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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ABSTRACT

Hyperlinked web trust marks have been a popular topic of discussion during the past 10 years. However, the discussion has focused mostly on what these trust marks are not doing in terms of helping patients (or other lay end users) find reliable medical information on the web. In this paper, we discuss how this focus on patients and their actions with respect to trust marks, has overshadowed, if not rendered invisible, what trust marks are doing to educate medical site/information providers. We draw on data from ethnographic research conducted at the Health on the Net Foundation in 2002 and 2003 in order to explore an alternate definition of what it means to be a 'user' of a trust mark and the importance of the review process in educating site providers. We argue that understanding the work involved in the process of assigning a seal is crucial to understanding the role that the seal plays as part of the medical internet.

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1. Introduction

Health care "trust marks" are hyperlinked 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 [1–3] and even practically applied by researchers trying to evaluate the quality of medical websites [4,5]. The conclusions of these studies have opened up the discussion about the relationship between guidelines, trust marks and content-based reliability [4–7].

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 [7]. 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 [8–11]. Third, offline tools are not sufficiently transferable and applicable to the web, as it is easier to copy seals and use them without permission [12–14]. 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 [13–15].

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 [9,16–20].

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 [17], 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 [21].

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 [1] 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. [22] 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) [23]; 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” [24]. 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 [25] or the QMIC seal issued by TNO in the Netherlands [26]) 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” [27]. The language of the information pamphlet 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)” [27].

Trust marks originally were static, not hyperlinked. (see Eysenbach et al. [28] 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 they are made into users and analyze this process from an ethnomethodological perspective.

2. Methods

We use as a case study the Health on the Net Foundation’s Code of Conduct and seal (the HONcode) [29], which is the oldest and best-known code of conduct [23]. 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.

Box 1
Reviewer 3: 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).

3. 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).

3.1. 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 in Textbox 1 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.

3.2. 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 [19,20,30], 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
Box 2

- Reviewer 2: 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.
- Researcher: It is sort of mixed in
- Reviewer 2: Yeah, just mixed in with everything else.
- Researcher: It only has this box around it.
- Reviewer 2: It clearly seems like advertising, because it goes to an outside site and it says, “Supplements for You”.
- Researcher: Is it properly marked?
- Reviewer 2: No, it is not, because I have … it needs to say here, advertisement. Plus, he needs to include an advertising policy (site three).

notable with respect to blending advertising with other forms of content [31]. 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.

Textbox 2 shows an example of a site provider who has mixed several types of information, including advertising. It is unclear if the different colors used in the layout 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 [32] for results from HON 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 also 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.

3.3. 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 that 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 con-
duct and their trust marks, despite the knowledge that their own site visitors might not.

4. 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 represent-ative 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 on- and off-line), 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 [21]. 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 user, preventing him or her from acquiring the information needed to make choices.

Eysenbach [13] and Burkell [8] 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, etc. 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 hyperlink seal. This process is of 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 hyperlink 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 [33–34] 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 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. Anecdot al 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.

5. 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 hyperlinked 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 also 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.

Acknowledgments

The ethnographic research conducted at HON is part of a larger research project about reliable health/medical information on the web that is funded by the Dutch NWO-MES program, dossier number 014-43-749. We gratefully acknowledge the willingness of Celia Boyer and the HON team in allowing research into their work practices. We also thank Roland Bal for his critical comments on various drafts of this paper.

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