Online health information search: what struggles and empowers the users?
Results of an online survey

Natalia Pletneva, Alejandro Vargas, Celia Boyer
Health On the Net Foundation, Geneva, Switzerland
Outline:

- Background and objectives
- Methodology
- Results
- Conclusions
Background

- Number of people going online is growing
- Number of people looking for online health information is growing
- The motivations for online health searches¹:
  - 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

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:
The **HONcode certification** based on 8 HONcode principles

<table>
<thead>
<tr>
<th>Principle</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Authoritativeness</td>
<td>Indicate the qualifications of the authors</td>
</tr>
<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>
</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>
Customized/personalized access

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?
Outline:

- Background and objectives
- Methodology
- Results
- Conclusions
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
Outline:

- Background and objectives
- Methodology
- Results
- Conclusions
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
- 30% worked in healthcare (excluding physicians); 21% had computer and/or mathematical occupations; and 13% worked in education and training (13%)
- 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

- Relevance of matches
- Questionable trustworthiness
- Quality and explicitness/fullness of description
- Overload with information quantity
- Lack of quality filter

---

<table>
<thead>
<tr>
<th>Difficulties Encountered</th>
<th>Always</th>
<th>Often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relevance of matches</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Questionable trustworthiness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality and explicitness/fullness of description</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overload with information quantity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of quality filter</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Always          Often        Sometimes    Rarely     Never
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

![Bar chart showing the importance levels of each feature]

Legend:
- Very important
- Important
- Moderately Important
- Of little importance
- Unimportant

+825x691 to 1013x759
Outline:

- Background and objectives
- Methodology
- Results
- Conclusions
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
Thank you!

NATALY.PLETNEVA@HEALTONNET.ORG
CELIA.BOYER@HEALTHONNET.ORG

WWW.KHRESMOI.EU
WWW.HEALTHONNET.ORG