- Reviewer: No, it is not, because I have... it needs to say here, advertisement. Plus, he needs to include an advertising policy. <snip> Everything on this site seems to be an ad, so I want to read the terms and policies and the "about us" information. (site three)

*Principle five* ("justifiability") requires balanced presentation of information – enabling the user of the information to weigh different angles and claims. We discuss it last because it is a "contingency" principle for reviewers – depending on the qualifications of the site provider, this can be applied in a variety of ways and more or less stringently. For example, although it is checked in numerical order, after checking all eight principles, reviewers can return to the principle a second time, using it to compare between individual principles and the entire feel of the site. Additionally, in cases of doubt, a medically trained person can be asked to review the content of claims.

After reviewing the site, HON sends the webmaster an email stating changes that are necessary for compliance with the HONcode and suggesting other improvements to the site. At this stage, how HON reviewers have applied the principles is confronted with the interpretation of the same rules by site providers. Differences in interpretation often results in "discursive emails" in which site providers argue, for example, that a principle does not apply to them or that the nature of the site makes them automatically compliant with one or more principles. To combat this, HON developed an additional set of guidelines for site providers that explain how all quality criteria apply to all sites, with examples of how information should be formatted to be compliant with the HONcode. That is, HON has made new rules for how the principles should be interpreted by site providers, how they should be applied by reviewers, and how compliance is physically shaped (how statements should be phrased) on each site. However, the addition of this set of guidelines does not take away the need for ad hocing on the part of the reviewer and subsequent communication between HON and site providers. Rather, it creates an extra layer of rules that need ad hocing in their own right.

Although a formal review procedure is followed, judging compliance often requires gathering additional information, asking a medical professional to check claims, or using the flexibility in principle five to position the individual components against the overall feel of the site. One reviewer divides principles into two categories, "clinical" (principles 1, 2, 4 [references] and 5) and "non-clinical" (principles 3, 4 [date], 6, 7 and 8) – this distinction is of added importance when the site is considered to be borderline, such as where nutrition topics are discussed. In engaging with the presentation of information on a site, HON's expectations for physical presentation of information reinforces that nothing inherent in a site makes it compliant by default – the reliability is always actively constructed.

HON's construction of reliability reinforces conventional dualisms and boundaries because both principles and practices reflect a traditional view on the doctor-patient relationship. Firstly, reviewers insist that web sites are complementary to, rather than replacements of, an existing physician-patient relationship. Secondly, they apply standards differently out of respect for the training that a medical professional has undergone. Thirdly, although they do not purport to check the content of a site, in cases of doubt, non-medical reviewers defer judgment to medically trained persons that assist in review.

In addition to deferring to recognized medical expertise, they utilize established scientific standards in checking authorship and links to articles. The principles reinforce the expected display of information – not only disclosure of multiple viewpoints (balanced information), but also support for claims coming from sources that arguably, due to their being published, have also at some point been reviewed for content. In this way, HON can insist on content review without being responsible for reviewing the content itself (which reviewers are not necessarily qualified to do), instead making use of knowledge and prior review by content specialists elsewhere using other guidelines. HON trusts standing institutions of scientific quality assurance and 'older' practices traditionally used for publishing in journals. Content reliability is checked by others and HON double checks how this is then transferred to and takes shape on a website, prescribing how different types of information should be labeled and phrased in order to be compliant with principles.

Finally, HON defers to governments and the laws of nation-states. In building itself as an institution that builds claims of reliability, HON has used its position in Geneva to assert its neutrality – considered to be an additional part of the definition of reliability. Part of the work of HON outside of reviewing sites is in building itself as an institution actually qualified to attach a quality label to medical websites. Central to this process was attaining recognized NGO status; how it conducted its own affairs was part and parcel to positioning itself among the score of international actors dealing with reliability issues, such that it could claim neutrality and deference to both medical practice and the regulatory affairs of nation-states.

## ■ APPLYING CODES AND GUIDELINES: CASE 2

We juxtapose *Medlineplus* with HON for several reasons. Although it was only created in 1997, the site was developed by the US National Library of Medicine (NLM), which has been active longer in disseminating medical information to a lay public. The website is not so much a response to the reliability debate, as a result of patterns of use on NLM's



institutional home page and MEDLINE<sup>7</sup>, which revealed that individuals without medical training were increasingly seeking medical content information. Medlineplus appears on the web as a “consumer-friendly” portal with links to diverse types of information. It is intended primarily for US citizens and carries information in English and Spanish. In 2003, NLM also began “Go Local” initiatives to create spin-off portals that have a geographically local (state-based) orientation for services and care, but a parallel structure and vocabulary to Medlineplus, with links to the medical content on Medlineplus. Whereas HON has developed more specific guidelines to lend support to its principles, NLM has built more flexibility into the review process. Guidelines for reviewers in Go Local projects, for example, give explicit instructions that reviewers use their own judgment or consult other reviewers.<sup>8</sup>

Data about Medlineplus were collected through interviews in 2002 and 2003 with one project leader and one primary site reviewer at NLM, and in 2005 with one participant in a Go Local project. Because of the limited nature of this research, application of selection policies was made visible in the identification of difficult websites for which a final decision regarding inclusion had not yet been made. We were actively looking for instances where individual reviewer discretion was necessary and questions were asked of other reviewers. During the interview, a reviewer at the top of the review hierarchy (see below) provided a list of five examples of “iffy” sites, which forms a basis for our analysis.

In contrast to HON, not all reviewers comprehensively apply the selection criteria when reviewing a site. Instead, there is a formalized hierarchy in which different reviewers are trained to look at specific types of information on websites. The lowest level involves selecting potential topics for inclusion on the site. The first step is creating a topic record and listing information about who provides a site for that topic. Another reviewer contacts organizations to inquire about who they are and to decide if they are “authoritative.” Higher level reviewers print and check the information on basis of four selection guidelines, while another reviewer manually checks the integrity of hyperlinks. The highest reviewers field questions and make final decisions about including information and giving it form within the portal. Discussion is an important part of this review hierarchy on both the local and national levels.<sup>9</sup>

Medlineplus claims that the site is designed to help users find appropriate and authoritative health information. It also states that the information is either produced by NLM and the National Institutes of Health (NIH, of which NLM is a part) or pulled from MEDLINE and ClinicalTrials.gov<sup>10</sup>. Resources are selected according to four primary selection criteria<sup>11</sup>. The first regards quality, authority and accuracy of content: the source of the content is established and dependable, the names of advisory board members for the site

are published, information comes from primary resources and lists of links are reviewed and filtered. NLM does not like to link to other portal sites because of the importance of information coming from primary, reviewed resources and the lack of guarantees that links are checked in accordance with this criterion. The second criterion regards the purpose nature of the information. The content should contain special features or unique information and contain as little as possible overlap with other resources included for that topic. The site may not be of a commercial nature or charge for access to content. The third criterion lists conditions of availability of information with respect to web page maintenance: the site and its links are consistently maintained and available, sources of content are posted, an update date is included and registration is not required. The fourth criterion addresses special features: the topic is unique, information is not repetitive when compared to other resources, and the site is accessible to persons with disabilities.

Because it was not possible to observe the review process or the work of different individuals in the hierarchy, it is more difficult to see how the individual criteria are individually judged. However, we do see clearly how, as Dodier suggests, in order to make a decision different points must be put into relation with one another. The primary reviewer identified websites that contained both positive and negative aspects with respect to the selection criteria, thus making visible the difficulty of decision-making beyond the mere weighing of different factors.

- Site two: "The site appears to have good content, has a good [Board of Directors], authorship, and content, but this is a portal site with problems, including commercial content (see medical device articles, no attribution given), unlabelled ads, ads for painkillers on pages about pain, content taken from other sites including commercial or portal sites, sponsors produce some content, intrusive physician locator. Violation of the 'one click rule': with one click you shouldn't get to somewhere you don't want to be."

This example reveals the tensions that exist between different components of the selection guidelines. For example, one criterion states that all information on the website must be primary information. Most websites are heterogeneous in terms of types and sources of information, such that this criterion almost always involves weighing the balance of other criteria to reconcile problems that links to information can present. A secondary problem is the tension between how information is written and the idea that it is commercially produced. Does a good explanation outweigh the source of that information? These two components cannot be considered in isolation from one another, but only considering them results in a deadlock – from here that the positive and negative aspects of a site must be juxtaposed. As part of this balance, we interestingly see the emergence

of the “one-click rule,” an unwritten or informal<sup>12</sup> rule that is understood among reviewers and needs to be explained to outsiders not familiar with or involved in review practices.

NLM’s treatment of content is somewhat precarious in that it is difficult to understand if, and to what degree, content is reviewed and what the guidelines for this review are. Although *Medlineplus* is considered to be a site with high-quality content, and general comments are made about the content of sites under review, the selection guidelines actually do not specify by what criteria content is judged. Much like HON, guidelines address circumstances around the provision of the information, rather than the information itself. The Go Local guidelines, for example, list currency (date is listed), coverage (scope and depth of content), links, uniqueness and then “other content factors” as points to consider when deciding on a site. Although quality and accuracy are included in the *Medlineplus* selection guidelines, accuracy is vaguely defined (information comes from a primary resource) and the government disclaims responsibility for completeness and accuracy<sup>13</sup>.

■ Site three: “Scientific Advisory Board and site authors are essentially the same [people], some reasonably well-credentialed; others are not and are affiliated with supplement business. Site claims not to accept ads from supplement business, but an ad for vitamin company displays. Highly questionable statements that sound as if manufacturers may have supplied them... In several cases site recommends specific brands of vitamins.”

The reliability of this particular site is called into question because of the commercial nature of the information. Because the site is inconsistent in its policies and actions, it is difficult to differentiate between types of information. Reviewers are generally wary of recommendations that are made, particularly about topics that are contested in medical literature. Two other “iffy” examples also demonstrate the importance of government institutes positioning themselves against commercialism in various forms.<sup>14</sup> “Commercial” refers to pharmaceutical companies, ads, product recommendations, the language of statements, and paid (or registered) access to information – forms suggested in the selection criteria to be, by default, not reliable and therefore non-includable. However, in looking for the most consumer-friendly or unique explanations (consistent with criterion four), or for sites reviewed by experts in a given topic area, they are taken into consideration.

Comments regarding the last site differ from the other four in the nature of the negative aspects of the site and the final decision that must be made. In the last example, the uniqueness of resources, persons involved with the advisory board, or timeliness of the

topics cannot compensate for the political agenda of the site and how/which sources are used to support this agenda.

■ Site five: “Site is mostly about research ethics and alternatives, plus vegetarianism. Most consumer health articles are seriously out of date. Many don’t display dates; others have few references after the 1980s. Site has timely topics on page, but controversial sources and claims. . . . Often when evaluating an organization’s credibility we search PubMed to see if the persons writing the information or at least responsible for the information are publishing in peer-reviewed journals in that subject area. Good medical board (filled with physicians), but PubMed search reveals that agenda is clear: anti-animal testing, promotes vegetarianism, etc.”

In the case of the NLM portals, the boundary between actors is not just about the profit/non-profit divide (although this is reified in practice), but also about positioning the role of the government and the authority of medical professionals. Positioning the government also involves creating a combination of resources provided at the federal level and intricately linked with those of a geographically local nature (organized by counties within individual US states) – topical content remains in hands of NIH, while local sites are used to lead web-users to practical (offline) resources. The amount of available information is kept in check by constructing information as relevant to the individual, with “relevance” being determined by the reviewers as a combination of topic popularity and geographical proximity.

## ■ DISCUSSION

Ad hoc solutions created during the negotiation and completion of tasks serve a dual role: they indicate the shared background understandings of actors who participate in the same activity and they are reactions to concrete problems that appear in daily negotiations. (Garfinkel, 1967) We see the shared background and common understandings of review both within the example organizations and between them. In both case studies, actors carefully emphasized the evolutionary nature of review – evident in adjustments to the review process and in changes to types and presentation of user tools. In this respect, they confirm Garfinkel’s assertions: the formalized, written rules (and the guidelines to accompany them or the databases to support the collaborative work of the reviewers), also emerge out of, and change in response to, practices of ad hocing. Despite increasing specificity and formalization, reviewers must always seek supplementary information, discuss with site providers, ask questions of one another, and utilize the classification of “iffy”. Additional rules (informal rules, such as the one-click rule) and ad hoc decisions will always be necessary to the completion of reviewing tasks.

More importantly, they enable us to see more behind the process of reviewing websites. Review practices behind claims about information reliability are in many ways new, in that they were created in the building of institutions such as HON or added to existing guidelines within institutions such as NLM. They are also suggested to be web specific, in that they react to technology-specific publication issues, such as the number of clicks that distance the user from approved information, which is special to web-based information. However, while review practices may be web specific, most of the formal rules determine practices by transferring more traditional ideas about the reliability of information, mainly those that have been developed for peer reviewed journals, to web-based health information. These rules concentrate on how information is produced, gathered and presented (“published”) on sites. How the rules distinguish between types of information is determinant for how individual reviewers interact with different components of websites.

These interactions reiterate the standards set forth in traditional scientific structures, such that the review organizations follow similar patterns to those that Power (1997) outlines. Reliability review practices are analogous to Power’s “meta-audit” and the process of reviewing sites is one that doubles itself continuously – through the layering of primary processes that seek to understand and judge *how* something is done rather than *what* is done. Reviewers construct concepts of reliability in terms of what is already established. By reviewing the background processes for assembling information on a given web page, reliability practices are used to verify a trickle-down process of review. This is a feasible, practical solution, given the large number of medical websites that currently exist. Yet, it is also a strategy for making and maintaining a claim under the guise of being “neutral” or “independent.” Additionally, it avoids issues surrounding content by laying the responsibility for content elsewhere – if a site follows established publishing guidelines, then content arguably has already been checked.

Different initiatives carry different notions of reliability. Each initiative – a technique for lay end users to use in evaluating information – is a combination of heterogeneous materials, practices, and local considerations that are transformed into a claim about the reliability of that information. The final products, such as state-based portals, hyperlinked seals, checklists, and special browsers, are different because they each carry a notion of reliability that is comprised of ideas about the web, which selection criteria are deemed most relevant, what is feasible for the organization and what is appropriate to the projected user (target audience) for that particular tool.<sup>15</sup> Despite their different approaches to reliability on the web, in the two initiatives discussed here, there is much overlap between the selection criteria/guidelines for review and how these are applied in practice. Within each of these initiatives, guidelines and practices privilege professionals over lay

providers of information. As considerations are made about sites, evidence-based information is privileged above CAM information. Content judgments are deferred elsewhere, to past professional review that arguably took place during the production of the primary resources that support the claims being made. Once sites are approved and labeled in one way or the other as reliable, these types of differences and the complexity of reviewing information disappear.

We have attempted to make reliability practices visible by studying how rules are followed – how the selection policies of each assessment technique are applied. Beyond merely building a claim about the reliability of information, applying guidelines in practice constitutes other definition work – defining conditions for information production, acceptable forms of knowledge, roles of institutions and individuals, and expected behaviors of both ‘producers’ and ‘consumers’ of information. In following and applying selection policies and procedures, review also defines what is not reliable (e.g.: commercial interests, contested areas of medicine, and certain political agendas). In many cases, there is a suggestion that information can vary in degree of reliability. When the reviewers combine criteria in order to weigh the different aspects of sites, a rank order emerges that can be used to privilege biomedical actors and discourse in various forms, control the dissemination of messages about health and establish the roles of different actors. In distinguishing the “reliable” from the “unreliable,” reviewers actually re-solidify well-known boundaries that are otherwise suggested to be broken down by lay use of internet-based information.

Our research contributes three points to the discussions about rating information and the empowerment of patients. Firstly, discussions about the importance of making processes transparent for site users (such as HON asserts) and discussions disputing this transparency (Eysenbach, 2001; Burkell, 2004) are somewhat misplaced. Because sites are judged differently and the criteria can be applied in variable ways, the process is never fully transparent. Secondly, although different and new types of actors have emerged to help patients find reliable information on the web, they do not undermine existing boundaries between actors and the roles that they play. Bounding practices of review means that decisions are used to establish the political and leadership positions of various actors, to indicate what qualifications are necessary to review different types of information and to reinforce the existing boundaries between producers of information, types of information, and uses of information.

Finally, we suggest that more attention should be given to alternative positions to the more prevalent discourse about the dangers of unreliable information and what empowers patients (see also endnote 6). This enables us to question both the efficacy and

added value of these types of initiatives, especially when patient searching practices are taken into consideration. The different approaches to web-based information and its users that emerge from these practices suggest that assessing information is actually a shared responsibility between different actors, such as governments, non-governmental organizations, professionals and patients. This is further evidenced in the transformation of guidelines into user-friendly checklists, and the development of different tools that reflect, or are complementary to, the different reviewing codes. How responsibility is shared occurs on the terms laid out by the review institutions and, as both Singleton and Fox et al point out, there is little room for alternative practices to those that are defined. However, the practices that are defined do not always align with the established searching practices of patients and their ideas about what makes information reliable, creating tension with respect to this idea of shared responsibility.

Sharing responsibility for information in this case means creating, disseminating and/or using information that meets certain criteria - criteria that serve to reinforce conventional dualisms and keep current power structures in place. We see this not only in these examples, but also in the greater suggestion that these practices are necessary prerequisites for the construction and emergence of empowered patients. The idea of empowerment through access to choices would suggest openings to different types of knowledge – more acceptance of, for example, information about CAM or about another patient's personal experience. However, as the word is used in biomedical and informatics discourse, and especially in discussions about the reliability of information, the empowered patient is redefined as one who, in using information from the web, nonetheless actively adheres to more rigid definitions (lists of criteria) and conventional ideas about who should be producing and disseminating medical information.

## NOTES

<sup>1</sup> Statement made during a think tank meeting for [kiesbeter.nl](http://kiesbeter.nl) – a Dutch health-information web portal that attempts to provide high quality, patient-centered information related to medical content (e.g.: individual illnesses) and health care decision making (e.g.: waiting lists). The first author participates in the think tank.

<sup>2</sup> We realize that patients are not the only lay end-users of medical information. We use the term here for ease of reading.

<sup>3</sup> See Berg and Timmermans (2000) for a discussion about the simultaneous production of concepts and their “others”.

<sup>4</sup> This website is formerly associated with former US Surgeon General C. Everett Koop.

<sup>5</sup> Dr. Eysenbach, editor of the *Journal for Medical Internet Research*, is the most prominent author on this topic.

<sup>6</sup> It is important to note that within medical informatics there is some disagreement with this position. See, for example, Coiera (1998, 2003) and Ferguson (2002). Also Risk and Dzenowagis (2001) saw the “burgeoning output of codes” that resulted from efforts to create quality standards as equally problematic to the reliability issue itself.

<sup>7</sup> MEDLINE is an online, professional database for peer-reviewed medical articles, provided free of charge by NLM.

<sup>8</sup> This aligns with the idea of “discretionary space” as discussed by Lipsky (1980). The guidelines are available online at: <http://www.nhealthinfo.org/Documentation/TableOfContents.cfm> under Cataloging, module 7.

<sup>9</sup> Blake et al (2005) discuss a current study on the process of communication where questions are raised during websites review. The study has, however, the practical goal of investigating how technical changes can support this communication.

<sup>10</sup> ClinicalTrials.gov is a database of research studies from NIH. For many topics on *medlineplus*, one subject heading is Clinical Trials, which provides a hyperlink to information in the database.

<sup>11</sup> <http://www.nlm.nih.gov/medlineplus/criteria.html>

<sup>12</sup> Berg (1997) discusses formal versus informal application of rules.

<sup>13</sup> “For documents and software available from this server, the U.S. Government does not warrant or assume any legal liability or responsibility for the accuracy, completeness, or usefulness of any information, apparatus, product, or process disclosed.” See: <http://www.nlm.nih.gov/medlineplus/copyright.html>.

<sup>14</sup> This is evident not only with websites coming from the National Institutes of Health, but also with health-related websites provided by the US Department of Health and Human Services.

<sup>15</sup> For an extension of this argumentation, see also Adams and de Bont (2003) and Adams and Berg (2004).



## ***Chapter Four***

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### **Information Rx: Prescribing good consumerism and responsible citizenship**

Adams, S.A. and A.A. de Bont. *Forthcoming*.

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In discussions about the increasing use of internet technologies in health care a new kind of patient has slowly been constructed – a patient that is reflexive and informed, with highly-specified information needs and perceptions as well as highly-developed skills and tactics for acquiring information. This specific depiction of the patient transforms the patient into an active participant in his or her care, “empowered” through training, skill development and the use of technologies such as the world wide web, all of which can be provided or enabled by government organizations or other political actors. Through increased access to medical information coming from outside of the health care arena, it is suggested, the boundary between lay and expert is breaking down, enabling patients to become experts, be more assertive in managing their own care and change the nature of their existing relationships with health care professionals. (Hardey, 1999, 2001; Anderson et al, 2003)

As Henwood et al (2002) point out, however, just because the potential for empowerment exists, it does not necessarily occur. Patients conform only with difficulty to the images associated with the reflexive consumer and the concept of the “informed patient” is empirically difficult to sustain. (Lupton, 1997) Becoming informed requires skills related both to information and to the various media that can be used to access that information. Patients reflect low-level skills for searching for information, rely on intermediaries and experience concrete barriers during the medical encounter, all of which act as actual constraints on the emergence of informed patients (Henwood et al, 2002, 2003).

In literature about the questionable reliability of web-based information, the suggestion that lay information seekers are constrained in conforming to this image is too mild. This body of literature asserts the stronger position that they are actually *prevented* from being empowered because of the large amount of information and the questionable quality of much of that information. Central in this discussion is the concern that even if patients manage to find web-based medical information, they lack the skills necessary to evaluate the quality of that information, and therefore are especially vulnerable to harmful information in the form of errors, fraud and “quackery.” (Eng and Gustafson, 1999; Eysenbach, 1999; Kiley, 2000; Rigby et al, 2001; Kiley, 2002; Risk, 2002) This concern is answered by the argument that a pressing need exists for educating patients in how to judge a website’s reliability. (Jadad, 1999; Eysenbach 2000a; Eysenbach 2000b; Rigby, et al, 2001; Fogg et al, 2002; Stanford et al, 2002; Peterson et al, 2003; Bomba and Land, 2004)

Taken together, these discourses construct patients-as-web-users that are simultaneously skilled and capable, but also incompetent and unskilled. The informed patient must be educated in how to search for and assess information in order to conform to the defini-

tion of a reflexive, empowered consumer. Patients are not empowered merely through access to the internet or web-based information, but rather, this literature suggests, must be constructed in the process of being led to pre-selected information by health professionals and information specialists. (Pitts, 2004; Adams and Bal, *forthcoming*) In suggesting the need to create user tools that have pre-selected information, as well as guidelines for patients to use to check the individual characteristics (author, sources, date, underlying financial sponsorship, etc.) of the information they encounter, authors emphasize the boundary between lay and expert information assessment, privileging the latter over the former. Existing literature prescribes that patients utilize government-provided medical/health portals, click on hyperlinked icons (seals of approval or “trust marks”) provided by non-profit or non-governmental organizations, follow checklists created by professionals or health educators, and/or download special toolbars, all of which will assist them in finding and evaluating information on the web.

Because web pages provide powerful examples of pre-defining (or pre-confining) how information technologies should work, how they should be perceived and how different actors should utilize them, it is important to study the discourses that they carry. (Markham, 2003) However, little attention has been given to the underlying prescriptions about skills and use, as well as additional political agendas and messages about individual behavior, that individual web-based reliability initiatives, such as portals, seals and special toolbars, convey. In this article, we look not at how patients assess information (or what skills they do/not reflect), but rather, at what health educators, medical professionals and review organizations suggest the skills of a reflexive consumer *should be*.<sup>1</sup> We view the various user tools, such as guidelines, checklists portals, and clickable seals, as artifacts with politics (Winner, 1980) – particularly, the politics of building consumer-citizens and shaping their skills, perceptions and behaviors.

We begin by looking at more general literature about the construction of users and designers, followed by a review of the literature that transforms potentially informed patients into reflexive consumers. Using two types of data: “front page” data (information, images, quotes gleaned directly from websites and their accompanying promotional items) and supplementary “behind the scenes” data from interviews and observations carried out with those working to sustain given initiatives, we examine how users are directly addressed and discussed. How are users enrolled by sites and promotional items? What ideals are represented in these user tools and in what kind of practices are they embedded? We argue that, although these examples claim to target “all citizens,” the prescriptions for action that these user tools carry suggest that the user envisioned by the developers of these tools is not everybody, but rather a specific, ideal type of user: the good consumer/ responsible citizen.<sup>2</sup> In order to develop skills for finding and assessing

information on the internet, patients must engage in certain practices – practices that also enable developing the skills necessary to share the responsibility for information reliability and to be an empowered health consumer and responsible citizen.

## ■ THE IMPORTANCE OF THE STATE IN CONFIGURING USERS OF TECHNOLOGIES

Studies of science, technology and society (STS) have a long tradition of reflecting on how users are or are not included in the design and implementation of different technologies.<sup>3</sup> Woolgar (1991) argues that designer preconceptions about use can shape what counts as legitimate behavior and that users are “configured,” i.e.: their identity and skills are defined and constraints upon their (possible, future) actions are set, before the technologies ever reach the anticipated user group. Because of this configuring, technologies can be read as carrying specific scripts for use. (Akrich, 1992) Rose and Blume (2003), however, have criticized much of the subsequent work on configuring users because it attributes configuration largely to market-driven design and pays too little attention to the possibility of states as providers or enablers of technology use, and therefore neglects to consider the potential role states have in user configuration.

According to Rose and Blume, focusing on technologies that are developed or facilitated by the state and its institutions may highlight significant tensions between individuals as users and the state of which they are members and citizens. Policy documents can develop meanings for information technologies by providing, for example, the language of discourse about those technologies. (Klecun-Dabrowska and Cornford, 2000) In their behavior and discourse, collective providers, much like market-like providers, presume that individuals will be active consumers of technologies, meaning that the state may enact policies that, while not overtly or explicitly configuring the user, do create or maintain an environment that helps in shaping how users are configured. In using certain technologies (or by using them in the specified ways), individuals fit with their configurations and follow the technologies’ scripts and actualize their potential as “good” citizens. (Rose and Blume, 2003)

Singleton (2005) makes a similar point with her suggestion that the New Public Health in the UK seeks to train citizens in more ways than one. She asserts that training programs for healthy citizens are not just about physical health but also about practical skills and about distinguishing between active and inactive citizens. Klecun-Dabrowska and Cornford (2000) have also looked at the recent discourses on health in the UK, specifically focusing on the role of telemedicine within wider national and international debates on

health. They, too, saw that documents convey a vision of a refocused health care system to serve a population that has enough information resources to enable individuals to manage their own care and participate more actively in the health care process. Information, they argue, is transformed into something that is easily captured, understood and transformed to achieve wider goals – goals related to social responsibility and community values.

At the same time, states want to forward their political agendas and invent new modes of indirect steering for empowering their members such that they freely, willingly and self-reflexively choose the paths toward the desired outcomes of the state. The possibility of the state to influence its citizens directly is made relative, as the state competes with other types of influences. This has led to the development of new types of steering, where governments seek to rule the social *indirectly* through designing, facilitating and moderating processes of self- and co- governance. (Bang, 2004) More communicative and cooperative modes of re-centering allow for bottom up articulation, without relinquishing everything to citizen preferences. Again, these programs are not just about the empowerment of individuals or about the distribution of expertise, but are also about distinguishing between active and inactive citizens. Although states demonstrate a readiness to engage in active teamwork and argue the need for collaborative solutions, Bang argues that they nonetheless reveal how key relationships are re-imagined and redrawn.

Two things are worthy of note: first, the terms “re-imagining” and “redrawing” suggest that something new can emerge, which is a distinct possibility. However, with respect to the internet, at least, studies have shown that the boundaries that are constructed around information, for example, tend to reinforce existing social ideas (Pitts, 2004) and geographic borders (Halavais, 1999). The lines that are redrawn serve only to reinforce what is already there. Second, the exclusive focus on states tends to neglect the role of other political actors. Especially in activities regarding reliable medical information, states are not alone, but are joined by non-governmental organizations (NGOs) and inter-governmental organizations (IGOs), as well as non-profit organizations voicing their own political/advocacy agendas.

We extend the analysis in this paper to look at both programs from federal agencies and initiatives created by other types of political institutions. These programs and initiatives provide tools for accessing and assessing information on the web, in some cases enabling information provision. (See Table 1 for an overview of the different initiatives that are used as examples.)<sup>4</sup> For example, the US Department of Health and Human Services provides a portal with contact information for organizations (<http://www.healthfinder.gov>)

and the US National Library of Medicine (NLM) provides a portal with health content from the National Institutes of Health (<http://www.medlineplus.gov>). Outside of the US, the Health on the Net Foundation (HON) in Geneva seeks to raise awareness about ethical issues related to providing medical information, while the World Health Organization (WHO) proposes the creation of a “.health” domain afforded only to sites meeting specific criteria.<sup>5</sup>

These self-ascribed roles lead to numerous questions, such as why UN NGO status (in the case of HON) or a “neutral position” (claimed by the WHO) is crucial to building claims about the reliability of medical information. Why is a ‘.gov’ domain “more reliable” than a ‘.com’ and where does the ‘.org’ domain rank in relation to other existing and proposed domains? What potential tensions arise between states and citizens (or even NGOs and citizens) in these settings? Although these questions would be difficult to answer, they do give us cause to think about the political messages that are sent to lay information seekers when they are instructed on how to search for, evaluate and use web-based medical information.

URL	Description
<a href="http://www.healthfinder.gov">http://www.healthfinder.gov</a>	Healthfinder is the Federal Gateway to health information, provided by the US Department of Health and Human Services.
<a href="http://www.medlineplus.gov">http://www.medlineplus.gov</a>	Medlineplus is provided by the US National Library of Medicine (NLM).
<a href="http://www.quackwatch.org">http://www.quackwatch.org</a>	Quackwatch is an independent organization run by Dr. Stephen Barrett.
<a href="http://www.hon.ch">http://www.hon.ch</a>	Health on the Net is a Geneva-based non-governmental organization that provides diverse user tools. The focus of this study is the 8 principle HON Code of Conduct and accompanying hyperlinked seal.
<a href="http://www.medcertain.org">http://www.medcertain.org</a> and <a href="http://www.medcircle.org">http://www.medcircle.org</a>	MedCERTAIN was funded by the EU from 2000-2002 under the “Action Plan on promoting safer use of the Internet by combating illegal and harmful content on global networks”. The collaborative MedCIRCLE is a follow-up that provides users with a downloadable toolbar.
<a href="http://www.who.int">http://www.who.int</a>	The World Health Organization recently released a list of approved sites for vaccine safety.
<a href="http://www.qmic.nl/qmic/home.do">http://www.qmic.nl/qmic/home.do</a>	TNO's QMIC is a three-tiered trust mark for medical websites. The third tier signifies content review of information.

Table 1: Overview of home pages for examples cited in this chapter.

*Informed patients...reflexive consumers...ideal citizens?*

This entire line of discourse about empowering patients and the role of web-based information has led to the semantic challenge of properly naming those non-medically trained individuals searching for information online. For example, the term patient does not encapsulate those persons who search for information regarding the health situation of a family member or friend. Miller and Reents' (1998) alternative, "information retrievers," makes the user too passive, while the suggested informatics alternative "medical end-users," (Ferguson, 2002) makes the route to the information too technology specific, without reflecting the social aspects of information use and broader information "landscapes" (Henwood, et al, 2003; Doupi, 2005; Hargittai, *in press*) that persons can access. Furthermore, the term medical does not reflect broader issues related to health and fails to allow for use of information by those that Kivits (2002b) calls "healthy patients," those not necessarily afflicted by illness, but nonetheless interested in health information.

The concepts "citizen" and "consumer" are terms for users that are used most often by those creating different web-based reliability initiatives, working under the suggestion that these terms are neutral and avoid the semantic problems mentioned above (see, for example, Nater and Boyer, 2000; Ball and Lillis, 2001; Baur and Deering, 2001). However, these words also carry connotations; Anderson et al even go so far as to state, "When speaking about consumers, from this model it should become clear that we mainly refer to educated patients with chronic diseases from developed countries." (2003: 72) Using these two terms more generally implies certain rights, such as Gustafson and Wyatt's (2004) assertion that consumers *deserve* both high quality content and a certain degree of confidence in the information they use, but such use also connotes certain responsibilities. Each of the initiatives to which the usage of these terms is attached defines particular types of participation that extend beyond gathering information to include activities in the health care process and social community at large. The consequence, of course, is that teaching patients how to search for and assess information on the web becomes more than just a process of constructing empowered patients – it extends further to inscribe notions of good consumerism and responsible citizenship.

When we couple the discussion about empowerment on the practical skills that users are expected to develop, we see that it takes place within an overt and dominant biomedical discourse (Fox et al, 2005), which is framed not only by medical professionals, but also by political actors. For example, in relation to assessing web-based health information, Edgar et al (2002) describe three essential skills: the ability to conduct a search and find the "right" sites, the ability to judge the quality of information found on a given site and the ability to synthesize that information into a useful context for personal/individual health.



Eng and Gustafson (1999) argue, however, that the skill is more than just assessing and using information, but is actually about deciding which of the existing tools works best for the individual. Only in finding the most appropriate tool can s/he implement a personal evaluative framework and learn how to be an educated consumer.

## ■ HOW THE INITIATIVES ENROLL CITIZENS AND CONSUMERS

Each of the initiatives discussed in this paper attempts to enroll internet users in specific activities of finding and assessing health information. The most prominent strategy of enrollment that we see is the suggestion of abounding risks to personal health and the simple ways to combat them. Involvement – learning how to check information actively and always – becomes a matter of personal responsibility and an identifying component of reflexive information consumption. Failure to learn about user tools and use them as prescribed is to be inactive, and therefore, deviant or lacking (Rose and Blume, 2003; Singleton, 2005).

### *Highlighting risks and providing simple instructions for combating them*

One evident strategy for enrolling patients to check the reliability of the information is to construct web-based information as information that puts individuals at risk. Because of the nature of the web, information can come from anyone, anywhere – it originates outside of a given country, in another medical tradition or health care context – and, as such, it is foreign and worthy of suspicion. If information isn't pre-approved, individuals could be making their decisions based on wrong information, fraud, or quackery. An individual's health is potentially endangered because this information is always potentially just one mouse-click away and is difficult to distinguish from "truly reliable" information. In the language of this discourse, boundaries are constructed around information – these boundaries distinguish, for example, between geographic locations, but also reinforce more traditional ideas by distinguishing between different approaches to health and between lay persons and experts.

The proposed need to implement user education programs for checking the reliability of the information they encounter suggests that anyone online should be aware of this potential for harm and, therefore, actively involved in policing that information (Eysenbach and Kohler, 2002a; Kiley, 2002). HON, for example, currently includes information on its website about being a "vigilant user." Instructions about clicking and verifying proper use of its HONcode icon is prefaced by the following:

■ Unfortunately, we cannot banish incompetence or fraud from the medical Internet. If you come across a healthcare Web site that you believe is either possibly or blatantly fraudulent and does NOT display the HONcode, please alert Quackwatch. Of course, if such a site DOES display the HONcode, **alert us** immediately. HON cannot prevent dishonest operators from simply cutting and pasting the HONcode seal onto their Web sites in a bid to enhance their credibility. We do conduct our own random checks on subscribers to ensure they remain compliant with the HONcode. But we also rely heavily on vigilant Web surfers to alert us to dubious sites - and they do. . . . There are three quick ways users can check whether a chosen site featuring our seal is a *bona fide* HONcode subscriber.<sup>6</sup>

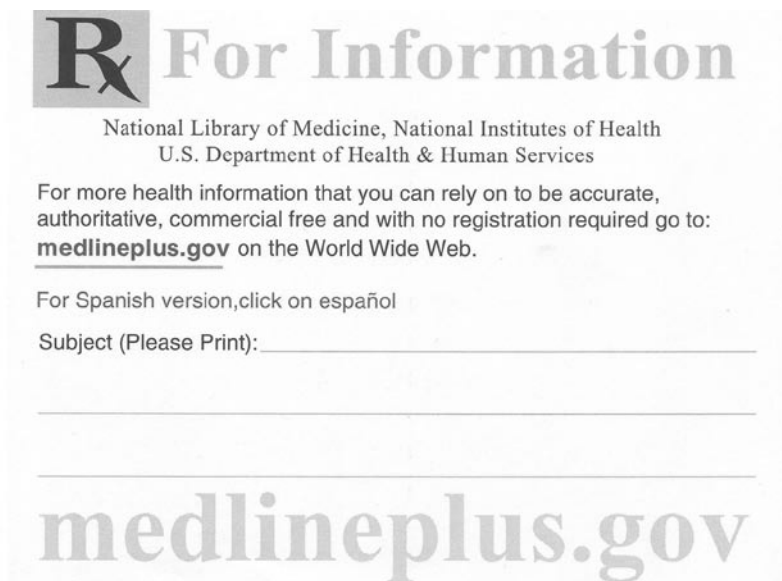
HON points out to users that it needs its users to help police information on the internet. It invites them to join in a partnership with two types of authorities, the first being itself, an overarching political organization and the second being participants from the community of medical professionals. Active policing on the part of the user is made extremely simple and practically effortless – checking information is as easy as a single mouse click (merely clicking on a small icon) or just running through a short checklist.<sup>7</sup> Taking a few seconds can prevent all users from encountering bad information, whereas not checking could subject the user to fraudulent or otherwise harmful information. With its clickable trust mark,<sup>8</sup> HON provides users with an easy tool to double check the *background* of the web information provider. This type of tool makes the action of checking information simple and non-time consuming – as easy as a mouse click. The MedCertain project, which proposed a mechanism similar to HON’s clickable seal, except that it proposed to include content review in addition to review of ethical principles, produced a prototype with the instruction, ‘Remember to verify by simply clicking on it.’<sup>9</sup> Similarly, the Dutch QMIC trust mark states, ‘In the blink of an eye, you can see that information is reliable and correct.’<sup>10</sup>

The user that all of these organizations presuppose is someone who, like the project reviewers, is (or should be) familiar with the ethical issues underlying the provision of any, but especially medical, information on the web. We begin to see how political actors invent new modes of indirect steering for empowering users such that they choose specific paths. They attribute to these users skills and practices more in keeping with professional levels of information assessment and action. But they also make these practices “user friendly” in emphasizing the ease with which information can be checked, with little additional thought or demands on time and in encouraging participation in partnerships with them.

### *Directing paths toward information*

Initiatives also emphasize the partnerships that they have developed with the medical community and/or other similar organizations. This is evident in at least three forms: logos from other departments and organizations placed on websites, joint projects with physician's organizations and overt statements about the best course of action that are located on websites. On HON's website, we find the logos of the University Hospital, the EU, the city of Geneva and Sun Microsystems. The tag lines for each individual logo identify how these different groups provide social and technical support for HON and its web activities. These logos show that HON is part of a larger national and international community that transcends medical practice, politics and businesses – and suggest that evaluating medical information on the web can only be done in this context.

Some studies of patient searching behaviors have indicated that patients refer to their physician for information about where to search for information on the web. (See, for example, Cotton and Gupta, 2004) Recognizing the potential of taking advantages of this preference for physicians as trusted sources of website recommendations, but also recognizing that physicians probably do not have time to review scales of sites, some initiatives have developed (or furthered existing) relationships with professionals. The US National Library of Medicine (NLM) has worked with professional communities to develop prescription pads for web-based information (see Figure One).



{Figure One: Physicians can give this to patients during the consultation to refer them to web-based information about a specific health topic.}

This project enabled NLM to inform physicians about the topics available on *medlineplus*. Additionally, it supports the physician and patient in post-consultation searches for health information. With this information prescription, the physician gives the patient a place to start and the term to use when searching on the web for information specific to his or her health situation – and that starting place is a government portal:

- In this trial, the doctors each had their own pre-printed prescription pad. The prescription pad that we used in the first part of the pilot had room for 12 URLs. There were about 40 to choose from and they chose the ones that they saw most often in their practices. What we found is that the doctors don't want to bother with all that. They want to have their own prescription pad, they really like that. But they just want to be able to write something on it and then send people to *Medlineplus*.<sup>11</sup>

Finally, websites send patients back and forth between the various initiatives and tools, implicitly and explicitly endorsing one another. HON, for example, recommends that English-speaking site visitors follow a specific and narrow path to information:

- To find good (English-language) healthcare information, you can bypass the all-purpose commercial search engines and go straight to healthcare portals like Health on the Net ([www.hon.ch](http://www.hon.ch)) or Healthfinder (<http://www.healthfinder.org/>). These portals have already eliminated the irrelevant for you. A useful rule of thumb is first check out the governmental, not-for-profit and hospital Web sites, or those carrying an immediately recognizable and trusted name.<sup>12</sup>

It is interesting in this case that HON excludes more commercial search engines as a valid route to information. The message is that web tools that are general in scope, rather than specifically directed toward health information, or that are funded by commercial interests (or both) are incorrect choices because they contain too much extra “stuff”<sup>13</sup> and will not enable the user to find what s/he is looking for. Reliability is redefined as an issue of what is “relevant” and proper behavior involves not wasting time sifting through information and other materials that are, according to HON de facto irrelevant. Furthermore, in emphasizing that HON and the US gateway are the best types of sites, HON suggests that there exists one direct line to this relevant information and privileges state (implicitly working with medical) actors over other types of actors providing medical information on the web. The suggestion, then, is that engaging in good searching practices and finding/using the “right” information means prioritizing government and medical channels.

Through these statements, the organizations affirm each other, arguing not only the importance of a joint approach to reliability, but also the importance of collaboration between different countries and regions. The risks associated with misinformation are

countered with initiatives that seek to rein in information, centralizing it at certain web addresses and judging it according to politically and professionally defined criteria. One example would be the criterion for levels of readability (Eng and Gustafson, 1999) applied to sites such as *Medlineplus*. Another would be the use of selection criteria for information that derive from similar roots (Baur and Deering, 2001) or the transfer of existing publishing standards to evaluate how information is produced (Adams and Bal, *forthcoming*). Website providers enable access to information that is consolidated and repackaged in a uniform format for readability and then placed on the respective site under a uniform design structure for ease of navigation. Once again, finding and using “good” information is made “easy” in the design of technology-specific tools.

What is interesting are the personalized messages and rhetoric of choice in which these standardized formats are embedded. Healthfinder is “your guide to reliable information,” while *Medlineplus* provides “Trusted health information for you.” Access to information gives users new choices, but these initiatives convey that responsible consumerism and reflexive use of information mean choosing narrow routes to prepackaged information. The internet offers numerous avenues to information, but “good” participation means utilizing one’s choice in order to choose for the routes provided by one’s own government and combining these with overarching non-governmental organizations or other non-profit organizations.

### *Individualizing choice along the way*

Both HON and the MedCircle initiative have taken this one step further – emphasizing the need to combine top-down control of information with bottom-up user choices. They have both developed special toolbars that can be downloaded and coupled on the user’s internet browser (See Figure Two for the MedCIRCLE prototype). Such a toolbar allows the user to set his/her preferences with respect to which components of information are most important and then gives a confidence rating for how well an individual website answers to these preferences. The toolbar sends the message that user preferences about the reliability of information are important and that users should actively set their own criteria for assessment. However, this is acceptable only once users are already searching within the confined space of pre-approved sites.



{Figure Two: Patients can download this toolbar from [www.medcircle.org](http://www.medcircle.org) and set their own preferences for characteristics that they find important in the provision of health information.}

The confidence rating and other information provided by the tool are only available for sites already in the HON or MedCircle databases. While these types of tools suggest the importance of individual choice, they nonetheless hold individuals responsible for following the 'right' paths to information. In this sense, the discussion is not merely an issue of creating reflexive consumers, but also of judging non-reflexivity as irresponsible and deviant.

### *Following the path back to the state*

The responsibility for finding good information and avoiding the risks associated with bad information on the internet becomes collaborative and distributed. Within this context, individuals are held responsible for the choices they make, how they engage with available information and how they engage with other actors in the collaborative process. This process involves new actors, such as HON and MedCertain/MedCircle, but also longer standing actors, such as the WHO, state governments and medical associations. Reliability is created through the distribution of skills, information, and practices, and is intertwined with the creation of new networks that bind together the technical and social. We see this in especially in uses of internet-based technologies to further public health education.

Healthfinder, for example, sends monthly newsletters to inform its public about changes and updates to the site and about different services it provides. Every newsletter also contains a list of "health observances" for that month, each of which includes hyperlinks to special sites with more information. These observances are, where possible, coupled on the (national) holidays being celebrated in that month. For example, February is 'the month for all kinds of hearts' and the newsletter's healthy observances are all related to cardiac issues, while July's newsletter focuses on food safety tips for warm summer days and firework safety tips specifically related to the July 4<sup>th</sup> holiday. Although other months are more general, all months prescribe topics of suggested interest for the general population:

- All of us, in all stages of life, can find a health observance of interest this month. April's observances range from National Donate Life Month, a request for us to consider giving another person life, to WalkAmerica, a campaign to promote the benefits of carrying babies to term, sponsored by March of Dimes, to many observances in between.<sup>14</sup>

The observances further point out special days of awareness and political activism, and also broadly publicize public health education opportunities:

- The National Headache Foundation is sponsoring National Headache Awareness Week June 5-11 to recognize headache pain as a real and legitimate condition and encourage those who suffer with headaches

to see a physician for proper diagnosis and treatment. This year's campaign, "Stop Migraines Before They Stop You," will feature public education activities nationwide."<sup>15</sup>

The links that are selected for inclusion in the newsletters link largely to other parts of the Department of Health and Human Services and to other health-related government institutions (.gov domain endings), such as the National Institutes of Health (of which NLM is also a part) or the Centers for Disease Control and Prevention.

As these examples show, different actors have developed practices that place various elements in new and unique relationships with one another. Issues related to health become intertwined with, for example, federal holidays. The health practices of the individual are now inextricably linked with diverse forms of community participation. In this sense, health education and enrollment is no longer only or primarily about verifying online health information, but rather about diverse activities that extend beyond the online realm.

### *Directly linking health practices and citizenship*

These initiatives are tools to help people find and/or check information and about helping lay persons become empowered, not merely through distribution of information, but also through coaching or education in how to participate more actively in the search for and use of information. Users are invited to join specific, defined communities that will, in one way or the other, protect them from misinformation and inform them about better ways to act. HON even emphasizes the strength and necessity of its partnership with lay users in order to be able to do what it sets out to do – HON cannot help lay users if the lay users do not help HON.

Additionally, there is a normative message about responsible citizenship. HON, for example, responds to individuals who follow their instructions and report (suspected) misuse of the HONcode icon by thanking them for their "sense of civic duty" and healthfinder's newsletters make the initiative much more than just a gateway, or portal, to links of organizations with information. They also serve a promotional function to keep visitors returning to the healthfinder website and enabling/motivating them to link through to other government sites. Further still, they show that being an active consumer and responsible citizen involves more than merely checking the information one encounters on sites or reporting misinformation and/or misuse of seals through certain channels. The responsibility extends into all areas of daily life (from good nutrition to awareness about possible diseases) and extends beyond individuals to include not only family or friends, but also the community-based or social responsibility that accompanies participation in educative programs, activism, or fund-raising events.

What begins as a prescription for how to search for and assess information on the web actually extends to the entire lifestyle in which these searching activities are contextualized. (Important because, as Dessauer [2004] notes, much of what we think of with cyberspace loses meaning and referents if it excludes the external context.) Interestingly, despite the varied forms of the messages emanating from the different initiatives, each of the prescribed behaviors, such as entering the web at a location of geographical significance (within government borders), participating in a chain that actively polices adherence to an ethical code and reports misuse, or even downloading and using a browser with a special toolbar, emerges as simultaneously optional and obligatory. (Singleton, 2005) Herein lie strains of the tensions that are suggested by both Rose and Blume and Singleton: initiatives are created and promoted under the guise of increasing choice and democratization, but the actual prescriptions that they carry entail more powerful suggestions about which choices (both online and off) are the “right” or “better” choices – with alternatives to those choices being (explicitly or implicitly) discouraged.

## ■ DISCUSSION

In this paper, we discuss how political actors have enabled access to web-based information largely in terms of specific user tools; however, through these examples, we see that, as Markham (2002, 2003) argues, access to the internet is access not just to a tool, but to a place (emergent in for example, how the interface is designed or the level of engagement in a given activity) and a way of being (dependent on the degree to which the individual integrates the technology into his or her understanding of social construction). As providers or enablers of technology use, political actors at various levels (primarily states, but also NGOs and IGOs that provide different types of sites and tools) provide points of entry and create avenues not just to online information, but to online and offline social communities with specific rules for behaviour. This has implications for how technology is configured within the relationship between individuals and the state and other political actors. Especially important is that it highlights how the emphasis on claims of “neutrality” within the reliability debate is misplaced. Organizations such as HON or WHO, who claim their neutrality based on their international scope and/or their position outside of national governments, nonetheless carry specific normative ideas of acceptable politically or socially related user behavior. Likewise, individual state governments that claim to represent the needs of their own “general public” impose values on the information that they recommend to that public – for example, in privileging a .gov above all else, followed by a “.org” or “.edu” and reducing as much as possible endorsement of a “.com.”



Existing literature arguing the need for collective solutions to reliability problems, together with the abundant presence of initiatives offering different options for interactions between lay end users and those providing assessment tools, indicate a readiness among political actors and some health professionals to engage in active teamwork with the public. There is even the possibility that this language of collaborative efforts suggests that the public is/can be seen as just another interest group balanced with physicians. (Harrison and Mort, 1998) However, in the examples provided above, we see that partnership does not necessarily imply equal footing for each of the three types of actors. Organizations use the term reliability as a rhetorical device to capture attention and enroll users – redirecting their information-seeking behaviors, but also emphasizing deeper-rooted values that situate individual health-related practices within a greater context of idealized citizenship. As such, in addition to prescriptions for use of specific tools, we find underlying prescriptions for practices that reflect good citizenship.

What, then, comprises the construction of a 'good' citizen? First and foremost a good citizen is one who is interested in a healthy lifestyle and reflects this through choosing to participate in activities such as searching for information about his/her health and the health of loved ones. Secondly, in searching for this information, the citizen reflects the possession of basic practical skills by choosing to align his/her practices with political actors, thereby choosing for sites that have been created or in some way reviewed by these actors. Thirdly, the citizen actively participates in the *online* community in which these sites are embedded. Active participation includes helping to "police" the information online by checking links and actively reporting misuse. Additionally, active participation includes extending knowledge accrued online to participate in *offline* community activities (activism, education, and fund-raising).

This participation also forms a reciprocal relationship between the participant and the given organization – in return for making oneself available to the community, the burden to search for, find, and evaluate information is made easier. Searching can be done using tools within which information has been pre-selected and/or information can even be sent directly to the individual's personal e-mail. Both of these technical options for acquiring information also carry an implicit social promise of being taken care of – protection from misinformation or mis-action due to lack of information. The readiness to participate in this partnership – the commitment of the organization to helping protect its user community is made explicit.

Through the creation of initiatives that respond to debates about the reality of information online, organizations prescribe both online and offline behaviors, such that these are inextricably intertwined. This leads to the emergence of new collectives, counteracting

the idea that internet enables people to separate activities with ease, compartmentalizing on and offline activities and leading to division.<sup>16</sup> These collectives further counteract notions of individualization and separation from the community, as well as arguments that certain actors can be rendered irrelevant. Existing relationships become re-conceived as new alliances between medical and political actors, where internet technologies can be used to strengthen existing public education activities. Additionally, new (types of) communities emerge: families and friends or geographically concentrated communities are supplemented by communities that share aspects of visiting the same web sites and participating in the same self-policing chains – online and offline, individuals participate in communities by watching out for one another and sharing in the same activities.

Although these initiatives claim to target “all users, everywhere,” they actually idealize use such that discussions about increased choice and how this leads to patient empowerment also carry the normative implications that “true” empowerment is only possible when the “right” choices are made. Within these discussions, individuals have the responsibility to develop skills that make them informed consumers, and the process of acquiring these skills also enables them to contribute their part to the greater civic communities in which they engage. The additional implications connoted by the terms “citizen” and “consumer” raise the question of whether these really are more suitable as replacements for the word “patient” than other suggested alternatives.

## ■ CONCLUSION

Whereas discussions of technologies and their users have largely neglected to consider the role of states (and other political actors), discussions of the relations of states and individuals have not always considered the important reciprocal effects of and on changing technologies. Discussions of skill manage to link individuals to individual technologies, but they have not successfully coupled this back on the role of states. This paper has used the discussion about the reliability of web-based information to attempt to bridge these gaps and demonstrate the integral relationship between technologies and users, states and individuals, and individuals and the development of skills. It shows that political actors, including both governmental and non-governmental organizations, make presumptions about citizen willingness to use certain technologies and, as such, utilize soft power to encourage these citizens-as-users-of-technologies to forward certain agendas.

Under the guise of democratizing ideals and suggestions of empowerment, they use policy, programs and web-based tools to encourage citizen participation. Underlying these different modes of participation, these actors are able to re-create boundaries both on-

line and off, not only by demarcating geographical boundaries on the web, but also by supporting conventional understandings of social norms, such as the role of the medical expert as a primary leader. In so doing, they give patients “choices” with respect to how to behave, with strong normative undertones about rights and responsibilities associated with being informed and reflexive consumers. As others have pointed out, where medical or health-related information is discussed, an issue of power is usually at stake. (Kivits, 2004) The power in question is generally interpreted as that of medical professionals, but this is not necessarily the only interpretation, as political actors clearly use this for their own means and ends, as well.

## NOTES

<sup>1</sup> Adams, de Bont and Berg (2006) discuss how Dutch patients assess the reliability of information and how their assessment strategies relate to the tools designed to help them.

<sup>2</sup> See the work of Bruno Latour (1987, 1991) for a discussion of translation. See Oudshoorn et al (2004) for further discussion on how configuring users as “everybody” can constrain design.

<sup>3</sup> For a thorough review of this body of literature, see Oudshoorn and Pinch (2003).

<sup>4</sup> Because each of these examples is discussed individually elsewhere, I will not go into too much depth here. For a historical review of all of the initiatives, see Adams and Berg (2004). See also Adams and de Bont (2003) for a review of the different notions of reliability that emerge from healthfinder, HON and Quackwatch, and Adams and Bal (*forthcoming*) for a discussion about how review work reinforces existing boundaries in the case of NLM and HON.

<sup>5</sup> The .health domain was rejected by ICANN (the organization responsible for assigning domain names), and an alternative failed to emerge from discussions (Brown, 2002); however, the WHO has entered into action in this area by producing a list of recommended websites for information on vaccinations on its home page (World Health Organization, 2005).

<sup>6</sup> <http://www.hon.ch/HONcode/audience.html>

<sup>7</sup> We do not discuss checklists in depth here. For examples of such a checklists, see, <http://www.discern.org.uk> or <http://www.quick.org.uk>. See also Eysenbach (2002) and Bomba and Land (2004).

<sup>8</sup> See <http://www.hon.ch/honcode.html> for info on HON’s ethical Code of Conduct and the HONCode icon placed on sites.

<sup>9</sup> <http://www.medcertain.org/english/consumer/explanation.htm>

<sup>10</sup> Translated from Dutch by the first author: “Zodat u in een oogopslag ziet dat de informatie betrouwbaar en inhoudelijk juist is.” [http://www.tno.nl/kwaliteit\\_van\\_leven/preventie\\_en\\_zorg/kwaliteit\\_in\\_de\\_zorg/kwaliteitsborging\\_voor\\_in/](http://www.tno.nl/kwaliteit_van_leven/preventie_en_zorg/kwaliteit_in_de_zorg/kwaliteitsborging_voor_in/)

<sup>11</sup> Quote taken from an interview with two employees of the US National Library of Medicine responsible for Medlineplus.gov.

<sup>12</sup> [http://www.hon.ch/HONcode/FAQs\\_HONcode.html](http://www.hon.ch/HONcode/FAQs_HONcode.html)

<sup>13</sup> Markham (2003) suggests using the term “stuff” to encapsulate the various things other than information that internet users can encounter when searching on the web.

<sup>14</sup> All excerpts are from 2005 newsletters. The links were omitted for ease of reading. These were: <<http://www.organdonor.gov/donatelife.htm>> and <<http://www.walkamerica.org/>>, for National Donate Life Month and WalkAmerica, respectively.

<sup>15</sup> Omitted links are : <<http://www.headaches.org/consumer/pressindex.html>> and <<http://www.headaches.org/consumer/presskit/NHAW05/FiveStrategies.pdf>>

<sup>16</sup> For argumentation about how online and offline worlds are compartmentalized, see Suler (2000). For refutation of this line of argumentation, see, for example, Markham (2002, 2003).

## ***Chapter Five***

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### **Looking for answers, constructing reliability: An exploration into how Dutch patients “check” web-based medical information**

Adams, S.A., A.A. de Bont and M. Berg. 2006.

Looking for answers, constructing reliability: an exploration into how Dutch patients “check” web-based health information.

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Health care professionals and policy makers are concerned about the quality of online medical and health information. (Cho, 2000; Gottlieb, 2000; Rigby et al, 2001) Various organizations have created initiatives to help patients find and assess information on the web. Although these types of initiatives have been criticized as ineffective and possibly counter-productive for lay end users (Jadad, 1999; Delamothe, 2000; Eysenbach, 2000a; Gagliardi and Jadad, 2002; Meric et al 2002), little is actually known about how they align with lay search and assessment practices. Eysenbach and Kohler (2002b) reported a focus group study wherein patients claimed beforehand to follow icons, guidelines, etc., but in practice neglected to do so. Stanford et al (2002) compared opinions between lay persons and professionals regarding both finance and health websites, while Fogg et al (2002) examined how lay persons evaluate website credibility, with health being one of many categories. While these studies have been insightful for understanding how patients judge websites, they nonetheless reflect the need for more research into patient practices.

There has been a considerate discussion in the literature about how to help patients search for reliable information. Despite how little is known about lay assessment practices, it is argued that patient assessments lack important components for evaluating the quality of information (Risk, 2002; Burkell, 2004), and that leaving the assessment of reliability of information to patients puts them in a real danger of trusting knowledge that is essentially untrustworthy. It has been suggested that the best course of action is to label reliable websites and to educate patients to use guidelines for judging a website's reliability. Emphasis is laid on steering them away from factors such as site design and layout, and toward guidelines that they can follow to check the source, date, etc. (Jadad, 1999; Eysenbach, 2000a; Eysenbach, 2000b; Rigby et al, 2001; Fogg et al, 2002; Stanford et al, 2002; Peterson et al, 2003; Bomba and Land, 2004) Reliability is discussed in this literature as a black-and-white, inherent property of information, which can be assessed by anyone on the basis of pre-established criteria. Through the focus on established professional forms of and criteria for judging information, even those studies focusing on the patient perspective allow the dichotomy between lay and expert understanding to overshadow the importance of lay practices. In concentrating on how patients "fail" to follow prescribed measures for checking reliability, other authors have failed to notice the importance of the patients' directed processes of searching for answers to *highly specified questions*. The current approach to the reliability of information neglects to consider that information must be applied to the individual situation and that this has consequences for how patients assess reliability.

In this paper, we discuss the results of an ethnographic study of how Dutch patients approach health care information on the web. Our findings suggest that patients, indeed,

do not use national portals, icons or standard checklists to assist their searches. However, in contrast to what is often suggested, patients do construct rather elaborate judgments of the adequacy of the information for their purposes. It is in the context of piecing together answers to questions, we argue, that the reliability of information is assessed. We examine how different elements are intertwined in the individual patient's understanding of both individual web site reliability and the reliability of the assembled answer to his/her question.

## ■ METHODS

Because of existing criticisms of studies that have approached the issue of information reliability solely from a professional perspective, or by using students who are arguably more experienced in using the internet than the general populace of patients-as-end-users, we decided to include actual patients (and other lay end users) in the study. Because we were trying to answer the question of where lay health information seekers are going on the internet, it was a deliberate choice to recruit participants who already had some experience in searching for health information online. Nonetheless, participants were recruited both offline and online.

Recruitment methods included selecting a sub-set of patients from a separate study in a Dutch hospital, involving patients from a general practice, placing magazine ads, posting to discussion groups and informing patient associations about the study. We were looking for diversity in patient type (patients with a chronic illness, patients with an acute need for care, patients recently diagnosed with a new problem, high-risk patients, patients changing their health behaviours, "healthy" patients [Kivits, 2002b], caregivers of elderly or children, etc.), rather than a representative sample. The only selection criterion was prior use of the internet to search for medical or health-related information.

Eighteen persons – five men and thirteen women, aged 20 to 60 – were interviewed at the primary location of internet use (home or office). All interviews were semi-structured qualitative interviews and ranged from one to one-and-a-half hours. Patients were asked two series of questions: one series about independent review of sites and different types of user tools and one series about the nature of their health/medical-related searching. After this, they were asked to engage in a series of searching exercises. Because we wanted to capture the search process in a natural setting but knew that our presence would preclude this, we tried to create an "as real as possible" search situation, where patients were instructed first to "do what you normally do" when starting the computer and using the internet. After checking e-mail or visiting favorite sites and chat groups, patients gen-



erally showed the researcher their home pages and explained why they utilized particular sites or groups. After this, they were asked first to describe and then to repeat the “last search” that they had done for medical/health information, explaining step-for-step what they had done. (See, for example, Bruce [1999] for comments on this method.) Finally all patients were given standard questions for searching. Although this was removed from actual search practices, given the diverse nature of the patient group, this enabled comparison between individuals.

## ■ RESULTS

Interviewees could not explicitly remember using specific types of tools to aid in the search for information, or even seeing them when searching. They generally gave the reason that they had not known what to look for, quickly supplementing this with promises to pay attention and use these tools the next time. In the practice of searching, only one patient actually encountered a trust mark – a shopping guarantee on a site where products could be purchased. Three others encountered analogous mechanisms, such as logos in the margins. As Eysenbach and Kohler (2002b) saw, none of the patients clicked on the trust marks or other logos that they encountered. Although the hyperlinked icon and one of the logos were animated, the patients failed to even notice their presence while searching.

During the follow-up discussion to the searching exercises, patients reversed the promise to look for and use specific types of user tools. They revealed being as skeptical about the value of various tools and the sometimes incomplete or contrasting criteria these entail as they are about the quality of information on the internet. Patients were of the opinion that there was no reason to automatically trust that a tool would help them. This was because most tools are new, unknown or otherwise of empty meaning and could not positively contribute to their established search processes.

The creators of user tools generally depart from the assumption that patients are searching for categorically reliable information and for an automatic guarantee (label) of that reliability. However, the patient’s focus is not on finding such a label of reliability, but on finding an *answer* to a highly specified health-related question. For patients, the tools have nothing inherent that makes them automatically trustworthy and as such are no better or worse than the information itself. Likewise, there is no singular *de facto* reliable piece of information. In their respective search processes, patients engage in diverse practices of including and excluding pieces of information to assemble answers to these questions. Reliability is about the conglomerate *answer* that results and is constructed during the search process itself.

## Searching

Although using a search engine is the common interpretation of internet searching, it should not be considered as the only definition. Patients had diverse ways for getting to sites, including visiting well-known Dutch portals and typing in topical keywords, followed by the Dutch “.nl” domain, awaiting the single site that would result. Once on a site, a typical strategy used by patients was that of “playing around” (see below).<sup>1</sup> This enabled them to find and focus on information about a condition that they or a loved one had experienced and to compare that information with what they knew from personal experience and/or with information received from other sources during that experience. Patients attempt to assess simultaneously both the accuracy and depth of the information about one topic on the site in order to extract clues regarding the reliability of that site in general.

- Patient C: Hmm, let's see what they have for women. Obesity is a big issue now. Oh, here, skin, hair and nails. I think that's an interesting section to look in. Ah, look here, shingles – that is so painful. (She clicks on the link and begins to read.)
- SA: What can you tell me about the information?
- Patient C: Well, I know a lot about shingles because my husband had them. What is says here is quite good, but it is nothing new, actually. I would like to be able to read more.

Although patients stressed the importance of having a clear overview of information and navigation possibilities, they were also looking for sites that allowed them *diverse avenues* for playing around and exploring, such as different ordering structures. The physical components of a site contribute to being able to gain an overview of information, learn to navigate a new site and keep up with changes to content on favourite sites. Soft colours, large print, simple headings or tabs, bulleted points and reduced or no use of flash enable the patient to peruse a site at his or her own leisure, and, as far as the patients are concerned, reduce the chance for confusion. Although in the eyes of many these have no bearing on content and reliability, in the eyes of patients, they are crucial elements that lend credibility to a site.

## Anticipated Search Results

All internet users are confronted with the challenge of finding those one or two specific pieces of information that they are searching for out of numerous, general search returns. We saw that patients actually already have an idea of the type of answer they want to find – and the conditions for this answer are highly specified. For this reason, the patients rarely found complete answers directly on a single site, but instead worked

to piece answers together out of varied, selected bits of information from several sites. Because finding the essential components of an answer plays a central role in how patients construct a given site's reliability, the amount and types of barriers perceived or encountered in getting to their expected answers become crucial to the final assessment of the site:

- Patient B: If there were to be a test of sites, I think they should also control for physical elements. What we saw when I was searching should have been easier, but there was absolutely no overview of the site. For me, that is practically a guarantee that I am only getting half of the information. We got to my answers eventually, but I'm not sure that would always be the case. Why should I trust the site a second time?

Critical to this understanding of the reliability, again, is the patient's feeling that he or she has a clear overview of the site: does the site enable navigation between topics and ease in sorting through the information? It is navigation, the process of *how* the answer is found, that becomes significant in the patient's attribution of reliability to sites and the information they contain.

During the process of scanning search engine lists for contextual clues, patients also pay attention to the source of the website. The checklists and user tools prescribe that the patient look for this information once they are on the site itself – to verify (among other things) the author of the information on the site. However, the patients that we observed looked at the source of the information before deciding to visit a site in the first place. In their descriptions of past searches, they were explicit about which sources were or were not relevant, exemplified by patient J:

- Patient J: As I said, I have much discomfort in my shoulder, so I am often searching for orthopedic sites with information about the shoulder. I also keep a folder of sites to recommend to other patients.
- SA: Okay.
- Patient J: Through Geocities, I found a Belgian site with a lot of information. Let me show you. I didn't think it was all that user-friendly – difficult to navigate and difficult to work. I would have organized it differently. It had some nice options, like a David that you could click on to learn about the body, but on the whole it wasn't really user friendly... Then I found this site from a patient group, but they weren't interested in providing information, they were interested in gaining new members. I was looking for information. Maybe if they had good information, they wouldn't have to worry about the membership (laughs) ... Finally, I found a private practice for physiotherapy that I now regularly use. It is set-up nicely and has a lot of information. It is also easy to read. I think that is well done for a private practice.

We also saw that, when transitioning between sites, patients utilized different combinations of quality criteria to position segments of information from different sites against

each other. They liked to weigh their options and compare and contrast between sites, sources and types of information:

- Patient F: I was trying to stop smoking and I was searching for information to convince me that I should – a sort of moral support for my decision. I always use Google because it always gives a couple of sentences with the search terms in boldface type. Usually, you can use those to see whether the search engine makes the same connection with the search term that you intended. One of the first few listings (site name omitted) seemed to have what I wanted.
- <segment deleted>
- Patient F: Since I can't find the information on my favourite site, I'll return to Google. Okay. This is from a news site, from ABC and that is a well-known news, uh, news company, I guess you could say. And, I guess you could say that, well, on the basis of how the information is presented that it's very factual, so that gives the impression that it is trustworthy. But, I don't see a date anywhere and I want to know when it was posted. On the previous page I noticed the date and that's important. Here it is, April 10<sup>th</sup>. What is today, May 16<sup>th</sup> or so? Is that not a bit old for news? Since it is a new virus and information can change, I prefer to have a newer page. I saw earlier that there was an article somewhere. (He refers to Google and reads through the options before clicking.) This was updated on May 2<sup>nd</sup> and there is all sorts of information from King County. I think it is fairly reliable.
- SA: And why is that? It has the same information and I have the idea that [information] from a public health department must be fairly reliable.

### *Specific Processes*

Although some patients in this study had developed loyalty to one or two sites, it is more appropriate to describe all patients as having developed loyalty to a *specific process* of combining sites and sources (also offline resources) that they have compiled through repeated search experiences. Through these standardized, routine processes of selecting and combining, patients disassemble component parts of individual, often disjunctive, web sites and reassemble them as an integrated answer to their health questions. In finding how the separate pieces of information are interrelated as a body of knowledge about a given topic and thereby in evaluating and categorizing those pieces of information, engaging in this process constructs for the patient confidence in the answers that are found and more clarity regarding how that information can play a role in health care and daily activities – and thereby, the reliability of one or several web sites.

## ■ DISCUSSION

Although patients are concerned about the quality of the information they encounter, they do not claim to look for “reliable” information. They find it important to look for answers to questions, whereby the reliability of the *answer* results from the process of finding and piecing together that answer. Thus, “reliability” is not a separate characteristic of a singular “piece of information.” Rather, it is a process of developing a comprehensive answer, which is built up through many sentences and component parts found on different websites. It includes developing confidence in the robustness of this answer in comparison to other (types of) information. “Reliability” is in many ways not simply a yes-or-no kind of attribute. Many aspects play into the end judgment by the user of what is or is not reliable.

Searching, navigation, having an overview, and the idea of information overload all become redefined within the context of how they contribute to providing the patient with an answer to his or her medical question. Where the patient begins searching determines how many and what types of results are returned, thereby contributing to how the patient chooses between different options. Therefore, 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. Moreover, in the eyes of the patients, one of these is not more or less reliable than the others because they must be used in combination. This can potentially place those creating user tools in a problematic position since they want to label a site or its information as reliable from the start.

For this reason, the specificity of the question prompting the search becomes important – not so much because of the nature of the question, but because of the expectations of and prescriptions for the *anticipated answers*. Patients are not looking for everything there is to know on one topic and are uninterested in scores of general information that reach with more breadth than depth. They expect individual pages containing tailor-made answers to *their* specific questions. Moreover, patients tend not to read long, drawn-out segments of text, but favour simple lists of bulleted points or question-and-answer formats. At the same time, however, they expect explanations to be thorough and clear. This leads to appreciation for sites with deep linking, which allows the individual to select the level of profundity and amount of information accessed on a site – information that will, in turn, be coupled with similar bits of information found in other places.

Because no single site can perfectly match the specific needs of any given patient in answering a health-related question, patients look for sites that allow them to splice together their own answers. Being able to piece together these answers often depends on

those very factors that other authors have suggested are irrelevant or unimportant. It is not a question of whether a site is “pretty” or not (Chin, 2002) – it is, instead, a question of whether or not the layout of a site provides an overview of the information options and diverse avenues for searching, as well as of how easily the patient can transition between two or more sites.

Nonetheless, it is important to stress that relying on specific components of design and relying on the presence or absence professionally prescribed factors are not mutually exclusive. Judging partially by site design does not automatically exclude attention to source (for example) and we see both types of judgments working together in the interview examples above. Although the specific combination of factors that are used to assess information (both online and off) vary per patient, they all deduce to the situated process, where the patient is comfortable in putting together answers and confident in applying those answers to the individual health care situation.

In this study, we see that a site or a tool ‘works’ for a patient when it fits with the search routine that s/he has established. This process of combining sites and resources is established by the individual through repeated search experiences. These routine processes, as well as patients’ understandings of what it means for a site to be reliable, are variable; but for each individual, they progress over time, and continue to contain elements specific to the patient’s specific needs. (See also Josefsson [2003].) These processes comprise an implicit process of source triangulation. It is now known that patients often engage in event-sparked searching (searching for information in response to a specific diagnosis or occurrence), but this is not necessarily the reason that a patient searches for health information. It can also be on the basis of something they have seen or heard in communication, through offline media, or elsewhere online. Patients use the internet to position against what they have heard, which helps them to understand better the various types of information around them.

This process also works conversely. Patients compare the results of several different sites to make sure the “core” information they have found remains unchanged, while paying attention to how the information is presented on each of these sites. They check the information by submitting it as a question to a discussion forum or (online) medical practitioner. Burkell (2004) has suggested that online triangulation carried out by patients uses too few sites or options to be sufficient. However, we saw that patients also compare information found online with information from offline resources – information they have read or heard elsewhere, such as from different types of media or from their physician. The process is carried out in search of repetition, which, as has been noted in other studies, gives an implicit indication of validity of information (Henwood et al, 2003), but

they also look for instances of deviation from the repeated claims, which acts as a check on the “core” body of information.

The different practices indicate that the absence of a click on a seal, use of a checklist, or a visit to a portal is not necessarily a reflection of lack of quality measure by the patient. In relation to the internet, Vaughan (1999) discussed that, “...while users seem to highly regard exacting methods of accessing pages (that is via a bookmark or typing in a known URL) they *prefer* the less accurate search engine and opportunistic methods of searching for information as opposed to subject catalog searching.” (p. 91-92, emphasis added) Similarly, we have seen that while seals and portals suggest a clear-cut, yes-or-no reliability and an easy division between true and untrue or safe and unsafe in classifying information, users know that it is not so simple. Hence, the less accurate search engine and more opportunistic methods of searching, in fact, are perfectly suited to search among information that is often characterized by fuzzy reliability and grey areas of information classification.

The (lack of) use of different tools for assessing medical information on the web can only be understood in the context of the patients’ attempts to make sense of the various components that they encounter during the search process. In the daily practices of searching for information, patients use a variety of techniques, drawing from online and offline sources that allow them to find answers, and thereby, to check the reliability of information. For this reason, predefining and labelling information as reliable is insufficient – the reliability of information from a patient’s perspective is continuously being constructed during the search for answers to specific health questions. Because the reliability of information for the patient becomes intertwined in the search process, it is necessary to re-conceptualise what it means to search for and assess health care information. Patients do not have a standard list of points, but instead pragmatically juxtapose different signs in order to build their judgment.

Two organizations, MedCIRCLE and Health on the Net have recently developed web browsers that allow patients to use a preferences dialogue and set their own standards for assessing sites.<sup>2</sup> For sites already in the databases of these organizations, the browser calculates in how far the patient preferences and the site align. This appears to indicate recognition that the chasm between patient and professional judgment of information is not as large as contemporary literature suggests. It also seems to recognize that patients use a combination of resources to judge information that is not necessarily found on the better known checklists. However, the very presence of the tools also actually *reiterates* the idea of a division between lay assessment and professional assessment. Additionally, these tools continue to emphasize the need for an authoritative tool that works for pre-

approved, certified sites. The question remains whether these will fit with the already established search processes of patients.

All searches for answers to specific questions will continue to be organized by mundane troubles in the search process and practical resources that are found in various locations and combined in many ways. The judgment of reliability will comprise how users articulate the actions they undertake in finding information in response to a particular health situation. Because of this continued bringing together of an “array of partial, heterogeneous devices into coherent assemblages,” (Suchman et al, 1999, p. 399) any such user tool will add value only in so far as it aligns with this process.

## ■ NOTES

<sup>1</sup> All interview segments have been translated from Dutch by the first author.

<sup>2</sup> Prototypes of these are available at: <http://www.medcircle.org/info/bar> and <http://www.hon.ch/HON-code/Plugin/Plugins.html>, respectively.



## ***Chapter Six***

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### **More than just a mouse click: Research into work practices behind the assignment of medical trust marks on the world wide web**

Adams, S.A. and A.A. de Bont. *In press*.

More than just a mouse click: Research into work practices behind the assignment of medical trust marks on the world wide web.

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Health care “trust marks” are hyper-linked icons or seals that are placed on websites to denote review by an independent third party. These icons enable a site’s visitors to click from the website through to a special window, which provides extra information about the site, including when it was last reviewed by the third party assigning the seal. Existing codes of conduct have been extensively reviewed (Jadad and Gagliardi, 1998; Risk and Dzenowagis, 2001; Gagliardi and Jadad, 2002) and even practically applied by researchers trying to evaluate the quality of medical websites. (Sandvik, 1999; Meric et al, 2002) The conclusions of these studies have opened up the discussion about the relationship between guidelines, trust marks and content-based reliability. (Sandvik, 1999; Meric et al, 2002; Wilson, 2002; Sinclair, 2003)

Existing literature on the topic of trust marks is very critical – outlining how the review and policing processes are insufficient forms of quality control and how trust marks can be misleading to web users. There are four primary lines of criticism in the discussion about the role that these codes of conduct and their accompanying trust marks play in indicating the reliability of websites. First, the value of trust marks as one type of user tool is questioned. It is argued that the lay medical end user either will not notice such a seal at all, or will notice the seal but not understand what it means. (Wilson, 2002) Second, without proper information about the guidelines underlying a given seal, the presence of any trust mark on a website can be counter-productive, because the end user will make mistaken assumptions about what it represents or about the criteria upon which it is based. This can, arguably, lead to a false sense of security about the site. (Terry, 2000; Kaplan and Brennan, 2001; Rigby et al 2001; Burkell, 2004) Third, offline tools are not sufficiently transferable and applicable to the web, as it is easier to copy seals and use them without permission. (Eysenbach, 2000b; Rigby and Forsstrom, 2000; Eysenbach, 2001) Fourth, the underlying process of assigning a trust mark (who is reviewing sites, how often they are policed, etc.) is criticized. Especially the absence of content review has been an important issue. (Delamothe, 2000; Rigby and Forsstrom, 2000; Eysenbach, 2001)

An overarching point in all of these criticisms is that lay end users must understand both the process and the product – they must learn not only about the criteria and review, but they must also understand how the trust mark “works.” The suggestion is that prior to or in the midst of an information search process, visitors to a site that carries such a trust mark are expected to take the time to learn about what these trust mark signifies, so that they know to click (and actively do click) in order to verify proper its usage on that site. In relation to this suggestion, different authors have discussed the need for understanding more about both how users engage with the web in general and whether they follow actions prescribed by specific technologies. (Kaplan and Brennan, 2001; Fogg et al, 2002; Schulman, 2002; Stanford et al, 2002; Eysenbach and Kohler, 2002b; Morris and Avorn, 2003)

Mouse clicks (which are observable, traceable, and quantifiable) are incorporated into studies of lay medical end use of the web. Researchers have tried to pay attention to whether or not users click on the seals they encounter as part of accounting for the reliability of websites. Eysenbach and Kohler (2002b), for example, make specific mention of patients' failure to click when encountering the HON-code icon during a searching study in a usability lab. Although the non-use by lay end users of seals is by now almost an established fact, this does not mean that lay end-users are not concerned with the reliability of the information they find on sites. Rather, they use specified methods other than seals or checklists to assess reliability and these methods tend also to incorporate some components of existing codes of conduct. (Adams, de Bont and Berg, 2006)

The criticisms of trust marks and the studies of end use depart from the perspective of lay web end-users. Little attention is given to the actors involved in the review process, and the intricacies of the work practices that comprise the review process have remained largely unstudied. For example, little is published about the long waiting lists at certifying organizations of the site providers who want to be certified and want to carry the seal. Even less attention has been given to the work that the third-party reviewers carry out, together with the site providers, to make a given website compliant with a given ethical code or to the time involved in this process.

Although site providers are mentioned in literature, their role is usually reduced. In their review of quality initiatives, Risk and Dzenowagis (2001) discuss burdens placed on various actors by quality initiatives and in so doing, give some attention to health information providers and site providers. However, they refer to users and use largely from the perspective of lay end users and fail to mention site providers at all in their concluding discussion of scope and reach. Eysenbach et al (2001) discuss the importance of encouraging health information providers to label their sites, but only in the context of facilitating the assessment process for lay end users. Site providers and the educative role of the review process are also included as a topic heading in the 2002 Communication from the Council of European Communities (also known as eEurope 2002: Quality Criteria for Health related Websites); however, this subsection devotes more attention to how new tools educate consumers, rather than demonstrating the importance of educating site providers.

Because of the focus on end use, on assessing whether or not patients even notice the seals, let alone click on them, not only the authors in the medical informatics literature, but also the tool developers themselves have relegated to the background other potential users of the seal. For example, visitors to HON's website receive the instruction: "HON recommendation to Internet users: Before consulting healthcare information, click on a

website's HONcode accreditation."<sup>1</sup> Sites under review not only display the seal, but also include the sentence, "We subscribe to the principles of the HON Code of Conduct, verify here." Text and explanations accompanying similar mechanisms from other organizations (such as the project proposed under the name MedCERTAIN<sup>2</sup> or the QMIC seal issued by TNO in the Netherlands<sup>3</sup>) also give this type of instruction.

In order to shift the focus away from this end use, it is important first to consider that the process of reviewing sites based on a list of ethical principles is intended to serve a different purpose than merely getting users to click on a recognizable seal. For example, in 2001, HON explained the relationship between its code of conduct and the trust mark as follows, "The HONcode is based on an 'active seal' concept and primarily intended for healthcare site developers, holding them to fundamental ethical standards of honesty and transparency in publishing." (HON, 2001) The language of the information pamphlet quoted here emphasized that the site provider was to be the primary user of the HONcode, thereby suggesting that the potential role that the seal could play for other types of users was an additional benefit: "...But for Web users, too, whether patients, care providers or just curious surfers, the blue-and-red, 'clickable' HONcode seal acts as a quick quality identifier. It helps clarify the source and the purpose of the information they are reading. It raises awareness of Internet self-regulation and fosters responsible use of the web." (HON, 2001)

Trust marks originally were static, not hyperlinked. (See Eysenbach et al [2000] for an explanation of "generations" of trust marks.) The "burden of use" was placed on site providers to be compliant, rather than on users to click and verify that compliance. Use at this time was not about clicking and reading a certificate to verify honest display of the seal. It was about understanding the seal as representing a process of site review – an interaction between the organization and site provider.

We suggest, therefore, that it is necessary to study these processes of exchange between a given certifying organization and the providers of the sites that are being certified. In this paper we argue that site providers are important users of trust marks, although "use" in this context is defined differently than in the current literature. We look into the review process to identify how site providers are made into users and analyze this process from an ethnomethodological perspective.

## ■ METHODS

We use as a case study the Health on the Net Foundation's Code of Conduct and seal (the HONcode)<sup>4</sup>, which is the oldest and best known code of conduct. (Commission of the European Communities, 2002) We conducted ethnographic research at the Health on the Net in 2002 and 2003. During the first visit, research activities included semi-structured interviews with five members of the HON team and observations of their work, review of the historical archives, and familiarization with the database that supports the HON Code of Conduct. During the second visit, research included semi-structured interviews with six members of the HON team (including three who had been interviewed during the first visit), participant observation of work processes, and active participation both in the annual team business meeting and in exercises that are used to train new site reviewers.

The process of reviewing a site and deciding about compliance involves tacit knowledge and, as such, is difficult to make visible. In an attempt to make these practices visible during the ethnographic work carried out at HON, reviewers were asked to assess the same four sites (one new applicant site and three sites eligible for periodic review). Each individual reviewed the site in the presence of the researcher and explained why the site was or was not compliant with each of the eight principles of the code. After each reviewer had completed his/her reviews, the team met as a group, reviewed the sites, and discussed the individual decisions that had been made. The purpose of this exercise was to understand the work involved in reviewing a site and not to compare between reviewers. To protect the confidential nature of the review process, the sites were assigned a number and the researcher did not record the name or URL of the sites.

## ■ SITE PROVIDERS AS "USERS" OF THE CODE OF CONDUCT

A site provider becomes a user of the HON code of conduct by visiting the website of Health on the Net, familiarizing him/herself with the review process and officially applying for review and certification. The latter is a multiple-step process that includes completing a standardized questionnaire to help determine at first glance where the site is/is not compliant, filling in information about the site, providing contact information, receiving detailed guidelines for making a site compliant with each principle and selecting a user name and password. It is important to note that site providers approach HON and initiate the process and not vice versa.

The existing skills and levels of awareness of important issues among the site providers who apply for certification can vary greatly. Some site providers, for example, may

be completely unaware of the ethical issues and responsibilities, while others are aware of these issues, but have the idea that the nature of their organization, or the nature of activities carried out on the site, make the site automatically compliant with all or parts of the HON code. Site providers often do not understand how specific principles apply to their respective sites and incorrectly assume exemption status for these principles. They often engage in a series of discursive emails about why they are marked non-compliant meaning that the review process is not one-sided, but rather an interaction.

In explaining how every site must comply with all eight principles – without exception – HON educates site providers about the ethical responsibilities of providing medical and health information on the web. Thus, the exchange between the certifying organization and its clients forms the basis for raising awareness of the issues involved with, and the responsibilities coupled on, providing medical or health-related information on the web. We see in this particular process three key points that underlie the eight principles: the importance of explicating intent and explanations rather than relying on inference by others (Principle 1 for Authority, Principle 3 for Confidentiality and Principle 7 for Transparency of Sponsorship), the importance of differentiating between types, origin and currency of material that constitute a website (Principle 4 for Attribution, Principle 5 for Justifiability and Principle 8 for Honesty in Advertising and Editorial Policy) and the importance of facilitating continued human to human communication amidst the electronic exchange of information (Principle 2 for Complementarity and Principle 6 for Transparency of Authorship).

### *Explicit intent*

Reviewers try to approach each site through a new visitor's eyes. Reading a site in this manner is important for demonstrating how quickly a new visitor can become confused during a search. Part of this confusion can come through the ambiguity contained in everyday words and phrases. For example, although terms such as 'health professional', 'non-profit' and 'incorporated' carry specific connotations, they can be interpreted in different ways and as such tell the user nothing with respect to medical qualifications or financial interests of the site. In its correspondence with site providers, the Health on the Net tries to assist them in making changes by asking for precise terminology and recommending specific texts. A suggested text is concise and straightforward, leaving little room for alternative interpretation or inference on the part of the site visitor. As the example below shows, a second dimension of explicating and standardizing terminology also means ensuring that the presentation of information within a site is consistent. The review process brings these types of issue to the fore by demonstrating that what is

self-evident to the site provider is not only *not* self-evident to site visitors, but also has the potential to be confusing or even misleading for them.

- Reviewer: This is an interesting site. It says here not-for-profit, but then here it says incorporated. We will have to insist on their funding information. When they say it is not-for-profit, that's emptiness. It may not be for profit, but that still tells me nothing about how the site is funded. Furthermore, it is not-for-profit, but it is a business, so how on earth do you focus your funding if you're a not-for-profit business? (site four)

### *Differentiating between types, origin, and currency of material*

Websites are not homogenous, but are made up of arrays of different types of resources. Although patients have been criticized for using a good design or layout as a positive indicator of reliability (Chin, 2002; Fogg et al, 2002; Stanford et al, 2002), interestingly enough, certain elements of design are used to indicate *lack of* reliability. That is, poor design can contribute to the unreliable nature of a site if it leads to confusion on the part of the visitor. This is most notable with respect to blending advertising with other forms of content. (Cho, 2000) HON states that the site's policy with respect to the presence or absence of advertising should be clearly displayed. This policy should explain why certain types of advertising are or are not accepted. It should also describe how the site distinguishes between editorial and advertising content – and this should be reflected on the site itself. An example would be placement of the word “advertisement” under a banner and the sponsor of that banner should be clearly identified.

The following segment shows an example of a site provider who has mixed several types of information, including advertising.

- Reviewer: He seems to have a reference for everything, but look at this one – he begins discussing a financial interest in supplements, “with you, your family and your insurer, but...” Now, wait a minute, this seems like advertising.
- SA: It is sort of mixed in.
- Reviewer: Yeah, just mixed in with everything else.
- SA: It only has this box around it.
- Reviewer: It clearly seems like advertising, because it goes to an outside site and it says, “Supplements for You.”
- SA: Is it properly marked?
- Reviewer: No, it is not because I have...it needs to say here, advertisement. Plus, he needs to include an advertising policy. (site three)

It is unclear if the different colors used in the lay-out are also intended to indicate changes in types of content. Design that does not allow for an obvious display of differences



in origin and type of information can be misleading for the patient-as-end-user. This requirement from HON is not purely about design and indication of advertising, but it is really about indicating the origin and nature of all information contained on a site.

HON attempts to educate the site providers in what the scientific community will recognize as the expected display of information – not only disclosure of all sides of the story (balanced information), but also support for claims coming from sources that arguably, due to their being published, have also at some point been reviewed for content. Therefore, reviewers check links to cited sources to make sure that there is grounding for any claims that are made and that the source quoted is a correct reference for the claim made. This provides a secondary check on whether the medical literature has been interpreted and used correctly, especially when information is assembled by non-medically trained persons.

The review process enables HON to act as a mediator between the site and its visitors, not only because reviewers approach sites from the lay end-user's perspective, helping site providers to see themselves through the eyes of specific groups, but also because the Foundation can provide feedback based on studies of the general user population. (See HON's webpage<sup>5</sup> for results from their annual surveys.) For example, to help site providers better understand why posting the date is important, the Foundation can refer to survey data that shows that users appreciate that a site is active and current and that the information is recent. This shows the user that the person responsible for the site is interested in and considerate of the needs and expectations of its user group. It also explains the important differences between posting the date for when the site as a whole is updated and the date that a specific information section is updated – and why the distinction should be evident to the site user. This further serves to remind site providers to consider the ad hoc nature of searching, where visitors can enter a website from a specific content page and not necessarily the home page.

### *Human to human interaction*

Providing an information service is not merely a matter of writing an html code for a given URL. Rather, it implies a commitment to communicate and interact with users of that information. There must always be a real person behind the contact information who is available to answer questions that the patient may have about information or other materials found on the site. More importantly, educating site providers with the HON-code goes a step further by demonstrating the consequences of and additional responsibilities involved in disseminating medical and health information of any type via the web.

The most important human-to-human interaction with respect to the medical internet is outside the web itself – that is the interaction between a patient and his or her own physician. Any materials on any site must play a secondary/supporting, rather than primary/replacing, role in that relationship. HON is adamant that web site providers make explicitly clear that their sites are intended as supplementary information only and they do not replace the relationship that exists between physician and patient. Although this often means the addition of one sentence, it is again instrumental in the process of educating site providers.

In participating in this process of education, which explains the considerations that underlie the principles and why they apply to all sites without exception, site providers are users of the code of conduct and have a vested interest both in compliance with it and the physical representation of the seal. This is reflected in the long waiting lists at HON, but also in the physical and non-physical resources that are invested in updating or changing a site to achieve compliance. HON has recently given more attention to the standpoint of site providers regarding several aspects of the certification process. They have compiled survey data from 124 site providers (two-thirds of which were already compliant and one third of which were undergoing the review process at the time of the survey) in order to gain a better understanding of opinions regarding the importance of the process and estimates of the amount of time involved in changing a site to make it compliant. For example, when asked who benefits most from the accreditation process, roughly half of the respondents said individuals, while the other half indicated the site providers themselves. [Celia Boyer, personal communication, 27 July 2004.] This type of information from certifying institutions will contribute to understanding why and how site providers find it important to use codes of conduct and their trust marks, despite the knowledge that their own site visitors might not.

## ■ DISCUSSION

Although they now receive less attention in the literature, codes of conduct are still current. Trust marks should not be viewed as mere remnants of failed attempts in self-policing or assisting lay end users. Instead they should be seen as representative of processes that are not only still active, but also still evolving. HON provides site providers with guidelines, standardized and tailored email explanations and also continues to develop specialized tools (such as an online complaint form attached to the seal) that assist in the process of realizing compliance. During the review process, HON not only suggests where improvements can be made, but also verifies that they have been made. It is in

this work of mailing with site providers and witnessing physical improvements to the site that site providers are educated and ethical responsibility is created.

Part of this responsibility includes making sure that the voice or viewpoint of the site visitor is incorporated in the design process. But this is not just any visitor. In constructing a lay end-user who can easily become confused or misled through simple components of a site, HON demonstrates the importance of incorporating transparency of the background processes in the final form and presentation of information on that site. HON sees the HONcode as a pedagogical tool to assist in further communicating to various actors in the internet community why building this transparency is essential.

The underlying ideology is one of explicitness – if a site provides its own users with background information regarding how the site is run, it helps the user assess the information found there. It enables the user to determine if the information is intended for him or her (especially if the intended audience is explicitly described in accordance with Principle 2). It also contributes to the patient's weighing of various types of information in relation to his or her personal situation (through, for example, understanding how and when recent treatment information has been updated). Not disclosing information suggested by HON does not help the user to place the information in the greater context of other information from other types of sources (both online and off), nor in the context of his/her personal health situation, which is crucial both to assessing the reliability of information and to incorporating the information into decision making processes. (Adams, de Bont and Berg, 2006) Likewise, not presenting information clearly on all pages can be equally unhelpful and phraseology or design can lead to confusion on the part of the lay end user, preventing him/her from acquiring the necessary information for making choices.

Eysenbach (2001) and Burkell (2004) have criticized use of the term transparency by questioning in how far the complex network of actors underlying such a process of review and information provision becomes (self-) evident to the user merely through the presence of the code of conduct or its seal. Once again, we must think of this not only from the perspective of the lay end user, but also from the meaning of transparency for other actors – information providers who are putting together sites and linking to others or allowing links from others, information specialists who are helping users search in libraries or at information kiosks, medical professionals who are recommending websites to patients who ask, et cetera. From this perspective, it is not so much a matter of knowing who comprises the underlying network as it is the idea of understanding how the review process leads to changes on a site. Transparency is not about the network of actors, but about the work involved in making potentially confusing or hidden aspects of a site explicit.

The work involved in the process of reviewing sites is intensive and time consuming for both parties. Every site applying for review must be checked and rechecked, as no site is automatically reliable, regardless of who is behind it or what is being done. Site review is an extensive process, through which the reliability of a site is always constructed. The first part of this construction is found in the initial review process, where the reviewer engages with the public face of the site and seeks to understand it. The second part is found in the series of mails that are exchanged between the site providers and the members of the reviewing team. Standard mails discuss the changes that should be made or those that have been made. Additionally, there are discursive mails where site providers ask questions about HON's expectations for changes with regard to becoming compliant and HON responds by deepening its explanations, offering additional suggestions and convincing site providers of the importance of making the given changes. The third part is found when the site claims to have made all changes and HON reviews the site one last time prior to activating the hyper-link seal. This process of is repeated multiple times at the initial review and each time a site is spot-checked. These are the types of actions that make site providers into users of trust marks and that suggest that they see themselves as such. Otherwise, there would be little reason to invest in this process.

While assessors of seals have been focusing on whether users do or do not notice the presence of and for whatever reason do or do not click on the hyperlinks, they have missed the site providers that have continued to apply for review by organizations offering trust marks. Prescribing the clicking action as the primary use suggests that the icon is about little more than a hyper-link to a certificate full of extra information about the site, such as the date of its last review. Indeed, one can question how much this adds to understanding about the reliability of a site. For this reason, and without at all intending to marginalize the importance of including the patients' perspective(s) when discussing how trust marks play a role in their understanding of website reliability, we suggest that part of the problem with the current discussion is that it places too much emphasis on lay web end-users as the only users. More emphasis can be placed on other types of users of (and other manners of using) the same tool.

If we look at the process of information exchange between the certifying institute and the site provider whose site is under review, we see that the icon is also a physical representation of the otherwise invisible work (Suchman, 1995; Star and Strauss, 1999) carried out to change and improve sites. Despite all the criticisms of trust marks, and despite wide-spread recognition of the lack of click by their own site users, site providers are still interested in being reviewed and there are costs associated with including trust marks on their sites. In some cases, this is in the form of a fee for the review process (HON, however, does not charge a fee), in other cases, this is in the form of hiring specialists to ensure

that compliance is reached and the seal is acquired. In all cases, merely making small changes, let alone major changes, to the presentation of information on a site requires an investment of both time and resources. The review process is an intensive one, and one that site providers are willing to undergo in order to attain and keep the certification that allows the placement of a trust mark.

Carrying the trust mark also carries more consequence than just changes to one's own site. It also obliges site providers-as-users to protect the integrity of the seal. The seal acts as an intermediary in that it is a public indication of the more hidden review process. Adding the hyperlink was necessary to prevent fraud and add to the worth of the seal. But, this technical change shifted the attention away from use that already existed and that still exists now. Anecdotal evidence suggests that site providers actively look for the seal on other sites and use it as one standard of measure for collecting information from or in linking to one another's sites. Keeping the seal is important, but keeping the seal's good name is more important. Although there has been some criticism about the effectiveness of a self-policing initiative, looking from the perspective of an organization such as HON, in examining the mails they receive and seeing how they follow-up these mails, one sees how, when and how often the network actually works.

## ■ CONCLUSION

The purpose of this article was to step outside the confines of a discussion focused on lay understandings of codes of conduct and their accompanying trust marks. The focus on the patient or lay medical web end user as the primary target audience for the seal has allowed the *medical site/information provider* to be overshadowed in the discussion about what seals do. Understanding the work involved in the process of reviewing sites, from application for review to permission to post a trust mark and participating in a self-policing chain, is crucial to understanding the role that the trust mark plays as part of the medical internet. We suggest that the scientific community, in focusing on the outward, observable presence of trust marks, has also neglected to understand fully the purpose and role of the review process behind these trust marks and has missed important parts of the work performed by those marks. In other words, delineating all the ways that trust marks are insufficient has meant failure to notice the positive role that the review processes behind these trust marks are actually playing.

By examining the review work of one institution, we see the importance of the review process in educating site providers. Incorporated in this process is the trade-off that site providers are willing to make in order to attain and keep the right to display the seal.

What it means for the site provider to be a trust mark 'user' and what this use entails require a different interpretation of ideas of use. The site provider can "use" a trust mark in a diversity of ways, only one of which (education) is discussed here.

We see all of this emerging out of data gathered in order to learn about the work of certifying institutions such as the Health on the Net Foundation; however, more data can and should be gathered to show the changes in sites as a result of becoming compliant with an ethical code such as the HON code of conduct. There has been little real attention given to these actors in relation to the role of the hyper-linked icon on the medical internet. It would be fruitful to conduct research among site providers in order to learn more about the role that the icon plays in the process of keeping up a medical website. This would allow for evaluation of codes of conduct and seals that is based on more than opinion and conjecture. It would enable us to raise questions of how the process works with respect to education for those directly involved and to gain a better understanding of why they see this certification as an important investment, as well as how the trust marks are significant to them. It would be interesting to see how a site is improved in the course of the review process and how site providers identify their position in the self-policing chain. Before we discount the role that a given technique – the hyperlinked trust mark – plays, researchers in this field should consider more than just the presence or absence of a mouse click.

## ■ NOTES

<sup>1</sup> <http://www.hon.ch/Patients/individuals.html>.

<sup>2</sup> Archived homepage of the MedCERTAIN initiative: <http://www.medcertain.org>.

<sup>3</sup> See: <http://www.health.tno.nl/trust/new/englishinfo.html> and [http://www.health.tno.nl/trust/documents/english\\_page/Simple\\_explanation.pdf](http://www.health.tno.nl/trust/documents/english_page/Simple_explanation.pdf).

<sup>4</sup> HONcode, <http://www.hon.ch/HONcode/> ; see Appendix.

<sup>5</sup> Health on the Net user surveys. 1997-2005. Available online: <http://www.hon.ch/Survey/analysis.html>.

# ***Discussion and Conclusion***

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Network technologies, like most other technologies, emerged neither by accident, nor as carefully organized and designed; instead, they emerged in a somewhat ad hoc and piecemeal fashion. More importantly, they *still are being created and developed* in said fashion. (Langford, 2000; Slevin, 2000) The web continues to change and evolve: web presences fluctuate, with providers, websites and even users emerging and disappearing somewhat unpredictably. Even “established” web presences are not static – sites are re-designed for layout, information is removed or updated and continual technical developments affect how information is presented (one can think of flash technologies or more recent developments in full-fledged “talking” websites). Although many changes to the web are not all that evident, and although the technology has recognizable features that allow us to identify, discuss and study it as “the web,” it is nonetheless constantly changing. Through a progression of minute changes, the web of today differs from the web of just a few years ago and also from the web of the future.

Consequently, the effects of different developments are not easily inventoried and individual analyses of network technologies become difficult. (Langford, 2000; Slevin, 2000) The subject under study is not a static object that can be cautiously observed over an extended period of time, but instead will fluctuate during the duration of any study, implying that any research that has been done or currently is being done represents only a snapshot, or rather, a series of snapshots, that reflect a specific period of time in this developmental trajectory. This thesis, thus, not only contextualizes, but also is contextualized in and by the technologies, initiatives and mechanisms under study. In order even to address understandings of reliability, it was necessary to take into account that the portal sites included in this study (healthfinder, Quackwatch and Medlineplus) changed a seemingly infinite number of times, updating and adding information, or reaching out to new population-based user groups and that organizations providing other types of web-based tools (such as the Health on the Net) found it necessary to adapt to changes in the technologies, ideologies and social networks around them by dismissing or altering existing tools, as well as by creating new types of web-based tools. MedCERTAIN changed its name and approach to reliability, while the Dutch portal Gezondheidskiosk disappeared completely, only to be replaced more recently by a new portal, kiesBeter. As such, the methods and cases were necessarily adjusted up until (and even during) the final months of finishing this research project and writing this thesis.

By juxtaposing these various initiatives and accounting for their progressive developments, each chapter of this thesis linked understandings of reliability with knowledge of work practices and representations of users, simultaneously redefining and extending each of the three concepts, while twisting the overarching questions that are posed in the existing literature. In the first two chapters, work and users were held constant in

order to break open the concept reliability. Chapters three and four then looked at the interchange between the work that is being carried out and its influence on understandings of reliability. The final chapters then examined types of users and notions of use, not only redefining reliability once more, but also reflecting on the consequences of these understandings for the work that is done in producing initiatives.

Chapter one argued that the question of how to make the internet more like the book is misplaced, as no medium is reliable purely by the nature of its existence (nor even, for that matter, by the presence of regimes to regulate it). By looking at the web in relation to the history of other media, we saw that there are always groups working to create “official” initiatives that carry some sort of stamp of approval. Each initiative carries specific ideas, not only about producers and the production of (reliable) information, but also about users and the use of technology, as well as the sometimes-blurry lines between production and use. The conclusion that reliabilities are constructed (and that this, in practice, takes much work) is not surprising, as it has been extensively documented for other cases, such as the book. (Eisenstein, 1983; Johns, 1999) What actually becomes interesting in this case are the different reliabilities that emerge; that is, how different sources and types of work lead to different understandings of reliability and how they independently develop.

Chapter two, therefore, examined three different reliabilities that co-exist on the web. In so doing, it argued against the idea of “universal reliability,” showing instead the localized meanings that are given to the concept with the creation of different types of initiatives. “Reliability” for Quackwatch means a normative content judgment made by licensed professionals and based on rules of evidence-based medicine, while Health on the Net supervises completion of a given procedure, and healthfinder links to established organizations. With these different initiatives, information is demarcated along, for example, national and professional lines, thereby creating multiple types of spatialities, which arguably can appeal to the existing plurality of web users.

Chapter three further examined the consequences of multiple reliabilities by analyzing how two different initiatives use guidelines to review information and sites. This chapter made the point that guidelines are not enough to enable labeling information as reliable, because the “work” of applying guidelines to information/sites involves use of discretionary space – a space that relies on existing distinctions, such as those made between types of medical and health information or those made with respect to print media. However, this work becomes invisible in the process of presenting information and sites as reliable to the public. In this regard, this chapter demonstrated the difficulty of engaging in discussions about “transparency” as a necessary prerequisite to guaranteeing information reliability, because even the practices of certifying organizations are never fully transparent.

Chapter four then examined how the results of the decisions made during these review practices are translated into particular forms of expression in order to build a network through which the initiatives can be sustained. This demanded looking beyond behind-the-scenes work and examining the publicized work of enrolling different groups (professionals, lay individuals, or other organizations) to engage in specific behaviors. In this understanding, reliability is redefined – not as a property of the information or the website, but as the diverse actions in which different actors must collectively engage. Conversely, the presence of these initiatives is also redefined – the work that they carry out is about more than just reviewing information or helping lay end users. It is also about spreading ideals of social responsibility. In this respect, although the focus was not on any specific type of web user, we see that ideas of user behaviors also become redefined. Messages about expected behavior extend beyond prescriptions for checking information to include prescriptions for civic behavior that is extra, but nonetheless still related, to practices around individual health.

Chapter five returned to more traditional understandings of use by questioning the assertions that users are not properly searching for information and must be re-educated in how to use the web to search for health information, such that they actively visit specific links, review pages on the basis of a checklist, or consistently click on trust marks and review extra information about sites. This chapter argued instead that it is first necessary to understand *how* lay practices of searching for information inform user understandings of the reliability of that information. Even though different understandings of reliability were also evident among the interviewees, they all shared the standpoint that labeling information as reliable was not enough: the sources of the labels were often as questionable as the information itself and the individual websites were not the issue anyway. Individuals are interested in reliable information and in engaging in practices that help them assess the reliability of medical information, but they do not assess the overall reliability of an entire website. Instead, they place that website in an experiential frame of reference such that it contributes to their assessment of an answer to a given question. This answer is a conglomerate answer that is derived from disjunctive pieces of information that are assembled using any number and variety of sources. As such, this understanding of patient search behaviors calls into question the strategy of focusing on the reliability of individual sites.

Chapter six reflected on understandings of users, both in the literature and in the preceding five chapters of this thesis. It argued that discussions about whether or not web end users “click” on hyperlinked seals are misplaced because they focus on the entirely wrong user group. Focusing on the clickable seal redirects attention away from the site provider and toward lay web users and also erroneously again brings to the fore the discussion

about “transparency.” Assuming the alternative perspective that *site providers* are users highlights how organizations collaborate with information providers to gain access to content (in the case of portals) and engage in pedagogical work to raise awareness about ethical issues and help providers improve the presentation of information on their sites (in the case of review institutions). Reliability is again defined in terms of participation, with the understanding that site providers must share different types of information with organizations and/or commit to self-policing chains. Use is linked to demonstrable willingness to engage in work that enables attaining (and keeping) third-party certification. Site provider uses can also include other forms – judging other sites using the same criteria by which they are judged, or setting certification by the same organization (thereby including participation in the same self-policing chain) as a prerequisite for linking to the information on other sites – but this is a hypothesis still in need of directed research.

## ■ GENERAL DISCUSSION

During the course of this research, I often fielded academic questions that were posed in terms of the efficacy of initiatives or their success relative to one another: do patients visit portals? Do the seals really work? If the answer to either of those questions is no, why is so much time and effort still devoted not only to existing portals and seals, but also to the development of new portals and seals? What is their added value? And so forth. Indeed, it would be easy to read the various arguments throughout this thesis in terms of efficacy and, consequently, as an implicit suggestion that the development of patient-targeted mechanisms is fruitless labor; but, that would be to miss the point. Rather than seeking to conclude on which approach works most successfully and could be privileged as better, to criticize any approaches that differed from well-voiced expectations found in medical literature, or to concentrate on pre-determined definitions of users and use, I sought instead to historicize and contextualize network technologies, and enable reconfiguration of our current experiences with them. (Jones, 2004)

Although “reliability” is used in the literature in a manner that implies the shared understanding of an integrated concept, this thesis outlines a variety of reliabilities that co-exist on the web and/or are found in various ‘uses’ of different types of web-based information. Seals, portals, special domains, and other types of initiatives discussed here have developed concurrently with discourse about which persons or parties should provide medical information, by what standards this information should be judged and in what presentation form it is best suited to a lay public. When different institutions emerge, evolve, or adapt in order to serve a suggested social need – in this case, in order to protect information integrity – they significantly shape different techniques and related ac-

tions. (Brown and Duguid, 2000) As such, these initiatives in their various forms represent a materialization of diverse, and sometimes conflicting, representations of information reliability, proposed users and prescribed use. (Oudshoorn and Pinch, 2003)

With the creation of different types of initiatives, localized meanings are given to the word reliability, rebutting the idea that there is common ground shared by the different initiatives that can be used to produce a single, universal “reliability.” Even within the different categories of reliability first typified in chapter two, interpretations and applications can differ – for example, standards for judging content can vary. Similarly, groups that use adherence to a “process” to assess reliability can make these determinations on the basis of different processes. Furthermore, the differentiations are not absolute – initiatives also combine different reliabilities into one, for example, by utilizing a practical, tiered review of different types of information on one website. With respect to review, various actors further attach to reliability the ideas of transparency and neutrality, transforming reliability in this case into a willingness among site providers to disclose and publicize their business practices and open themselves up to review by an independent third party.

Reliability comprises not only the individual properties of information or a website, but also the diverse actions in which different actors must engage. It is participation – on the part of all the actors involved – and extends beyond web-based information seeking to include responsible consumerism activities in online, offline and blended communities, thereby making reliability greater than the web and web-based initiatives. The chapters of this thesis (most especially, chapter five) show that despite the opined special nature of an initiative or its sponsoring institution, these different mechanisms are not independent to (and therefore outside of or above) the other forms of information that are found on the web (or even the web itself). Rather, the initiatives form an integral part of the existing information landscape, together with numerous other types of online and offline content and resources.

As a result, the organizations must, as an interviewee for one of the US initiatives stated, find their way “onto or into the sound spectrum of people’s attention to inform them about reliable information.” In the terms of this thesis, they must enroll different types of users to actually use these tools. We then see that, despite the lack of a convincing case against the web as a reliable resource and the lack of direct causal links between web-based information and specific cases of harm, and despite some professional recognition of this fact, the prominent discourse of both medical literature (directed at professionals) and the statements found on the home pages of initiatives (largely directed toward a lay public) use notions of *unreliable* information to create the image of an online environ-

ment that puts everyone at risk. That is, in order for the initiatives to produce reliability, they create a situation of un-reliability by engaging in a discourse that focuses on the dangers of online medical information, reflected, for example, in Eysenbach's (2002) suggestion that misinformation can be approached and studied as an epidemic. Organizations must actively construct information integrity as a problem in order to provide solutions – solutions that extend far beyond the information itself.

Protecting individuals and communities from the risks associated with misinformation becomes a civic responsibility that is shared between those actors that conduct a primary review of information and all other actors that are involved with the production, distribution, assessment or use of any form of (medical) information – namely, medical professionals, site providers and lay end users of the web. Risk and reliability are strategically employed as *rhetorical devices* that highlight specific issues surrounding web-based medical information. These strategic discourses suggest which web resources are the “right” resources for finding and communicating information and provide a normative foundation for accepting certain information behaviors and rejecting others. (Slevin, 2000)

As is addressed in chapters one, three and four, it is through this steering of behavior (guidance to the “right” resources), rather than through access to information technologies, that the empowered patient is to be constructed. Proposals for authoritative content review and information restructuring into searchable formats accessible via specialized tools have been the basis for this active construction. Furthermore, these tools were to be accompanied by wide-spread programs for patient education in how to search for and assess relevant medical/health information; that is, the issue became a matter of disciplining users. (Woolgar, 1991) Several years ago, there were ambitious proposals for initiatives (such as MedCERTAIN) that would review medical content on a site-by-site basis; however, these proposed programs for information review and patient education have largely been abandoned in favor of more feasible or practical solutions (with respect to how much information can be reviewed in a given amount of time) and the responsibility for determining which information criteria are most relevant in a given search situation has been redefined as distributed and shared. The role of a central authority has been de-emphasized in favor of aligning different initiatives that can be used in conjunction with one another.

As a result, understandings of what it means to enable and empower patients consequently become redefined. This points to Hesse's (1996) point that notions of discourse that categorize individuals are not an inevitable consequence of the development of network technologies, but instead will or will not emerge as a result of particular social and

political choices. Empowerment is not a self-evident or guaranteed result of access to a technology or more information; it, too, must be achieved through active construction. Every-day, situated factors, which can prevent or constrain the emergence of the identifiable “empowered patient,” also remain. (Henwood et al, 2003) Therefore, it is important to continue to consider how such modified definitions and understandings of the ideal of empowerment will take concrete shape in practice.

For this reason, it is necessary to give more attention to lay information-seeking practices and how their understandings of the reliability of information develop in relation to their experiences and activities on the web. Addressing the issue from a lay perspective reveals that although individuals sometimes have difficulty in finding what they are looking for, they nonetheless can and do differentiate between good and bad sites, biases in information, and information that is ill-informed, incorrect, or out of date. (Fox and Fallows, 2003) They make these judgments using their own understanding, reason and algorithms, which are specific to the circumstances of their searches for information. Similar to the point made by Johns (1999) about early readers of books, the use that we observe is not arbitrary practice, but contributes to varied manners and processes for assessing information. The reliability of a conglomerate answer to a specific question relies both on repetition of pieces of information and the relevance of those small pieces in a context of information sources and experiences. Searching for information is an iterative process and lay techniques for assembling information that can be used in health care decision-making (and thereby, their understandings of reliability of that information) continue to develop over time as experiences increase. Interestingly, although this differs from how organizations purport to review information, essentially it employs a different form of the same trick in the sense that both processes of checking information also necessarily make up ad hoc rules. Practical assessment solutions and lay assessment practices arguably resemble or align with one another more than is recognized.

Reliabilities are shaped by normative ideas about information and participation, by practical applications or solutions and also by histories. This is not just the history of different media that become blended into one, but also the fundamental social struggles with respect to what constitutes knowledge, who has the right to profess that knowledge, and how information is recognized (for example, through peer review and referencing) or certified (for example, through labeling or audit). Knowledge and/or “authorship” are protected through political efforts to discipline readers and distribute knowledge via channels that are considered to be “safe.” (Johns, 1999) Discourses of web-based information follow a repetitive pattern dating back at least four centuries: first, questions regarding who has the right to profess knowledge, then removal of the burden of professionalism that limits exchange of ideas and finally, complaints about uneven discussions.

(Nunberg, 1996) Together with practice, these discourses rely on (among other things) the creation of dichotomies: between public and private, between authority and constituency, between author and reader, and between lay experience and expertise. (Foucault, 1970; Shapin and Schaffer, 1985; Hesse, 1996) The issues that accompany understandings of internet reliability are at once specific to and greater than the web. Most importantly, existing reliabilities are part of a trajectory for which the outcome is still unpredictable. Not only are the reliabilities still being shaped, but also the meanings attributed to concepts such as “authors,” “readers,” “patients” and “the web,” continue to develop and shift.

## ■ A SHORT REFLECTION ON THE METHODOLOGICAL PUZZLE

Throughout this thesis, I discuss the internet and web either as media or as technologies (and, of course, as research subjects). There exist, of course, many interpretations of both the internet and the web, and other researchers point out the importance of viewing these not as technologies, but as places, with real politics and real stakes (Erickson, 2002; Markham, 2003; Paul, 2005). As is stated throughout this thesis, the developments I followed are not neutral; they will have significant bearing on how the internet and the web, as well as the concept reliability and notions of what constitutes medical information, are interpreted in future. Researchers also play a crucial role in determining how network technologies as research subjects are addressed, discussed, perceived and further studied.

It is this point that brings us full circle, such that we can think, once again, about the role of research contributions in historicizing and contextualizing network technologies – to reconsider the methodologies and theories that are used to study the web and the debates associated with the reliability of information. A wide body of literature on the topic points to the need to adapt existing “offline” methodologies in order to study the web and to search for alternative methodologies or triangulate multiple methodologies. (Jacobson, 1999; Jones, 1999; Mann and Stewart, 2000; Seymour, 2001; Kivits, 2002a; Paul, 2005) Using and adapting existing methodologies is obviously to be expected, and the triangulation of multiple methodologies conforms to the requirements of validity and reliability (referring to the methodological definition of the term) in all qualitative research. (Silverman, 2000) Only the search for alternative methods is a more challenging proposition; however, it is still not all that radical.

This study reflects that, regardless of which methods are used to study internet-related topics, these must be adjustable *and adjusted* during the duration of the study, and the given frame of reference must, likewise, piece together different theories, especially in-



corporating theories that transcend multiple academic disciplines. One can (correctly) argue that ad hoc adjustments and the piecing together of methods and data types can occur in any research, especially qualitative research. Changes *can* and, indeed, *do* occur; however, this is more the exception than the rule and such fluctuations are certainly not encouraged (nor are they often reported in scientific literature). Concerns for the validity and reliability of data generally constrain deviation from a given research plan.

As is stated above, this entire study not only contextualizes its subject, it is contextualized by it. When this research project began, the future of network technologies in health care was a “hot topic,” demanding much research attention into the many aspects that this future entailed. Although the topic now appears to have faded from the limelight, this does not decrease the need for continued, longitudinal research that provides more than just anecdotal evidence or speculative consensus about the potential and actual roles that these technologies now play, and, of course, the future roles that they will (or perhaps, will *not*) play. The reliability initiatives discussed in this thesis demonstrate how little is self-evident and how much is still developing. In this regard, it is insufficient to take a static approach to a technology that is still changing; one can only study internet technologies “in context” if there is also room for adaptation. Although this logic contradicts the established rules of research, I assert that any longitudinal research must account for continued changes to the subject under study and, therefore, will be necessarily piecemeal.



# ***Appendix***

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## **Health on the Net Code of Conduct (HONcode) for medical and health websites**



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### 1. Authority

Any medical or health advice provided and hosted on this site will only be given by medically trained and qualified professionals unless a clear statement is made that a piece of advice offered is from a non-medically qualified individual or organization.

### 2. Complementarity

The information provide on this site is designed to support, not replace, the relationship that exists between a patient/site visitor and his/her existing physician.

### 3. Confidentiality

Confidentiality of data relating to individual patients and visitors to a medical/health website, including their identity, is respected by this website. The website owners undertake to honor or exceed the legal/requirements of medical/health information privacy that apply in the country and state where the web site and mirror sites are located.

### 4. Attribution

Where appropriate, information contained on this site will be supported by clear references to source data and, where possible, have specific HTML links to that data. The date when a clinical page was last modified will be clearly displayed (e.g. at the bottom of the page).

### 5. Justifiability

Any claims relating to the benefits/performance of a specific treatment, commercial product or service will be supported by appropriate, balanced evidence in the manner outlined above in Principle 4.

### 6. Transparency of Authorship

The designers of this website will seek to provide information in the clearest possible manner and provide contact addresses for visitors that seek further information or support. The webmaster will display his/her email address clearly throughout the website.

### 7. Transparency of Sponsorship

Support for this website will be clearly identified, including the identities of commercial and non-commercial organizations that have contributed funding, services or material for the site.

### 8. Honesty in Advertising and Editorial Policy

If advertising is a source of funding, it will be clearly stated. A brief description of the advertising policy adopted by the website owners will be displayed on the site. Advertis-

ing and other promotional material will be presented to viewers in a manner and context that facilitates differentiation between it and the original material created by the institution operating the site.

Available online: <http://www.hon.ch/HONcode/Conduct.htm>

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## ■ SUMMARY IN ENGLISH

What does it mean for web-based medical information to be reliable? That is the central question underlying this thesis. It is accompanied by the methodological questions of how to study both patients' use of the web in context and the theoretical questions of how different notions of both reliability and users have become inscribed in the available web-based tools for finding health-related information. These questions are interpreted largely within the contexts of political theory and science and technology studies, but also draw on insights from new media studies and the growing field of consumer health informatics.

Chapter one examines how current medical literature addresses information resources, as well as the resulting practical applications and developments that have emerged with respect to reliability. It especially points to the non-newness of debates about the web by placing these in relation to other media, such as the book. Furthermore, this chapter shows that the question of how to make the internet more like the book is misplaced. No medium is reliable purely by its nature; rather, the issue is one that resurfaces with each new medium. Further still, despite the tendency to categorize, for example, books and journals as reliable because of the review processes they undergo, this is not absolute; even after a medium becomes more or less black-boxed its reliability must be continuously constructed. There are always groups working to create "official" initiatives that carry some sort of stamp of approval. Each initiative carries specific ideas, not only about producers and the production of (reliable) information, but also about users and the use of technology, as well as about the sometimes blurry lines between production and use.

Chapter two identifies three different reliabilities that currently co-exist on the web. In so doing, it turns the idea of "universal reliability" on its head, instead showing the localized meanings that are given to the word with the creation of different types of initiatives. The differences that become evident are not only in how the word reliability is interpreted (as content, procedural or bound to an organization), but also in how initiatives that carry claims about the reliability of information work to create, differentiate and utilize the physical spaces of the web. This chapter demonstrates that the "politics" of the web (demonstrated along, for example, national or professional lines) are actually found in multiple types of spaces and geographies. Finally, this chapter argues that these differences are important components of the web, especially when one considers the plurality of web end-users.

Chapter three examines how two different organizations use guidelines for reviewing information and sites in order to see how stipulations for information review and the prac-

tices of review mutually shape one another. This chapter points to the fact that guidelines are not enough to enable labeling information as reliable. The “work” of applying guidelines to information and sites involves reliance on discretionary space – a space which relies on existing distinctions, such as those made between types of medical and health information or those made with respect to print media. However, this work becomes invisible in the process of presenting “reliable” information and sites to the public. In this regard, this chapter demonstrates the difficulty of engaging in discussions about “transparency” as a necessary prerequisite to guaranteeing information reliability, because even the practices of certifying organizations are never fully transparent.

Chapter four shifts the focus from behind-the-scenes work to the outward presentation of organizations to their publics. It focuses on the political messages emanating from these initiatives and shows that “user education” extends beyond prescriptions for checking information to include prescriptions for civic behavior. Revisiting different approaches to reliability reveals a progression beyond the idea of harmonizing initiatives into one universal standard to the idea of harmonizing the initiatives into a collaborative effort between professionals, patients and those providing the initiatives. In this understanding, reliability is again redefined – not as a property of the information or the website, but as the diverse actions in which different actors must engage. Further, these are greater than the web itself and incorporate different communities and social behaviors.

Chapter five takes a more practical approach to web-based activities by discussing the results of an ethnographic study into how Dutch patients use the web for assembling medical information. This chapter argues that it is necessary to understand *how* lay practices of searching for information inform user understandings of the reliability of that information. The results of the study show that individuals, while sometimes having difficulty in finding information, nonetheless differentiate between good and bad sites and identify information that is incorrect or out of date. They make these judgments using their own reason and algorithms (which continue to develop over time and increased experience). Tools such as portals, checklists and seals will only work insofar as they align with these existing searching practices of web users.

The final chapter of this thesis revisits the question of who constitutes a user group. In this way it is reflexive not only about the overarching lines of discussion, but also about how this thesis approaches the subject of the reliability of web-based information. It argues that discussions about transparency, and also those about whether or not web end users “click” on hyperlinked seals, are misplaced because they focus on the wrong user group. The decision to add a hyperlink to seals (thereby making them clickable), in order to protect the integrity of their placement on a site, also shifted the focus of the purpose

of the seal. Whereas they once physically represented site provider adherence to ethical principles, their clickability transformed them into a checkpoint for web end-users, thereby shifting the burden of controlling information away from the site provider and toward lay web users. By revisiting information review practices, we see that site providers comprise the primary user group of the trust marks, even though their position and relevance as actors are overshadowed (or completely ignored) in most of the existing literature on the topic. Further research into how, exactly, site providers use these trust marks is therefore necessary.

The chapters of this thesis, thus, redefine understandings of reliability, work and users. In this process of redefinition, we see how historical and local components are contained in supposedly universally understood terms such as reliability. We further see how these terms are used as rhetorical devices that attempt to steer both the health-related and non-health-related behaviors of various types of actors. Finally, we see how the issues that accompany and enable our understandings of internet reliability are simultaneously specific to and greater than the web. As a concluding reflection, this thesis highlights the importance of continued, longitudinal research into how the internet as a medium and place can be configured in the medical information landscape.



## ■ NEDERLANDSE SAMENVATTING

Wat houdt 'betrouwbaar zijn' in voor web-gebaseerde medische informatie? Deze vraag vormt de kern van dit proefschrift. Daarnaast worden zowel methodologische vragen, zoals het bestuderen van het gebruik van de patiënt van het web in context, als de theoretische vraagstukken over hoe verschillende opvattingen over zowel betrouwbaarheid als internet-gebruikers ingebed zijn in de beschikbare web-gebaseerde tools om gezondheidsgerelateerde informatie te vinden. Deze vraagstukken worden grotendeels beschouwd vanuit de context van politieke theoriën en wetenschap- en technologie-studies, maar putten ook uit inzichten van nieuwe mediastudies en het groeiende veld van consumentgerichte gezondheidsinformatica.

Hoofdstuk één beschouwt enerzijds hoe de huidige medische literatuur omgaat met informatiebronnen en anderzijds de resulterende praktische toepassingen en ontwikkelingen, die ontstaan zijn met betrekking tot betrouwbaarheid. Het hoofdstuk benadrukt het niet nieuw zijn van de discussies over het web door deze in relatie te plaatsen met andere media zoals het boek. Dit hoofdstuk laat zien dat de veelgestelde vraag 'hoe kan het internet meer als een boek worden gemaakt?' misplaatst is. Geen enkel medium is als gevolg van zijn aard per sé betrouwbaar en problemen met betrouwbaarheid komen bij iedere nieuwe medium aan de orde. Zo is bijvoorbeeld de neiging om boeken en tijdschriften als betrouwbaar te categoriseren als gevolg van de extensieve review-processen, die ze ondergaan, niet absoluut. Zelfs nadat een medium min of meer "black-boxed" wordt, moet zijn betrouwbaarheid continu geborgd worden. Er zijn altijd groepen die initiatieven ontwikkelen met het oogmerk een "officieel" keurmerk neer te zetten. Elke initiatief draagt specifieke ideeën met zich mee, niet alleen over de producenten en de productie van (betrouwbare) informatie, maar ook over gebruikers en het gebruik van technologie en over de soms vervagende grenzen tussen productie en gebruik.

Hoofdstuk twee identificeert drie verschillende betrouwbaarheden, die op dit moment gelijktijdig aanwezig zijn op het web. Door dit te doen wordt het idee van "universele betrouwbaarheid" onder vuur genomen en laat het hoofdstuk daarentegen de gelocaliseerde betekenissen zien, die gegeven worden aan het woord 'betrouwbaarheid' met het ontstaan van verschillende soorten van initiatieven. De ontstane verschillen blijken niet alleen uit de interpretatie van het woord 'betrouwbaarheid' (zoals over inhoud, procedureel of organisatiegebonden), maar ook over hoe initiatieven, die claims op betrouwbaarheid van informatie hebben, werken om de fysieke ruimte van het web te creëren, af te bakenen en te utiliseren. Dit hoofdstuk laat ook zien hoe de 'politiek' van het web (bijvoorbeeld gezien langs nationale of professionele lijnen) terug te vinden is in meerdere soorten ruimtes en geografieën. Tenslotte betoogt dit hoofdstuk dat de genoemde ver-

schillen belangrijke onderdelen van het web zijn, vooral wanneer men de verscheidenheid van de web eindgebruikers betracht.

Hoofdstuk drie onderzoekt het gebruik van richtlijnen door twee verschillende organisaties tijdens het nakijken van informatie en sites om te komen tot een begrip over hoe de eisen voor 'information review' en 'review practices' elkaar wederzijds vormen. Dit hoofdstuk laat zien dat richtlijnen alleen niet genoeg zijn om zeker te stellen dat informatie als betrouwbaar gelabeld kan worden. Het "werk" richtlijnen toe te passen op information en websites is afhankelijk van het gebruik van zogenoemde discretionaire ruimte – een ruimte die gebaseerd is op bestaande onderscheidingen zoals die gemaakt tussen soorten medische informatie of met betrekking op gedrukte media. Dit werk en de bijbehorende overwegingen worden echter onzichtbaar in het proces van websites als betrouwbaar naar het publiek presenteren. Op deze wijze laat dit hoofdstuk ook zien waarom het erg moeilijk is de discussie aan te gaan over "transparantie" als een noodzakelijke voorwaarde om de betrouwbaarheid van informatie te garanderen, ook omdat de werkwijzen van certificerende organisaties nooit geheel "transparant" zijn.

Hoofdstuk vier verlegt de focus van het werk achter de schermen naar de presentatie van de organisatie naar haar publiek. Dit hoofdstuk richt zich op de politieke boodschappen die vanuit het initiatief naar buiten komen en laat zien dat "user education" verder gaat dan voorschriften over hoe informatie te controleren is en ook gedrag aan burgers voorschrijft. Door terug te blikken naar verschillende benaderingen van betrouwbaarheid, wordt duidelijk dat het oorspronkelijke idee van het samenbrengen van alle initiatieven onder één universele betrouwbaarheid vervangen wordt door het idee alle initiatieven samen te brengen onder een samenhangend geheel van elementen van alle actoren – patiënten, professionals en desbetreffende organisaties. Binnen deze kaders wordt betrouwbaarheid alweer gherdefinieerd, niet als eigendom van informatie of van de website, maar als diverse activiteiten waarin de diverse actoren moeten ageren. Deze samenhang van activiteiten wordt groter dan het web zelf en behelzen verschillende gemeenschappen en sociale gedragingen.

Hoofdstuk vijf geeft een meer praktijkgerichte beschouwing van het zoekgedrag van de gemiddelde internetgebruiker door te rapporteren over een etnografische studie naar webgebruik van nederlandse patiënten, die medische informatie vergaren. Dit hoofdstuk stelt dat het noodzakelijk is om te begrijpen *hoe* de door de patiënt zelfontwikkelde strategieën voor het opzoeken van informatie een bijdrage leveren aan hoe betrouwbaarheid van die informatie beoordeeld wordt. De resultaten van de studie laten zien dat de individuele patiënten, hoewel ze soms moeite hebben met het vinden van de juiste informatie, toch onderscheid maken tussen goede en slechte websites en informatie opmerken, die



niet klopt of gedateerd is. Zij maken deze beoordelingen op basis van hun eigen logica en redeneringen (welke zich verder ontwikkelen naar mate de patiënt meer zoekervaring opdoet). Portalen, afvinklijsten en keurmerken werken alleen indien ze overeenkomen met de bestaande zoekstrategieën en ervaringen van de web gebruikers.

Het laatste hoofdstuk van dit proefschrift brengt wederom de vraag naar voren uit wie een categorie gebruikers bestaat. Hierdoor wordt niet alleen op de grotere lijnen van de discussie gereflecteerd maar ook op hoe dit proefschrift het onderwerp betrouwbaarheid van webinformatie benadert. In dit hoofdstuk wordt beweerd dat discussies over "transparantie", en ook de discussies over het wel of niet "klikken" op een internetkeurmerk door eindgebruikers van het web, zich niet op de juiste gebruikersgroep richten. De beslissing om een hyperlink toe te voegen aan bestaande keurmerken, om daardoor de integriteit van de plaatsing van deze keurmerken op sites te waarborgen, resulteerde tevens in het verschuiven van het beoogde doel van het keurmerk. In plaats van het fysiek representeren van de band van de site provider met ethische principes werden de keurmerken nu een controle voor web eindgebruikers, waardoor de taak informatie te controleren verschoof van de site provider naar de niet-professionele web eindgebruikers. Door opnieuw naar het reviewproces te kijken wordt duidelijk dat site providers de primaire gebruikers zijn van keurmerken, alhoewel hun positie en relevantie als actoren overschaduwde (of helemaal genegeerd) worden in de meeste wetenschappelijke literatuur over dit onderwerp. Verder onderzoek naar hoe deze keurmerken exact door site providers worden gebruikt, is dan ook noodzakelijk.

De hoofdstukken van dit proefschrift herdefiniëren aldus de begrippen betrouwbaarheid, werk, en gebruikers. In dit herdefiniëringsproces zien we hoe historische en locale componenten worden meegenomen in deze termen, zoals 'betrouwbaarheid', waarvan verondersteld wordt dat ze universeel begrepen worden. We zien verder hoe zulke termen worden gebruikt als retorische mechanismen die zowel de gezondheidsgerelateerde als niet-gezondheidsgerelateerde gedragingen van de verschillende types van actoren proberen te beïnvloeden. Tot slot zien we hoe de factoren die onze eigen begrippen van internetbetrouwbaarheid mogelijk maken tegelijkertijd én specifiek voor én groter dan het web zijn. Als concluderende reflectie pleit dit proefschrift voor langdurige, doorgaande onderzoek naar hoe het internet als medium én plek in het medisch informatie landschap wordt geïntegreerd.



## ■ EXPRESSIONS OF APPRECIATION

Words can never do it justice – the whole experience of “living abroad” while completing one’s PhD research. And yet, here I am, faced with the challenge of finding the words that will appropriately conclude an endeavor that, even after six years and many concrete learning moments, still seems so surreal. After having drafted this piece of writing so many times, I’ve decided not to try to provide words where there are none that suffice. I direct my focus, instead, toward a much easier task – one for which the appropriate words are readily available. In these last few pages, I can finally take the opportunity to thank those who have contributed so much to ensuring that this endeavor was a success. Although I would be hard pressed to name every individual that contributed to my work and the entire PhD experience, there are many who are worthy of mention and so, here goes:

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Antoinette de Bont was my “co-promotor” and, having just finished her own PhD just before I began this project, was the closest of anyone in relating to the tumult of “promotieonderzoek”. I could count on her in a pinch – especially when faced with the challenge of taming my verbosity. It was special to work with you in various contexts, Antoinette, and I have learned a lot about myself through working so closely with you.

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*"I went to the doctor; I went to the mountains. I looked to the children; I drank from the fountains. There's more than one answer to these questions, pointing me in a crooked line. The less I seek my source for some definitive, the closer I am to fine."*

(The Indigo Girls)

Samantha Adams  
Eindhoven, the Netherlands 2006



Samantha Adams was born in 1976 in Winston-Salem, NC, USA. She is a 1994 graduate of Trinity High School in Trinity, NC, USA and a 1998 graduate of Duke University in Durham, NC, USA, where she attained a BA in Political Science (with a concentration on international security and diplomacy) and a certificate in Women's Studies. Additionally, she was awarded the Alona E. Evans Scholarship for Outstanding work in International Law for her senior thesis in Political Science. In 1999, she received her MA from the European Program in Science and Technology Studies (ESST – University of Maastricht, The Netherlands and Oslo University, Norway). She began in 2000 as a PhD student in the Department of Health Policy and Management at the Erasmus University of Rotterdam, the Netherlands. From 2003, her research project was funded by the Netherlands Organization for Scientific Research under the auspices of the Society and Electronic Superhighway (MES) program. In addition to her research activities, she also taught an undergraduate course in qualitative research methods and currently serves as the coordinator for this course.