

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

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Abstract. The most popular mean of searching for online health content is a general search engine for all domains of interest. Being general implies on one hand that the search engine is not tailored to the needs which are particular to the medical and on another hand that health domain and health-specific queries may not always return adequate and adapted results. The aim of our study was to identify difficulties and preferences in online health information search encountered by members of the general public. The survey in four languages was online from the 9th of March until the 27th of April, 2011. 385 answers were collected, representing mostly the opinions of highly educated users, mostly from France and Spain. The most important characteristics of a search engine are relevance and trustworthiness of results. The results currently retrieved do not fulfil these requirements. The ideal representation of the information will be a categorization of the results into different groups. Medical dictionaries/thesauruses, suggested relevant topics, image searches and spelling corrections are regarded as helpful tools. There is a need to work towards better customized solutions which provide users with the trustworthy information of high quality specific to his/her case in a user-friendly environment which would eventually lead to making appropriate health decisions.

Keywords. Online health information, Search engine, Citizens, Quality

Introduction

Some studies proved that health searches start most commonly with the use of a general search engine such as Google[®], Yahoo[®], etc [1-3]. Seeking health information on the Internet can be very beneficial for lay users (non-medical professionals), but due to the overwhelming quantity and uneven quality of online health information, it can also be time-consuming and insufficient in providing customized information of good quality [1,4]. The information provided can be incomplete and in some cases misleading [5-7]. The understanding of online health information differs according to the ehealth literacy level of the user. Different approaches have been taken to tackle the difficulties of online health information search. Specialized search engines targeting the specific aspects of health domain have proved to provide more reliable results in contrast to general ones [8].

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The principal aim of this study was to evaluate how non-physicians self-report searching for online health information. The findings are further used in a framework of EU large-scale project “KHRESMOI” (2010-2014) which has as main aim/purpose to develop a multi-lingual multi-modal search and access system for biomedical information and documents.

1. Methods

Health On the Net Foundation (HON) surveys use non-probabilistic, convenience sampling. The ad-hoc questionnaire has been tested for usability, but no pre-test has been performed. The minimum time necessary to fill the questionnaire have been estimated to 35 minutes. All the responses below this response time has not been counted in order to avoid counting the questionnaire filled by users only click-through. The incomplete filled questionnaires have not been counted and excluded from the analysis. This questionnaire was hosted on the HON web site from the 9th of March until the 27th of April, 2011 and was available in English, French, Spanish and German. The survey was open, i.e. everyone could access it following the link (<http://www.healthonnet.org/kpat>) provided in HON newsletter and in the social media posts, or by clicking on the banner hosted on HONcode certified web sites. The questionnaire had an introductory note specifying that it was addressed to non-physicians.

It consisted of six parts, 53 questions in total: Part 1. Use of the Internet (9 questions). Part 2. Current Search of health information (8 questions). Part 3. Use of search engine for health topics (14 questions). Part 4. Difficulties and barriers (3 questions). Part 5. Let's dream of citizen-cantered health search engine (7 questions). Part 6. Tell us about you (12 questions)

One-way analysis of variance (ANOVA) with level of significance 0.05 and post-hoc comparisons with the Tukey method were conducted to reveal contrasts between subgroups in age and gender groups of the population. Furthermore, means comparisons cross tabulation and descriptive statistics were used to analyze the data. The Tool SPSS Statistics 18.0 was used for the analysis.

2. Results

Participants profile. 385 persons participated in the survey, slightly more females (53%) than males (47%), which corresponds to a general tendency that women are more active in seeking online health information [9,10]. Regarding age, the most active age groups turned out to be those aged 50-59 (25%) along with the ones aged 30-39 (24%). Overall, people aged between 20 and 59 seemed to be the most engaged age group (85% of all respondents). An US study reported that the most active health information seekers are aged 18-49 [9]. 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 of those aged 25-34 [11].

The respondents have above average education level. 79% of the respondents have graduated or just graduated from university, 43% of them also completed a Master's Degree and 28% held a PhD. Most of the respondents work in healthcare (30%) or have computer and mathematical occupations (21%), or work in education

and training (13%). The participants were coming from 42 countries worldwide with the largest numbers of contributors from France (23%), Spain (14%) and the US (10%), living and working mostly in urban areas (78%). The survey respondents have been using the Internet for a long time: 90% of respondents declared having more than six years of Internet experience, 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.

Health-related Internet use. 24% of 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.

For 71% of all respondents, the Internet is the second most important source of health and medical information after physicians (82%). Out of all sources of information, those aged over 60 seem to consider more important doctor consultation and friends/family advice than the age group 18-39 (means difference 0.469 and 0.648 respectively). On the other hand, the Internet is considered more important for those aged 18-39 than for those aged over 60 (means difference 0.383). Doctor consultation, radio and TV are more important to women compared to men (Sig.=0.010, 0.028 and 0.001 respectively).

82% of the participants in the survey indicated that they use a search engine often or always (those aged 18-39 use more frequently search engines to find online health information than the age group over 60 (means difference 0.499)). The most important characteristics of a search engine for users are relevance of matches (97% consider it (very) important), trustworthiness (93%), readability of results (90%) and quality of the description (90%). As mentioned above majority of the participants consider themselves as good or professional Internet users, nevertheless easiness or simplicity of search engine use is considered (very) important (67%).

What are the difficulties encountered in the process of online health information search while using a general search engine? Only 40% of respondents report rarely or never having difficulties in finding answers to their health queries, while half of the participants (51%) face this problem sometimes and the remaining 9% often. Facing a "complex" question, 54% of participants reformulate a query 2-3 time, and 36% need to do it more than three times.

Relevance of matches (86%), questionable trustworthiness (85%), quality and completeness of description (82%), overload with information quantity (76%) and lack of quality filter (74%) are the top-5 difficulties respondents face at least sometimes. Thus, current search results have low precision, lack trustworthiness and their number is overwhelming. Neither is the readability of search results properly addressed by current solutions as 65% admit facing this problem at least sometimes. Three out of four face the problem of lack of quality filter at least sometimes, which justifies the efforts of several initiatives to work on quality improvement of health information on the Internet.

The eventual consequence of having difficulties in using a search engine is failing to retrieve the answer to a question. When an answer is NOT found users "usually" or "always" modify search terms (80%), ask their medical doctor (48%), or verify the information on a website they trust (46%). When asked about the main reasons for failing to retrieve a satisfying answer, they are: search results do not guide towards an answer (64% face this problem at least sometimes), and the users are overwhelmed by the quantity of results (61%).

What would be the ideal healthcare consumer-centered search engine. 54% of respondents have chosen the categorization approach of results representation when all the links are grouped into scientific, clinical, commercial, forums and blogs. 24% would prefer a summary referencing the different sources, and 20% would like the “conventional” form of search result presentation as a list of links (such as Google®).

Most highly-ranked tools are: Medical dictionary/thesaurus (89% consider it at least moderately important), Suggested relevant topics (86%). Advanced search (86%). Search of images (81%). Spelling correction (80%). Risk factors assessment tools (74%). Suggested filling of query (72%). Body 3D anatomy visualization (70%). Word cloud showing the most prevalent terms across the search results (67%). Automatic translation of the results (65%). Tutorial on strategy of successful online health information search (65%). Sharing your search results with your doctor or peer (62%). Search of audio/video podcast (60%).

Age groups variance analysis revealed that those aged over 60 tend to place more importance to risk factors assessment tools comparing with those aged 18-39 (means difference -0.531). For daily health information seekers, advanced search is more important comparing with less frequent users. Less frequent users though give their preference to word cloud (Sig. =0.006).

Out of all proposed tools medical dictionary, search of images, audio and video, risk factors assessment tools, and body 3D anatomy visualization are highly health domain-specific. Nevertheless, even more “common” search engine functionalities as spelling correction, suggested filling of query or automatic translation should be customized due to the specificity of health and medical vocabulary.

3. Discussion

The search engine is an entry access to find health information online. To understand how the users experience the search exercise is an important issue for developing next generation of search engines.

In this paper, we showed that the two third of the respondents of the survey have difficulties for in finding answers to their health queries. This percentage of users failing to find an answer with the current search engines could be significantly higher if the survey respondents were performed with novice Internet users.

This survey confirmed that the Internet is the second most important source of health and medical information after physicians as a French study conducted in 2010 echoed [13]. This survey used non-probabilistic, convenience sampling and could not ensure that participants are representative of the entire online health information seekers' community as participation was voluntary. The fact that one third of the respondents are working in a healthcare, another third in math and IT sector shows great importance these users place on health-related online search. We considered important to keep the opinions of respondents from these groups as it shows the particular need in having an accessible and efficient search engine for health content. Also, taking into account the Internet use experience of participants, we believe they represent the most empowered and actively engaged part of the global Internet population seeking health information [9, 11, 12]. To reach the people with lower

levels of education in all age groups which often lack information and strategic² Internet skills, other means of conducting a survey need to be used, i.e. telephone- or paper-based as the Internet is not adapted.

4. Conclusions

There is still room for improvement for current search engines as their output often lacks relevancy and specificity. Users want to have trustworthy results adapted and customized to their needs. Working towards this direction will provide users with the trustworthy information of high quality that is specific to his/her case in a user-friendly environment which would eventually lead to empowerment of health consumers.

Overall, despite of various initiatives, 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 and facilitate user's access to it. In this way, educating the users and providing them with the quality health information enables them to take appropriate health decisions.

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² “Strategic Internet skills enhance the capacity to use the Internet as a means of reaching particular goals including the general goal of improving one's position in society.”