

Bringing pertinent medical information to medical doctors and the public

Célia Boyer



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- Mission: HON guides Internet users by highlighting reliable, comprehensible, relevant and trustworthy sources of online health and medical information, tackling the major obstacles of the Web:
 - the overwhelming quantity of information
 - the uneven quality of health information available online
- Funded by the Geneva state, European Commission, and the French National Health Authority

- Trustworthiness of health and biomedical information
 - Use of health and biomedical websites
 - Initiatives to promote the quality of online health information
 - HON's solution: the HONcode and certification
- HON technologies
- Why KHRESMOI ...

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"On the Internet, nobody knows you're a dog."

- Health information on the web:
 - Overwhelming: "cancer" in Google: 292 millions results
 - Uneven quality
- "Adults look for health information online: 88% in USA and 71% France"
- "Health search impacted treatment decision on six in ten e-patients"
- "Three-quarters of health seekers do not check the source and date of the health information they find online"

Sources: "Cyberchondriacs" on the Rise? Harris Poll Interactive Jul 2010
Internet et la relation patients-médecins, Apr. 2010 Ipsos Public Affairs
E-patients With a Disability or Chronic Disease, Oct. 2007,
Pew internet & American Life project, pewinternet.org

- **Cyberchondria: ... unfounded escalation of concerns about common symptomatology, based on the review of search results and literature on the Web...**

Cyberchondria: Studies of the Escalation of Medical Concerns in Web Search

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Microsoft Research

The World Wide Web provides an abundant source of medical information. This information can assist people who are not healthcare professionals to better understand health and illness, and to provide them with feasible explanations for symptoms. However, the Web has the potential to increase the anxieties of people who have little or no medical training, especially when Web search is employed as a diagnostic procedure. We use the term *cyberchondria* to refer to the unfounded *escalation* of concerns about common symptomatology, based on the review of search results and literature on the Web. We performed a large-scale, longitudinal, log-based study of how people search for medical information online, supported by a survey of 515 individuals' health-related search experiences. We focused on the extent to which common, likely innocuous symptoms can escalate into the review of content on serious, rare conditions that are linked to the common symptoms. Our results show that Web search engines have the potential to escalate medical concerns. We show that escalation is associated with the amount and distribution of medical content viewed by users, the presence of escalatory terminology in pages visited, and a user's predisposition to escalate versus to seek more reasonable explanations for ailments. We also demonstrate the persistence of post-session anxiety following escalations and the effect that such anxieties can have on interrupting user's activities across multiple sessions. Our findings underscore the potential costs and challenges of cyberchondria and suggest actionable design implications that hold opportunity for improving the search and navigation experience for people turning to the Web to interpret common symptoms.

Categories and Subject Descriptors: H3.3 [Information Storage and Retrieval]: Information Search and Retrieval – Search process, Query formulation
General Terms: Human Factors, Experimentation
Additional Key Words and Phrases: Cyberchondria

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| Symptom | Cause | Web crawl | Web search | Domain search |
|-----------------|----------------------|-----------|------------|---------------|
| headache | caffeine withdrawal | .29 | .26 | .25 |
| | tension | .68 | .48 | .75 |
| | brain tumor | .03 | .26 | .00 |
| muscle twitches | benign fasciculation | .53 | .12 | .34 |
| | muscle strain | .40 | .38 | .66 |
| | ALS | .07 | .50 | .00 |
| chest pain | indigestion | .28 | .35 | .38 |
| | heartburn | .57 | .28 | .52 |
| | heart attack | .15 | .37 | .10 |

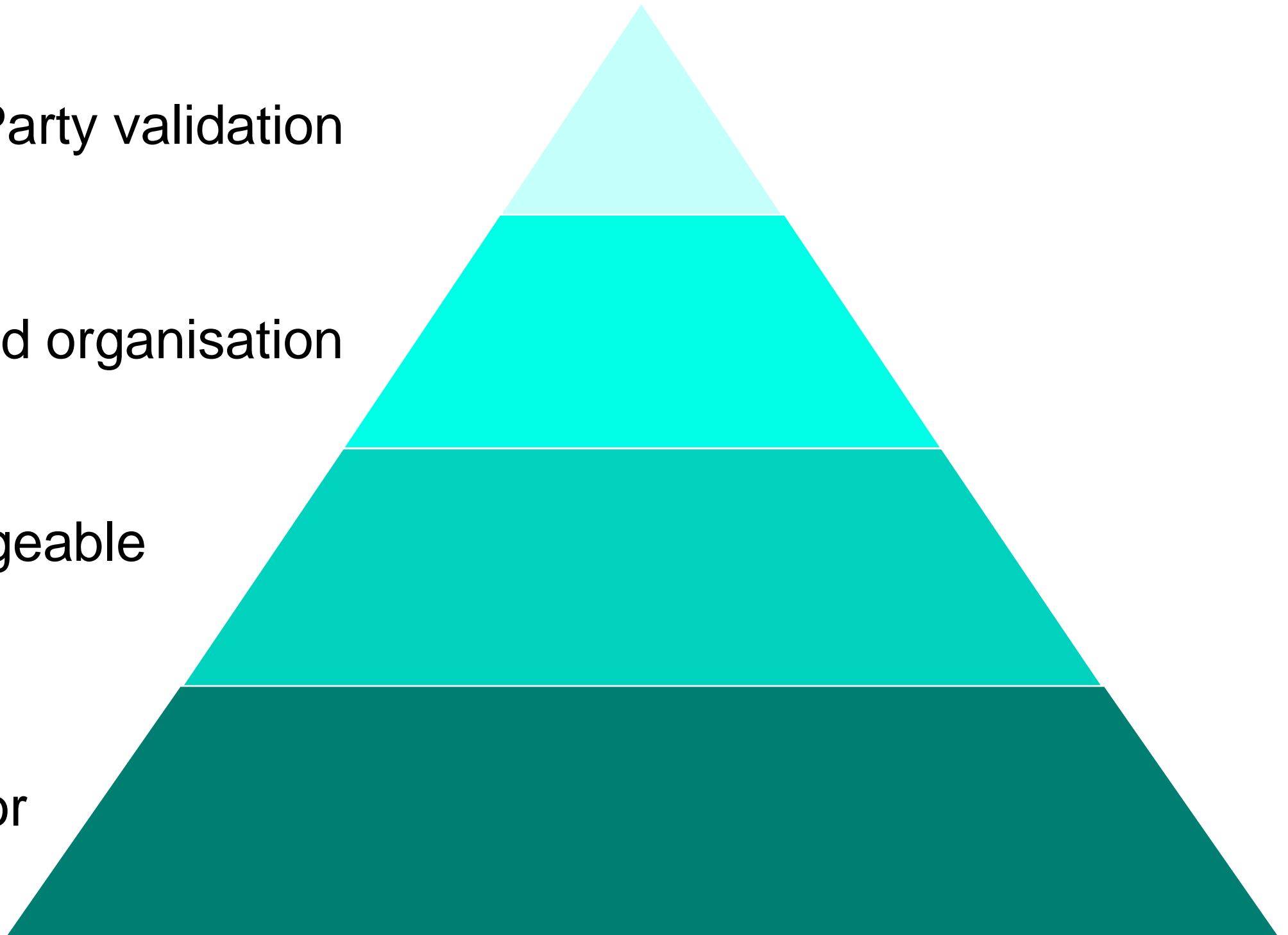
Information production process

Neutral Third Party validation

By a recognised organisation

From knowledgeable
references

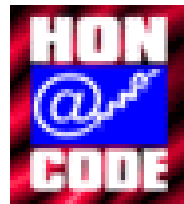
From the author



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Initiatives to control the Web...

... specific for health websites



Net Scoring®



... applicable for all sites



Trustworthiness Approaches (1/2)

- Selection or referencing:
 - OMNI-INTUTE (for study and research), 1996
 - Yahoo! DMOZ, MedlinePlus (Miller et al, 2000)
 - CISMeF (Darmoni et al, 1999), 500 sites (75'000 pages)
- Self-regulation (the most utopian):
 - Internet Healthcare Coalition: eHealth Code of Ethics (Risk, 2000)
- Certification of web pages (the most accurate):
 - **HONcode** (Boyer et al., 1996), +7'400 sites
 - URAC (urac.org, 2001), 25 sites, USA
 - TNO Health Trust : QMIC (Sheldon, 2002), The Netherlands
 - WMA (Bosch, 2002), + 500, Cataluña, Spain
 - The Information Standard (theinformationstandard.org, Dec. 2009), 34 sites

- Popularity of web pages (the most naturally used):
 - Google (Page et al., 1998)
- Collaboration of users (the most democratic):
 - Outfoxed / Lijit (www.lijit.com)
 - Google co-op (WebPages labelled by user organisation)
 - Wikipedia
- Education of users for quality evaluation (the most complementary):
 - Oxford University : DISCERN
 - HON's health websites users' evaluation toolkit

- eEurope 2002: Quality Criteria for Health related Websites, Communication from the European Commission (created with participation of HON)

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 sources which they have used and ensure that the information presented is appropriate, 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 to all visitors 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.”

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HON CODE

1. Authoritativeness
2. Complementarity
3. Privacy
4. Attribution
5. Justifiability
6. Transparency
7. Financial disclosure
8. Sponsorship

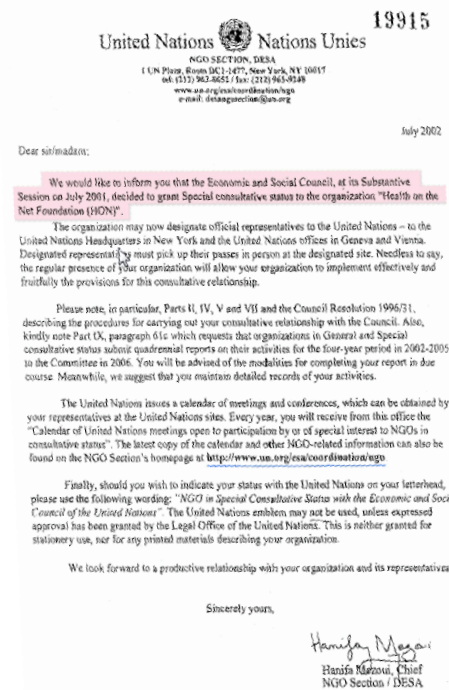
- Perimeter: human bio medical information websites
- Certification asked by webmasters
- Free of charge
- Neutrality and independence of actions
- Since 1996



- Health website certification since 1996
 - 8 principles
 - Free online application
 - Manual review and annual audit
 - Quality Management System
 - R&D of new technologies that can help certification
- eEurope Award for eHealth in 2004
- HONcode is the official international standard for quality of health websites in France since November 2007



International recognition



- In 2002, recognized as a non-governmental organization and granted special consultative status with the United Nations Economic and Social Council. Renewed in 2006 and in 2010.
- In Nov 2009, Health on the Net Foundation (HON) has been appointed as a Corporate Member of the International Medical Informatics Association (IMIA) during their General Assembly in Hiroshima.
- June 2010: HON Liaison A to the Health Informatics Technical Committee (ISO/TC 215)



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- Search engine:
 - Health information crawling and indexing (HON database)
 - WRAPIN
 - Question Answering system
 - HealthPedia (for iPhone)
- Document categorization:
 - Automatic quality and trust detection
 - Health document readability measure
- HON portal for a sustainable exploitation
 - Audience identification: patient vs medical professional

- Compliance with the HONcode principles
- Indexed with MeSH terms and HON labels
- 7,400 sites in 102 countries
- 35 languages
- + 15 millions web pages certified



■ Sources:

| | | |
|---|---|------------|
|  | HONcode : data base of HONcode-certified medical web sites (multilingual). | 10'000'000 |
|  | 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). | 15'000'000 |
|  | Medhunt : all the medical web sites indexed by HON (multilingual). | 80'000 |
|  | Drug FDA : Information in English about medicines issued by the Food and Drugs Administration (USA). | 1'000 |
|  | 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). | 23'000 |
|  | Uro : scientific articles in French covering the domain of Urology, made available to WRAPIN by " Association Française d'Urologie ". | 2'500 |
|  | Oeso : scientific articles in English specializing in the diseases of the oesophagus, made available by the Oeso Fondation. | 1'153 |
|  | HONnews : daily medical news in English from HealthDay. | 13'000 |
|  | Bookshelf : The Bookshelf is a growing collection of biomedical books from the NLM | 24'000 |
|  | PMC : is the U.S. National Institutes of Health (NIH) free digital archive of biomedical and life sciences journal literature. | 10'225 |

Regularly updated

≅ 25'154'800 web pages

- For the general public, patients and medical professionals
- Multi-source:
 - HONcode, Pubmed Central, ...
 - Trustworthy sources
- Multi-lingual support:
 - EN – FR – ES – IT – DE
 - Based on MeSH nomenclature
- Spell checking (\Rightarrow query reformulation)
- Term suggestion (\Rightarrow query explosion)

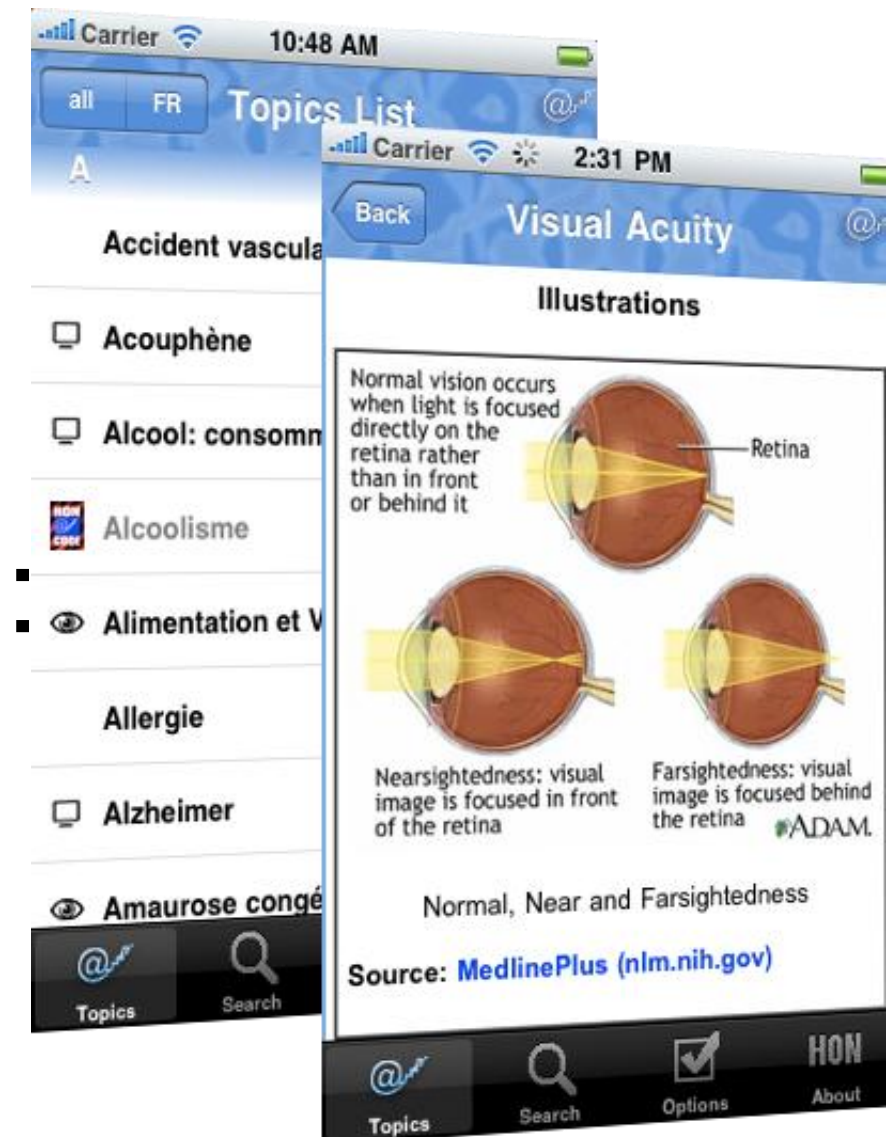


- For the general public and patients
- Returns answers in response to a question, rather than documents containing answers,
- Multi-lingual support (EN – FR – ES – IT – DE)
- Source = HONcode (\Rightarrow reliability)



[Advanced Search](#)

- For the general public, patients and medical professionals
- Trustworthy health information encyclopedia
- Multi-lingual search engine:
 - EN – FR – ES
- Multi-source (pre-selected):
 - Clinical trials
 - Scientific publications
 - TV health broadcast



- Trustworthiness: pre-selected web sites
 - HONcode, Pubmed, MedHunt, FDA, ...
- Quality: learn automatically ethical principles
 - Statistical analysis of sentences
 - Identification of date, email, phone number

| | HC1 (authority) | HC2 (complementarity) | HC3 (confidentiality) | HC7 (sponsorship) | HC8 (advertising) |
|-----|--------------------|--------------------------|--------------------------|----------------------|----------------------|
| HC1 | 99.7 | 0.30 | 0 | 0 | 0 |
| HC2 | 1.34 | 98.5 | 0 | 0 | 0.16 |
| HC3 | 0 | 0 | 100 | 0 | 0 |
| HC7 | 0 | 0 | 0 | 89.9 | 10.1 |
| HC8 | 0 | 0 | 0 | 1.00 | 99.0 |

- Numerical measure based on:
 - Words per sentence
 - Ratio of complex words
 - Ratio of complex medical words
 - Syllables per word
- Automatic readability measure based on:
 - Text compression ratio
 - Ratio of medical terms
 - Number of adjectives and adverbs

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- Current status: lack literacy skills to evaluate the information quality of health Web pages
- Exploitation of the citizen and the health professionals terminology specificities for searching health information
- Development of a model of trust
 - Automatic approach to judge the trustworthiness and objectivity of health and biomedical web pages
 - Filtering quality approach
 - Manual evaluation

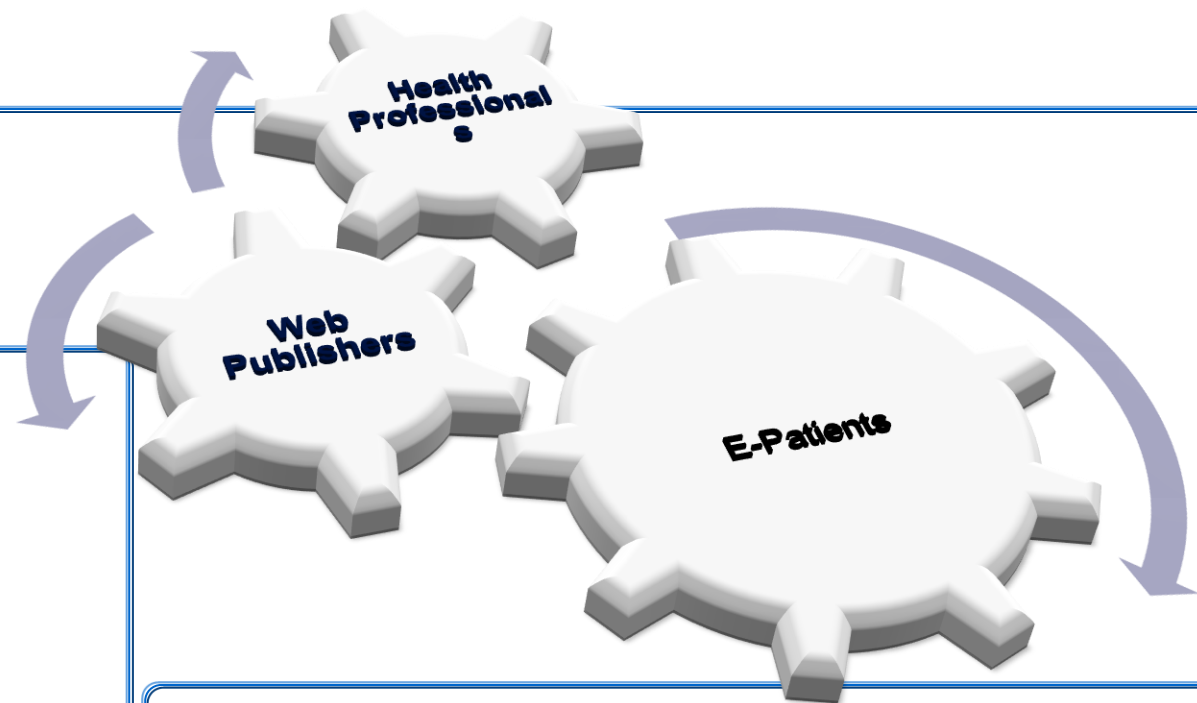
- For a health related question, collect information from many sources (semi automatic process)
- Adapted to the users (readability)
- Internet a multi-lingual environment not totally exploited: health answers not only available in the user's own language

Medical Information for European Citizens and Medical Professionals

- Understand the needs
- Validate the possible solutions with the users and,
- Assess the impact in filling the needs
- Massive testing
 - Patients: 8'665 visits per day;
 - Professionals: 2'704 visits per day and 2'300 physicians from the Geneva Medical Association
 - Users recruiting from patient-oriented certified websites

Why KHRESMOI ...

- Recommendation of trustworthy health information to patients
- Better communication on health- related online material
- Use of professional web sources
- Reliable peer support



- Higher employee loyalty
- Increased organization prestige
- Better users adherence to the web-site

- Access to and use of trustworthy health information
- Developed decision-taking skills
- Less cyberchondria

Questions?

- Automatic ethical principle detection
 - Philosophy: determine and localize ethics and quality criteria automatically from text
 - Detection of HONcode seal in web pages
 - Text categorization
 - IR with relevance feedback
- Complementary solution to help human certification and revision
- Opportunity to solve the challenge of the increasing number of websites
- Integration into general search engines

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- Indicate the qualifications of the authors
- Indicate the qualifications of the moderators
- Indicate if the platform is moderated or not
- Respect and Honesty



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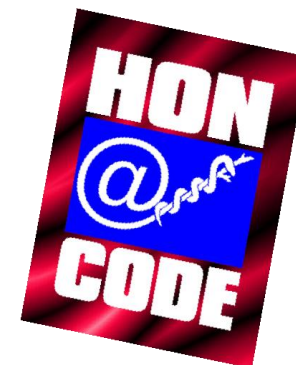
- Information should support, not replace, doctor-patient relationship
- Mission and Audience of the site
- Age limitation



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- Respect the privacy and confidentiality of personal data submitted to the site by the visitor
- Disclose that posted message are visible for all
- Disclose if posts can be modified, or deleted



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- Cite the source(s) of published information and dating of medical and health pages
- The collaborative platform rules must be easily accessible from the platform's homepage



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- Site must back up claims relating to benefits and performance
- Disclose conflict of interests



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- Accessible presentation, identities of editor and Webmaster, accurate email contact
- Disclose email address for social network platform members in order to contact the moderators of the forum



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- Identify funding sources
- Identify funding sources and if moderators are volunteers or not



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- Clearly distinguish advertising from editorial content
- Disclosure of links of interest

