The nature of the Net: constructing reliability of health information on the Web

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Keywords Internet, Personal health, Books

Abstract This article juxtaposes the history of the book to the current discussions about lay health information on the Internet in order to thoroughly open up the notion of “reliability” that underlies these discussions. It uses the parallels between the two media to improve understanding of what actors are involved and what issues are at stake, as well as how this is consequential for the reliability that is constructed.

Introduction

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 (Johns, 1998).

The World Wide Web, now approaching its second lustrum as a public medium, has seen so many fluctuations that a four year existence has been said to indicate the seniority of a Web site (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, as 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 and Diepgen, 1998; Gottlieb, 2000; Kiley, 2000.). In 1995, individuals, governments, professional groups and non-profit organizations in both Europe and the USA began calling for action to ensure the reliability of information on the Internet. 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 and 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 “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 absence of elements that are 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”[1].

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’s (1998) 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, p. 211), 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”.

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” (Johns, 1998, 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 sixteenth 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 to the current discussions on the reliability of lay health information on the Internet[2]. Our purpose in doing so is to thoroughly 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 is now constructed and seen as so crucial. Importantly, we do not suggest strong parallels in the developmental trajectories that the book and now the Internet take. Nor do we suggest that the history of the book has any predictive value for the future developments around the Net. 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, then, not so much to show that reliability is constructed. That would not be a very surprising message for the readership of this journal. 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 thing 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 communication – 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’s 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[3], before calling this idea into question by revisiting history. He traces a history that begins in the late sixteenth/early-seventeenth centuries, in various parts of
Europe[4]. 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” (Johns, 1998, p. 14)[5]. We must keep in mind that publication at that time was different than we currently understand it – and even then, it was also changing (Westman, 1980).

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[6]. Levinson (see footnote 2) argues that both the church and the state had their own ideologies of what should be printed – based, actually, 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 (Catholic) 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 completely prohibit books, or to control revision of certain material before they were returned to circulation (Goodman and Russell, 1991).

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, 2001, 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). Printers further used this point to argue that it was the press that actually enabled preservation. However, Johns 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[7] and the 1830s” (Johns, 1998, p. 91).
Searching for new solutions

In England, Francis Bacon expressed his opinion that the press was “a device discovered by chance and by disorganized artisans” (Johns, 1998, p. 50). Also, he felt, it encouraged dangerous ambitions. He was displeased by the devolution of content control to actors “independent of the state’s bureaucracy” (Johns, 1998, p. 50). That is, “… he certainly did not recommend unrestricted publication of knowledge, urging rather its retention within a tiny community of royal licentiates” (Johns, 1998, pp. 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 openly profess knowledge. Therefore, Bacon advocated the implementation by the state of an administrative mechanism that would best serve to advance the interests of the crown (and its 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, 1998, 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 attacking the content of a criticism, characteristics of the criticizing author were called into question. Especially in cases where criticism was offered anonymously, the lack of 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, 1998, 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’” (Johns, 1998, p. 263). A license was interpreted as a badge of distinction or “a public demarcation of knowledge from error” (Johns, 1998, 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 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” (Levinson, 2001, p. 112)

In later years, 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 (Johns, 1998, 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 . . .” (Johns, 1998, p. 49). 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, 1998, 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 some detail 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 (Pluscaskas, 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[8].

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 Web sites. Or, at least he or she should be questioning the available information, according to certain health professionals (Eysenbach, 2000).

A communication from the Commission of the European Communities (2002) categorizes the existing international reliability initiatives into five 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 gatekeeping 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[9]. A range of different types of authors, primarily from the USA and Europe, were placing various types and levels of information on the pages of their Web sites. 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 Web sites of the time, which possibly came not
from medical professionals, but rather from big businesses (Keating, 1997)[10]. Increasing scrutiny of medical Web sites 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 USA, the statement was made within government[11] 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. Randale Sechrest, addressing doctors about e-Health in 2000 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 so-called 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 Web sites by unknown sources was a problem that was quickly growing beyond any or all control.

Codes and seals
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 USA, 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.

In the immediate aftermath of 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)[12]. 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 Web site. Users could click on this...
Criticisms that were levied against HON and similar organizations contributing to what Risk and 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 inconsequent (Rigby and Forsstrom, 2000; Wilson, 2002; Meric, 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 and Jadad, 2002; Stanberry, 2002).

In March of 2000, Gunther Eysenbach published an opinion piece on the home page of his own Journal of Medical Internet Research (Eysenbach, 2000). Eysenbach 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 was funded by the EU under the “Action plan on promoting safer use of the Internet by combating illegal and harmful content on global networks”[14]. 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 (2000) 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[15], peer-review, give quality seals to ...) online published health information using labels consisting of a standard computer-readable vocabulary (meta-information). Eysenbach (2000) 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[16]) to place on Spanish-language Web sites. Another example is in the Netherlands, where the Ministry of Health established a national health information portal (www.gezondheidskiosk.nl) and TNO (a Dutch Research and Development organization) created a recognizable trust mark (QMIC) for Dutch-language Web sites.
**Portals and domains**

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, 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 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 this new creation 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 Web sites. 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 Web site since 1997) but also that many lay persons were searching the Web site 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 was, 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 *et al.*, 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 Internet that crossed country borders[17].

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 Internet for sites with information regarding managing 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 and Diepgen, 1998; Mitchell, 1999; Eysenbach et al., 1999; Ostrom, 1999; Mandl et al., 1998). However, the issue became one of more than just monitoring – how to enforce any initiative across state borders remains an unanswered question.

Risk and Dzenowagis (2001) contributed to the discussion by suggesting 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 uncontrollable 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 Internet initiatives discussed here are often referred to as “gatekeeping”. 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 (2001, p. 125) identifies one characteristic common to all: “The logic of gatekeeping, 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 USA 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”. 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 gatekeeping function for Internet publications, we actually see that, just as it was voiced with the book, the same gatekeeping 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 gatekeeping 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 an Internet 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 of 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 licensor’s stamp. In the case of Internet 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 Web site (see, for example, Brown and Duguid, 2000; Sechrest, 2000; Introna and Nissenbaum, 2000).

Establishing one’s role as “licenser”, then, is difficult work. Every project is centered on the building of 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[18]. 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 Web site, 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[19]. “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 licenser will prevail. There are several, related
differentiations here that are of interest[20].

First of all, much like in Johns’s 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[20].

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[21].

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 claiming itself 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[22]. 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 USA, it would be unthinkable that a Swiss organization would perform such an important “gatekeeper” 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 it relevance to a population whose Internet-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 USA, 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 USA. There are many Spanish Web sites – 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 footnote 17) assumed a double task of converting existing resources into a Web site 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 some common example, would abhor most Dutch physicians[23]. 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 client 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 gatekeeping 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 Web sites), 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 gatekeeping 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
2. 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 respective introduction of a specific technology into society (and consequently, into medical care) and, in so doing, refer 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. 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 of e-mail for communication between doctors and patients. Rigby et al. (2001) compare use of healthcare related software, telemedicine and Web sites 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 concerns voiced in 1963 about the marketing of products that were neither properly tested, nor independently controlled for safety and efficacy, as well as about the lack of protection for the public in this regard.
3. 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’s standpoint or the theories of Latour and Akrich? How would we feel about utilizing these works if they were pulled from the Internet? 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?

4. We acknowledge 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 (1983, p. 9) 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”.

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

6. 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 to handle the two in conjunction with one another.

7. The first version was published in 1611.

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

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

10. 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 (www.drkoop.com).

11. C. Baur, personal communication.

12. In the course of the next five years, other groups 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 Web sites 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 (IHC, n.d.). Other examples include the Health Summit Working Group (HSWG) from Miritek systems, which published seven major criteria for assessing information quality (HSWG, 1998), and Hiethics, 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 in 2000.
13. For extensive explanation of the HON Code and hyperlink set-up, see: www.hon.ch/HONcode/audience.html.

14. 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: www.medcertain.org or www.medcircle.org).

15. Guidelines for evaluating as were listed on the MedCERTAIN site are taken from the Washington Code of eHealth Ethics. See footnote 12.

16. www.accessible.org/wmc/wmc-1.htm

17. Concerns about illegitimate medical claims were not new. In the USA, 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 Web site under the name Quackwatch (www.quackwatch.org), seeking to improve the quality of health information on the Internet and to attack misleading advertising on Web sites. Among target sites were chiropractic, nutritional, dental and homeopathy sites.


19. For a discussion of such “reliability” work see, for example, Timmermans and Berg (1997) and Bowker and Starr (1999).

20. See Adams and de Bont (2003) for a discussion about different constructions of reliability in three of the initiatives discussed in this paper.

21. For more on this, see other works in STS. For example, Steve Shapin (1995, p. 257), 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”. See also Latour (1987), Shapin and Schaffer (1985) and Berg et al. (2000).

22. C. Boyer, personal communication.

23. See Payer (1989) for a rich discussion on the manifold cultural differences that inhabit biomedicine between countries. See also Berg and Mol (1998).

References


