Trustworthy health and medical information: the Health On the Net initiative

Celia Boyer, celia.boyer@healthonnet.org
Executive Director
Health On the Net Foundation
The Founders

Guy-Olivier Segond, President of the Geneva State Council

Prof. Jean-Raoul Scherrer (GUH, MIS)

President:
- Prof. Antoine Geissbühler
  Head of the Medical Informatics Service, Geneva University Hospital

Vice-presidents:
- Dr. Don Lindberg, Head of the National Library of Medicine (NLM)
- Mr. Michel Carpentier, European Commission, Director general, DG XIII
The Health On the Net Foundation
HON Team

HONcode accreditation
(13 persons)
- 6 physicians
- 1 pharmacist
- 1 Ph.D. in molecular biology
- 2 law graduates
- 3 medical students

Informatics developments
(5 persons)
- three computer scientists
- Two analyst in linguistics
- Web designer

Secretary

Direction

Celia Boyer
Celia.Boyer@healthonnet.org
How to judge the information on the Web?
The Health On the Net Foundation

Established in 1995 under the auspices of the Ministry of Health of the State of Geneva

Mission: To guide Internet users by highlighting reliable, understandable, relevant and trustworthy sources of online health and medical information

*HON tackles the major obstacles of Internet usage: the overwhelming quantity of information and the uneven quality of health information available online.*
HON initiatives for improving the quality of online medical information

- The HON Code of Conduct: the HONcode principles and its accreditation program
- Database of accredited websites
- Multilingual search engines specialized in health issues
  - European Union projects
- Collaborative initiatives
Standard HON

- The “HONcode” (Boyer, Selby, Scherrer, and Appel, 1996)
- Developed in 1996 by the Health on the Net Foundation, a non-governmental organization.

Excerpt from European Union ministerial meeting 2586, June 2004

“RECOGNISES that to make reasonable decisions about what health information they will trust, or what products or services they will use, individuals need to know which sources of health-related websites make clear the standards they have used and ensure that the information presented is appropriate, independent, and is timely. Health-related websites should also identify who is most likely to visit the site and ensure that the information is as comprehensible and as easily accessible as possible, including disabled persons. As some sites may be sponsored by one party and hosted by a different one, these relationships should be clearly disclosed on the site.”
The HONcode

Authoritative
Indicate the qualifications of the authors

Complementarity
Information should support, not replace, the doctor-patient relationship

Privacy
Respect the privacy and confidentiality of personal data submitted to the site by the visitor

Attribution
Cite the source(s) of published information, date and medical and health pages

Justifiability
Site must back up claims relating to benefits and performance

Transparency
Accessible presentation, identities of editor and webmaster, accurate email contact

Financial disclosure
Identify funding sources

Sponsorship
Clearly distinguish advertising from editorial content
HONcode accreditation protocol

- Websites are evaluated according to the conformity assessment document.
- The outcome of the accreditation is stated in the HONcode certificate. The HONcode seal is issued when the website is found to be in compliance with the HONcode.
- The HONcode seal is valid for one year. The website is re-assessed before the end of the period.
- All violations of the Code must be remedied. Webmasters receive guidelines and instructions from HON.
- The webmaster pledges to respect the HONcode during the time the website displays the HONcode seal. The webmaster must notify HON when the website changes significantly.
- The assessments are confidential, except for the information that must be published in the HONcode database on HON’s website.
- Complaint submission forms are available online.
- Defined according to ISO norms
HONcode Facts

- 5533 sites
- 72 countries
- 32 languages
- 1,200,000 web pages accredited

Examples:
- Orphanet
- webpacientes.org
- Portal Mayores: imsersomayores.csic.es
- linfoma.roche.es
- Asociación Española de Pediatría
- Hospital 12 de Octubre ClinicalTrials.gov
- The National Urban League
- MEDLINEplus.gov
- PubMed
- WebMD
- Stop-tabac.ch
- Diabetes Netzwerk Deutschland
- Sociedad Argentina de Pediatría
Semantical annotation during the accreditation process

Web site annotations

69 categories in 8 languages

Example of categories
- For patients; From medical authorities; For health professionals
- Women health; Men health; Kids; Newborns; Adolescents; Seniors; People with disabilities
- Nutrition;
- Drugs- Side effects, interactions, warning & recalls
- Symptoms; Causes/risk factors; Tests/diagnosis
- Alternative medicine
- Continuing education; Practice guidelines; Clinical trials
- Treatments

80’000 annotations
HONcode Facts: repartition regarding the type of web sites

- Commercial: 34%
- Non-profit: 19%
- Educational: 16%
- Organization: 16%
- Individual: 11%
- Government: 4%
HONcode Facts: repartition regarding the geographical repartition of Web sites
# Most linked health web sites

<table>
<thead>
<tr>
<th>Website</th>
<th>Links</th>
</tr>
</thead>
<tbody>
<tr>
<td>pwmc.org</td>
<td>51</td>
</tr>
<tr>
<td>wma.comb.es</td>
<td>276</td>
</tr>
<tr>
<td>iqua.net</td>
<td>518</td>
</tr>
<tr>
<td>cismeff</td>
<td>5'700</td>
</tr>
<tr>
<td>medlineplus.gov</td>
<td>19'400</td>
</tr>
<tr>
<td>medscape.com</td>
<td>41'700</td>
</tr>
<tr>
<td>webmd.com</td>
<td>42'000</td>
</tr>
<tr>
<td>hon.ch</td>
<td>42'000</td>
</tr>
<tr>
<td>nih.gov</td>
<td>53'100</td>
</tr>
</tbody>
</table>

Second highest rate of web penetration in health issues

http://tools.marketleap.com/publinkpop/
MARKETLEAP – Digital Impact Company
Specialized search engines

National projects: Personalization
- Health themes: Provisu (eye diseases), stop-tabac.ch (smoking prevention)
- Regional: SantéRomande (french speaking directory)

European research projects
- WRAPIN: World-Wide online Reliable Advice to Patients and Individuals (6th FWP)
- ActiveHealth: Active Environment for Health Promotion and Disease Prevention (5th FWP)
- PIPS: Personalized Information Platform for Life and Health Services (6th FWP)
Search engine to trustworthy medical sources

WRAPIN

WRAPIN addresses three major problems of Internet information

- Overwhelming quantity of information
- Uneven quality of information
- Multilingual information

Partners

HON (Health On the Net), coordinator

HUG-SIM (University Hospital Geneva)
LERTIM (Marseille University Laboratory for medical informatics)
MISS (French Government Agency for health systems computerization)
NICE Computing
THALES Information Systems
XR-Partner
Worldwide online Reliable Advices to Patients and Individuals

WRAPIN trustworthy medical databases

**HONcode** : data base of HONcode-certified medical web sites (multilingual).

**Medline** : a data base of over 15 million medical and scientific articles (most of them in English) indexed from the sixties to date, made available by the NLM (National Library of Medicine USA).

**Medhunt** : all the medical web sites indexed by HON (multilingual).

**Drug FDA** : Information in English about medicines issued by the Food and Drugs Administration (USA).

**Clinical Trials** : a data base of clinical trials in English made available by "the National Institute of Health" developed by the NLM (National Library of Medicine USA).

**Uro** : scientific articles in French covering the domain of Urology, made available to WRAPIN by "Association Francaise d'Urologie ".

**Oeso** : scientific articles in English specializing in the diseases of the oesophagus, made available by the Oeso Fondation.

**HONnews** : daily medical news in English from HealthDay.
WRAPIN project outcome:
Shark Cartilage / Cartilate / Cartilade / Benefin / AE-941 / Neovastat: BC Cancer Agency

... Press). "There is a protein in cartilage that can inhibit angiogenesis in test-tube labora ... However, this does not mean that cartilage can fight tumors in the human body. In addition t ... results into research on live patients; cartilage has other potential problems. The most serious pr ... use. There is no firm evidence that cartilage treatment is effective against cancer. Given the ... URL: http://www.bccancer.bc.ca/PTl/UnconventionalTherapies/Shar...

,... This trial was unable to demonstrate any suggestion of efficacy for this shark cartilage product in patients with advanced cancer....

ActiveHealth: Active Environment for Health Promotion and Disease Prevention

- Privileged access for accredited sites through HON selective search engines

- Accessible to everyone: specific toolbar in your web browser
Luxación

Purpose

This is an initial placebo-controlled study followed by open treatment evaluating the effectiveness and tolerability of ropinirole long-term in patients with moderate to severe Restless Legs Syndrome.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Intervention</th>
<th>Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Restless Legs Syndrome</td>
<td>Drug: Ropinirole oral tablets</td>
<td>Phase IV</td>
</tr>
</tbody>
</table>

MedlinePlus related topics: Restless Legs

Study Type: Interventional
Búsqueda de sitios Web confiables que se ajustan a los principios de HONcode

Su solicitud: luxacion (23)

Total: 7 sitio(s) que suscribe(n) los principios de HONcode

Resultados (1 para 7)

1. Luxación de cadera
   Palabras clave: luxacion, ecografía, femur, radiografía, cadera, displasia, torticolis, radiologo, pediatra, peinatal
   Como corregir la luxación de caderas.
   Palabras clave: luxacion, femur, gluteo, pelvis, displasia, femoral, cavidad, cadera, osificacion, mucculatura
   Cuando operan a su hijo
   Meta description: portal chileno de Pediatría
   Resultados de: Pediatraldia.cl
   http://www.pediatraldia.cl/
   Lugar: - Santiago - Chile Idioma: Spanish Tipo: Organisation

2. CODIFICACION OSABIDE
   Palabras clave: contusion, pediatría, umbilical, granuloma, equimosis, luxacion, cardiopatia, hospital, estenosis, exantema
   Resultados de: Asociación Vasca de Pediatría de Atención Primaria
   http://www.avarpap.org/
   Lugar: - Vitoria-Gasteiz - Spain Idioma: Spanish Tipo: Organisation
International activities

Partnerships with:
- The World Health Organization
- National Library of Medicine
- Google

Local representation in:
- Mali,
- South Africa,
- Spain
Collaborative projects with WHO

- 2006-2007, project funded by the Geneva International Academic Network

- Study on cultural determinants of trust in French-speaking African countries

- Partners:
The most active partner

Google Co-op profile

Health On The Net Foundation (HON)
Geneva, Switzerland
www.healthonnet.org

Last activity: 1 day ago
Member since: Feb 20

Health Information You Can TRUST.

The Health on the Net Foundation (HON) promotes and guides the deployment of useful and reliable online health information, and its appropriate and efficient use. Created in 1995, HON is a non-profit, non-governmental organization, accredited to the Economic and Social Council of the United Nations. For ten years, HON has focused on the essential question of the provision of health information to citizens, information that respects ethical standards. To cope with the unprecedented volume of healthcare information available online, the HONcode of conduct offers a multi-stakeholder consensus on standards to protect citizens from misleading health information.

At a Glance

Annotations submitted: 103222
Sites recently labeled: nhs.nhs.uk, health.org, kidshealth.org, details
In 2002, HON Foundation was recognized as a non-governmental organization and granted special consultative status with the United Nations Economic and Social Council.

In May 2004, HON won the «eEurope Award for eHealth» presented by the European Union and the EU Commission.
**Conclusion**

- Standards can infer the quality from the information production process.

- Ethical quality standards overcome difficulties posed by large volumes of information and disagreements on scientific matters.

- Local identity of sites can be preserved by implementing the HONcode, which is essential.

- The HONcode enhances overall quality: editorial pedagogy.

*More than just a mouse click: Research into work practices behind the assignment of medical trust marks on the World Wide Web*

Adams SA, de Bont AA. *IJMI*, June 2006, PMID: 16807085
This paper was produced for a meeting organized by Health & Consumer Protection DG and represents the views of its author on the subject. These views have not been adopted or in any way approved by the Commission and should not be relied upon as a statement of the Commission's or Health & Consumer Protection DG's views. The European Commission does not guarantee the accuracy of the data included in this paper, nor does it accept responsibility for any use made thereof.