Intelligent Information Access techniques for on-line health information search: a survey of non-physicians

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The Health On the Net Foundation

- Created in 1996, HON is a not-for-profit foundation
- Since 2002 NGO with special consultative status with the UN Economic and Social Council
- Since 2010 a Category A Liaison to the Health Informatics Technical Committee (ISO/TC 215) of the International Organization for Standardization
- Our mission is to guide the growing community of healthcare consumers and providers on the World Wide Web to sound, reliable medical information and expertise.
- Funded by the Geneva state, the European Commission, and the French National Health Authority
Outline:

- Background and objectives
- Methodology
- Results
- Conclusions
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Background

- The number of people going online is growing
- The number of people looking for online health information is growing
- The motivation for online health searches\(^1\):
  - the desire for reassurance,
  - the need for a second opinion,
  - seeking of greater understanding,
  - avoidance of perceived barriers in accessing traditional information sources

Online health search

**Advantages:**

1. Access to a wide range of health topics
2. Convenience of use
3. Peer experience and support
4. Private/confidential questions
5. Easy access to stigmatized health topics

**Disadvantages:**

1. Overwhelming quantity of search results => time-consuming
2. Veracity of search results
   - Contradicting, confusing statements,
   - Miraculous treatments, unjustified claims
   - Biased information, manipulated content
3. Often «technical» language of online medical/health information
4. Phenomena of cyberchondria
5. Doubting physician authority
6. Self-diagnosis

Better informed and empowered patients vs. Confused and misled patients
A complex solution

Curated online health sources

Customized/personalized and easy access

Good communication with a physician

Trustworthy, reliable health information

Information adapted to patient’s knowledge in a user-friendly environment

Web sites «prescription», conversation between a physician and a patient
Curated online health sources

Our approach: **HONcode certification** based on 8 HONcode principles

<table>
<thead>
<tr>
<th>Principle</th>
<th>Description</th>
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<tbody>
<tr>
<td>Authoritative</td>
<td>Indicate the qualifications of the authors</td>
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<tr>
<td>Complementarity</td>
<td>Information should support, not replace, doctor-patient relationship; Mission and Audience of site</td>
</tr>
<tr>
<td>Privacy</td>
<td>Respect the privacy and confidentiality of personal data submitted to the site by the visitor</td>
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<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>
KHRESMOI is a EU-funded project (2010-2014) aiming to build a multi-lingual, multi-modal search and access system for biomedical information and documents.
Aims of this study were to answer:

- How do non-medical professionals search for health information?
- What difficulties do they encounter when searching for health information?
- What functionalities should a tool for online health information search have?
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Methodology

- Web-based questionnaire
- Available for 2 months in spring of 2011
- Promoted via HONcode certified web sites and social media channels
- Available in 4 languages: English, French, Spanish and German
- Descriptive statistics to analyze the results
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Respondents profile

- **385** completed at least 90% of the questionnaire
- 53% females and 47% males
- 85% between ages 20 and 59
- 79% graduated from a university
- From 42 countries worldwide, with **23% from France**, **14% from Spain**, and **10% from the US**
- 90% had used the Internet for more than six years
- 84% rated themselves as good or professional users
- 95% used the Internet on a daily basis
How do they search for health information?

- 49% at least several times a week
- 82% used a search engine often or always
- Typically type 2-3 words, usually medical terms
- Advanced options: language filter, data range and country limitations
Difficulties encountered

- 60% have difficulties finding the information at least sometimes

**Readability**
- Distracting Ads

**Evaluation of the link for each search result**
- Poor organization of search results
- Search results lack specificity
- Lack of quality filter

**Quality and expliciteness/fullness of description**
- Questionable trustworthiness
- Relevance of matches

**Overload with information quantity**
- Lack of quality filter

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Desiderata for the future

- 54% would like links to be categorized

- Medical dictionary/Thesaurus
- Suggested relevant topics
- Advanced search (country, language, date...)
- Search of images
- Spelling correction

[Diagram showing percentage of respondents rating each feature as very important, important, moderately important, of little importance, or unimportant]
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Conclusions

Most of the aims in Khresmoi are supported by our survey findings:
- provision of trustworthy content
- readability level customization
- geographical and language customization
- categorization of results
- query formulation support
- search for multimedia files

New points in the agenda:
- the integration of a medical thesaurus
- relevant topic suggestion
- 3D body visualization
Currently we are working on:

- An automated estimation of the suitable target audience (e.g., required education level)
- Autocompletion techniques and spell checking of search queries,
- Cross-linguistic information retrieval (CLIR)
- Enhanced methods to search for images and videos
- Customization by language and geographical area

A wide range of NLP (manual annotation coupled with active learning algorithms) and IIA techniques will be used to return trustworthy results that are customized and suitable to the user’s knowledge.
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