

The Health On the Net Code of Conduct for medical and health Web sites

Celia Boyer^b, Mark Selby^b, Ron D. Appel^{a,b}

^aMolecular Imaging and Bioinformatics Laboratory, Geneva Hospital, Switzerland

^bHealth On the Net Foundation, Geneva University Hospital, Switzerland

Abstract

The growth in the number of medical and health web sites and the varying quality of medical and health information currently available on the World-Wide Web has created the need for guidelines to help homogenise this quality. Health On the Net Foundation (HON) has initiated the Code of Conduct (HONcode) in response to concerns expressed to the Foundation, by members of the Net community. This article presents the HONcode's principles since its launch in 1996 and its status in 1997. This initiative offers information providers good practice guidelines and offers users an indication of commitment to quality by those providers.

Keywords

Internet ethics; Internet information policy; Medical web site management; Quality standards; Medical search; Education

Introduction

The World-Wide Web and on-line services offer enormous potential benefits to the medical and health communities. Specific beneficiaries include patients and medical/health professionals. To realise the anticipated benefits will require continual experimentation and analysis of results. The quality of medical and health information currently available on the World-Wide Web (WWW or Web) is varying. In view of the rapid proliferation of new medical and health web sites, it is not easy for a user to identify sites offering useful information or advice. A core requirement of users is the quality of information made available on the Web and on-line services. The Code of Conduct for medical/health web sites (HONcode) [1] is an initiative to help unify the quality of medical and health information available on the WWW.

The first published version of the Code of Conduct, version 1.5 [2], was issued by the Health On the Net Foundation (HON) [3] after extensive consultation with medical/health webmasters around the world in 1996 to help address this core requirement. It was decided that the HONcode would be of self-governance through a widely agreed set of principles. It should also provide a timely, effective solution to improve the quality and practice of medical/health information and advice on the Net.

By displaying the HONcode logo [4] on a web site, the owners of the site are demonstrating a desire to provide medical/health information, services or resources via the WWW that are of genuine value to the Net community and that meet specific quality standards. The HONcode is now considered as a de facto standard, due to its world-wide use.

The number of medical/health world-wide sites and new internet users are still growing exponentially. Therefore, the core requirement is still the assessment, improvement and the assurance of the quality of information made available on the Web and other on-line services [5]. To meet the users and the health and medical sites' webmasters' requirements, a new version of the Code of Conduct, version 1.6 was proposed [1].

In the following paragraphs, we first detail the methods of evaluation and the principles of the HONcode version 1.5. Then, we describe the HONcode's status in 1997 and finally, we present the world-wide use of this initiative and its impact on the Net community.

Materials and methods

A distinguished group of experts in medical informatics and telemedicine [6] met to discuss the opportunities and risks associated with the Web at an international working conference in Geneva in September 1995 [7]. Organisations represented included W3C, European Community DGXIII, National Library of Medicine, World Health Organization, International Telecommunication Union, European Bioinformatics Institute, International Medical Informatics Association, CERN and the Japanese Ministry of Health and Welfare.

One of the pressing issues to emerge from the conference was the quality of information being made available on the Web. Post-conference analysis indicated further cause for concern:

- 113% compound annual growth rate of Internet users [8]
- evidence that recently diagnosed patients were seeking medical/health information and details of potential treatments [9].
- recognition that some patients were seeking information while in a state of stress/anxiety
- examples of questionable claims for unproven treatments

- examples of medical advice being offered by individuals lacking formal medical training and qualifications (in the vast majority of cases this advice was not being offered in a malicious or fraudulent manner).
- newly emerging applications and technologies providing significant information on individuals accessing Web servers.
- ignorance of these technologies by most Web server visitors.

Physicians indicated the risk of patients pursuing unproven treatments rather than following recognised treatment/procedures and thereby impacting the effectiveness of their early adoption.

The authors also recognised the risk of patients seeking information on "sensitive" medical/health topics, e.g. sexually transmitted diseases, being reluctant to do so if they could not be offered some guarantee of anonymity.

All of these observations pointed to the need for a clearly stated procedure/advisory to ensure that patients and qualified professionals could have confidence in the medical/health information they were accessing on the Net and be offered personal confidentiality and anonymity where appropriate.

The HONcode version 1.5 contains a set of principles that owners of Web servers can agree to abide by. If they so agree, they may display the HONcode logo on their Web server. This logo must be linked to the HONcode's Web page. The HONcode logo can be downloaded by webmasters for their site from the HON Web site [4] and they must advise the Health On the Net Foundation by E-mail (HONcode@hon.ch) of their participation in this initiative.

The 6 Principles of HONcode version 1.5 were as follows:

Principle 1.

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

Principle 2.

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

Principle 3.

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

Principle 4.

Where appropriate, information contained on this site will be supported by clear references to source data and, where possible, have specific HTML links to that data.

Principle 5.

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

Principle 6.

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

Health On the Net Foundation reviews sites bearing the HONcode logo on a regular basis and uses a variety of search techniques to identify Web servers using the logo that have not been registered with the HON Foundation.

In the event that a Web server is blatantly misusing the HONcode, a clear procedure exists for notifying then warning the owner of that Web server. Continued misuse will result in an advisory notice being issued to all HONcode initiative participants, the Hospital-Webmaster mailing list [10] and other appropriate channels. Legal action for trademark and copyright infringement will be initiated as a last resort.

Its status in 1997

The Principles are dynamic. After discussion and consensus between Health On the Net Foundation and the owners of Web servers bearing the HONcode logo, modifications to the Code of Conduct, version 1.5 [2] were discussed in an open manner.

On the 14th January 1997 a Request For Comments (RFC) was issued asking for feedback on the new version of the HON Code of Conduct. HON received considerable feedback from many individuals and institutions. These included a range of constructive comments, some of which, naturally, conflicted with each other. The proposed modifications were also discussed on several mailing lists, Hospital-Webmaster and MEDWEBMASTERS-L [10, 11]. After analysis and further discussions with many respondents, a new version of the Code of Conduct (version 1.6) was proposed. The main changes to the HONcode version 1.5 are as follows:

Principle 4. (addition)

The date when a clinical page was last modified will be clearly displayed (e.g. at the bottom of the page).

Principle 7. (new)

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

Principle 8. (new)

If advertising is a source of funding it will be clearly stated. A brief description of the advertising policy adopted by the web site owners will be displayed on the site. Advertising and other promotional material will be presented to viewers in a manner and context that facilitates differentiation between it and the original material created by the institution operating the site.

Results

Since the launch of this initiative in July 1996, feedback from institutions, medical/health professionals and patients has been extremely positive. Those Web servers bearing the HONcode logo offer reassurance to visitors that the information being provided and the operating principles of the Web server meet specific quality standards. The authors believe that this initiative helps address a key prerequisite in realising the potential benefits to the medical and health communities of the Web and on-line services.

Participants in the HONcode initiative are growing daily. The desire from the Net community and pharmaceutical industry to participate in this initiative demonstrates the growing need for information quality assessment procedures. More than 500 medical and health Web servers now show the HONcode logo, including:

- New York University Medical Center
<http://www.med.nyu.edu/>
- Virtual Anaesthesia Textbook
<http://gasnet.med.yale.edu/vat/>
- SwissWeb Prevention
<http://www.prevention.ch/>
- University of Bonn Medical Centre and CancerNet
<http://imsdd.meb.uni-bonn.de/cancernet/cancer-net.html>
- PharmInfoNet
<http://www.pharminfo.com/>
- Institute of Internal Medicine IV, University of Florence
<http://peggy.mt.unifi.it/Welcome.html>
- Hôpital Cardiovasculaire et Pneumologique Louis Pradel Cardiovascular and Thoracic Imaging
<http://creatis croisille.univ-lyon1.fr/>
- CRC Academic Dept. of Clinical Oncology, University of Nottingham,
<http://www.ccc.nottingham.ac.uk/~nozwww/frames.htm>
- The breast Cancer Compendium
<http://www.microweb.com/clg/>
- Virgil's Prostate Online
<http://www.prostate-online.com/>

Discussion and Conclusions

World wide owners of medical/health web sites are aware of the need to unify the quality, to ensure that accurate, unbiased, ethical health/medical information prevail on the Internet. For that purpose, VirSci Corporation organized a meeting of members of the MEWEBMASTERS-L discussion group with the participation of the Health On the net Foundation in Washington, DC on June 11, 1997 [12]. The discussion mainly pointed to the need to educate and continue providing clear guidance for med-

ical/health web site managers (HONcode).

From a legal perspective, it was apparent that:

- there was a lack of common law decisions on matters relating to medical information/practice on the Web, Internet and On-line Services
- the ability of legislative bodies to address the dynamics of this global on-line medium in a timely manner was questionable
- the Net community was displaying considerable resistance towards governmental regulation

For these reasons, it was decided that self-governance through a widely agreed set of principles could provide a timely, effective solution to the concerns outlined above, improving the quality and practice of medical/health information and advice on the Net.

The Health On the Net Code of Conduct (HONcode) was drafted with the help of physicians and respected members of the Net community in Europe and North America.

The Honcode initiative has demonstrated that precise guidelines for improving the quality of information on the Web are requested both by webmasters and users. It has also shown that simple means such as a self-governing code of conduct can serve as a first step towards a high quality medical and health Web [13]. Nevertheless, much work remains to be done and additional, more innovative methods to assess the quality of data on the Net still have to be elaborated.

Acknowledgments

Health On the Net Foundation and the authors express their thanks to the many people who provided valuable input to the HONcode principles and to all those participating in this initiative.

References

- [1] <http://www.hon.ch/Conduct.html>
- [2] http://www.hon.ch/HONcode/ConductVs1_5.html
- [3] <http://www.hon.ch>
- [4] http://www.hon.ch/Code_Gifs.html
- [5] W. M. Silberg, G. D. Lundberg, R. A. Musacchio, "Assessing, Controlling, and Assuring the Quality of Medical Information on the Internet," *Journal of the American Medical Association - JAMA*, vol. 277, no. 15, pp. 1244-1245, Apr.15, 1997.
- [6] <http://www.hon.ch/participants.html>
- [7] "The Use of Internet and World-Wide Web for Telematics in Healthcare", *Geneva - papers and reports available at* <http://www.hon.ch/cgi-bin/about>, Sept.6 - 8 1995
- [8] ITU World Telecommunication Development Report 1995.
- [9] An example is Dr. Andy Groves search for prostate cancer information - *Fortune magazine* Vol. 133, No 9.
- [10] <http://www.hon.ch/MailingList/hospital-webmaster.html>
- [11] http://www.pharminfo.com/conference/MWM_faq1.html

- [12] http://www.pharminfo.com/conference/MWM_pr2.html
- [13] M. Selby, C. Boyer, D. Jeneffsky, R. D. Appel, "The Health On the Net Code of Conduct for medical and health sites," the European Congress of the Internet in Medicine, MEDNET'96, Oct. 14-17 1996, Brighton, United Kingdom.

Address for correspondence

Célia Boyer,
Division d'informatique médicale,
Hôpital cantonal universitaire de Genève,
rue Micheli-du-Crest 24,
CH-1211 Geneva 14, Switzerland.
E-mail: Celia.boyer@hon.ch