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# CASE STUDY: ACCESS TO TRUSTWORTHY INFORMATION FOR CITIZENS AND PROFESSIONALS - THE HEALTH ON THE NET FOUNDATION[1]

## Abstract

***The Health on the Net Foundation (HON) provides high quality health information. In 1996 HON introduced the first Code of Conduct for online medical and health information providers, the HONcode, which now has more than 3,600 participating websites in 72 countries. HON's highly dedicated search engines MedHunt© and HONselect© offer all users the best-available Websites and support groups, medical images and terminology, journal articles and news. HON won the eEurope Award for "eHealth information tools and services for citizens" at the eHealth High Level Conference in Cork, May 2004.***

| ***Case characteristics*** | |
|---|---|
| • Sector focus | Health |
| • Business focus | Citizen and professional health information |
| • Geographical focus | Global |
| ***Case objectives*** | |
| • high quality online medical/health information | ✱✱✱✱ |
| • standard for trustworthy health information | ✱✱✱✱ |
| • multilingual / multicultural online information | ✱✱✱✱ |
| • highly specialised search engines | ✱✱✱✱ |

✱ = some relevance for case; ✱✱✱✱ = high relevance

## Background and objectives

Health On the Net Foundation's origins go back to a conference on "The Use of the Internet and World-Wide Web for Telematics in Healthcare", September 7-8, 1995, in Geneva, Switzerland, where the need of a quality assessment (cf. Exhibit 1) of the constantly increasing volume of online health information was repeatedly addressed. As a follow up, the Health On the Net Foundation was created later the same year by Prof. Jean-Raoul Scherrer, former director of the Geneva University Hospital; Donald

[1] This case study was conducted by empirica GmbH, Oxfordstr. 2, 53111 Bonn, Germany.

Lindberg, Director of theUS National Library of Medecine; Michel Carpentier, former director general of the European Commission DGXIII; and Mr. Guy-Olivier Second, former minister of the Geneva Ministry of Health. According to Ms. Célia Boyer, Executive Director of HON, “they foresaw that consumers, newly empowered to research their own medical conditions, can easily fall prey to misleading advice ... Over nearly ten years, HON has responded to the risks and dangers posed by online health and medical information.”

All HON services are free of commercial influence, thanks to the support of the Direction générale de la santé, Département de l'Action Sociale et de Santé (DASS - République et canton de Genève, Switzerland) and the Geneva University Hospitals. In July 2002, HON was granted consultative status to the Economic and Social Council of the United Nations (ECOSOC). This status was given because the organisation is "internationally recognised in its domain of expertise," which the United Nations considered relevant to the work of ECOSOC. Non-Governmental Organization (NGO) status gives HON a seat at ECOSOC and U.N. meetings and conferences, as well as the ability to provide input to the U.N. agenda.

***Exhibit -1: The HON logo and the HONcode as a quality seal creating trust***

Source: www.hon.ch

## Activities

### The HON Code of Conduct (HONcode)

The mission of the Health On the Net Foundation is to guide the growing online community of healthcare consumers and information providers to sound, reliable medical information and expertise. The first attempt at “truth in labelling” for online health content was the HONcode, developed in 1996, upon consensus between content providers, webmasters, medical experts and lay users.

The HONcode principles for medical and health Websites (see Exhibit 2) are as follows[2]:

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

**2. Complementarity.** 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.

**3. Confidentiality.** Confidentiality of data relating to individual patients and visitors to a medical/health website, including their identity, is respected by this website. The website owners undertake to honour or exceed the legal requirements of

2 http://www.hon.ch/HONcode/Conduct.html

medical/health information privacy that apply in the country and state where the website and mirror sites are located.

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

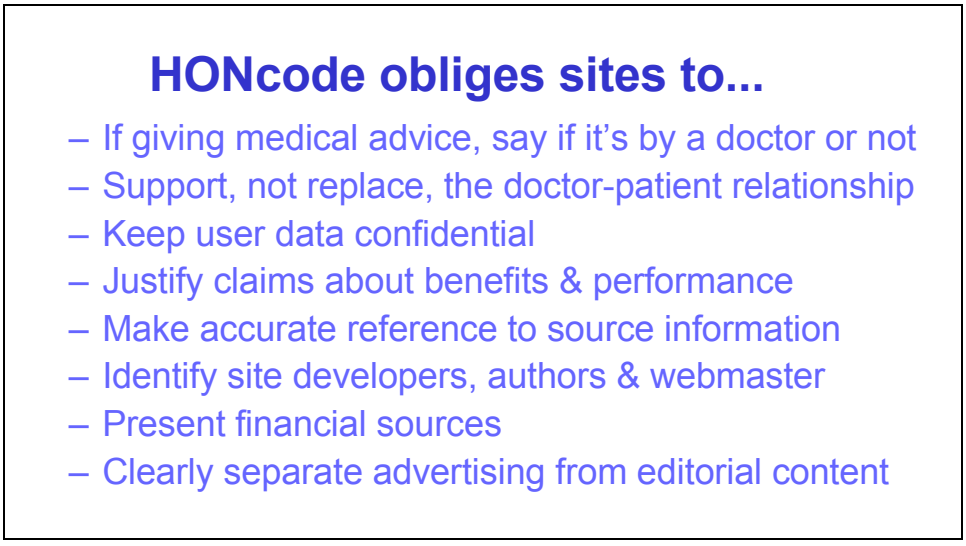
**5. Justifiability.** Any claims relating to the benefits/performance of a specific treatment, commercial product or service will be supported by appropriate, balanced evidence in the manner outlined above in Principle 4.

**6. Transparency of authorship.** The designers of this website will seek to provide information in the clearest possible manner and provide contact addresses for visitors that seek further information or support. The Webmaster will display his/her E-mail address clearly throughout the website.

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

**8. Honesty in advertising & editorial policy.** If advertising is a source of funding it will be clearly stated. A brief description of the advertising policy adopted by the website owners will be displayed on the site. 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."

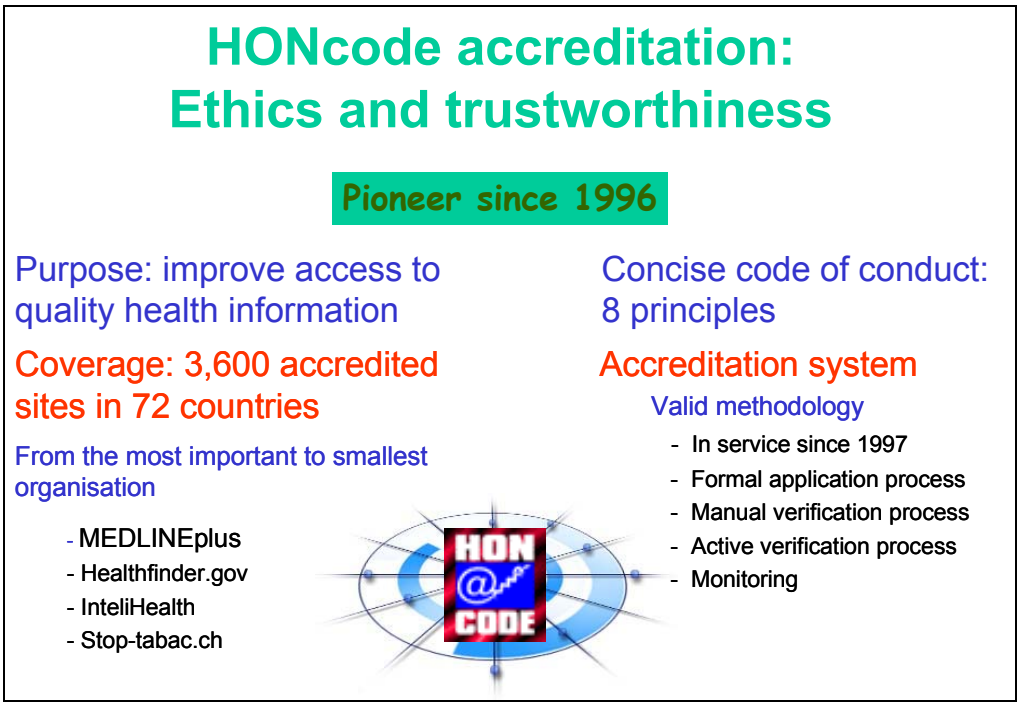
***Exhibit -2: HONcode principles***




Source: HON presentation at the eHealth 2004 conference in Cork

The HONcode is a voluntary accreditation system based on an "active seal" concept creating a "confidence space" of qualifying websites (see Exhibit 3). Site administrators must take the initiative to apply for HONcode accreditation, then each request for accreditation is examined by a member of the **HONcode review/accreditation team**.

***Exhibit -3: HON created a "confidence space" of qualifying websites***

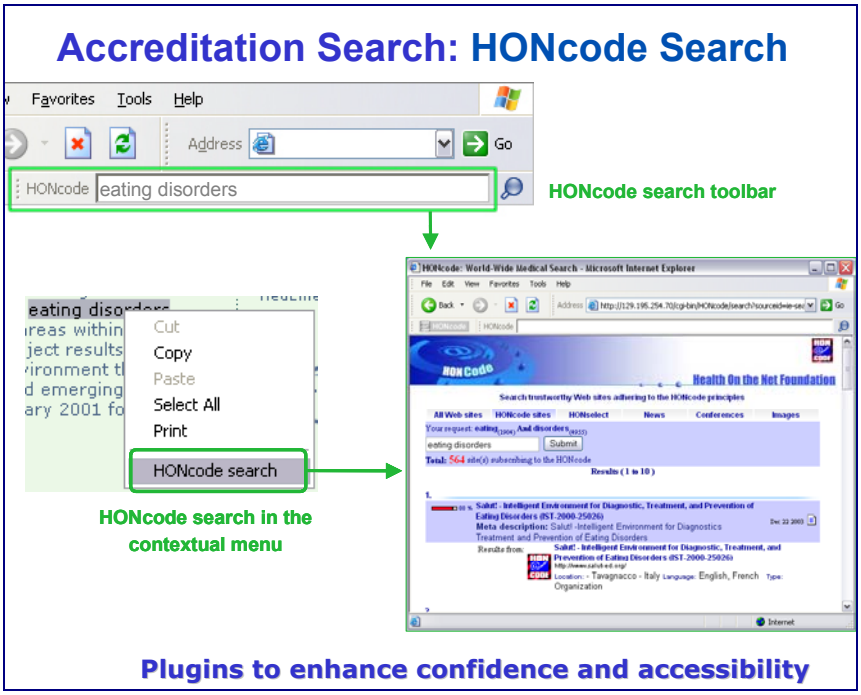



Source: HON presentation at the eHealth 2004 conference in Cork

HON undertakes a thorough visit of the site and verifies that all eight of the HONcode ethical principles are respected. The site is accredited by HON when it not only complies with the HONcode principles but also demonstrates how each principle is implemented. As the result of the HONcode accreditation the site, which is found to respect the eight HONcode principles is given a unique **"active seal"** to place on their pages. While primarily intended for healthcare site developers and publishers, the presence of the distinctive blue and red HONcode seal on subscribing sites also helps users identify sources of reliable information. The term "active seal" refers to the link which webmasters are required to maintain from the HONcode seal to a certificate attesting to their accreditation status, which resides on the HON site.

HON has recently released a multifunctional browser plug-in (**HON Toolbar** – see Exhibit 4) (http://www.hon.ch/HONcode/Plugin/Plugins.html), which, when activated, automatically displays a site's HONcode status. This toolbar was implemented in order to assist Web surfers to access trustworthy websites and make sure the sites they visit have been checked by an independent authority. Two other features of the HON Toolbar allow web surfers to highlight and select text from a web page and search for HONcode-accredited sites about that subject. A search function lets users explore the "confidence-space" of HON-accredited sites.

***Exhibit -4: HONcode Toolbar***




Source: HON presentation at the eHealth 2004 conference in Cork

The HONcode accreditation process is strengthened by regular monitoring. An accredited site receives a check-up visit periodically, beginning one year after initial accreditation, or in case of a complaint or technical malfunction detected by their monitoring services.

HONcode now has over 3,600 participating websites from 72 countries and has recently expanded its accreditation and enforcement activities to include collaborators in diverse linguistic and cultural areas.

## Specialised search engines

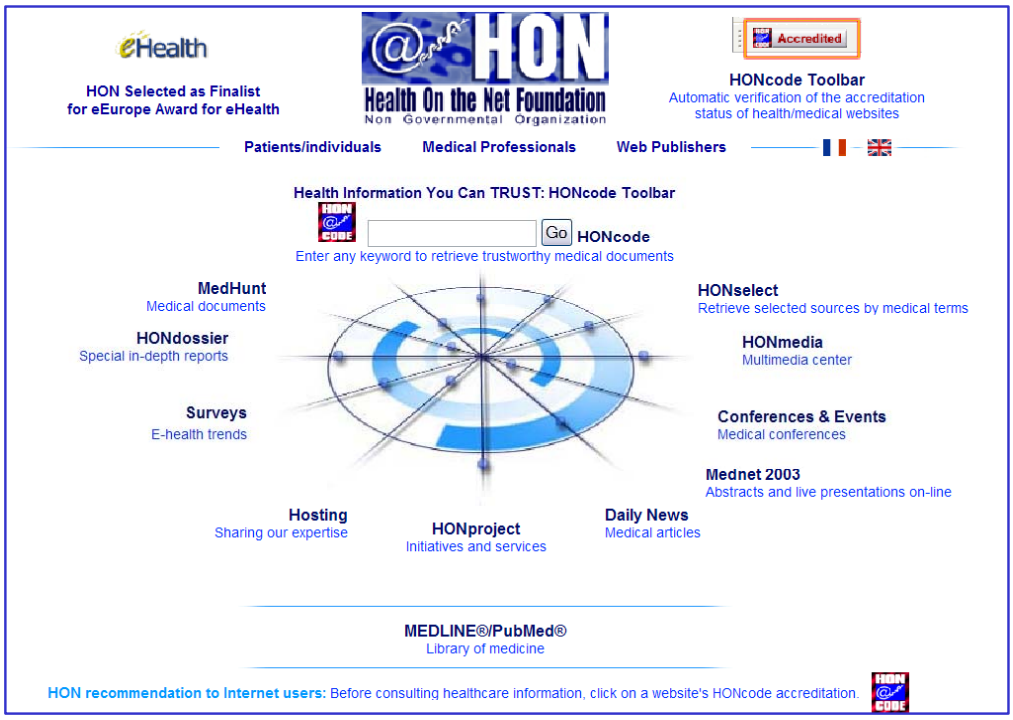
HON's specialised search engines (Exhibit 5) – a sort of "Michelin guide of the web" – are: MedHunt (free search within approximately 75,000 documents), HONmedia (6,800 images concerning 2,000 different topics), HONcodeHunt (trustworthy website adhering to the HONcode principles), and HONselect (medical encyclopaedia containing 33'000 medical terms in 5 languages). In addition, HON provides direct access to trustworthy sources combining five information types: MeSH® (Medical Subject Heading) terms, authoritative scientific articles, healthcare news, websites and multimedia. HON also provides HONdossiers concerning specific subjects: allergies, children, rare diseases, hepatitis B, vision and eye care, ageing, stop smoking. Furthermore, HON offers Daily News (latest health news from selected trustworthy sources) and Conferences & Events with schedules of international medical conferences.

***Exhibit -5: HON's search engines***

Source: HON presentation at the eHealth 2004 conference in Cork

The variety of services offered by HON is illustrated in Exhibit 6:

***Exhibit -6: The website of HON with all services offered***




Source: www.hon.ch

## MedHunt – The Medical Document Hunter and MARVIN - Multi-Agent Retrieval Vagabond on Information Networks

MedHunt is a dedicated medical full-text search engine, using a global database including annotated and auto-indexed websites retrieved by MARVIN, HON's robot. The **global database** contains ca. 75,000 documents of two types:

- annotated websites which are updated daily and created manually by the HON team; each site has been visited and a short description is given.
- auto-indexed websites which are automatically retrieved from the web by MARVIN.

MARVIN combines crawler and extraction technologies. It uses a purpose-built medical dictionary of 20,000 words plus the 33,000 Medical Subject Headings (MeSH) from the National Library of Medicine, USA, to automatically retrieve the unreviewed sites. Each word has been given a weight describing its relevance and specificity in documents for health and medicine. The weightings have been obtained by performing a statistical evaluation of all words contained in a preselected set of 1,000 medical documents. MARVIN searches the web and selects only documents that are relevant to a specifically selected domain. Document relevance is computed according to a formula that takes into consideration the number of words from a glossary of significant terms that MARVIN finds in the document, as well as their place in the document and their associated weights.

Selected documents are stored in MedHunt's global database which is organised in four categories; a general one including all the health/medical websites and the three others dedicated respectively to hospitals, support groups and conferences. MedHunt also proposes a simultaneous translation of the queries in eight languages (English, Danish, Dutch, French, German, Italian, Portuguese and Spanish) with a pre-formatted search associated with the translations.

Since January 1996, MARVIN tirelessly scans the web for new sources of medical information and constantly updates MedHunt and HON’s databases (conferences, HONmedia and news).

There are also specifically tailored search engine applications already in use: a version for searching 2-D electrophoresis documents (2DHunt), a molecular biology version (BioHunt), a version for searching documents related to the PACS (Picture Archiving Computer System) and two versions for searching website content (the HON Foundation and ExPASy, the proteomics server).

### HONselect: a multilingual and intelligent search tool

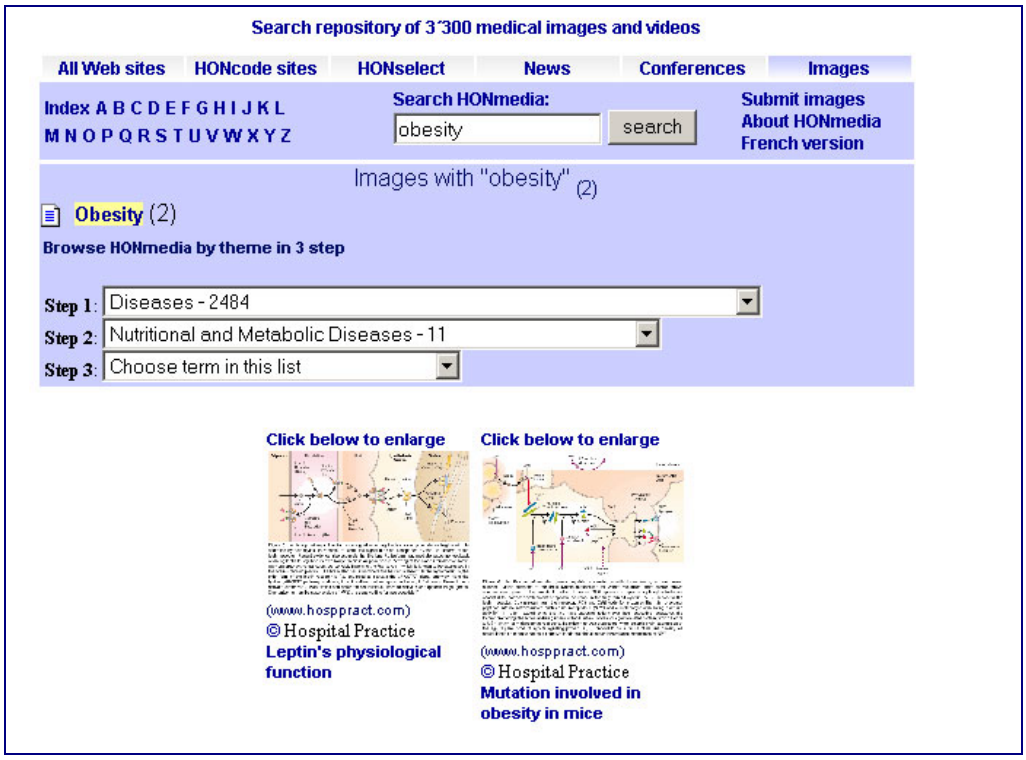
HONselect, HON's new search integrator (meta search engine) for medical and health queries, combines five information types – MeSH terms, authoritative scientific articles, healthcare news, websites and multimedia – into one service to focus and accelerate the search. No other search engine offers this level of innovation, ease of use and time-saving functionality. It also integrates **four separate databases**: MEDLINE – for bibliographic references corresponding to the term, with the possibility of refining the results further using criteria such as "therapy", "etiology", "prognosis", and "diagnosis", as well as "recall" or "precision" (these are intended for doctors and medical students); HONmedia, an unique repository of over 6,800 medical images and videos, pertaining to 2,000 topics and themes classified according to MeSH nomenclature; NewsPage, for daily medical news, and MedHunt, the full-text search engine developed by HON and powered by the HON's proprietary robot MARVIN. HONselect's database also contains sites that have been reviewed by HON, as well as those adhering to HON's Code of Conduct for medical and health websites (HONcode).

HONselect's hierarchical organisation offers educational opportunities for the lay person. A search for "diabetes", for instance, will yield: "Diabetes Insipidus", "Diabetes Insipidus Neurogenic", "Diabetes Insipidus Nephrogenic", "Diabetes Mellitus", "Diabetes Mellitus Insulin-Dependent", "Diabetes Mellitus Non-Insulin-Dependent", "Diabetes

Mellitus Lipoatrophic", "Diabetes Mellitus Experimental", "Diabetes Gestational", "Pregnancy in Diabetes", "Obesity in Diabetes", "Glycosuria Renal", "Hypophosphatemia Familial". The user may then select the term of interest and refine his or her search.

MARVIN technology can be applied to any medical speciality or other domain as already implemented for molecular biology, used by the SIB (Swiss Institute of Bioinformatics).

***Exhibit -7: HONmedia***




Source: HON presentation at the eHealth 2004 conference in Cork

## Multilingualism and multiculturalism

All HON's Services are offered in 5 European languages: English, French, German, Spanish, and Portuguese. The HONcode is available in 28 languages (http://www.hon.ch/HONcode/). HON's search services incorporate a spellchecker to help the citizen in finding the correct medical terms and retrieving coherent results for the initial query. The medical spell checking technology is available in 5 languages.

To reach the greatest number of users, HON's services rely on standard W3C protocols: HTML, HTTP, XML and web services, which provides for multilingual handling of documents.

Innovative use of ICTs also makes possible the day-to-day work of HON's multilingual accreditation team whose members reside in several European countries. A web-based system gives platform independence to members of the team who work in various institutions, and speeds integration of new collaborators. The tool provides workflow-based access to HON databases, as well as messaging and chat facilities for team members.

## New/further developments

Most users find it difficult to formulate queries that are well designed for retrieval purposes. In fact, as observed with web search engines, users might need to spend a large amount of time reformulating their queries to accomplish effective retrieval. Here a recently completed project, **WRAPIN,** enables the user to interact with the knowledge the system has obtained during the first retrieval, proposing a list of keywords to help the user refine the query. WRAPIN (Worldwide Reliable Advice to Patients and Individuals) is a set of technologies developed within the framework of a two-year EU project (IST–2001-33260). The project built on experience acquired during five years of work with MARVIN, using an improved tool to identify relevant documents and make assertions as to their trustworthiness.

The system, powered by Natural Language Processing (see Exhibit 8), is able to identify the main scientific concepts described in a text, and performs "background checks" on a document to ascertain the origins and relations of the ideas it contains. A reference database of trustworthy sources includes Medline (US National Library of Medicine), Clinical Trials (US National Health Institute), FDA Drug Information (US Food Drug Administration), Vidal (French drug database), UROFrance (French Association of Urology) and OESO (World Organisation for Specialised Studies on Diseases of the Oesophagus).

***Exhibit -8: WRAPIN URL or free text search and query reformulation***

Source: www.wrapin.org

WRAPIN uses XML to facilitate portability and comparison of documents from different databases.

The HON accreditation team also makes use of an advanced version of WRAPIN. This test phase provides feedback to HON engineers as they prepare the public version of WRAPIN. With a more efficient sharing of reliable knowledge, WRAPIN will help the citizen/individual in making better choices on medical information available on the Web.

## Surveys and statistics

HON conducts annual surveys to ascertain its own impact on its audience, to detect trends in consumer health internet use and improve its services. Survey findings from 2002 include results from 2,621 voluntary respondents who were asked what was, from their point of view, the most important issue with respect to Internet health information. 59% of the respondents favour accredited websites, with those familiar with the HONcode: 50.3%; Good Housekeeping Seal: 27.5%; Trust-e: 13.4%; IHC: 6%; and URAC < 5%.

The latest evaluation of "Internet Users' Confidence in Health Websites and its Impact on Behaviour" was conducted in September 2003 through the www.stop-tabac.ch website. 476 persons voluntarily responded (English 36% and French 64%, 75% aged 20 to 50). 71% believe that an accreditation seal (logo) is helpful to guide people in selecting health websites; 74% think that an external, independent, international organization should intervene in accrediting health websites; 73% have much trust toward a site with seal of approval; 74% were more confident printing out pages from an accredited website to show and discuss with their doctors; 75% think that the use of verifiable seals (linked to the accrediting site) is a good way to inform Internet users about the credibility of a health website.

Some 16,000 people visit the HON website every day. In 2003, over 700,000 searches were conducted monthly using HON's search tools by over 500,000 visitors who viewed collectively more than two million pages.

## References to HON and awards

The HONcode was often named as one of the "major indicators of accuracy in content" in scientific studies. Some examples concerning HONcode are:

- "They [HON] attempt to standardize the reliability of medical and health information available on the Web and protect the privacy of online consumers by publishing principles and guidelines for health Websites to follow." [3]
- In fact "three indicators correlate with accuracy: displaying the HONcode logo, having an organization [dot org] domain, and displaying a copyright."[4]
- As an established parameter of authority, the oldest system for validating health-care Website in this study, authoritativeness was determined by the presence of a valid HON certificate on a returned Website, and/or the researchers conclusion that the given site adhered to the eight specific principles outlined within the HON code.[5]
- "HON produces the oldest, and perhaps the best known, quality label".[6]

The introduction of the HONcode in 1996 was a milestone for online health information, as evidenced by numerous references to the HONcode in the Health Informatics

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[3] Wenhong Luo and Mohammad Najdawi, COMMUNICATIONS OF THE ACM January 2004/Vol. 47, No. 1 109 - 113

[4] Fallis D, and Fricke M. Indicators of accuracy of consumer health information on the Internet: a study of indicators relating to information for managing fever in children in the home. JAMIA, 2002 Jan-Feb;9(1):73-9.

[5] Mintz, Anne P. (2002). Web of Deception: Misinformation on the Internet. New Jersey: Information Today Inc.

[6] Wilson, Petra: How to find the good and avoid the bad or ugly: a short guide to tools for rating quality of health information on the internet. BMJ 2002;324:598–602, http://bmj.bmjjournals.com/cgi/reprint/324/7337/598.pdf

literature. Similar initiatives were launched, but none so far has gained the notoriety nor the number of adherents that the HONcode has. HONcode-accredited websites are always among the top results when searching Google for popular health topics such as “Diabetes”, “Cancer” or “HIV/AIDS”. Outstanding websites such as aegis.org, aids.org, American Cancer Society, National Concern Institute, National Institute of Mental Health, The American Council for Headache Education, Guillain Barré Syndrome Support Group, Healthfinder, InteliHealth, MayoClinic, Meningitis Research Foundation, Multiple Sclerosis Foundation and others are all HONcode subscribers. According to the “Web Impact Factor” of Alta Vista, over 800,000 quality web pages link to the HON website, which has resulted in high visibility for HON and its projects. For several years, HON has consistently ranked in the second or third position when searching Google for “Health”.

HON was the winner of the Best Content in e-Health category of the World Summit Awards announced at the World Summit on the Information Society (WSIS) in Geneva, 10-12 December 2003, for a comprehensive overview on best practice in e-content and creativity on the Information Society, and the winner of the eEurope Award for “eHealth information tools and services for citizens” at the eHealth High Level Conference in Cork in May 2004 (see Exhibit 9).

***Exhibit -9: HON won the eEurope Award for “eHealth information tools and services for citizens” at the eHealth High Level Conference in Cork, 2004***

Source: www.ehealthconference2004.ie

## Lessons learned

The HON website has become a reference for medical websites on the internet. HON’s search tools and code of conduct, the HONcode, are de facto standards for the quality of online health and medical information. According to Ms. Célia Boyer, Executive Director of HON, “one reason why the HONcode is so widespread today is because it was probably the first such service offered to the Internet community. Another reason lies in its brevity, simplicity and effort to address the main ethical issues. Also, links to the HONcode grow whenever influential bodies, such as the Mayo Clinic in the USA, actively adhere to it and promote it. ... The ethical standards embodied in the HONcode were based on consensus among all actors, and can be maintained through the continued commitment of the greatest number of them. Equally, consumer education is needed to raise awareness among Internet users of issues in health information. Ethical standards are best promoted through voluntary, constructive efforts, backed up

by enforcement. Maintenance of the consensus through effective communication, negotiation and learning are the necessary counterpart to HON's ongoing research on automated solutions."

Demand for HONcode accreditation has consistently exceeded HON's capacity, and waiting times of several months have become commonplace. There is need for automated means to verify compliance with any code of conduct or future legislation.

HON's specialised search engines proved highly efficient. HON is further developing additional tools for automatic determination of information quality, use of natural language queries, or interaction of the user with HON's databases for refining the search.

## References and acknowledgments


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- http://www.ehealthconference2004.ie
- http://www.wrapin.org


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