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

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Outline:

- Background and objectives

- Methodology

- Results

- Conclusions

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Background

- Number of people going online is growing

- Number of people looking for online health information is growing

- The motivations 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

(1) Powell J, Inglis N, Ronnie J, Large S. The characteristics and motivations of online health information seekers: cross-sectional survey and qualitative interview study. J Med Internet Res 2011; 13(1): e20

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
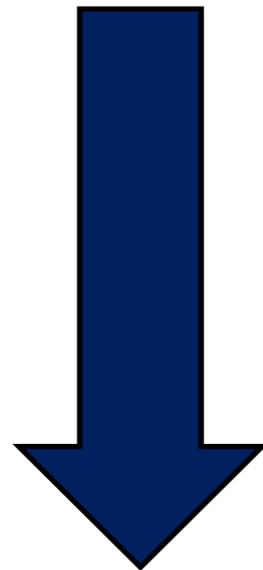
Better informed and empowered patients

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
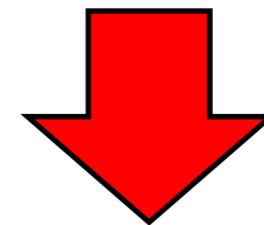
Confused and misled patients

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

Authoritativeness	Indicate the qualifications of the authors
Complementarity	Information should support, not replace, doctor-patient relationship; Mission and Audience of site
Privacy	Respect the privacy and confidentiality of personal data submitted to the site by the visitor
Attribution	Cite the source(s) of published information and dating of 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
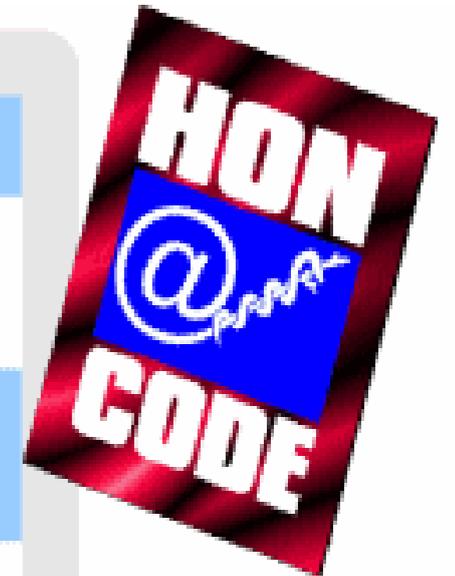
Customized/personalized access

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.
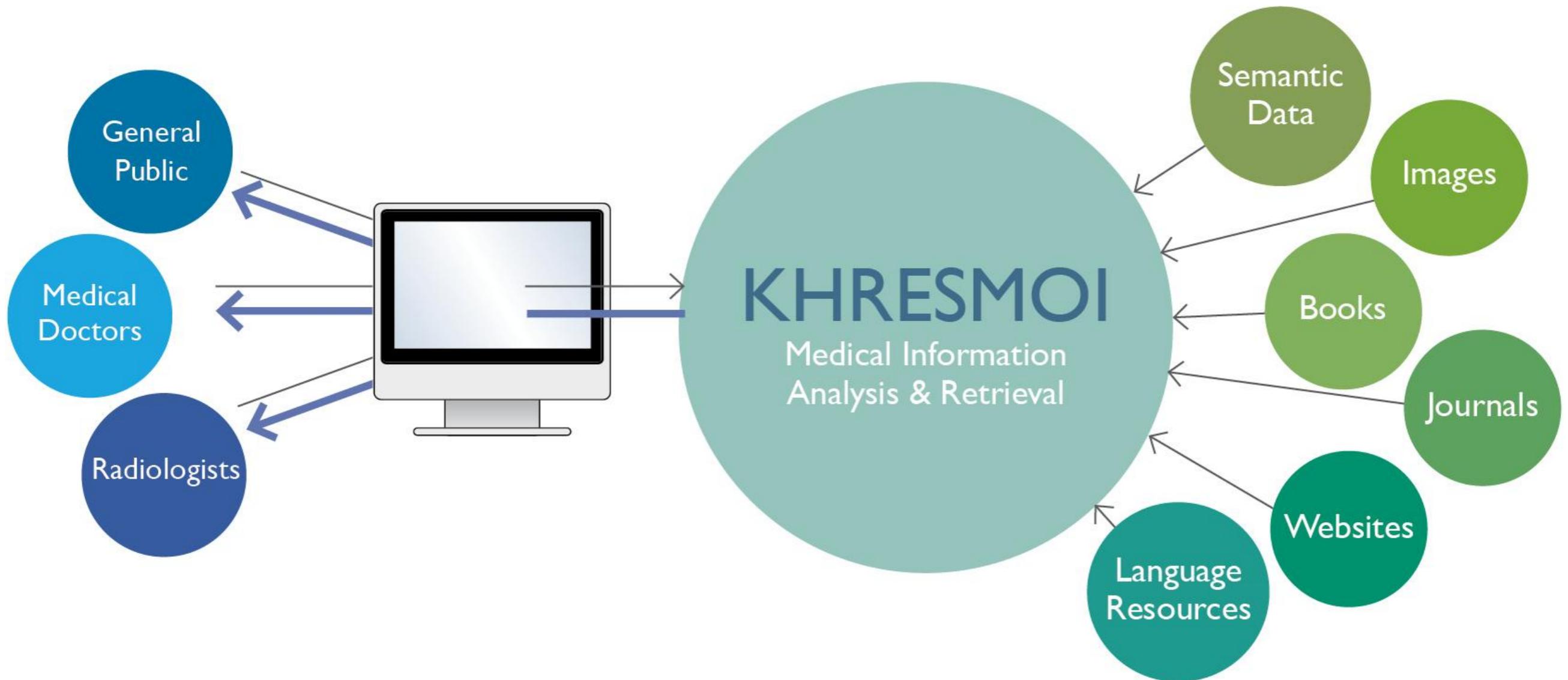
Aims of this study were to answer:

- 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?

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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

- 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 expliciteness/fullness of description
Overload with information quantity
Lack of quality filter

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

■ Always ■ Often ■ Sometimes ■ Rarely ■ Never
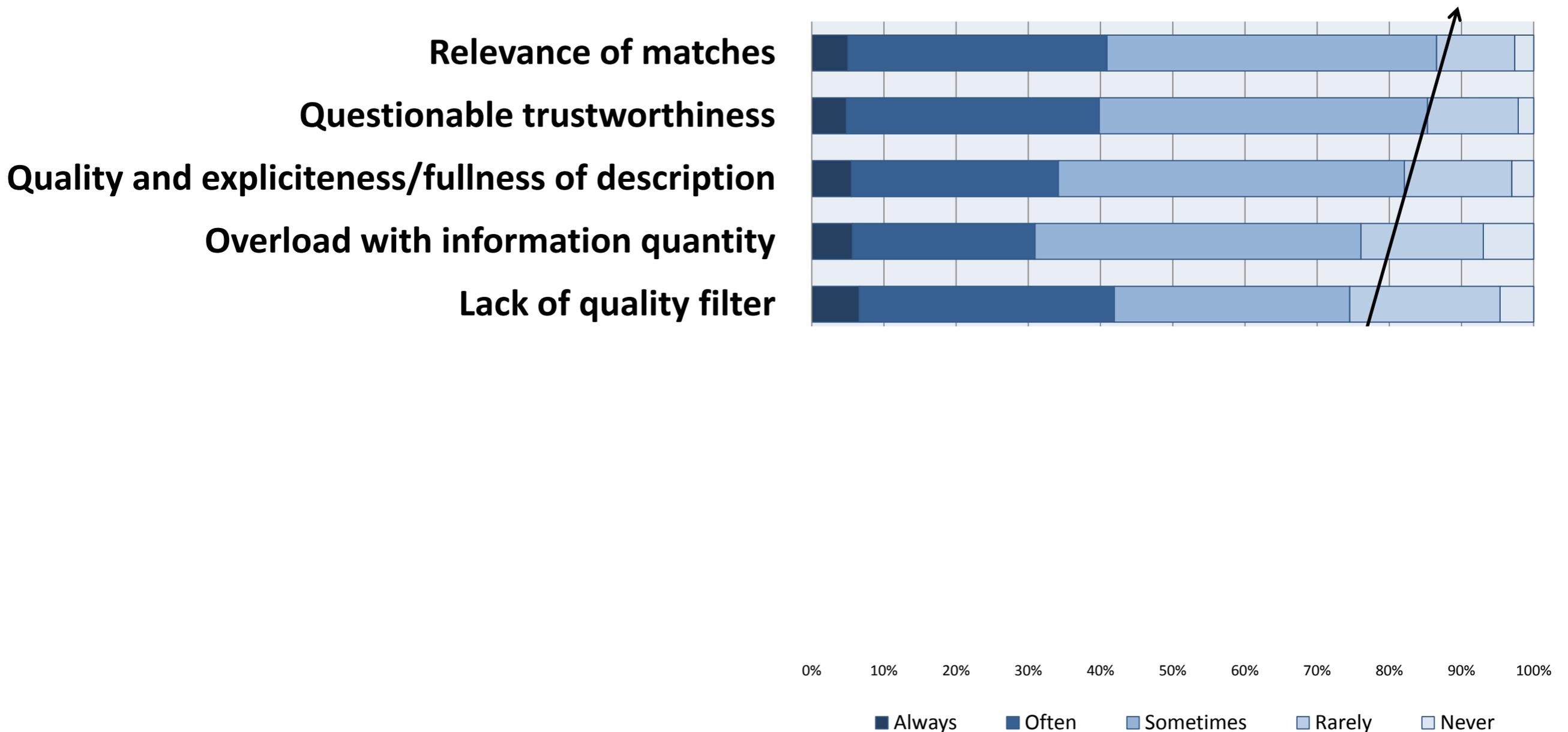
Desiderata for the future

- # 54% would like links to be categorized

Medical dictionary/Thesaurus

Suggested relevant topics

Advanced search (country, language, date...

Search of images

Spelling correction

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

■ Very important   ■ Important   ■ Moderately Important   □ Of little importnace   □ Unimportant
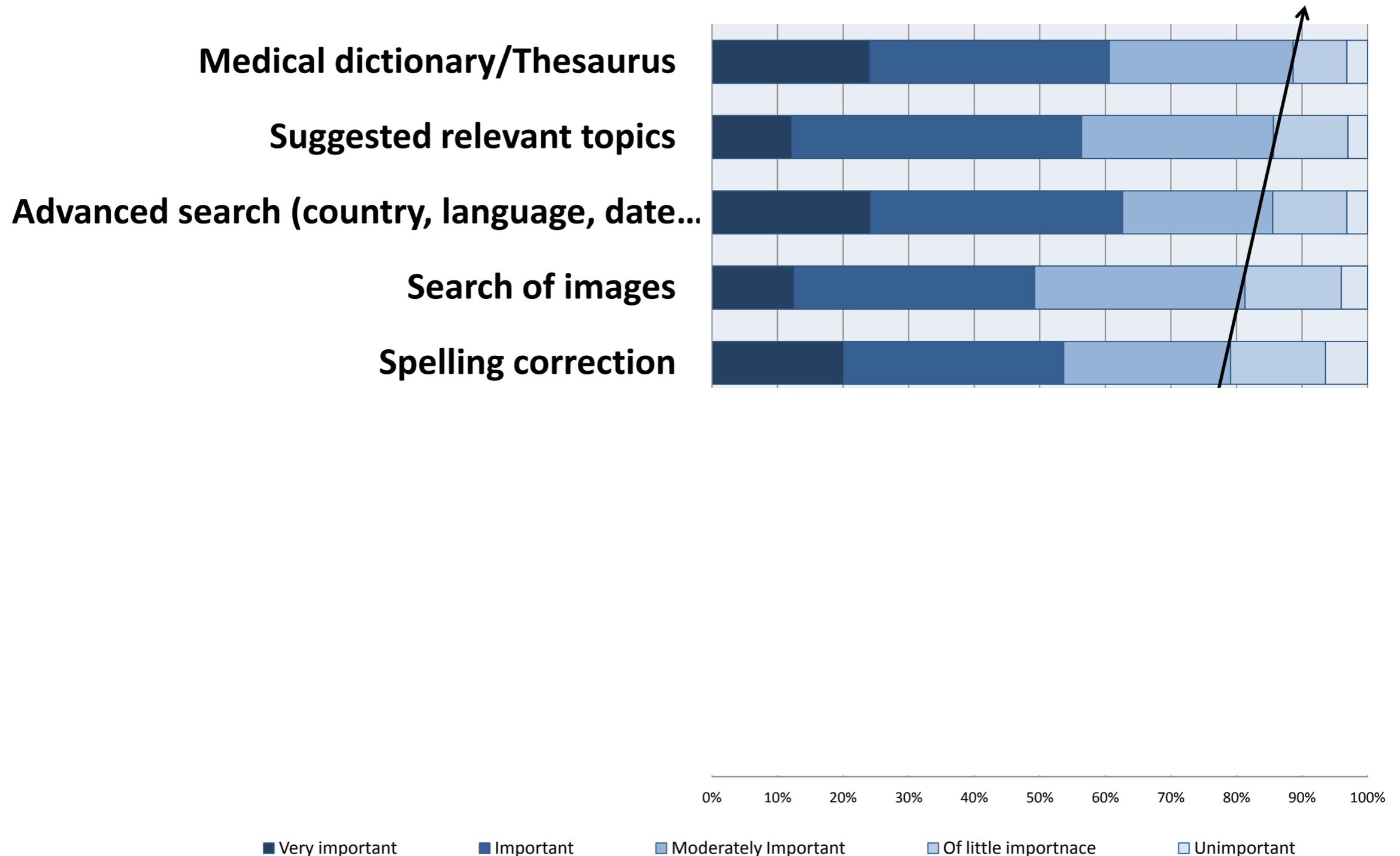
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Conclusions

- 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

Thank you!

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