User Centred Networked Health Care
A. Moen et al. (Eds.)
IOS Press, 2011

doi:10.3233/978-1-60750-806-9-53

Evolution of Health Web certification through the HONcode experience

Célia BOYER[a], Vincent BAUJARD[a], Antoine GEISSBUHLER[a,b]
[a] *Health On the Net Foundation*
[b] *Service Cyber Santé et Télémédecine, Hôpitaux Universitaires de Genève*
Geneva Switzerland

Abstract. Today, the Web is a media with increasing pervasiveness around the world. Its use is constantly growing and the medical field is no exception. With this large amount of information, the problem is no longer about finding information but assessing the credibility of the publishers as well as the relevance and accuracy of the documents retrieved from the web. This problem is particularly relevant in the medical area which has a direct impact on the well-being of citizens and in the Web 2.0 context where information publishing is easier than ever. To address the quality of the medical Internet, the HONcode certification proposed by the Health On the Net Foundation (HON) is certainly the most successful initiative. The aims of this paper are to present certification activity through the HONcode experience and to show that certification is more complex than a simple code of conduct. Therefore, we first present the HONcode, its application and its current evolutions. Following that, we give some quantitative results and describe how the final user can access the certified information.

Keywords. HONcode certification, Trustworthiness, Transparency, Health Web, Internet

1. Introduction

In recent years the ease of publishing on the Internet has been further increased with the advent of the Web 2.0 phenomenon. Thus, despite the wealth of content available, the question is not just about finding information but also whether the information provided is credible. The problem is particularly acute in the medical information domain which has a direct impact on the health of public [1]. In response to the lack of transparency of the health information, many theoretical and practical initiatives have marked the short history of the Web. The most significant trends that have been applied to the Web on the quality of information (medical or not) are: the selection of webpages (e.g. Yahoo), self-regulation (e.g. Discern[2]), the popularity of webpages (e.g. Page Rank[3]), the certification of websites (e.g. URAC[4], HONcode[5]), education of the user (e.g. OMNI[6]) and the collaboration of users.

2. Material and Methods

Initiated in 1995, the implementation of the HONcode (see Table 1) [7] (third party certification) began in 1996, Discern (self-evaluation) in 1998, WebMedica in 1998 (certification only for Spanish), Hi-Ethics (third party certification) in 2000, eHealth Code of Ethics (self-evaluation) in 2001, URAC in 2001 (very detailed but expensive), European Guidelines in 2002 (Eq. HONcode principles of the HON which participated in the development) and AFGIS in 2003 (dedicated to German sites). While some initiatives have disappeared or others do not have many candidates, the HONcode has been translated into 35 languages, had over 7400 sites certified by the end of 2010 in 102 countries and had been selected in 2007 by France to be the official certification body of French health websites. HONcode certification [7] is a voluntary act on the part of the site applicant; the first step is submitting the application form on the HON website. A pre-assessment is proposed to the webmaster to identify the missing principles. Once the certification request is submitted, HON experts evaluate the website. Each ethical principle which is not being complied by and should be added to the content of the webpages is indicated. Once the changes have been made, a unique seal of certification is issued. All HONcode sites are certified for 1 year and are reviewed annually. If a website no longer respects the HONcode, the webmaster receives a warning and if required changes are not made, the site may lose its certification. In addition if a user considers that a web site does not respect one or more of the HONcode principles while displaying the HONcode seal, he/she can report the violation using the complaint system accessible via the HONcode certificate linked to this website. The complaint is treated within 2 weeks by members of the HONcode team. If it is justified, the webmaster of the site is asked to bring modifications. As you can see, the certification process is interactive and provides a constructive contact between HON and the webmaster. Indeed, the aim is to bring up sites to a certain level of transparency. In keeping with this aim, some additions have been made to address the peculiarities of Web 2.0 [7]. The collaborative platform in addition to the current guidelines should respect as well the ones added specific to the Web 2.0. In view of the dynamics of the Web, the certification is in continuous expansion. Initiatives based on algorithms of criteria recognition, based on rules or by automatic learning were presented to give an indication of ethics to the health Web pages. While the model of supervised learning Aphinyanaphongs [8] is based on static examples of good and bad pages and therefore dependent on fields, the HON approach is more generic since it is based on the model of the HONcode [9]. This last approach offer good results with 78% of accuracy over all principles, and its integration in HON daily activity is in progress. The text retrieval was also used in creation of WRAPIN [10], a tool helping to determine the reliability of documents by checking the ideas contained against established benchmarks, and eventually enabling users to determine the relevance of a given document from a page of search results.

Currently the visual information retrieval is being developed what is especially important for the doctors working with the images as radiologists. The retrieval of images can be done in two ways. The first one is done via simple text-based queries associated to an image. The second one is performed via requests based on matching exact database fields. The development and use of the second one for medical field is the subject of further research.

One of running researches in the field is the 4-year EU project “KHRESMOI” [11] started in September of 2010, which aims to create a biomedical search engine targeted

to the needs of lay populations, medical doctors and specifically radiologists. The KHRESMOI will archive effective automated extraction from biomedical documents, including improvements using crowd sourcing and active learning, and automated estimation of the level of trust and target user literacy, automated analysis and indexing for medical images in 2D, 3D and 4D, link unstructured and semi-structured information extracted from texts and images to structured information in knowledge databases, support cross-language search and create the adaptive user interface to assist in formulating the queries. The sources of information retrieval are: books, journals, web sites, images, and semantic data. It will also utilize the language resources to allow the translation and make the results available for a whole EU population. The expected impact on target users is fast availability of required trustworthy information.

Figure 1. Dynamic HONcode logo following the current status of the HONcode certification process

Table 1 Presentation of the HONcode Principle (summarized)

1. Authoritative: indicate the qualifications of the authors
2. Complementarity: information should support, not replace, the doctor-patient relationship, the mission and the audience are explicated.
3. Privacy: Respect the privacy and confidentiality of personal data submitted to the site by the visitor
4. Attribution: Cite the source(s) of published information, date and medical and health pages
5. Justifiability: Site must back up claims relating to benefits and performance
6. Transparency: Accessible presentation, accurate email contact
7. Financial disclosure: Identify funding sources
8. Advertising policy: Clearly distinguish advertising from editorial content

3. Results of the Certification and Access to the Final User

Currently the database represents more than 10 million pages indexed in Google. 52% of the certified sites are in English and about 11% in French, followed by sites in Spanish, Italian, German and Portuguese. For each evaluated site, the following information is collected: 1/ the HONcode principles respected, 2/ text extracted corresponding to the 8 principles, 3/ URLs of these text extracts, 4/ MeSH terms keyword [12] selected from the site and 5 / more general site label. In early 1996, a simple seal was introduced, allowing users to identify a certified site from a non-certified. However, the HONcode seal quickly became an additional safeguard for the Internet by requiring the sites to link the seal to the unique HONcode certificate on the HON site. The idea is to limit misuse of the HONcode seal, as the final verification is done on the HON site. The new basic principle is that custody by HON ultimately enables control of the display of the HONcode seal depending on the status of web site certification (the unique image generated for a given site is hosted at HON web site, Figure 1). Google is the search engine most used by the Internet; it can become the perfect tool for the promotion and awareness of the quality of medical information on the Internet when a user installs the HON Toolbar. HON Toolbar [13] is the most

integrated way to access HONcode certified sites. It is composed of 3 features that are 1/ Identification of the HONcode membership in real time while browsing the Web. 2/ The search tool, HONcodeHunt, exclusively dedicated to certified HONcode sites accessible from the search bar of the browser. 3/ The emphasis of certified sites in popular search tools such as Google, Yahoo, MedlinePlus and Wikipedia.
13 years after the HONcode implementation, HON has looked for a way to evaluate the impact of the certification. To measure this impact a comparative and longitudinal study has been conducted in 2008 in collaboration with the French National Health Authority (HAS). The first study mentioned compared the compliance of 6 to 8 months certified websites (A) with the HONcode to the compliance of non certified French health websites that never asked for a certification and were taken as a Control sample (B).
The second one compared the compliance to the eight HONcode principles of health websites before (T0) and 6-8 months after the certification (A). A second analysis was made to observe the website conformity to HONcode Principles 1, 4, 5 and 8 (see Table 1).
Certified websites were ordered by their publisher's type, to allow the building of a comparable sample of Control websites. The use of various sources allowed the decrease of distortions in the studies of non certified Control websites.
0.6% of health websites not asking for HONcode certification (control group B) does respect the eight HONcode ethical standards vs. 89% of certified websites (A). Regarding the principles 1, 4, 5 and 8, 1.2% of B respect these principles vs. 92% for A.

4. Conclusion and Perspectives

We aim to show the many facets of the HONcode through its history, its evolution, implementation and use. During the past 15 years, HON has sought to promote the trustworthy medical information on the Web on a global scale. To meet the quantitative requirements of the Web, human expertise is assisted by many automated systems for a systematic, reliable and faster evaluation of websites. It is very important to expand distribution channels to reach as many potential users. Thus the realization of collaborations, to share our information, our philosophy and our vision, with major players such as the National Library of Medicine (USA) or Google is essential. The approach led by the HON is comprehensive and covers more than 35 languages around the world. At the same time, HON aims responding to local needs, the variety of languages, cultural differences and different regulations. The creation of local branches in different parts of the world, such as those initiated in Africa, Italy and Spain, should enable us to think locally and act globally to improve the quality of medical information on the Internet. France is the pioneer in quality eHealth by legislating on the issue of quality of health sites. A similar approach in other European countries will be welcomed to continue promoting the quality of medical information on the Internet for the benefit of Internet users.

References

[1] Fox, S. (2007) E-patients with a Disability or Chronic Disease. Pew Internet & American Life Project, 2007.

[2] Charnock, D. The DISCERN Handbook. 1998. Radcliffe Medical Press.
[3] Borges, .H. M. Cervi, P.T. ´Alvarez de Arcaya, G. Guardado, R. Rabaza, J. Sosa, Rate of compliance with the HON code of conduct versus number of inbound links as quality markers of pediatric web sites, in: Proceedings of the Sixth World Congress on the Internet in Medicine, Udine, Italy, 29 November—2 December 2001.
[4] URAC: http://www.urac.org/MMandQualityChasm.asp, Nov 2008.
[5] Boyer, C. Baujard V. and Scherrer, J.R. HONcode: a standard to improve the quality of medical/health information on the internet and HON's 5th survey on the use of internet for medical and health purposes. In 6th Internet World Congress for Biomedical Sciences (INABIS 2000), 1999.
[6] OMNI: omni.ac.uk, Dec 2008.
[7] HONcode Guidelines: http://www.hon.ch/HONcode/Guidelines/guidelines.html, May 2010.
[8] Aphinyanaphongs, Y. Aliferis, C. Text categorization models for identifying unproven cancer treatments on the web. Stud Health Technol Inform, 2007.
[9] Gaudinat, A. Grabar, N. Boyer, C. Automatic retrieval of web pages with standards of ethics and trustworthiness within a medical portal: What a name page tells us - 11th Conference on Artificial Intelligence in Medicine (AIME 07) - 07-11 July 2007 Amsterdam, The Netherlands.
[10] Joubert, M. Gaudinat, A. Boyer, C. Geissbuhler, A.. Fieschi, M. HON Foundation Council Members. WRAPIN : a Tool for Patient Empowerment within EHR. Stud Health Technol Inform. 2007;129:147-51.
[11] Hanbury, A. Boyer, C. Gschwandtner, M. Müller, H. KHRESMOI: towards a multi-lingual search and access system for biomedical information, Medetel 2011
[12] National Library of Medicine, Bethesda, Maryland. Medical Subject Headings, 2001. http://www.nlm.nih.gov/mesh/meshhome.html.
[13] HON Toolbar: http://www.hon.ch/HONcode/Plugin/Plugins.html