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D8.1.1. Requirements for the general public health search

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Executive summary

This report presents the results of the survey conducted by the Health on the net (HON) Foundation in the framework of the EU project KHRESMOI. The aim of the survey was to identify the most important user requirements and difficulties in a process of online health information retrieval to be further used for use case elaboration. Following a literature review, no study was found that clearly explained the search process and identified Internet users' preferences. Thus, it was necessary to design a specific questionnaire based on HON logs, previous HON surveys and a literature review. The questionnaire was developed from December 2010 to March 2011 in collaboration with the Society of physicians of Vienna, Austria. Furthermore, it was translated from English into French, Spanish and German and put online. The promotion of the survey started in the end of March, 2011 and lasted for about a month.

385 answers were collected, representing mostly the opinions of highly educated users from healthcare (not physicians) and IT areas of occupation. Overall, the representatives from 42 countries around the world filled in the questionnaire with top contributors from France and Spain.

Currently, most of the respondents reported connecting to the Internet via Wi-Fi, and many of them are using mobile devices (laptops and smartphones mostly). The Internet was mentioned to be the second source of health information after physicians, due to its accessibility and "easiness". The most researched topics were general health, chronic diseases and lifestyle. Illness-related information can be prioritized in the following way: treatment/therapy, detailed and general disease description, drugs and scientific articles. The most important characteristics of a search engine are relevance and trustworthiness of results. It seems that the main problem is that results currently retrieved using a general search engine do not satisfy these requirements. Additionally, advertisement banners, contradicting information found on different web sites, and difficulties related to very precise queries are some of the barriers encountered.

The ideal representation of the information will be a categorization of the results into different groups. Helpful tools, which are highly appreciated by respondents, are advanced search, medical dictionary/thesaurus, suggested relevant topics, image search, and risk factor tools. Most users say they tolerate ads in order to have a search engine free of charge, but would like to be ensured that the ads have undergone a rigorous quality control. Some respondents have also mentioned they would like to have free access to the medical literature.

Finally, users will always find health information of poor quality, thus efforts should be made to create an approach where understandable, good-quality information is available, leading to potentially better health choices.

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2 List of abbreviations

FDA	the USA Federal Drug Administration
GAW	Gesellschaft der Ärzte in Wien (The Society of physicians of Vienna)
HON	Health On the Net Foundation
IMIA	International Medical Informatics Association
NHS	the UK National Health Service
SPA	Swiss Patient Association
WHO	World Health Organization

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4 Background

4.1 Internet users in Europe

The amount of people surfing the Internet is constantly growing. According to the Internet World statistics, nearly two billion people, or 28.7% of the world's population, are using the Internet¹ [1]. The numbers vary from one region to another, in North America, 77.4% of the population is online, with numbers growing steadily for the past ten years (146% growth between 2000 and 2010). In Africa, only 10.9% of the population uses the Internet, but the growth was 2357% over the past ten years.

Europe (as a geographical region) accounts for almost a quarter (24,2%) of the world Internet user community. The Internet penetration across European countries is 58,4% (2010) and the growth in Internet use for the period 2000-2010 has been 352%. The biggest Internet user communities are in Germany (65,1 million), Russia (59,7 million), the UK (51,4 million) and France (44,6 million) in 2010. The highest Internet penetration was noted in the Northern European countries² [2].

	European Country	Percentage of population, 2010
1	Iceland	97.6
2	Norway	94.8
3	Sweden	92.5
4	Netherlands	88.6
5	Denmark	86.1
6	Finland	85.3
7	Luxembourg	85.3
8	United Kingdom	82.5
9	Andorra	79.5
10	Germany	79.1

Table 1. The European countries with the highest Internet penetration (2010)

¹ <http://www.internetworldstats.com/stats.htm>

² <http://www.internetworldstats.com/stats4.htm>

4.2 The Internet for health

4.2.1 International trends

Since its inception, the Internet has been used for health purposes and the trend is growing steadily. 59% of the American population looked for health or medical information online in 2011³ [3]. According to the Harris Poll the percentage of all US adults who have ever searched for health or medical information online has increased from 27% to 76% from 1998 to 2010 and the percentage of those who do it sometimes or often (on average 6 times a month) increased from 42% to 73%⁴ [4]. There are no aggregated statistics for the EU countries. The first cross-country European study showed a relative growth from 14% to 39% in the 2005-2007 period [5]. More recently, national bodies reported in 2010 that 52,5% of adults in Spain were looking for health content on the Internet [6] and 39% in the UK⁵ [7].

4.2.2 Digital divide and mobile access

Emerging technologies have always produced a gap between those who adopt them and those who do not. Since 1997, this has been known as the ‘digital divide’ [8], the term was further changed to ‘social digital divide’, signifying that divide was predetermined by the level in education, income, and race. Naturally, this divide created a gap in access to online health information. However, a recent tendency called “mobile health” promises, if not to erase, at least to narrow the gap in access to online health information. With the growing number of mobile phone service subscribers using the Internet [9], online health information will become accessible to more people. In 2010 in the USA, 17% of cell phone owners used their phone to look up health or medical information, and 29% of cell owners aged 18-29 did such searches⁶ [10].

4.2.3 Benefits, drawbacks and consequences of health information surfing on the Internet

Online health surfing can be very beneficial for the novice users in terms of feelings of reassurance, confidence, and relief⁷ [11] but due to the overwhelming quantity and uneven quality of online health information it might also be dangerous and health threatening [12]. Although medical professionals are qualified to evaluate information quality, they can also be overwhelmed with its quantity and put off by the associated time consumption.

The quality of online health information is often questionable. In an ideal world everyone would post and share information in an ethical and comprehensible way. Reality however is different. The information provided is often incomplete and in some cases misleading [13,14,15]. This happens for example when an author does not reflect all sides of a phenomenon unintentionally due to his/her health literacy or outdatedness of posted information, or when the information is biased due to commercial interests directly or indirectly declared by the owners of the web site. The consequences on the users’ health are unpredictable: so far there are no studies showing that online health information causes harm. Nevertheless, with experience both users’ scepticism and the demand for high quality information are growing. For example, in the USA, among those looking for health and

³ http://www.pewinternet.org/~media/Files/Reports/2011/PIP_HealthTopics.pdf

⁴ <http://www.harrisinteractive.com/vault/HI-Harris-Poll-Cyberchondriacs-2010-08-04.pdf>

⁵ <http://www.statistics.gov.uk/pdfdir/iahi0810.pdf>

⁶ http://www.pewinternet.org/~media/Files/Reports/2010/PIP_Mobile_Health_2010.pdf

⁷ http://www.pewinternet.org/~media/Files/Reports/2006/PIP_Online_Health_2006.pdf

medical information online, the number of people dissatisfied with their online health information search results and with the reliability of information has been increasing from 6% to 9% and from 5% to 8% respectively in the last five years [4]. Despite mostly positive outcomes reported by Pew, 25% of e-patients said they are overwhelmed by the amount of information found online: 22% feel frustrated, 18% confused and 10% frightened by the serious or graphic nature of the information found online [11].

The Internet influences the doctor-patient relationship. Physicians remain the most significant and valuable source of information for patients. In France, in 2010, patients preferred asking their physician rather than the Internet (89% vs. 64%)⁸ [16]. On the other hand, an international study of 2008 revealed that 88% turn to their physicians to validate online information. Conversely, the same number (88%) turns to other sources to validate information from their physician⁹ [17].

Some studies [11, 18, 19] proved that health searches start most commonly with the use of a general search engine such as Google®, Yahoo®, etc. However, the trustworthiness of the search results is often questionable as was discussed above. It was also proven that a search engine specially designed for health and medical information retrieval provides more reliable results [20].

4.3 The objectives of the report

KHRESMOI aims at allowing members of the general public to obtain reliable and understandable medical information by developing automated and semi-automated approaches to classifying information. In addition, machine translation should ease the access to information in a user's own language.

To develop this new search engine focused on biomedical information, it is necessary to understand what is valued and desired by the general population looking for online health information as well as identify the usability barriers for further elaboration of a use case.

Despite a variety of studies dedicated to the quality of online health information and the influence of the Internet on the doctor-patient relationship, there are no studies that deal in depth with the process of health information retrieval by member of the general public. Thus, the aim of this report is to present the result of the online survey in order to understand how people search for online health information. Eventually, a list of requirements identified will be used for the elaboration of the use case.

5 Methodology

5.1 General approach

To understand the opinions of the general public regarding health information search on the Internet, a survey was conducted. The questionnaire was developed by the HON team. The general approach was to analyse previous HON surveys, HON search logs and to conduct a literature review (mostly literature from 2005 until now was taken into account due to a fast development in health information on the Internet). The interview with the Swiss Patient Association¹⁰ allowed us to validate

⁸ <http://www.conseil-national.medecin.fr/article/vers-une-meilleure-integration-d%E2%80%99internet-la-relation-medecins-patients-982>

⁹ http://static.edelman.com/wwwedelman/healthengagement/docs/Edel_HealthBarometer_R13c.pdf

¹⁰ Full report: Appendix 1

the first set of questions and to add new ones. As a part of cumulative efforts to prepare two similar questionnaires (one targeting the general public, and a second one for medical doctors), the development of the questionnaire was also discussed with the project partner, the Austrian Society of physicians in Vienna (GAW). When the questionnaire was prepared it was also validated by other partners of the project. The questionnaire was further translated into French and Spanish by HON team, and German (GAW) and uploaded on the HON Foundation web site¹¹.

- **Questionnaire preparation:** December 2010 – March 2011
- **Online survey:** End of March 2011 – End of April 2011
- **1st version:** four parts and 17 questions in total
- **Final version:** six parts and 53 questions¹² in total
- **Available in** four languages (English, Spanish, French and German)

5.2 Structure of the questionnaire

Part 1. Internet use (9 questions)

- User experience description
- User frequency of health search

Part 2. Current Search of health information (8 questions)

- Current search of health information
- Identification of user preferences and requirements regarding to health information search
- What users look for

Part 3. Use of search engines for health topics (14 questions)

- Identification of user preferences and requirement regarding the use of search engines
- User behavior while typing a query and analyzing search results

Part 4. Difficulties and barriers (3 questions)

- Technical and non-technical obstacles
- Influence of advertisements

Part 5. Let's dream of a citizen-centered health search engine (7 questions)

- Display of search results
- Helpful tools
- Funding

Part 6. About you (12 questions)

- Socio-demographic characteristics
- Availability of resources in a mother tongue

¹¹<http://www.healthonnet.org/kpat>

¹² full version: Appendix 2

5.3 Promotion of the survey

In the beginning of January the first banner was created and hosted on the HON web site (international audience), on SanteRomande.ch (French-speaking part of Switzerland) and Provisu.ch (English, French and Spanish-speaking audience) (see Figure 1). Its aim was to create awareness and to recruit Internet users for the interviews and survey.



Figure 1. The first KHRESMOI survey promotion banner (HON Foundation web site).

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The banner links to a page¹³ containing a detailed study description in English and French. Initially, there was a possibility to choose how users wished to participate (telephone interview, questionnaire, and focus group); however it appeared that a vast majority wished to fill in a questionnaire.

When the general public survey was launched, there was a possibility to choose between a citizen questionnaire and a physician questionnaire¹⁴ (as the physician questionnaire is not yet available we asked the interested persons to leave their email, so we can notify them as soon as it is online).

When the survey started, HON Facebook and HON Twitter promotion campaigns were launched and we sent emails and newsletters to:

- Seven web masters who promoted the previous HON survey with flashing banners (En/Fr/Es).
- 7300 HONcode certified web sites, asking webmasters to promote the survey via their web sites with the banners (En/Fr/Es/De)¹⁵ (see Figure 2). It was promoted on 35 web sites including the International Medical Informatics Association (IMIA) website (Figures 3-5).

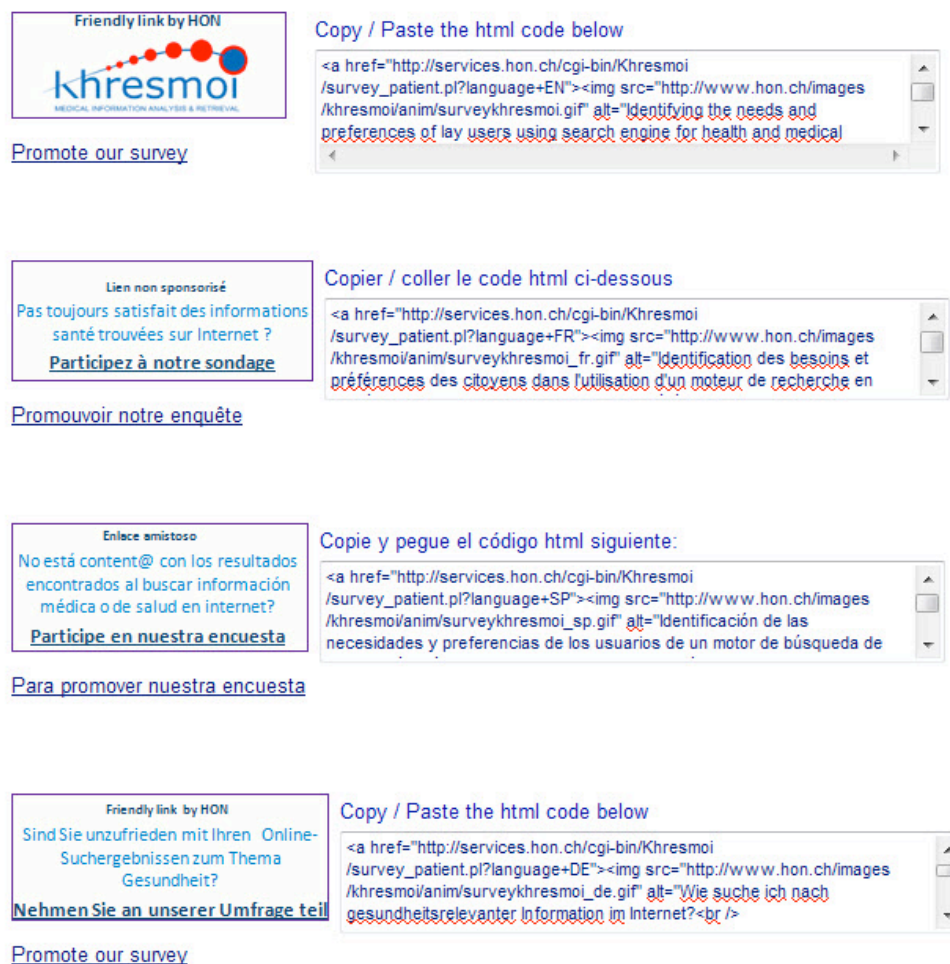


Figure 2. The second version of the KHRESMOI survey promo banner (En, Fr, Es, De).

¹³http://www.hon.ch/KHRESMOI/survey_khresmoi_en.html

¹⁴ Deliverable 8.1.2 “Requirements document for health professional search”

¹⁵http://www.hon.ch/Khresmoi_survey_promotion_v2.html

Santé romande.ch

Confort de lecture
Choisissez ci-dessous
A A A A A

Informations sur les maladies les plus communes:

Bébés/Enfants - Adolescents - Adultes - Femmes enceintes - Séniors

- Alcoolisme
- Allergies
- Alzheimer
- Amblyopie
- Anorexie
- Anorexie mentale
- Arthrose
- Asthme
- Attaques cérébrales - AVC
- Autisme
- Boulimie
- Bronchiolite
- Bronchite chronique
- Cancer du colon
- Cancer des ovaires
- Cancer de la peau
- Cancer du poulmon
- Cancer de la prostate
- Cancer du sein
- Cancer des testicules
- Cancer de l'utérus
- Cataracte
- Cholestérol
- Conjonctivite allergique
- Conjonctivite infectieuse
- Décollement de la rétine
- Dépression
- Diabète
- DM/LA
- Endométriose
- Epilepsie
- Fatigue chronique
- Fibromes
- Gastrite
- Glaucome
- Grippe
- Grippe aviaire / Grippe porcine
- Hépatites
- Hypertension
- Légionellose
- Lépre
- Lombalgie
- Maladies du cœur
- Maladies rares
- Maladies visuelles
- Méningite
- Migraine
- MST
- Obésité
- Oreillons
- Ostéoporose
- Otite
- Parkinson
- Phlébite
- Polyarthrite
- Psoriasis
- Rhumatismes
- Saturnisme
- Sciaticque
- Sclérose en plaques
- SIDA
- Spondylarthrite
- Strabisme
- Suicide
- Tabagisme
- Toxicomanie
- Thyroïde
- Ulcère
- Varicelle
- Zona

Figure 3. Example of banner promotion on the web site Santeromande.ch (Switzerland).

HEALTH DIRECT
NHS advice, news, information, spin on the NHS.

RECENT POSTS

- ★ Cannabis could be used to treat epilepsy medical researchers discover
- ★ Europe losing superbugs battle
- ★ Money woes linked to rise in depression
- ★ NHS could save millions of pounds with better prescribing
- ★ Surgeons raise alarm over NHS waiting times
- ★ Government putting NHS patient care at risk over EU red tape
- ★ David Cameron to take charge of NHS reforms
- ★ Labour left taxpayer £60 billion PFI bill for new hospitals
- ★ Prescription charges postcode lottery extended
- ★ Health On The Net questionnaire

TAGS

Accident and Emergency
Andrew Lansley BMA

Health On The Net questionnaire

March 31, 2011 By: Dr Search-Principal Consultant at the Search Clinic Category: Health, Health Direct, Health Professionals, Health Websites, Uncategorized

Health Direct have been accredited by the Health on the Net Foundation since 2008 and we have been asked if you would kindly help them by completing a short questionnaire to find out your views on finding health information online.

A survey on search behavior conducted by HON for the KHRESMOI EU project What is your ideal search engine?

Friendly link by HON
Not happy with your online health information search results?
[Participate in our survey](#)

We would like to inform you that Health On the Net Foundation is currently participating in a European Union project KHRESMOI which aims to develop a search engine for health and medical information search to meet the needs of general population, MDs and radiologists. In this project, the Foundation and the Society of physicians in Vienna aim to better understand the needs of users (citizens and doctors) searching health information on the Internet. Currently a survey addressing the needs of the citizens is available online.

Help us by participating in our general public survey up until the 17th of April !

You can help us to promote this survey, [few options are available here](#).

English version: Not happy with your online health information search results ?
>> [Participate in our survey](#). Our goal: 500 responses by the 17th of April 2011.

How do you search for health-related information on the Internet?

The survey is intended for the representation of the general public who are looking for

HON-ACCREDITATION

The Health Direct blog adheres to the eight principles of the Health On the Net's HON Code of Conduct (HONcode) for medical and health websites.

This site complies with the HONcode standard for trustworthy health information: [verify here](#).

The Health Direct listing on MedHunt, Health On the Net's medical search engine: <http://www.hon.ch/cgi-bin/update.pl?HON17856>

RECENT COMMENTS

Robert on MRSA Action UK's fears for government's continued failings over hygiene
Britain's National Health Service cuts physical therapy for many disabled

Figure 4. Banner promotion and accompanying text on the Health Direct NHS web site (UK).

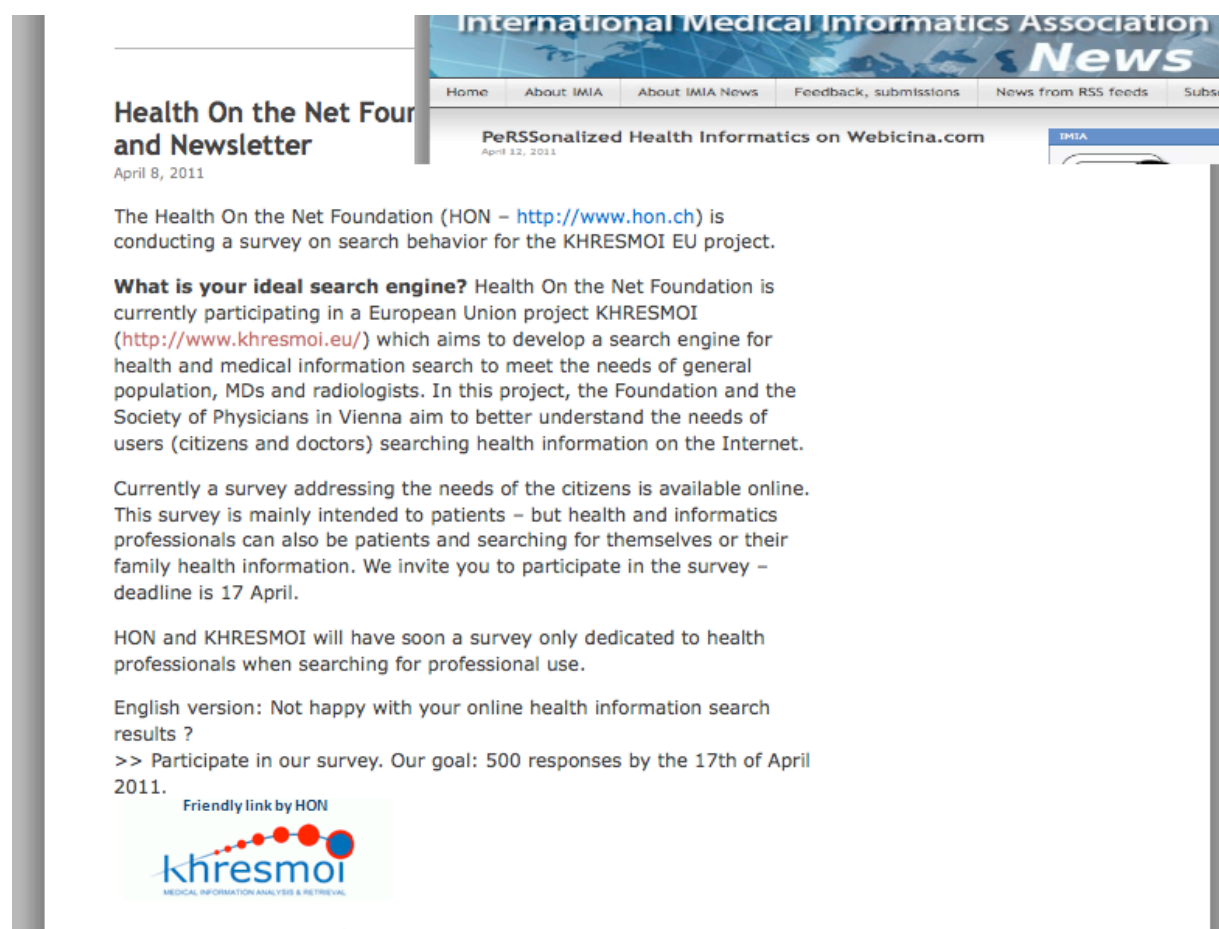


Figure 5. Survey being promoted on the web site of IMIA.

- 5000 subscribers to the HON newsletter.
- 550 participants to the 2010 HON survey also received the information about the KHRESMOI survey.

The information about the survey was disseminated in a newsletter from www.stop-tabac.ch (8000 subscribers).

The survey was also promoted by the KHRESMOI partners via social media (LinkedIn, Twitter, and Facebook) and newsletters (see Figures 6, 7).

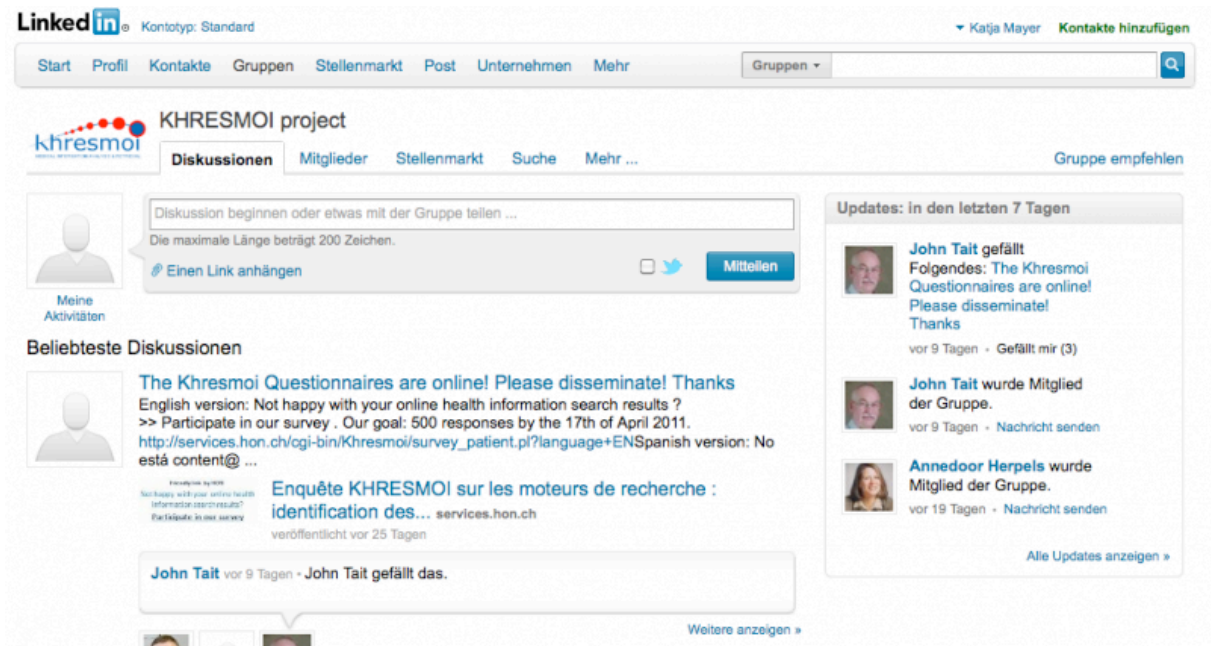


Figure 6. Survey promoted via the KHRESMOI LinkedIn group.



Figure 7. Twitter promotion.

6 Results of the survey and discussion

6.1 Who participated?

385 members of the "general public" participated in the survey, slightly more females (53%) than males (47%), which corresponds to a general tendency that women are more active health information seekers, especially in the health domain [3, 21].

As for age, quite surprisingly, the most active age groups turned out to be those aged 50-59 (25%) along with the ones aged 30-39 (24%). People aged between 20 and 59 seem to be the most engaged age group (85% of all respondents) (see Figure 8). In the USA the most active health information seekers are aged 18-49 [3]. An international study stated that around 60% of people of all ages are looking for health information online, but the peak of those who do it often is for those aged 25-34¹⁶ [22].

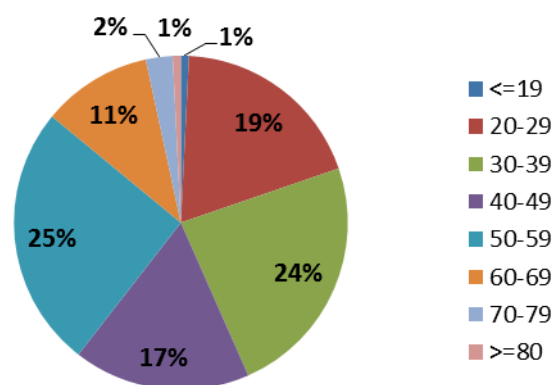


Figure 8. Age structure of the respondents.

79% of the respondents graduated from University, 43% of them also completed a Master Degree and 28% hold a PhD. Those who have at least high school education are more likely to be online, thus more likely looking for health information, too [2]. An international comparative study conducted in 2010 confirms that higher income and higher level of education are associated with higher level of online health search [22]. A recent study has proven that people with lower levels of education in all age groups often lack information and strategic Internet skills [23]. It explains why a vast majority of participants have higher education. To reach a less educated audience, other means of conducting an online survey need to be used.

Most of the respondents work in healthcare (30%), or have computer and mathematical occupations (21%), or work in education and training (13%) (see Figure 9).

¹⁶ <http://www.bupa.com/jahia/webdav/site/bupacom/shared/Documents/PDFs/media-centre/Health%20Pulse%20-%20HW/Online%20Health%20-%20Untangling%20the%20Web.pdf>

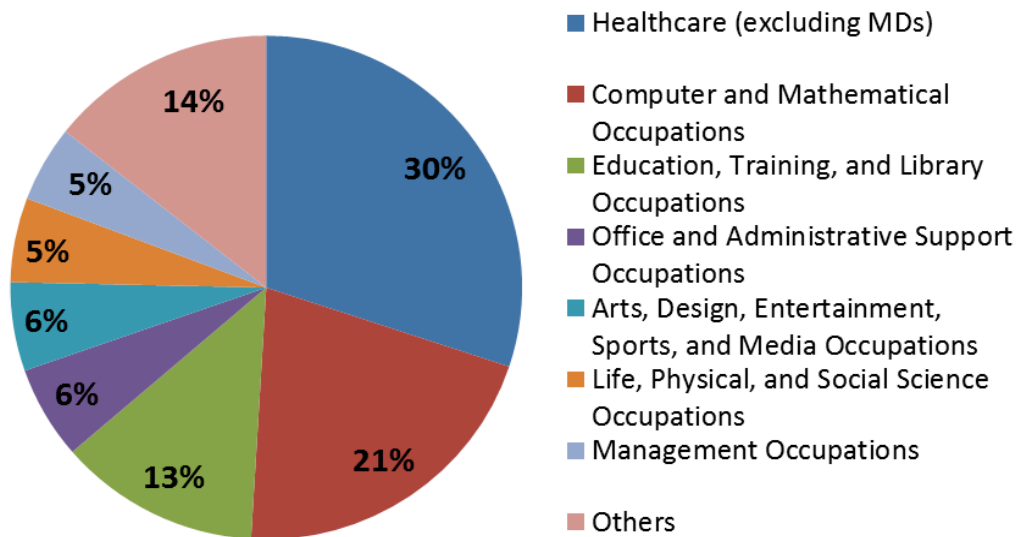


Figure 9. Occupation of respondents.

The 385 participants were coming from 42 countries (Figure 10) worldwide with the largest numbers of contributors from France (23%), Spain (14%) and the USA (10%) living and working mostly in urban areas (78%).

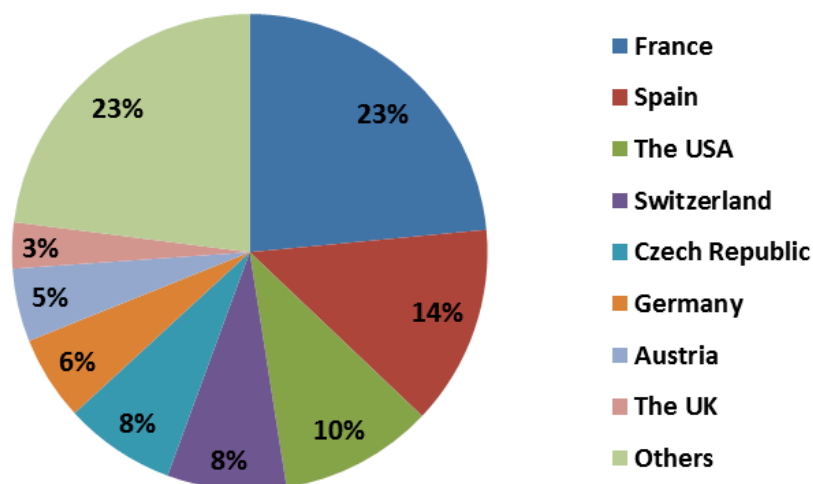


Figure 10. The countries which participated.

Despite the fact that the survey was offered in only four languages, the participants represent 25 languages from around the globe. However, not surprisingly the most represented languages are the ones that the questionnaire was translated to: 34% are French speaking, 19% Spanish speaking, 17% English speaking and 13% German speaking. 3% of participants were bilingual (as for example Catalan and Spanish, or Dutch and French).

6.2 Use of the Internet

90% of respondents declared that they have been using the Internet for more than six years, thus 84% rate themselves as good or professional users. 100% stated they have a regular Internet access and 95% are using the Internet on a daily basis, the remaining 5% several times a week. 45% stated they spend from two to four hours online a day, 25% spend from four to eight hours, and 13% spend even more than eight hours. In 62% of the cases the respondents connected to the Internet using Wi-Fi and a modem (47%). Regarding the devices used, respondents have PCs (71%), laptops (68%) and mobile phones (28%) at their disposal, and 5% are using other devices such as iPod touch. Out of all mobile devices, the most widely used are laptops (56%) and smartphones (36%); tablets and netbook have not yet gained much popularity in our audience. We have not asked whether all these devices are also used for health information search, however, evidence shows that wireless connections are associated with deeper engagement in health related social media, and more generally with gathering, sharing and creating content [10]. It was also proven that most health searches are done with mobile devices when related to sexual health such as sexually transmitted diseases, or emergency contraception¹⁷ [24].

6.3 How is health and medical information sought?

24% of the respondents are looking for health information on the Internet at least once a day (some mentioned from four to six times a day in comments), 25% do it several times a week. The 11% who answered “Other” specified that they look for health information “from time to time” or “when needed” (see Figure 11). Pew reports that those who access online health information at least once a day are more likely to search for health content in the future.

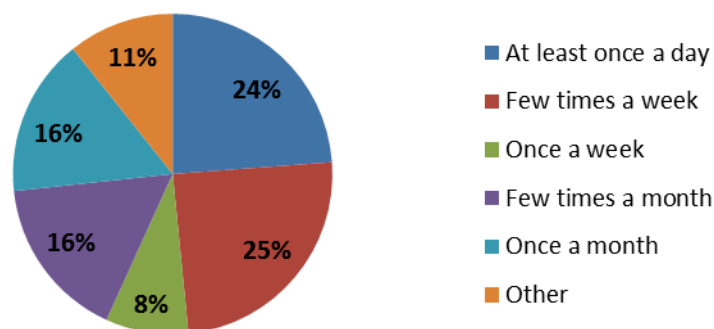


Figure 11. How often do you use the Internet to search for health information?

We asked respondents, which sources they prefer to use when looking for health and medical information (Figure 12). The most important source remains physicians (82% rate it as important or very important). The Pew study (2011) specifies that professionals are more helpful when an accurate medical diagnosis, information about prescription drugs, alternative treatments, or a physician or hospital recommendation are needed¹⁸ [25]. The second place is held by the Internet (71%). Among “others” respondents mentioned patient organizations and medical/scientific/peer-review journals.

¹⁷ <http://www.cnn.com/2010/HEALTH/10/21/top.health.searches.answered/index.html>

¹⁸ http://www.pewinternet.org/~media/Files/Reports/2011/Pew_P2PHealthcare_2011.pdf

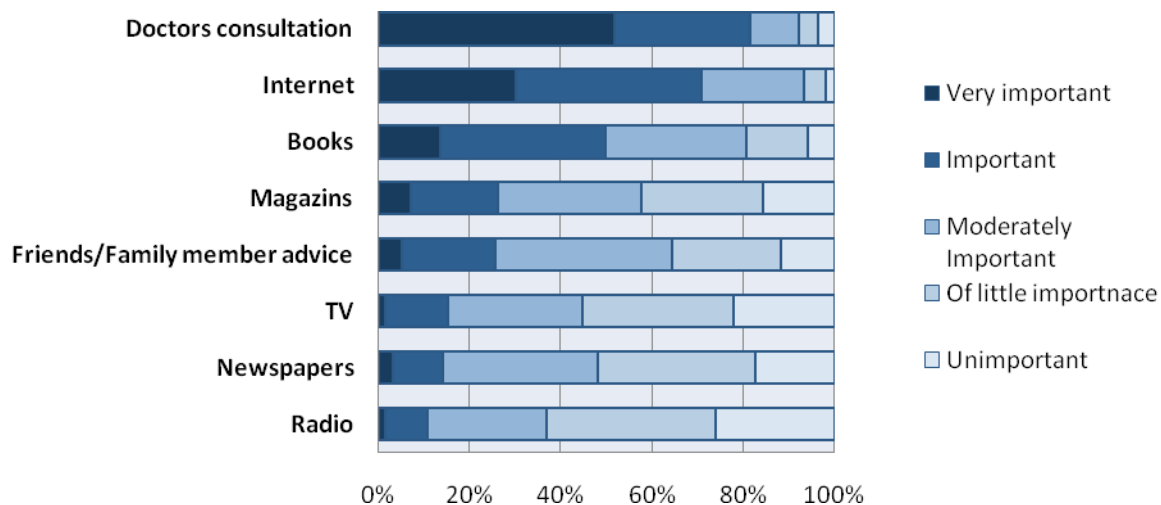


Figure 12. Which sources of information do you prefer to use when looking for health and medical information?

We were also interested in knowing when respondents prefer to use the Internet rather than other sources of information (see Figure 13). Mostly, the reasons for using the Internet are accessibility from home (some mentioned the office too, and 85% considered it as important or very important), support (66%), lack of time (61%), willingness to know other people's experience (60%) and absence of other (traditional) means of information (56%). The low importance of the financial situation (lack of money to pay for a physician consultation, 20%) signifies that our respondents have sufficient income to afford healthcare costs, which may not be the case in "emerging" world markets [22]. Those who chose "other" mentioned the desire to protect their privacy, to learn more and access huge amounts of information that is considered more updated and reliable than other sources. Another reason for preferring the Internet as a source of information can be the management of a stigma in case of embarrassing health conditions.

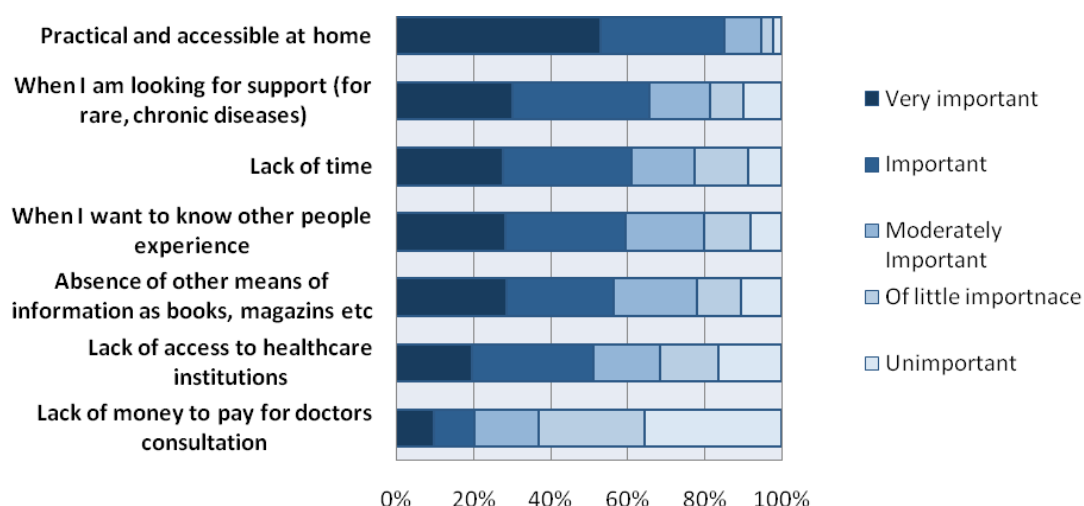


Figure 13. What are the cases when you would rather use Internet than other sources of information?

The search activity of users is mostly focused on general health information (68%), long-term chronic diseases (59%) and healthy lifestyle and nutrition (50%) (see Figure 14). Those who chose

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“other” mentioned addiction (tobacco, alcohol) and sport. Other activities include locating a specialist or clinic, environmental and occupational health information, medical images, first aid, advocacy and ethical issues.

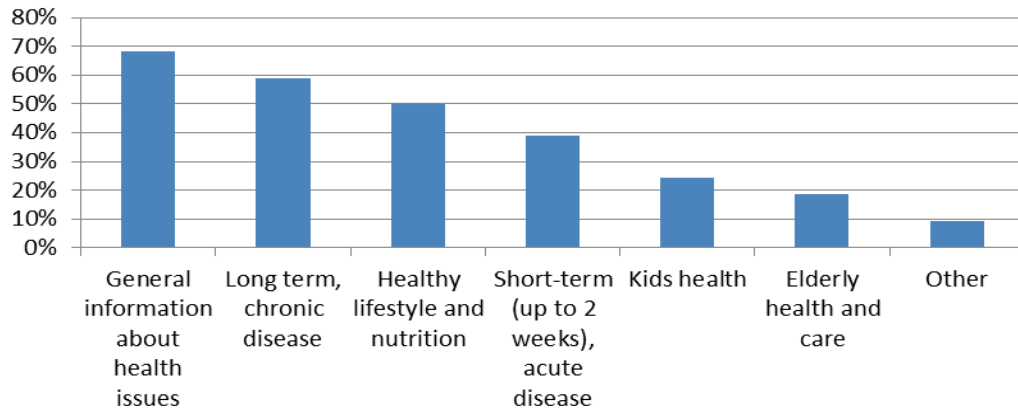


Figure 14. What is your search activity focused on?

Studies on health information seeking behavior also consider how search processes may fluctuate according to environmental phenomena. For example, Carolsson (2009) documented an increase in cancer patients’ use of particular information channels over time [26]. In relation to specific events, Cooper et al. (2005) noted that Internet search activity for cancer terms is positively correlated with news coverage of the topic [27].

The most commonly searched types of online health information are treatment/therapy (62% rated it as always or often), detailed (58%) and general (53%) disease descriptions, drug information (51%), side effects (51%) and scientific articles (50%) (see Figure 15). Those who chose “other” mentioned: statistics of symptoms and healing prognosis, public health programs, mental health as a specific area of human well-being, caregivers practices and guidelines, nutrition.

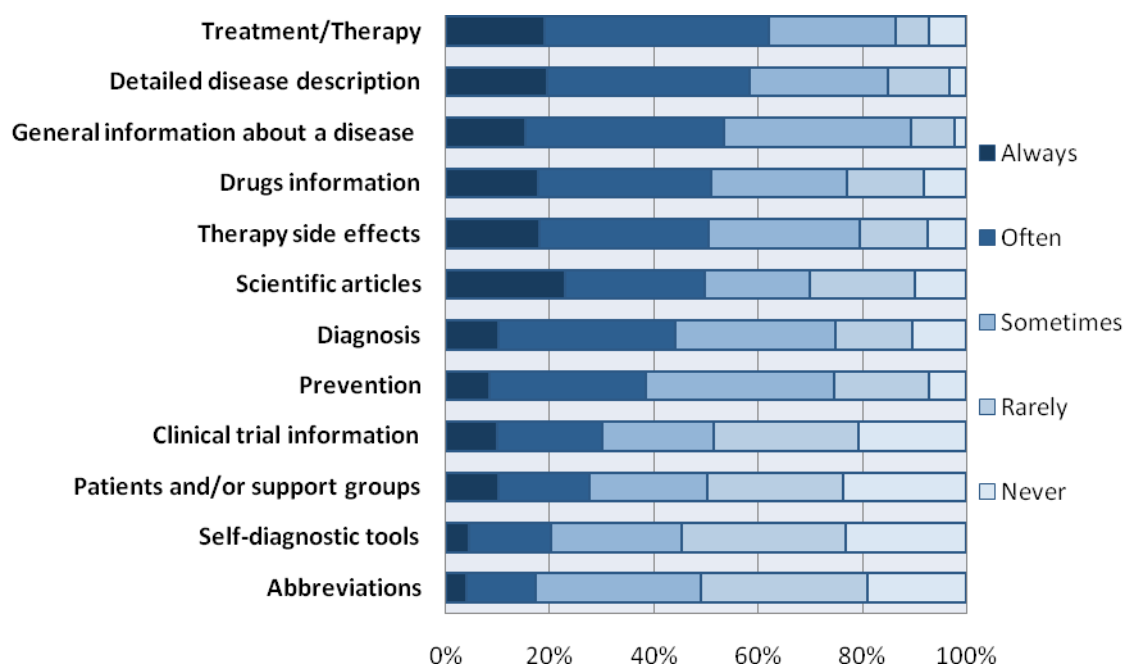


Figure 15. What type of online health information are you looking for?

The questions asked in the survey diverge from other international studies used as reference as we were more interested in medical information than information generally related to health. However, there are some similarities and differences. The international trends show that the primary e-patient activity is focused on medical information (68%), self-diagnosis (46%), other patients' experience (39%) and information on hospitals/clinics (38%) [22]. USA citizens are mostly focused on specific diseases and medical problems (66%), certain medical treatments or procedures (56%), information about doctors or other health professionals (44%), hospitals or other healthcare facilities (36%) [3]. In all cases, the largest interest is paid to disease and drug information. The search for other persons' experiences (see Figure 13) is also similar to international findings. However, regarding self-diagnosis, very few of our respondents reported such an activity, although on the international level the percentage is quite high. Probably, the explanation is that our respondents are well educated and have higher income, thus they can easily have physician consultations, and are using the Internet mostly for informational and peer-supporting purposes.

Furthermore, the following information about drugs is usually sought: side effects (58% are looking for such information often or always), contraindication (53%), safety, toxicity (50%), interactions (49%) and descriptions (48%) (see Figure 16). In addition, people are looking for pharmaceutical industry relations, marketing and patent information, information from authorities such as the FDA, drug names in different countries. Others were interested in getting more information about vitamins and new drugs that are still under development.

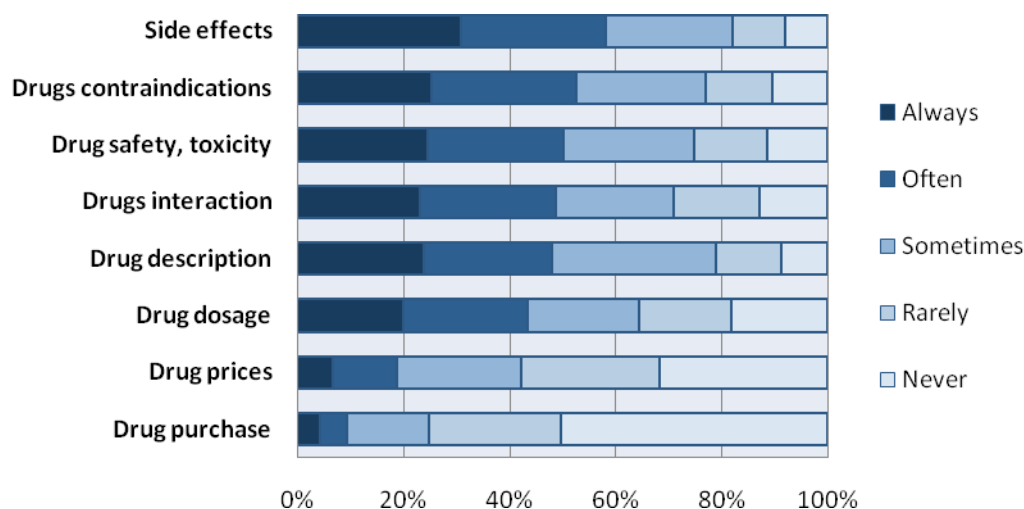


Figure 16. Looking for drug information which kind of content are you interested in?

In most cases participants look for health information for themselves (64% of those who do it often and always), a partner (32%), a child (26%) or parents (22%), family members (16%) or friends (14%). When a search is performed on behalf of someone else, the impact of the queries can be more significant as the information found may influence not only the personal health of an e-patient, but also the ones s/he is taking care of (3).

6.4 How are search engines used to retrieve health information?

As mentioned above, a general search engine is the most frequently used means to look for online health information. 82% of the participants in the survey indicated that they use a search engine often or always (see Figure 17). Other popular sources include: websites providing health information (Hospital, University, Pharma, Publishers) (38%), Wikipedia and specialized search tools such as HONselect, Medline Plus (37%),¹⁹ and links from health websites (36%). Forums and blogs are always or often used by 23% of the respondents, and 5% use Facebook or other social networks. Those who chose “other” mentioned patient organization web sites, social networks such as LinkedIn and Twitter, some less known search engines and governmental organization websites.

Pew reported in 2006 that younger groups of Internet users and those without a chronic condition or disability are more likely to start their search with a general search engine (74% of those aged 18-29), whereas those who have a chronic condition or disability are more likely to start from a health web site [11].

¹⁹Some participants in the comments mentioned PubMed <http://www.ncbi.nlm.nih.gov/pubmed/>

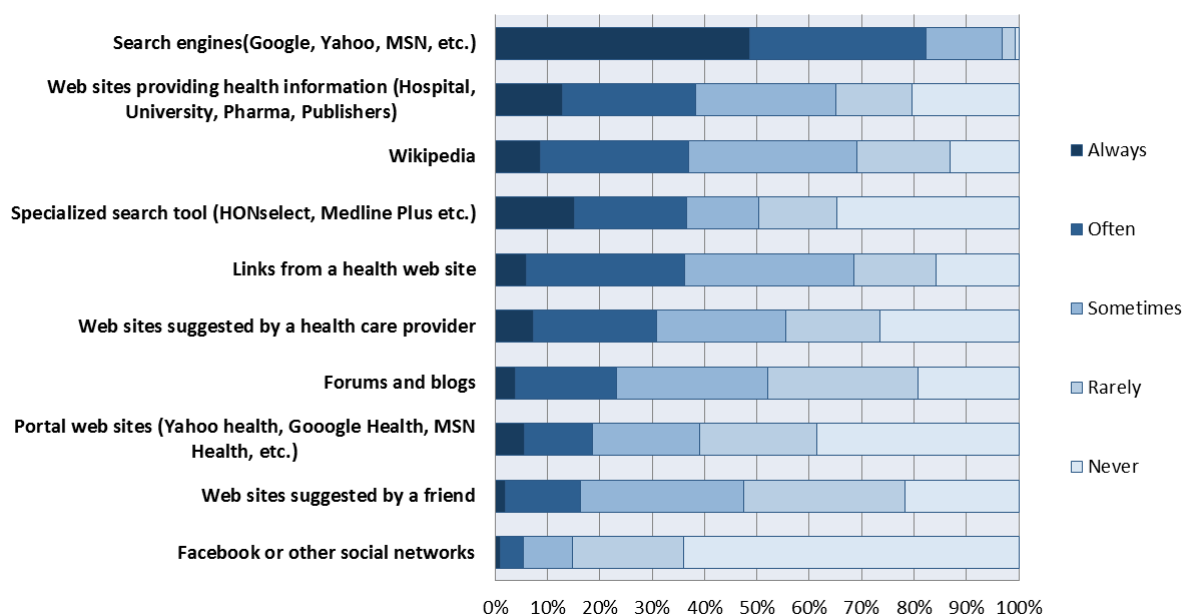


Figure 17. How often do you use the following types of online sources to find online health information?

The most important characteristics of a search engine for users are relevance of matches (97% consider it as important or very important), trustworthiness (93%), readability of results (90%) and quality of the description (90%) (see Figure 18). Easiness or simplicity is still important (67%) despite the fact that most participants consider themselves as good or professional Internet users.

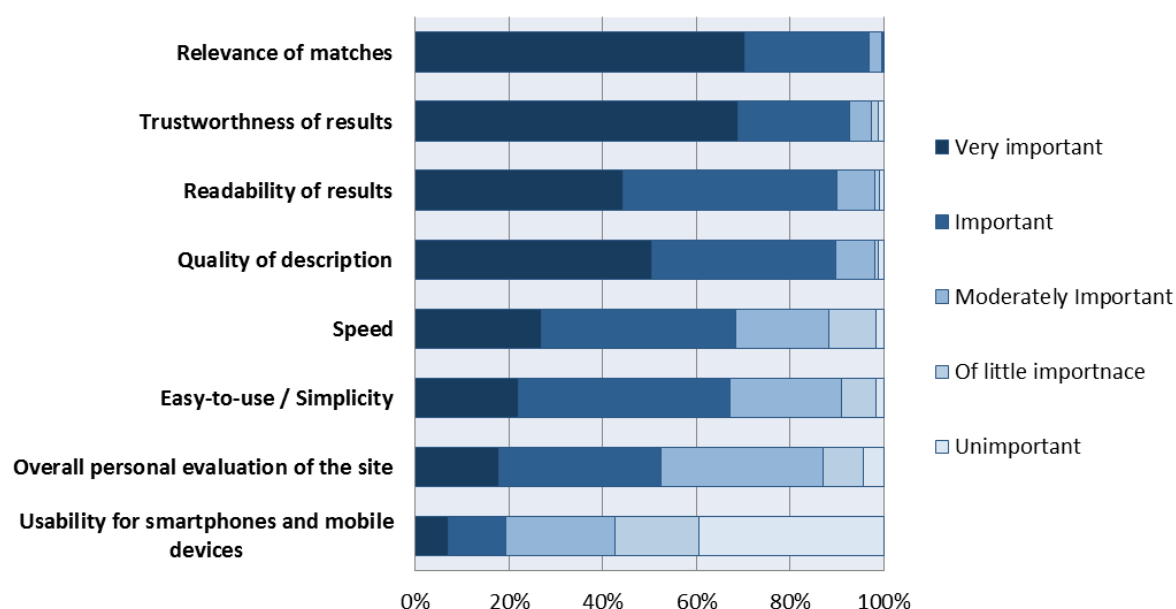


Figure 18. What are the most important characteristics of a search engine for you?

Most respondents (60%) type two to three words in a search bar, 29% type up to five words. The terms typed in a search bar are medical terms such as a diagnosis or drug name (in 82% of the cases). 14% prefer to type a query in a question format in the same way they would have asked their physician. Some mentioned that they type a physician's name. The most widely used advanced options are language (70%), date range (57%) and country (50%). Some respondents indicated that they

include a website's name, restrict the domain and exclude certain terms, use a geolocation function, search for videos and images and use notifying alerts for subscribed tags.

When search results appear, 62% of the users scroll down and click on the results, which seem to be the most relevant and credible, 25% simply click on the first five links. We also got a few answers stating that users do not click on first results because they consider them to be sponsored, i.e. biased. 71% of respondents check the second or third page of results sometimes or often. 81% stated that they rarely or never access restricted information that requires paying membership fees etc.²⁰ However, most respondents check web sites that are clearly intended for healthcare professionals: 21% do it always, 27% often, and 27% sometimes.

We were also interested in knowing which kind of content users prefer: web 1.0, i.e. informative, or web 2.0, i.e. collaborative and interactive platforms such as forums, blogs, social networks etc. It appeared that 57% give preference to the information itself, but another 40% have chosen a mix of both webs.

When an answer is found, do users double-check it?

- 42% verify results on trustworthy websites found by themselves;
- 21% ask their medical doctor after performing the search;
- 13% use another search engine, and
- 10% do not verify the answer and trust the search results.

Other options mentioned include: checking books and other information channels, presence of HONcode seal, adherence to a similar ethical code, or verification on a governmental web site. Many however mention that they prefer to use common sense to evaluate different websites and other sources of information, including physicians, before drawing the final conclusion.

When respondents face a **“complex” question**, they usually spend more than 10 minutes to explore it and to find an answer (36%), 30% spend 5 to 10 minutes, and 20% spend 3 to 5 minutes. In such cases, 54% of users change the terms of their search 2 to 3 times before they get the desired answer, and 36% do it more than 3 times.

6.5 What are the difficulties and barriers?

It is important to understand difficulties encountered by users when searching and evaluating online health content. It appears that distracting ads (44% say it is the case always or often), lack of quality filters (42%), irrelevance of matches (41%) and questionable trustworthiness (40%) are the most important difficulties encountered (see Figure 19). Thus, it is not surprising that users want relevant and trustworthy results. Technical issues such as accessibility in terms of customization of letter size and font colours (18%), usability for smartphones and other mobile devices (14%), speed (9%) are the least important.

²⁰ As one of the participants mentioned: “For me the Internet is a library for free”.

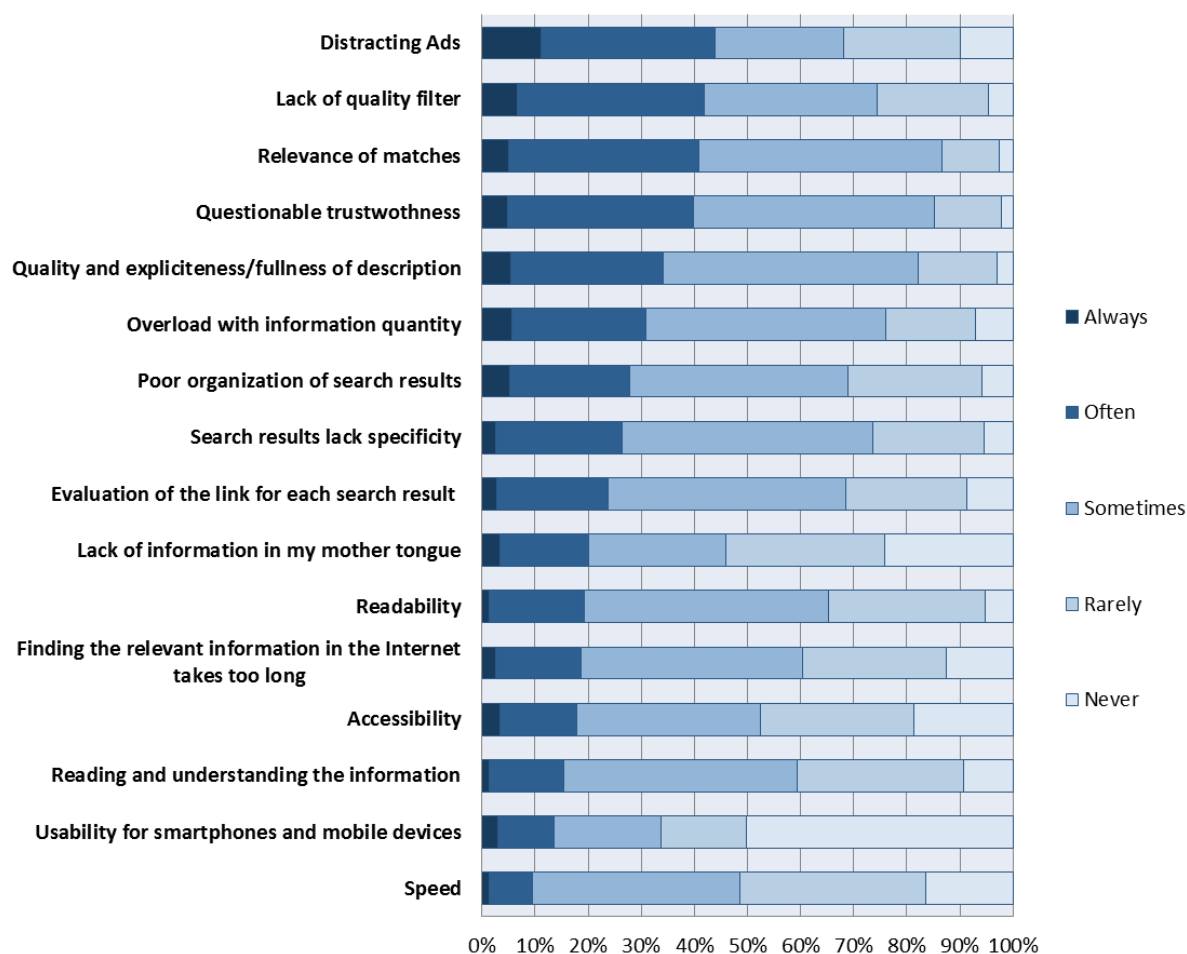


Figure 19. What types of difficulties do you face when searching for health information?

Another problem that respondents do not consider important is reading and understanding information, or health information literacy (15%) (see Figure 19). Additional questions were asked regarding the way respondents perceive their level of understanding of medical information. 88% state they often or always understand health/medical information found online. This result is difficult to be interpreted. Are the respondents answering positively because in the end they were able to answer their initial question, no matter how long it took or does it reflect the fact that their health knowledge and capacity of adaptation are high? High self-esteem can be explained by the high education level of the participants, thus they consider themselves able to research medical and health information on the Internet. However, very little evidence justifies a positive correlation between higher education level and higher health literacy [28]. It is important to note that most respondents have a high level of education and this does not reflect the education level of the public at large. The problem of health literacy is acknowledged by international organizations such as the WHO [29]. One of the approaches to ensure access to “readable” and understandable information for users was elaborated in the PIPS project (2004-2008)²¹ when automatic assessment of the readability level of medical websites was developed and tested. A user can thus choose a readability level of “easy”, “medium” or “difficult” depending on his/her knowledge of the particular domain [30].

50% of the respondents state that advertising banners do not influence their search; however almost the same amount of respondents (42%) say they are distracted by ads. In a comment field some

²¹<http://www.pips.eu.org/>

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mentioned that they do not trust ad banners, ignore or even block them and eventually doubt the credibility of the information. In some cases respondents state they do not return to a website with many advertising banners.

The consequence of having difficulties in using a search engine is failing to retrieve the answer to a question.

When an answer is NOT found, which is sometimes the case for 51% of respondents and often the case for 9% of respondents, users “usually” or “always” modify search terms (80%), ask their medical doctor (48%) or verify the information on a website they trust (46%) (see Figure 20).

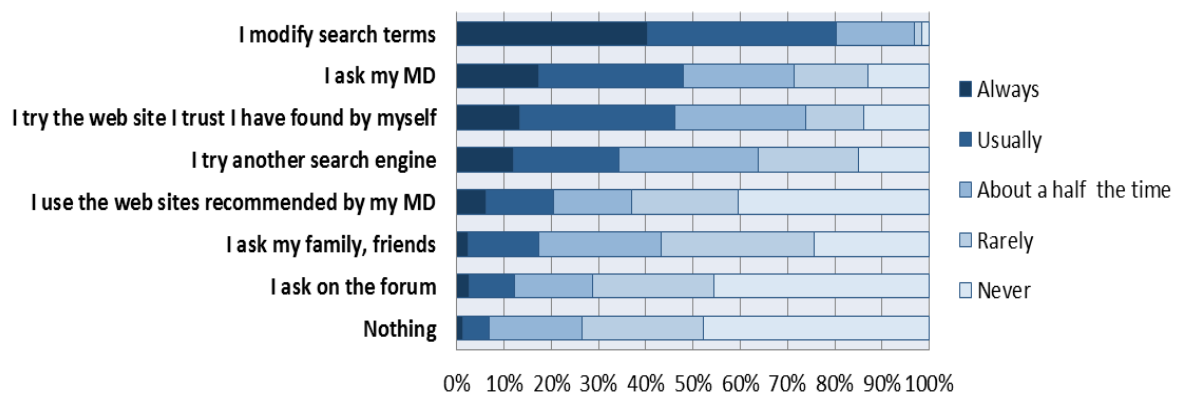


Figure 20. What have you done to overcome a situation where you cannot find the answer on the Internet?

Possible reasons for failing to retrieve a satisfying answer are: search results do not guide the user towards an answer (32% of the responses are “always” or “usually”), or the user is overwhelmed by the quantity of results (30%) (see Figure 21).

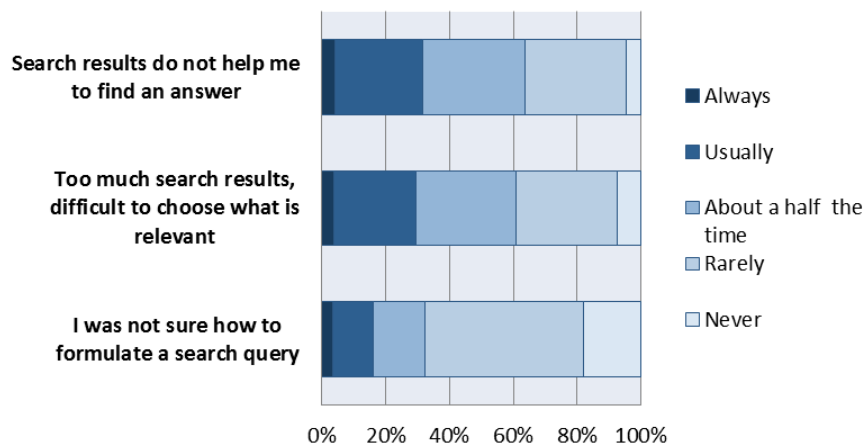


Figure 21. Why do you think you could not find the answer?

We received a variety of other answers to this question:

1. Contradicting and conflicting data: different web sites provided contradicting and conflicting data, thus a final conclusion cannot be drawn.
2. Lack of time for surfing: some respondents stated that they do not check the first results because they are sponsored, and do not have patience and time to look through all the pages to reach the answer.

3. Very precise questions do not have an answer in a plain language: some admitted they were asking very precise questions, and after having been redirected to physicians' websites it was difficult for them to understand the information there, so they had to go back to more basic questions to understand the terminology etc. In other cases a professional site required membership to access the data.
4. Very precise questions do not yield any answer at all.
5. No results relevant to a user's country.
6. Social media obscure scientific results.

6.6 What would be the ideal citizen-centred health search engine?

This part deals mostly with the “ideal” presentation of search results and “helpful tools”.

First of all we were interested in knowing how the information should be presented. 54% of respondents have chosen the categorization approach when all the links are grouped into scientific, clinical, commercial, advertising, forums and blogs. 24% would prefer a summary referencing the different sources, and 20% like the “conventional” form of search result presentation as a list of links (such as Google®). Some proposed a combination of two options, i.e. all links being categorized, and for each category having a summary. Another option is to have a list of all links with a possibility of manual categorization, including also date, certification, geolocation, language and text size. Users also want to know if the information they search for exists on the Internet, and whether it is explained in the same way their doctor would.²²

Regarding the amount of results presented, 36% would like to see between five and ten trustworthy results, 30% - more than ten results, and 24% would like to have all possible results.

The next question proposed several tools that may be of interest for members of the general public (Figure 22). Most highly-ranked tools are: advanced search (country, language, date range) (63% find it important or very important), medical dictionary/thesaurus (61%), suggested relevant topics (56%), spelling correction (54%) and image search (49%). Risk-assessment tools (42%), 3D anatomy visualization and suggested filling of queries (40%), automatic translation of results and a tutorial on successful online health information search (38%) are listed.

²² “I want to see an answer to my problem or to know that the answer is not available on the web :-)” and “One that can categorize information in the same way a doctor would who knows me”.

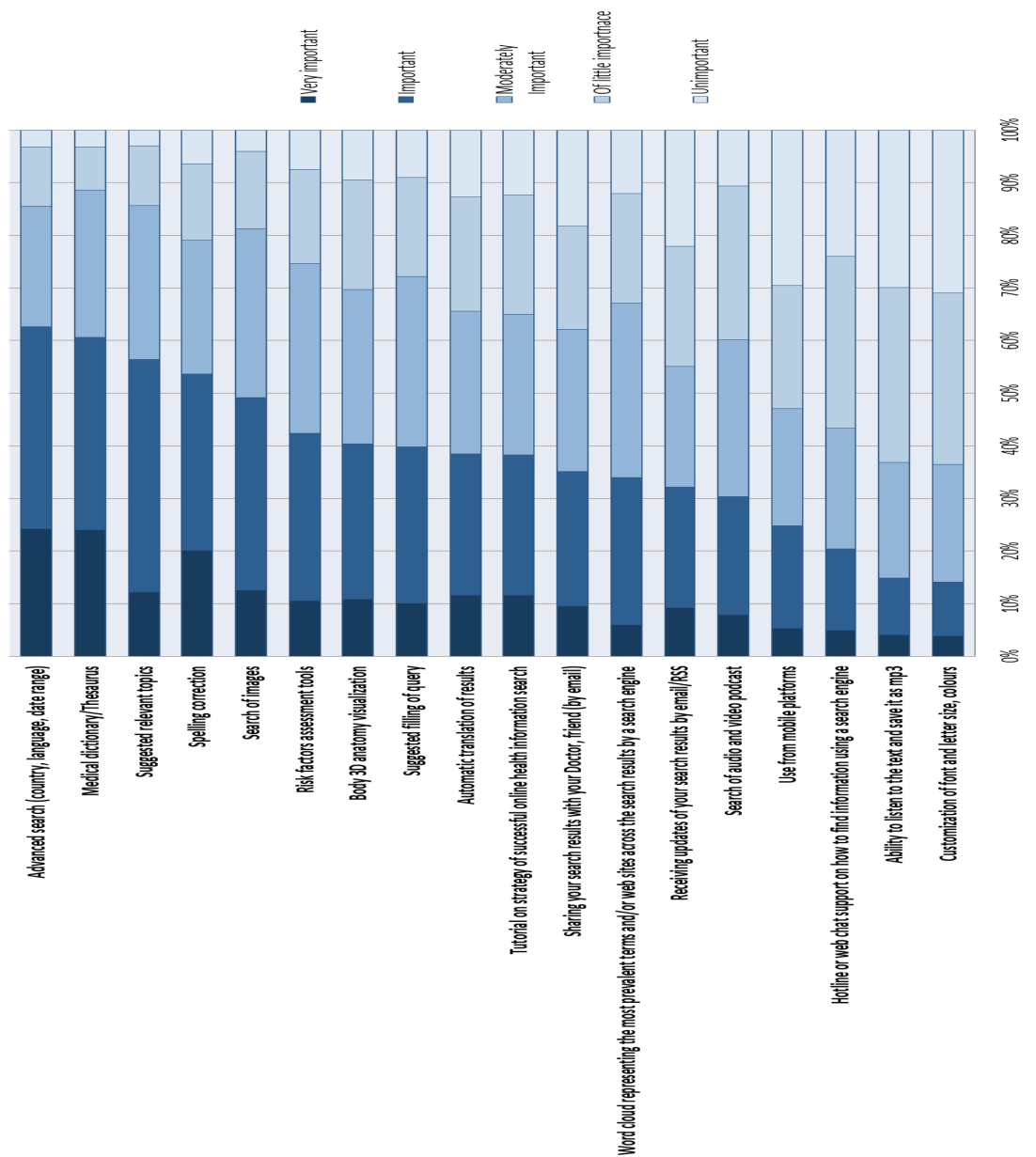


Figure 22. Do you find these tools helpful?

54% think it would be useful to directly rate search results and view other users' ratings. This is similar to the WOT (World of Trust)²³ or Jabber²⁴ initiatives. 22% have no definite opinion about it, which means that such initiatives are not well known, i.e. users do not know how it works.

Apart from that we offered respondents a space to add any other idea or suggestion they think would enhance a search engine:

- Ability to search in social media content, but with clear separation from scientific content (i.e. when someone is looking for specific articles, the original source should appear first, and then

²³<http://www.mywot.com/>

²⁴<http://www.sitejabber.com/>

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blog posts referring to it). Preferably, these two areas should be graphically split, or the user could choose which type of content s/he wants to access.

- User's customization of search results based on the intended audience (e.g. in case a page offers information for professionals, there should be an interpretation service for the general public) dates, language, certification marks, ranking, funding and (inter)national authorities' recognition etc.
- Key words highlighted in the search results (i.e. Biowisdom (UK)).
- Interpretation of the question in context.
- Natural language search engine.
- Free access to scientific and medical journals and literature (to be able to search in a literature of the last 70 years).
- A search engine as a self-diagnosing tool²⁵.
- Regarding the content: not only disease information, but also information on prevention, food, tests, physiological and psychological changes that can occur during disease and therapy.
- Saving a search history and organizing search results.
- A correct display and functioning of a search engine with all browsers
- No advertising banners and no commercial influence on the ranking of search results.

Regarding the last issue, we were interested in knowing whether users would tolerate ads or whether they would be prepared to pay a membership or fee-for-service to avoid ads. We had quite a few people complaining about the presence of ads and doubting the credibility of information accompanied by advertising banners, 84% of the respondents tolerate ads in order to have a search engine that is free of charge, 9% are prepared to donate money, 5% prefer membership subscription and 2% would prefer a fee-for-service, meaning that the user would pay each time s/he uses a search engine. Nevertheless, 67% of the respondents think that it is important or very important that ads undergo a rigorous quality control.

The self-diagnosis option (mentioned among the desired features of a search engine) needs to be discussed separately. We have already seen that 46% across 12 countries use the Internet for self-diagnosing [22]. The tendency cannot be changed or influenced but taking into account that it is a complicated ethical issue, a certain approach has to be developed that would protect users from misinterpretation of the information found on the Internet and assist them in understanding their own symptoms. The consequences of a wrong self-diagnosis are difficult to estimate if actions are taken without a consultation with a qualified physician. However, the desire of patients to be more educated and able to research their own health symptoms is understandable, especially in countries where access to healthcare facilities is uneven or expensive. Thus, risk-assessment tools can be proposed, which implies that upon answering a set of questions about a specific disease, a patient will be given a range of potential disease developments, preventive recommendations and a notification of urgency to have a medical consultation. However, such tools cannot be created automatically by using information retrieval technologies; the help of qualified physicians with extensive experience is required.

²⁵ "I'd love it if I could type in my symptoms and it would come up with various possibilities with the symptoms I entered highlighted next to each one so I could decide what my problems might be."

7 Conclusions

7.1 Reaching a consensus between highly educated respondents and the general population

The results presented in this report reflect the views of educated people. A vast majority of participants graduated from a university, many of them have a Master or PhD. This group of people cannot represent the entire e-patient community or Internet community. Nevertheless, having highly educated individuals as respondents allowed us to collect different ideas more elaborated and conscious than with the general public. It is important to contrast the respondents' opinions with the ones of people who have no such Internet experience, but still use the Internet to obtain health information.

To do so, we compared the results of the survey with the main points identified during the interview with the Swiss Patient Association (SPA)²⁶. Some issues are in line with the survey results. For example, toleration of ad banners and importance of result categorization are similar. However, it is more important to focus on the following, contradicting points:

- 1) Advanced search: In contrast with the survey results, SPA reports that patients do not use this function, do not know how to use it, or are not aware it exists. Some tutorials are needed to educate people on how to use it.
- 2) Use of social networks: Young people tend to use social networks for health information too. Often the *Like* button is used and a health-related material is discussed with friends in a social network (i.e. Facebook), which eventually can influence a decision regarding health. As we have seen in the survey results, only few participants stated that they use forums or social networking web sites to look for health information.
- 3) Verification of the answer: Patients rarely consult other sources to verify an answer found on the Internet. Often, information found in a blog is considered authoritative, which actually is not always the case as a blog can be written by anyone. As we have seen, respondents report using multiple strategies for results verification.
- 4) If an answer is not found: Due to the low Internet literacy of many patients, they often cannot find the answer to their request. In this case they abandon, or refer to family and friends. To help such patients, a hotline could be a solution, however costs should be taken into account. For our respondents who are experienced Internet users, this is not the case.
- 5) Accessibility: SPA stated that patients, especially older ones, appreciate readable text format and illustrations. Again, for respondents of the survey accessibility in terms of text format and accompanying images was not a very important issue due to high level of literacy.
- 6) Multicultural aspect: This is more suitable for Geneva or any other multi-lingual city (Paris, Berlin, Vienna, to name few). Many people who are coming to work in an international organization may not speak the local language in the beginning of their stay, but may need medical assistance at any time. Thus, it is important to give them access to information about local facilities in their mother tongue.

²⁶ The full report is in Annex 1

7.2 Summary of the most important requirements

Summarizing the results of the survey we can identify the following milestones in creating a user-centred search engine.

First of all, as most respondents are connected to the Internet via Wi-Fi, the use of mobile devices will keep growing. Thus, if the problem of web site accessibility from a mobile device is not a priority for now, this might change.

Second, the Internet is the second source of information after physicians, and it is more likely to be used due to its accessibility and easiness. Most researched topics are general health, chronic diseases and lifestyle. Illness-related information can be prioritized in the following way: treatment/therapy, detailed and general disease description, drugs and scientific articles.

Third, a majority of e-patients are using a general search engine to find the answers to their health queries. The most important characteristics are relevance and trustworthiness of the results. This appears to be the main problem, as current results do not satisfy these requirements. Additionally, advertising banners, contradicting information found on the different web sites and difficulties related to very precise queries are among other barriers.

Fourth, the ideal representation of the information is a categorization of results into different groups with the possibility to perform this automatically or manually. Tools that are highly appreciated by the respondents are advanced search, medical dictionary/thesaurus, suggested relevant topics, image search and risk assessment tools. However, taking into account the low Internet literacy of the general population we need to develop tutorials to explain how to use all these options. Most users will tolerate ads in order to keep a search engine free, but would like to be ensured that the ads have undergone a rigorous quality control. Some of the respondents proposed the possibility of creating a profile with a search history for follow up investigation of the topic. Some respondents have also mentioned they would like to have free access to the medical literature. Many users would like to see search results appear in social networking web sites but it is important to clearly identify which source is original (for example, article), and which is a discussion or opinion about a health topic.

7.3 Proposal of a 3-step search engine for the general public

Taking into account all these problems and the results of the studies, the following scheme is proposed:

7.3.1 STEP 1. Typing key words or question into a search bar

In the first step a user has to define a query and type it into a search bar. Two additional services are proposed to him/her.

A. Advanced search options (optional):

- Language
- Country
- Date
- Trustmark
- Intended audience
- Search of images
- Etc.

B. Interpretation of the context of a user's query / Choice of readability level (optional)

Basic information about a person for whom a search is performed such as gender, age group, race, origins, and education is requested. In the case of a user searching on behalf of someone else, the user's level of education needs to be known.

Choice of relevant scenario:

1. I am looking for information about a health condition to improve my general knowledge.
2. I suspect I can have this condition and I want to know more about it.
3. I have just been diagnosed with this health condition.
- 4A. I have managed the health condition for quite a while and I want to clear some doubts.
- 4B. I manage the consequences of the treatment²⁷.
4. I am caring for someone who has this condition.

Alternatively, a readability level can be proposed: easy – medium – difficult to read. In this case a person can evaluate him/herself his/her familiarity with the topic and choose the results with the most adequate level of complexity.

7.3.2 STEP 2. Categorization of results

After typing a query, a user has to decide whether (s)he wants the results to be automatically or manually categorized for him/her.

- A. *Automatic categorization* means that all the results are categorized into a standard category scheme in the same way a clinician would do while explaining a problem orally during a consultation. For example: definition of a disease and basic explanation, possible treatments and therapies, recent research, patient organizations, some social security or legal documents if relevant, forums and blogs, psychological burden of the disease.
- B. *Manual categorization* offers more possibilities, but a user has to spend more time configuring it. For example, he/she can choose only a few of the categories proposed for automatic categorization, but also: audio and video podcasts, type of editor or organization providing the information (University, Hospital, Government, Pharma or Insurance company).

7.3.3 STEP 3. Presentation of results

At this stage the categorized results are presented. For example in case of automatic categorization, there are 5 categories presented. For each category there is a “standard” summary relevant to each health condition (e.g. from the National Institute of Health, USA) and the three-five most suitable links are proposed. Links contain the name of a web site / document, abstract with key words highlighted, and a URL. Alongside a medical thesaurus is offered, so a user can consult a term that he/she does not understand in a window with the search results. On the bottom of the page relevant topics are suggested.

If a concrete answer is not found, two options are possible:

- 1) A query is not properly formulated, i.e. it is suggested to rephrase it. Relevant topics are also suggested, which can be helpful in understanding the investigated topic.

²⁷ Mostly for acute disease or post cancer

- 2) The information does not exist in the databases, thus a message should notify the user accordingly.

This is the first approach on how the “ideal” search engine for health topics could look like. It goes without saying that it will be further elaborated in the future.

7.4 Final considerations

The creation of a search engine that addresses members of the general population needs to be based on a deep understanding of the needs and preferences of final users. The most important is not to impose the way we think people have to search for health information on the Internet, and thus to avoid information protectionism or a paternalistic approach. We cannot prevent users from finding irrelevant and misleading information on the Internet. What we can and should do is to highlight good quality information proved by research and current medical practice. A group representing people with different professional backgrounds and level of education, preferably from different European countries should be involved in the development of the new search engine and help to understand how to better categorize results, how to make ads tolerable and less distracting.

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10 Appendix

- 10.1 Interview with the Swiss Patient Association on the 10th of February, 2011
- 10.2 Questionnaire in English
- 10.3 Figures from international comparative study BUPA Health Pulse 2010

10.1 Interview with the Swiss Patient Association on the 10th of February, 2011

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- 1) Specifically regarding Geneva : Geneva is a multicultural and Multilanguage environment, many people who live here and do not speak French find it **difficult to find medical and health information in their language which applies to Geneva/Switzerland**. (e.g.: they look for information in Spanish and obtain results about health institutions in Spain).
- 2) When obtaining results with a search engine, patients find too much information. As the results found and presented by the search engine is not structured, **patients are unable to sort the relevant information they are looking for**. When they choose a link, they don't know if they are going to be redirected to a blog, a forum, a patients or association website.
- 3) **Advanced search**: Patients do not use this functionality. It is considered too complicated by most of the population. They do not know how to use it, or that it exists. Also, patient associations mentioned that patients are not able to use keywords correctly. They say it would be important to educate users in this regard. However, such kind of education is often considered as boring.
- 4) Medical terms: When looking for health information, patients do not understand what they read. The patient association mentioned the necessity of a “medical dictionary” specifically to help patients understand the information related to a medical field. The patient association explained that this situation also applies to “live” consultations. Patients do not understand the diagnosis given by the doctor. Sometimes patients then go find the information on the Internet.
- 5) Young people and health information: the patient association mentioned that **young people use social networks to find health information**. Also, many sites contain the “I like” function that links the article to Facebook. This is a way to share information found on the Internet and discuss it with the network. The patient association mentioned that comments from ‘friends’ often influence a decision. For example, a status posted in Facebook allows others to share their own experience, and sometimes, influence the decision-making (for example an operation).
- 6) Accessibility: The presentation of the site is very important. When the text is not readable, or too heavy, there is a tendency to choose another page. **Good (readable) text format and illustrations are appreciated by patients**, especially older patients.

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7) When patients do not find the information on the Internet, they give up or ask family and friends. In such cases, the patient association suggested a “live” helpline (phone call) with a person qualified to help users find information online. A problem would be the cost of the phone call to the helpline.

8) **Will people pay for finding health information on the Internet?** The patient association answered no with regard to young patients, because they are accustomed to having everything “for free” on the Internet. People up to 50 will maybe pay, in order not to bother themselves with understanding the Internet.

9) **Advertising:** To sum up, the association explained that the presence of advertisement, when well distinguished from the editorial content is not a problem. However, when pages contain “aggressive” advertisements (such as popups), patients usually quit the page and consult another one.

10) **Consultation of various sources:** patients searching for health information usually consult the page containing what they search and then stop the research. They rarely consult other sources to verify the information. If they find the information for example in a blog, they often consider it as “true” and do not consult other sources. This is a major problem related to education on the use of the Internet, said the patient association.

10.2 Questionnaire in English

How do you search for health-related information on the Internet?

Target audience: general public (not medical doctors)

(English version)

- The survey is intended for the representatives of the general public who are looking for health information online at least once a month.
- The questionnaire was developed by the Health On the Net Foundation, an independent Non-Governmental Organisation dedicated to improving the quality and accessibility of online health information, in collaboration with the Society of physicians in Vienna in the framework of the European Project [KHRESMOI](#) - project 2010-2014.
- Your participation will contribute to better understanding on how the general population is searching for online health information, what are the preferences and difficulties. The results of the survey will contribute to the creation of a new search engine specifically designed for search of health content.
- You will need around 20 minutes to complete the questionnaire.
- All the information collected is used exclusively for the purpose of the study. We do not collect personally identifiable information without your consent. More information on the [Confidentiality](#) and data privacy usage.
- All the results will be available on-line for free.
- Contributions from around the world are welcome.

Part 1. Use of the Internet

1.1 You have been using the Internet for:

- | | |
|---|--------------------|
| 1 | Less than 6 months |
| 2 | 6 to 12 months |
| 3 | 1 to 3 years |
| 4 | 4 to 6 years |
| 5 | More than 6 years |

1.2 How experienced do you rate yourself in using the Internet as an informational search medium?

- | | |
|---|-------------------|
| 1 | Newcomer |
| 2 | Moderate user |
| 3 | Good user |
| 4 | Professional user |

1.3 Do you have a regular Internet access?

- 1 Yes
- 2 No

1.4 How often do you connect to the Internet?

- 1 Daily
- 2 Few times a week
- 3 Once a week
- 4 Few times a month
- 5 Once a month
- 6 Other Please, specify

1.5 About how many hours a day (both at home and at work) do you normally take to check your email and surf the web?

- 1 Less than two hours a day
- 2 2 to 4 hours a day
- 3 4 to 8 hours a day
- 4 More than 8 hours a day

1.6 How do you connect to the Internet?

- 1 Through a modem
- 2 Through a Wi-Fi
- 3 Through a USB
- 4 Through a mobile phone
- 5 Other Please, specify
- 6 Do not know

1.7 Which device do you use to connect to Internet normally?

- 1 PC at home or office
- 2 Laptop
- 3 Mobile phone
- 4 Other mobile devices

1.8 If you use a mobile Internet device, what do you use?

- 1 Smartphone (e.g. I-phone, Blackberry, etc.)
- 2 Tablets (e.g. Ipad, Samsung Galaxy, Tablet PC, ViewsonicViewpad, etc.)

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- 3 Netbook
- 4 Laptop
- 5 Other device Please, specify
- 6 I don't use a mobile Internet Device

1.9 How often do you use Internet to search for health information?

- 1 Once a day
- 2 Few times a week
- 3 Once a week
- 4 Few times a month
- 5 Once a month
- 6 Other Please, specify

Part 2. Current Search of health information

2.1 Which sources of information do you prefer looking for health and medical information?

<i>Unimportant</i>	<i>Of little importance</i>	<i>Moderately Important</i>	<i>Important</i>	<i>Very important</i>
1	Doctors consultation			
2	Friends/Family member advice			
3	Books			
4	Magazines			
5	Newspapers			
6	Radio			
7	TV			
8	Internet			
9	Other Please, specify			

2.2 What are the cases when you would rather use Internet than other sources of information?

<i>Unimportant</i>	<i>Of little importance</i>	<i>Moderately Important</i>	<i>Important</i>	<i>Very important</i>
1	Lack of time			
2	Lack of access to healthcare institutions			
3	Lack of money to pay for doctors consultation			4
	When I am looking for support (for rare, chronic diseases)			5
	When I want to know other people experience			6
	Absence of other means of information as books, magazinesetc			7
	Practical and accessible at home			
8	Other			

2.3 What is your search activity focused on?

1	Long term, chronic disease
2	Short-term (up to 2 weeks), acute disease
3	General information about health issues
4	Kids health
5	Elderly health and care
6	Healthy lifestyle and nutrition
7	Other Please, specify

2.4 What type of online health information are you looking for?

	<i>Never</i>	<i>Rarely</i>	<i>Sometimes</i>	<i>Often</i>	<i>Always</i>		
information about a disease						1	General
2							Detailed disease description
3							Scientific articles
4							Abbreviations
5							Prevention
6							Clinical trial information
7							Diagnosis
8							Treatment/Therapy
9							Therapy side effects
10							Drugs information
11							Patients and/or support groups
12							Self-diagnostic tools
13							Others Please, specify

2.5 Looking for drug information which kind of content are you interested in?

		<i>Never</i>	<i>Rarely</i>	<i>Sometimes</i>	<i>Often</i>	<i>Always</i>
1	Drug description					
2	Side effects					
3	Drugs interaction					
4	Drugs contraindications					
5	Drug safety, toxicity					
6	Drug dosage					
7	Drug prices					
8	Drug purchase					
9	Other					

2.6 For whom do you search health information online?

<i>Never</i>	<i>Rarely</i>	<i>Sometimes</i>	<i>Often</i>	<i>Always</i>
1		Myself		
2		My partner		
3		My child		
4		My parents		
5		Other family member		

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- 6 A friend
- 7 Other

2.7 What type of content do you prefer looking for online health information?

- 1 Articles
- 2 Forums, blogs, Facebook and other social networks
- 3 Combination of both

2.8 Do you check web sites which are clearly addressed to medical professionals?

- Never
- Rarely
- Sometimes
- Often
- Always

Part 3. Use of search engine for health topics

1.1 How often do you use the following types of online sources to find online health information?

Never Rarely Sometimes Often Always

- | | |
|----|---|
| 1 | Search engines (Google, Yahoo, MSN, etc.) |
| 2 | Portal web sites (Yahoo health, Google Health, MSN Health, etc.) |
| 3 | Specialized search tool (HONselect, Medline Plus etc.) |
| 4 | Web sites providing health information (Hospital, University, Pharma, Publishers) |
| 5 | Web sites suggested by a health care provider |
| 6 | Web sites suggested by a friend |
| 7 | Links from a health web site |
| 8 | Wikipedia |
| 9 | Forums and blogs |
| 10 | Facebook or other social networks |
| 11 | Other Please, specify |

3.2 In case of using a search engine how many words do you type normally?

- | | |
|---|----------------|
| 1 | One |
| 2 | Two-tree |
| 3 | Three-five |
| 4 | More than five |

3.3 Which words do you introduce into search bar?

- | | |
|---|--|
| 1 | Medical terms (diagnosis, drugs names) |
| 2 | A question I would have asked my doctor (i.e. What is the difference between two drugs?) |
| 3 | Other Please, specify |

3.4 In case of a complex question (for ex. "how the drug X influences a high pressure of a pregnant woman") how much time do you usually spend trying to find the answer using the Internet?

- | | |
|---|------------------|
| 1 | Less than 3 min |
| 2 | From 3 to 5 min |
| 3 | From 5 to 10 min |
| 4 | More than 10 min |

3.5 In case of a complex question how many times do you change your search terms before you get the desired answer?

- 1 Once
- 2 Two-three times
- 3 More than three times

3.6 What are the most important characteristics of search engine for you? *Unimportant*
Of little importance *Moderately Important* *Important* *Very important*

- 1 Speed
- 2 Relevance of matches
- 3 Readability of results
- 4 Quality of description
- 5 Trustworthiness of results
- 6 Overall personal evaluation of the site
- 7 Easy-to-use / Simplicity
- 8 Usability for smartphones and mobile devices?

3.7 When search results (list of links) appear which results do you normally choose to click?

- 1 The First
- 2 The first five links
- 3 Scroll down and click some of them
- 4 Scroll down and click all of them
- 5 Other Please, explain

3.8 How often do you check the second or third page of results?

- Never
- Rarely
- Sometimes
- Often Always

3.9 Do you verify the answer you have found in some other information source?

- 1 No, I trust Internet sources I find
- 2 No, I use the web sites recommended by my MD

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- 3 Yes, I ask my MD after performing the search
- 4 Yes, I use another search engine
- 5 Yes, I verify the results on the web site I trust I have found by myself
- 6 Yes, I ask on the forum
- 7 Yes, I ask my family, friends
- 8 Other Please, specify

3.10 Have you faced the situations you could not find the answer?

- Never
- Rarely
- Sometimes
- Often
- Always

3.11 Why do you think you could not find the answer?

Never Rarely About a half the time Usually Always

- 1 Too much search results, difficult to choose what is relevant
- 2 Search results do not help me to find an answer
- 3 I was not sure how to formulate a search query
- 4 Other Please, specify

3.12 What have you done to overcome the situation when you cannot find the answer in the Internet?

Never Rarely Sometimes Often Always

- 1 I ask my MD
- 2 I use the web sites recommended by my MD
- 3 I try another search engine
- 4 I modify search terms
- 5 I try the web site I trust I have found by myself
- 6 I ask on the forum
- 7 I ask my family, friends
- 8 Nothing
- 9 Other Please, specify

3.13 Which Advanced search options do you use?

Yes No

- 1 Date range
- 2 Country
- 3 Language
- 4 Document format (pdf, doc,ppt)
- 5 Other Please, specify
- 6 I do not use Advanced search options

3.14 Do you currently access restricted information (which requires paying the membership fees?)

- Never
- Rarely
- Sometimes
- Often
- Always

Part 4. Difficulties and barriers

4.1 What types of difficulties do you face when searching for health information?

Never Rarely Sometimes Often Always

- 1 Speed
- 2 Relevance of matches
- 3 Readability
- 4 Usability for smartphones and mobile devices
- 5 Accessibility
- 6 Overload with information quantity
- 7 Questionable trustworthiness
- 8 Quality and explicitness/fullness of description
- 9 Evaluation of the link
- 10 Reading and understanding the information
- 11 Distracting Ads
- 12 Lack of information in my mother tongue
- 13 Search results lack specificity
- 14 Poor organization of search results
- 15 Lack of quality filter
- 16 Finding the relevant information in the Internet takes too long

4.2 Do you understand health/medical information you find online?

- Never
- Rarely
- Sometimes
- Often
- Always

4.3 How do you evaluate presence of advertising banners along with search results?

- 1 It helps to find an answer
- 2 It distracts
- 3 It does not influence my search
- 4 Other Please, specify

Part 5. Let's dream of citizen-cantered health search engine

5.1 How the final answer of your search should be presented?

- 1 List of links (Google, Yahoo)
- 2 Summary of information derived from different sources
- 3 All the links are categorized into the groups such as scientific, clinical, commercial, advertising, forums and blogs, etc.
- 4 Other Please, specify

5.2 Would you prefer to have?

- 1 All possible search results
- 2 Less than 5 trustworthy results
- 3 From 5 to 10 trustworthy results
- 4 More than 10 trustworthy results

5.3 Would you find useful to be able to directly rate and perceive ratings of information/websites made by other users during your search process?

- 1 Yes
- 2 No
- 3 I do not know

5.4 Do you find these tools helpful?

<i>Unimportant</i>	<i>Of little importance</i>	<i>Moderately Important</i>	<i>Important</i>	<i>Very important</i>
1	Advanced search (country, language, date range)			
2	Suggested filling of query			
3	Spelling correction			
4	Search of images			
5	Search of audio and video podcast			
6	Automatic translation of results			
7	Tutorial on strategy of successful online health information search			
8	Hotline or web chat support on how to find information using a search engine			
9	Medical dictionary/Thesaurus			
10	Suggested relevant topics			
11	Word cloud representing the most prevalent terms and/or web sites across the search results by a search engine			
12	Risk factors assessment tools			

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- 13 Body 3D anatomy visualization
- 14 Use from mobile platforms
- 15 Customization of font and letter size, colours
- 16 Ability to listen to the text and save it as mp3
- 17 Sharing your search results with your Doctor, friend (by email)
- 18 Receiving updates of your search results by email/RSS
- 19 Other Please, specify

5.5 Other ideas/suggestions

open question

5.6 Would you prefer?

- 1 To have ads in order to keep a search service free
- 2 To donate and avoid ads placement
- 3 To pay fee-for-service each time you use the search engine
- 4 To subscribe to a membership subscription

5.7 In case of ads: Is it important that ads undergo a rigorous quality control?

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

Part 6. Tell us about you

6.1 Your age

<=19
20-29
30-39
40-49
50-59
60-69
70-79
>=80

6.2 Gender

Male
Female

6.3 Where do you live and work?

- 1 I live and work in urban area
- 2 I live and work in rural area
- 3 I live in rural area and work in urban
- 4 I live in urban area and work in rural

6.4 Your highest level of education

- 1 Elementary school
- 2 High school or equivalent
- 3 Vocational/Technical school (2 years)
- 4 University graduate (Bachelor degree)
- 5 Postgraduate Master Degree
- 6 Postgraduate Doctoral Degree
- 7 Other

6.5 Area of your occupation

- 4 Architecture and Engineering Occupations
- 9 Arts, Design, Entertainment, Sports, and Media Occupations
- 13 Building and Grounds Cleaning and Maintenance Occupations

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- 2 Business and Financial Operations Occupations
- 6 Community and Social Services Occupations
- 3 Computer and Mathematical Occupations
- 18 Construction and Extraction Occupations
- 8 Education, Training, and Library Occupations
- 17 Farming, Fishing, and Forestry Occupations
- 12 Food Preparation and Serving Related Occupations
- 10 Healthcare (excluding MDs)
- 19 Installation, Maintenance, and Repair Occupations
- 7 Legal Occupations
- 5 Life, Physical, and Social Science Occupations
- 1 Management Occupations
- 22 Military Specific Occupations
- 16 Office and Administrative Support Occupations
- 14 Personal Care and Service Occupations
- 20 Production Occupations
- 11 Protective Service Occupations
- 15 Sales and Related Occupations
- 21 Transportation and Material Moving Occupations

6.6 Country

- 1 Albania
- 2 Austria
- 3 Belgium
- 4 Bulgaria
- 5 Bosnia
- 6 Canada
- 7 China
- 8 Croatia
- 9 Cyprus
- 10 Czech Republic
- 11 Denmark
- 12 Estonia
- 13 Finland
- 14 France
- 15 Germany

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- 16 Greece
- 17 Hungary
- 18 Iceland
- 19 India
- 20 Ireland
- 21 Israel
- 22 Italy
- 23 Kosovo
- 24 Latvia
- 25 Lichtenstein
- 26 Lithuania
- 27 Luxembourg
- 28 Macedonia
- 29 Malta
- 30 Montenegro
- 31 Netherlands
- 32 Norway
- 33 Poland
- 34 Portugal
- 35 Romania
- 36 Russia
- 37 Serbia
- 38 Slovakia
- 39 Slovenia
- 40 Spain
- 41 Sweden
- 42 Switzerland
- 43 The UK
- 44 The USA
- 45 Turkey
- 46 Other Please, specify

6.7 Mother tongue

- 1 Albanian
- 2 Arabic
- 3 Bosnian

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- | | |
|----|---------------|
| 4 | Bulgarian |
| 5 | Chinese |
| 6 | Croatian |
| 7 | Czech |
| 8 | Danish |
| 9 | Dutch |
| 10 | English |
| 11 | Estonian |
| 12 | Finnish |
| 13 | French |
| 14 | German |
| 15 | Greek |
| 16 | Hindi/Urdu |
| 17 | Hungarian |
| 18 | Icelandic |
| 19 | Irish |
| 20 | Italian |
| 21 | Japanese |
| 22 | Latvian |
| 23 | Lithuanian |
| 24 | Luxembourgish |
| 25 | Macedonian |
| 26 | Malay |
| 27 | Maltese |
| 28 | Norwegian |
| 29 | Polish |
| 30 | Portuguese |
| 31 | Romanian |
| 32 | Russian |
| 33 | Serbian |
| 34 | Slovakian |
| 35 | Slovene |
| 36 | Spanish |
| 37 | Swahili |
| 38 | Swedish |
| 39 | Turkish |

40 Other Please, specify

6.8 How well do you understand medical English?

- 1 Excellent
- 2 Very Good
- 3 Good
- 4 Average
- 5 Below Average
- 6 Poor

6.9 Do you have enough health and medical information in your native language?

- 1 Yes
- 2 No

6.10 If in the language of area where you live is different from your mother tongue, do you easily find the health information in your language?

- 1 Yes
- 2 No

6.11 Would you like to obtain the results of the study?

- 1 Yes
- 2 No

6.12 Would you like to contribute to other studies conducted by HON Foundation?

- 1 Yes
- 2 No

Thank you!

10.3 Figures from the international comparative study BUPA Health Pulse 2010

