A decade devoted to improving online health information quality.

Celia Boyer, Executive Director
Outline

- Introduction
- Health website certification
- The HONcode database
- Research and development
- International recognition
- Conclusion and Future perspectives
Importance of the Online Health and Medical Information

- Internet is a mainstream media
  - 1.4 billion users worldwide connected in 2008*

Importance of medical information on the Internet

- 1.2 billion results for the search term, “health” on Google
- One in five patients are looking for health information online**
- Patients with chronic diseases more likely to use internet before making treatment decisions***

* http://www.internetworldstats.com/
** French National Health Authority
*** E-patients With a Disability or Chronic Disease, Oct. 2007, Pew internet & American Life project
Control the quality of health websites?

An old issue!

The New Yorker, 1993
Why should Health Information on the Internet be Quality Controlled?

53% health information seekers report that the health information they found had an impact on their own health care or the way they care for someone else:

- 58% say the information they found in their last search affected a decision on how to treat an illness or condition.
- 55% changed their overall approach to maintaining their health.
- 54% lead them to ask a doctor new questions or to get a second opinion from another doctor.
- 35% say the information affected a decision about whether to see a doctor.

BUT .... Just 15% of health seekers say they “always” check the source and date.
The mission of Heath On the Net Foundation

- To guide Internet users by highlighting reliable, comprehensible, relevant and trustworthy sources of online health and medical information

- Since 1995, HON has been tackling the major obstacles of Internet usage: the overwhelming quantity of information and the uneven quality of health information available online
Various initiatives for controlling the quality

... specific for health websites

... applicable for all sites
<table>
<thead>
<tr>
<th>Year</th>
<th>Country</th>
<th>Code/Standard</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>UK</td>
<td>OMNI*</td>
<td>19 themes -&gt; 80 questions. A directory of unaudited sites.</td>
</tr>
<tr>
<td>1996</td>
<td>CH</td>
<td>HONcode</td>
<td>8 principles - free online application with a simple questionnaire -&gt; manual review and annual audit.</td>
</tr>
<tr>
<td>1998</td>
<td>UK</td>
<td>Discern*</td>
<td>16 questions (unaudited self-evaluation)</td>
</tr>
<tr>
<td>1997/99</td>
<td>F</td>
<td>Netscoring*</td>
<td>49 criteria, 312 points (French only)</td>
</tr>
<tr>
<td>1998/99</td>
<td>Es</td>
<td>WebMedica</td>
<td>Based on existing codes (Spanish only)</td>
</tr>
<tr>
<td>2000</td>
<td>D</td>
<td>MedCertain*</td>
<td>Level 1 -&gt; 72 questions</td>
</tr>
<tr>
<td>2001</td>
<td>F</td>
<td>Toucanomètre*</td>
<td>French webmasters MD -&gt; 17 items; 40 points</td>
</tr>
<tr>
<td>2002</td>
<td>EU</td>
<td>Guidelines*</td>
<td>European Commission 6 directives. Created with participation of HON</td>
</tr>
<tr>
<td>2003</td>
<td>D</td>
<td>AFGIS Code</td>
<td>Membership fee (German only)</td>
</tr>
</tbody>
</table>

*little or no implementation
## The HONcode

<table>
<thead>
<tr>
<th>Authoritiveness</th>
<th>Indicate the qualifications of the authors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complamentarity</td>
<td>Information should support, not replace, the doctor-patient relationship; Audience</td>
</tr>
<tr>
<td>Privacy</td>
<td>Respect the privacy and confidentiality of personal data submitted to the site by the visitor</td>
</tr>
<tr>
<td>Attribution</td>
<td>Cite the source(s) of published information and dating of medical and health pages</td>
</tr>
<tr>
<td>Justifiability</td>
<td>Site must back up claims relating to benefits and performance</td>
</tr>
<tr>
<td>Transparency</td>
<td>Accessible presentation, identities of editor and Webmaster, accurate email contact</td>
</tr>
<tr>
<td>Financial disclosure</td>
<td>Identify funding sources</td>
</tr>
<tr>
<td>Sponsorship</td>
<td>Clearly distinguish advertising from editorial content</td>
</tr>
</tbody>
</table>

http://www.HON.ch/HONcode/
HONcode certification protocol

The Web publisher submits a request to be certified and to obtain the right to display the HONcode seal
The Web publisher fills in an online questionnaire
The HONcode review team conducts a thorough evaluation of the website
According to findings, website is:
- certified
- certified under condition to modify/add some statement on the website
- not certified
If certified, a unique HONcode seal is granted
Each website is re-evaluated each year
The certified website is integrated into the database of HONcode certified websites, HONcodeHunt
The HONcode database: HONcodeHunt

+ 6,500 sites
118 countries
34 languages
English: 51%
French: 15%; 500 HAS-HON
German: 9%
Italian: 7%
1,400,000 web pages certified in Google.com

The HONcode team:
8 MDs, 2 medical students, 1 pharmacist, 2 licensed lawyers and 1 biologist

Examples:
- ClinicalTrials.gov
- HealthInsite.gov.au
- Health-EU Portal
- The National Urban League
- MEDLINEplus.gov
- PubMed
- Stop-tabac.ch
- speichzimmer.ch
- patientenleitlinien.de
- Hospital 12 de Octubre
- Sociedad Argentina de Pediatría
- Diabetes Netzwerk Deutschland
- onmeda.de/
- Santemagazine.fr
- eurordis.org
Proof of the HONcode:
A logo linked to a dynamic, unique and dated certificate. The logo also displays last date of review.
HONcode application status:

Healthfinder is in compliance with the HONcode

Title of the site: Healthfinder
Web address: http://www.healthfinder.gov/
HONcode PIN number: HONConduct898345
Date of initial review: 22 Apr 1997
Date of last subsequent review: 22 Oct 2008
Duration of validity of certificate: 1 year with regular evaluation
Show the HONcode seal on this site

This certificate confirms the revision of the site by the HONcode Team at the above date. It respects and pledges to honor the 8 principles* of the HON Code of Conduct (HONcode).


Compliance violation?
Last HONcode certification activity

Flesh & Stone
Flesh and Stone is a public interest news site delivering independent reporting on health care and science news, trends, and commentary. Along with new research publi...
www.fleshandstone.net/ - USA | Certified since 7 Nov 2008 - Show the certificate

MediCorp Health System
This website is the consumer portal for Mary Washington Hospital and MediCorp Health System. The purpose of this site is to provide a single point of entry to informat...
www.medicorphealth.org/ - USA | Certified since 7 Nov 2008 - Show the certificate

Regionalt kompetansesenter for dobbelldiagnose rus og psykiatri
Nettsiden formidler ulike type informasjon om dobbelldiagnose rus og psykiatri. De to hovedmåleruene er helsearbeidere og casicenter/bærerende. Siden inneholder
Research and Development
European activities

European research projects

- WRAPIN: World-Wide online Reliable Advice to Patients and Individuals (2001-2003; IST-2001 33260)
- ActiveHealth: Active Environment for Health Promotion and Disease Prevention (2001-2002; IST-2001-37857)
A global approach by filtering processes

PIPS Trusted Search Engine

Enter Query: fever children aspirin
Language: English
Readability Filter: none
Trust Filter: Authority, Complementarity

Trust Filter: Authority | Complementarity

Found 1130 Trusted Pages

1. FLU SEASON--It's Just Around the Corner!- November/December 1996
   ... bed, drink plenty of fluids, and take medications such as aspirin or acetaminophen to relieve fever and discomfort. Children with flu should not be given aspirin without consulting a doctor because of the risk of Reye... www.nih.gov/news/HealthWise/Nov-Dec96/story4.htm ...
   Last visited: 16_01_2008
   http://www.nih.gov
   Automatic Detected Trust Criteria: Auth, Compl
   Medhunt

2. Tolmetin and salicylate therapy in acute rheumatic fever: Comparison of clinical efficacy and side-effects.
   ...equally effective, although no reports are available. METHODS: We studied 72 patients with rheumatic fever who were admitted to Dr Sami Ulus Children's Hospital between 1995 and 1999. Twenty patients with arthritis were treated with tolmetin (25 ... be used particularly in patients who cannot tolerate aspirin. Adolescent, Anti-Inflammatory Agents, Non-Steroidal, Aspirin, Child, Child, Preschool, Comparative Study, Female, Human, Infant, Male, Rheumatic Fever, Tolmetin...
   Last visited: 02_01_2008
   Trusted by Source: PubMed
Targeted search engine

WRAPIN
Worldwide online Reliable Advice to Patients and Individuals

Query: http://www.discount-vitamins-herbs.net/shark

Results in English: 1-10 of 23 found documents

1. Shark Cartilage / Cartilane / Cartilage / 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/PP1/UnconventionalTherapies/Sha...

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

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


Department of Oncology, Mayo Clinic and Mayo Foundation, Rochester, Minnesota 55301, USA. cloprinzi@mayo.edu

BACKGROUND: Shark cartilage has been a popular complementary or alternative medicine intervention. The basis for this popularity is the claim that sharks rarely get cancer because of the high proportion of cartilage in the shark's body. However, early studies were equivocal. Therefore, a clinical trial was conducted to look at the impact of shark cartilage in patients with advanced cancer. The primary goal of this trial was to determine whether a shark cartilage product improved overall survival for patients with advanced cancer who were getting standard care. Secondary research goals were to evaluate toxicities, tolerability, and quality of life associated with this shark cartilage product. METHODS: The study was a two-arm, randomized, placebo-controlled, double-blind, clinical trial. patients with incurable breast or colorectal carcinoma had to have good performance status and organ function. patients could be receiving chemotherapy. patients were all to receive standard care and then to be randomly selected to receive either a shark cartilage product or an identical-appearing and smelling placebo 3 to 4 times each day. RESULTS: Data on a total of 83 evaluable patients were analyzed. There was no difference in overall survival between patients receiving standard care plus a shark cartilage product versus standard care plus placebo. Likewise, there was no suggestion of improvement in quality of life for patients receiving the shark cartilage, compared with those receiving placebo. CONCLUSION: This trial was unable to demonstrate any suggestion of efficacy for this shark cartilage product in patients with advanced cancer.

PMID: 15912493 [PubMed - in process]
Search engine of HONcode certified sites

Results 1 - 10 for diabetes in kids. (1.14 seconds)

**Diabetes Information for Parents and Kids (Child) - American**
Diabetes information for children and kids with diabetes from the American Diabetes Association.
www.diabetes.org/for-parents-and-kids.jsp

**children with DIABETES Online Community**
Children with Diabetes is the online community for parents, kids, adults, and families living with type 1 diabetes.
www.childrenwithdiabetes.com/

**Kids Diabetes Alert**
We often think of overweight adults as being at risk for having diabetes, but it is now known that many overweight teens are at risk for diabetes too.
pediatrics.about.com/cs/diabetes/a/diabetes_alert.htm

**children with DIABETES - Children’s Corner**
Meet other kids and teens, read about parents’ feelings, and tips about tests and shots. Includes mailing list for kids and mailing list for teens.
www.childrenwithdiabetes.com/kids/

Kids’ Health, Topics, Diabetes
Identification of HONcode certified sites

Through the HON toolbar available to everyone, one can easily find and search all sites accredited by HON.
Active HONcode seals in Google (and Yahoo)
Active HONcode seals in MedlinePlus
International recognition
International recognition

- 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.
Government-level collaboration

The French bill 2004-810, 13th August 2004 regarding the health insurance, has mandated the French National Health Authority (HAS) to define a certification procedure for health websites: the HAS chooses HON for the certifying French health websites.

Collaboration:
HAS (Haute Autorité de Santé) and HON

Outcome:
HONcode is the official international standard for quality of health websites in France since November 2007. HON is accredited according to the standard EN45011/ISO 65.
International activities

- Partnerships with:
  - The World Health Organization
  - Google

- Local representations
Collaboration with WHO

- 2006-2007, project funded by the Réseau universitaire international de Genève

- **Trustworthy online medical information: A study on specificities in French-speaking African countries**

- **Partners:**
  - [World Health Organization](http://www.hon.ch/Project/HONmali/)
  - Université de Genève
  - Institut des Sciences Sociales au Mali
  - Institut Universitaire d’Études du Développement
  - Fondation La Santé sur Internet

http://www.hon.ch/Project/HONmali/
Global search engine: working with Google
Recognizing diversity in a globalizing world

“Just because someone is easier to reach does not mean they are easier to understand. The opposite, in fact, is true. » Dominique Wolton

Regional offices for the HON foundation:

Bamako, Mali: French-speaking Africa

Johannesburg, South Africa: English-speaking Africa

Valencia, Spain
Conclusion & Future perspectives
Conclusion

- Active for over 12 years
- Educate citizens to efficiently use the medical information
- Automatic tools developed in order to support human expertise and tackle the large number of existing Web pages
- 2001 eEurope Quality Criteria for Health Web sites is based on the HONcode principles
- Collaboration with Google-Coop for Health
- Collaboration with the French HAS to be the official certification body for all French health Web sites
- Adherence to the HONcode enhances a website’s overall quality

“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 2006
Future Prospectives

- HONcode to be a participating body in the implementation of the WHO eHealth resolution action plan

- Collaboration with governing bodies worldwide to provide quality control to all national health websites

- Ultimate goal: HONcode certification to cover the entire health Web
Regional services

Regional service: SantéRomande (directory for the French speaking Swiss)
http://www.SanteRomande.ch/

Health topics: Provisu (visual conditions)
http://www.Provisu.ch/

http://www.hon.ch/