How to protect the citizen in its quest of health information online?
The certification

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Health On the Net Foundation

PIPS workshop
Milano, April 21 2008
Control the quality of health websites?

The New Yorker, 1993

1.2 billion Internet users in the world in 2007

Internet usage has grown by 225% since 2000

"On the Internet, nobody knows you're a dog."
Online Health and Medical Information

Internet is mainstream media
- 1,173 million users worldwide connected in 2007*
- 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 ***
- One in five patients are looking for health information online ****

Is online information quality a real problem?

How to solve the problem?

* http://www.internetworldstats.com/
** http://www.ejic.org/ Germany, France, Great Britain, Spain, Belgium, Austria, Switzerland
*** Pew Internet and American Life Project Online Health Search 2006
**** French National Health Authority
Introduction: worldwide Internet users and population statistics (1)
**Introduction: worldwide Internet users and population statistics (2)**

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>933,448,292</td>
<td>14.2 %</td>
<td>33,545,600</td>
<td>3.6 %</td>
<td>2.9 %</td>
<td>643.1 %</td>
</tr>
<tr>
<td>Asia</td>
<td>3,712,527,624</td>
<td>56.5 %</td>
<td>436,758,162</td>
<td>11.8 %</td>
<td>37.2 %</td>
<td>282.1 %</td>
</tr>
<tr>
<td>Europe</td>
<td>809,624,686</td>
<td>12.3 %</td>
<td>321,853,477</td>
<td>39.8 %</td>
<td>27.4 %</td>
<td>206.2 %</td>
</tr>
<tr>
<td>Middle East</td>
<td>193,452,727</td>
<td>2.9 %</td>
<td>19,539,300</td>
<td>10.1 %</td>
<td>1.7 %</td>
<td>494.8 %</td>
</tr>
<tr>
<td>North America</td>
<td>334,538,018</td>
<td>5.1 %</td>
<td>232,655,287</td>
<td>69.5 %</td>
<td>19.8 %</td>
<td>115.2 %</td>
</tr>
<tr>
<td>Latin America/Caribbean</td>
<td>556,606,627</td>
<td>8.5 %</td>
<td>109,961,609</td>
<td>19.8 %</td>
<td>9.4 %</td>
<td>508.6 %</td>
</tr>
<tr>
<td>Oceania / Australia</td>
<td>34,468,443</td>
<td>0.5 %</td>
<td>18,796,490</td>
<td>54.5 %</td>
<td>1.6 %</td>
<td>146.7 %</td>
</tr>
<tr>
<td><strong>WORLD TOTAL</strong></td>
<td><strong>6,574,666,417</strong></td>
<td><strong>100.0 %</strong></td>
<td><strong>1,173,109,925</strong></td>
<td><strong>17.8 %</strong></td>
<td><strong>100.0 %</strong></td>
<td><strong>225.0 %</strong></td>
</tr>
</tbody>
</table>

**Worldwide: 1,2 billions internet users**

**Growth: 225% since 2000**
Cette slide présente l'intégralité des résultats, mais je la trouve un peu chargé. Tu choisis celle que tu préfères.
How to judge the information on the Web?
Can you trust this page?

**CARTILIFE**

**THE SHARK WHO CAN GIVE LIFE**

You will know the sharks as feared animals of the sea which even can be dangerous for the man. Also there will be heard something of the famous soup of shark fin. But possibly you do not know that these same sharks can help you using their cartilage. These fish have their skeleton entirely of cartilage and exist in their current version from more than 300 million of years. We can say that they have the most perfect cartilage. And this cartilage contains many substances that perhaps you miss and cause to you pains and nuisances.

The shark cartilage contains so valuable substances as condroitin sulfate, collagen, the factor inhibitor of tumors growth, hyaluronic acid, amino acids, calcium, magnesium, etc. The lack of many of these substances in our body can cause us huge nuisances. These substances of the cartilage seems to be related to:

- rheumatic diseases
- osteoporosis
- joints and bone diseases
- certain tumors
- the immune system
- certain diseases of the skin etc.

CARTILIFE offers to you their new pills of shark cartilage, agreeable of taking and product of the highest technology and investigation with their optimized formulation. We have our own manufacture and we make all directly from the fishing until the sale. Only we use the cartilage of the fished sharks for the nourishment, thus we do not waste valuable biomass neither we affect to the kind CARTILIFE is a PHYSIOLOGICALLY FUNCTIONAL FOOD it is not medicine but one of the richest foods as very beneficial substances for our body.

Only CARTILIFE has the pills optimized with vitamin C and B6 and a cap that avoids that they will be assimilated by the acid gastric juices and they are so potent that generally it will be enough to take 3 pills per day with quite liquid before be lam. In certain cases you can double this intake. Follow always the criterion of your physician.

The presentation is in flasks of plastic of 80 pills at a recommended price of $ 34,-.
How to identify trustworthy health information?

AE-941 in Treating Patients With Relapsed or Refractory Multiple Myeloma

This study is no longer recruiting patients.

Sponsored by

Aeterna Laboratories

Purpose

RATIONALE: AE-941 may help to slow the growth of multiple myeloma. PURPOSE: Phase II trial to study the effectiveness of neovastat in treating patients who have relapsed or refractory multiple myeloma.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Treatment or Intervention</th>
<th>Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>refractory plasma cell neoplasm</td>
<td>Procedure: biological response modifier therapy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Procedure: growth factor antagonist therapy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Procedure: anti-cytokine therapy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Procedure: antiangiogenesis therapy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Drug: shark cartilage</td>
<td>Phase II</td>
</tr>
</tbody>
</table>

MedlinePlus related topics: Immune System and Disorders; Lymphatic Diseases
How do we trust information?

Information production process

Neutral Third Party validation

By a recognised organisation

From knowledgeable references

From the author

www.healthonnet.org
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</th>
<th>Details</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
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 employs in developing content. Health-related websites must make clear the ________ which they have used so that the information presented is _________. Health-related websites should also ________ who is most likely to visit the site and ensure that the information presented is ________ as possible, including disabled persons. As some sites may ________ party and hosted by a different one, these relationships should be clearly disclosed on the site.”
HONcode is the official international standard for quality of health websites in France.
The French bill 2004-810, 13th August 2004 regarding the health insurance, has mandated the HAS to define a certification procedure for health websites: the HAS chooses HON for the certifying French health websites.
Non Gouvernemental Organisation

Created in 1995 under the auspices of Ministère de la Santé Genevois (DES)

Mission: 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
HON Quality Management System

- Addition from annual internal review, HON is now inspected by neutral qualified organisations according to stringent norms like EN45011/ISO65

- Standard of quality are applied for:
  - All HON personnel during recruitment, training and internal auditing
  - Documentation of all HON procedures

- New activities
  - Complaint handling and tracking system
  - Automatic difference tracker to monitor certified sites
  - HONcode Blog will soon be online
HONcode principles


1. Authoritative
   Indicate the qualifications of the authors

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

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

4. Attribution
   Cite the source(s) of published Information and dating of medical and health pages

5. Justifiability
   Site must back up claims relating to benefits and performance

6. Transparency
   Accessible presentation, identities of editor and Webmaster, accurate email contact

7. Financial disclosure
   Identify funding sources

8. Sponsorship
   Clearly distinguish advertising from editorial content
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
An example of a certified site

A logo linked to a dynamic, unique and dated certificate. The logo also displays last date of review.
After revision by the Honcode team the status of the site is in conformance with the HON code.

Unique, personalised identification number

http://www.santemagazine.fr/

HONConduct933387

Date de revue initiale: 29 Nov 2007
Date de dernière revue: 10 Jan 2008
Durée de validité du certificat: 1 an avec réévaluation systématique
The HONcode database: HONcodeHunt

+ 5,700 sites
72 countries
32 languages
English: 52%
French: 11%; 220 HAS-HON
Italian: 7%
1,400,000 web pages certified in Google.com

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

Examples:
ClinicalTrials.gov
HealthInsite.gov.au
10000steps.org.au
betterhealth.vic.gov.au
The National Urban League
MEDLINEplus.gov
PubMed
Stop-tabac.ch
Hospital 12 de Octubre
Sociedad Argentina de Pediatría
Diabetes Netzwerk Deutschland
e-sante.fr
chu-rouen.fr
eurordis.org
Research et Développements
Search engine of HONcode certified sites
Specialised search engine

Wrapin: Your search Tool to verify medical information - Mozilla Firefox

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

Query details | Same medical terms in: Fr De It Pt Sp
cancer: Overview | Causes & Risk Factors | Screening & Diagnosis | Complications | Treatment | Prevention

Total | ClinicalTrials | HONcode | MedHelp | Bookshelf | PMC | Pubmed | News

Results in English: 1-10 of 23 found documents

1. Shark Cartilage / Cartilate / 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/PPI/UnconventionalTherapies/Shark...

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

Reformulate your search:
- Cartilage
- Neoplasms
- Carcinoma Small Cell
- Amygdalin
- Drug Toxicity
- Complementary Therapies
- Trial...

EU project: IST-2001-33260
"... This trial was unable to demonstrate any suggestion of efficacy for this shark cartilage product in patients with advanced cancer. ...

Global search engine: working with Google
Identification of certified sites

Tool bar for HONcode certified sites:

Certified

Not certified

Trusted Search engine

Certified
Trust and security solutions in PIPS

- Mechanisms and Model of Trust to assess knowledge sources of internal and external documents
  - Automatic quality criteria detection
  - Information Retrieval within a Trusted environment
  - Language complexity identification within a trustworthiness environment
  - Knowledge coverage and accessibility by using a trusted Q/A system
  - User Interface and services to improve user empowerment about trust and security
  - Privacy reinforcement with automatic generation of P3P policies
### PIPS Trusted Search Engine

<table>
<thead>
<tr>
<th>Enter Query</th>
<th>Language</th>
<th>Readably Filter</th>
<th>Trust Filter</th>
</tr>
</thead>
<tbody>
<tr>
<td>fever children aspirin</td>
<td>English</td>
<td>none</td>
<td>Authority</td>
</tr>
</tbody>
</table>

**Trust Filter:** Authority | Complementarity

#### Found 1130 Trusted Pages

<table>
<thead>
<tr>
<th>Rank</th>
<th>Title</th>
<th>URL</th>
<th>Last visited</th>
</tr>
</thead>
</table>
Conclusion

- Active for over 10 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. IJ MI 2006
Future developments

- 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
- EU Recommendation of Quality Criteria for Health Related Web sites carried out by HON
- Continued advancement in this area