Quality standards for health and medical information on the Web

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Online Health and Medical Information

- Internet is mainstream media
  - 1,114 million users worldwide connected in 2006*
  - Half of all European Citizens connected (7 country survey**)

- Importance of medical information on the Internet
  - 4,000 million results for the search term, “health” on Google
  - Eight in ten internet users go online for health information ***

- Is online information quality a real problem?

- How to solve the problem?

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** [http://www.ejic.org/](http://www.ejic.org/) Germany, France, Great Britain, Spain, Belgium, Austria, Switzerland
*** Pew Internet and American Life Project Online Health Search 2006
How to judge the information on the Web?
How do we trust information?

Information production process

- Neutral Third Party validation
- By a recognised organisation
- From knowledgeable references
- From the author
How to solve the problem?

- Development of standards
  - By Government (EU Commission)
  - Civil society
  - Industry groups

- Implementation
  - Selection process
  - Accreditation process (educational process)

- Privileged access to trustworthy information
Standards

- **eHealth Code of Ethics** (e-Health Ethics Initiative, 2000), by the Internet Health Coalition (no longer exists)

- **HI-Ethics Code of Conduct** (Hi-Ethics Group, 2000), developed by an American group of leading for-profit consumer health information websites; implemented by URAC (cost $13,000: 24 websites accredited, visited on 4 March 2007)

- **Quality Criteria for Health-related Websites**, Communication from the Commission of the European Communities, Brussels, November 2002 (cooperation, working group including HON)

- **AFGIS Code**, developed in 2003 by AFGIS (aktionforum gesundheitsinformationssystem), a German association; Germany based; implemented by AFGIS (membership fee)

- **Web Mèdica Acreditada (WMA)**, developed in 1999 by the Medical Association of Barcelona; Spain based; (free of charge)
HON Standards

- 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 what standards a site uses in developing content. Health-related websites must make clear the sources which they have used so that the information presented is independent and timely. Health-related websites should also identify who is most likely to visit the site and ensure that the information presented 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.”

Principles

- Principle 1
- Principle 2
- Principle 5
- Principles 7 and 8
- Principles 1 and 4
The Health On the Net Foundation’s 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
The HONcode

**Authoritativeness**
Indicate the authors’ qualifications

**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
A dynamic, unique and dated seal linked to the certificate

We comply with the HONcode standard for trustworthy health information: verify here.
After revision by the HON team the website status shows compliance with the HONcode.
New generation of HONcode seal

Ways of fighting against the misuse of the HONcode:

Different warning levels

HON automatically displays the HONcode seal and shows its validity in real time
HONcode facts

- 5,533 sites
- 72 countries
- 32 languages
- 1,200,000 web pages accredited
- 50% of sites in Europe

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

Examples:
- ClinicalTrials.gov
- The National Urban League
- MEDLINEplus.gov
- PubMed
- Stop-tabac.ch
- Hospital 12 de Octubre
- Sociedad Argentina de Pediatría
- Diabetes Netzwerk Deutschland
- alkohol-leitlinie.de
- neuro24.de
- ebm-netzwerk.de
- eurordis.org
International activities

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

Local representation in:
- Mali,
- South Africa,
- Spain

In a globalized world, HON aims to preserve local identities; therefore we think globally and act locally, establishing regional representations respecting social and cultural identities.
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:*
Targeted search engine

Query: atkins diet

Results in English: 1-10 of 144 found documents

1. Rating the Atkins Diet: Advantages and Disadvantages
   ... Doctor ... Email this page ... Rating the Atkins Diet: Advantages and Disadvantages (c) The Right Chef ... controversial fad diets around, the Atkins Diet is famous for its carbohydrate-restricting rules ... your system - they may be foods on the Atkins diet! The diet works on the notion that weight gain is ... After the first couple of weeks, the Atkins Diet provides a maintenance program, which involves gr ...
   URL: http://www.betterhealthusa.com/public/250.cfm

2. Efficacy of the Atkins diet as therapy for intractable epilepsy.
   "... This provides preliminary evidence that the Atkins diet may have a role as therapy for patients with medically resistant epilepsy. ..."

3. Understanding the implications of adopting the Atkins' diet.
Specialized search engine

Results 1 - 10 for restless leg syndrome (0.58 seconds)

Restless Leg Syndrome Causes, Diagnosis, Symptoms, and Treatment...
The leg pain of restless leg syndrome typically eases with motion of the legs and becomes more noticeable at rest. Restless leg syndrome also features ...
www.medicinenet.com/restless_legsyndrome/article.htm

eMedicine - Restless Legs Syndrome: Article by Juan Latorre, MD
Restless Legs Syndrome - The term restless legs syndrome (RLS) was used initially in ... symptoms and motor disturbances of the limbs, mainly during rest.
www.emedicine.com/neuro/topic509.htm

Restless Legs Syndrome
Find out more: Seeking Rest for People with Restless Leg Syndrome - OSU Media Relations Office Requires Windows Media Player ...
www.healthonnet.org/healthsites/medical/restless_legs.html
Global search engine: working with Google
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 on the Net, the HONcode
(http://www.healthonnet.org/Conduct.html) of conduct offers a multi-stakeholder consensus on standards to protect citizens from misleading health information.

At a Glance

Annotations submitted: 18,322
Sites recently labeled: nlm.nih.gov/health.org, kidshealth.org, details
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.
Conclusion

The quality of the content can be deduced from the information production process using the HONcode *de facto* standards.

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*
Foundation

Founders (1995)
- Guy-Olivier Segond, President of the Geneva State Council
- Prof. Jean-Raoul Scherrer (GUH, MIS)

Presidency (2006)
- Prof. Antoine Geissbühler, Director of the Medical Informatics Department, Geneva University Hospitals
- Dr. Don Lindberg, Director of the National Library of Medicine (NLM)
- Mr. Michel Carpentier, European Commission, Director General, DG XIII