Users’ attitudes towards health-related Web 2.0 platforms

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Abstract
The Health On the Net Foundation’s (HON) mission is to guide users of the Internet towards transparent and trustworthy online health information. In May of 2012, HON conducted two surveys. The first survey had the objective of identifying current trends of the use of Web 2.0 platforms for health purposes among users and to gain a better understanding of their need for guidelines. The second survey aimed to find out the needs of webmasters regarding the implementation of Web 2.0 guidelines on their websites as well as to receive feedback on these guidelines. This paper presents the main findings of the first survey. The data gathered from a total of 115 respondents, representing men and women as well as all predefined age groups, was analysed. In total 55% of them reported to checking a Web 2.0 platform dedicated to a health topic at least once a week. Forums were the most used (46%) Web 2.0 platform, and the main purposes of using platforms were to get health-related information (42%) and to communicate with peers about health-related issues (34%). In total, 81% agreed that a set of ethical guidelines would be “very helpful” or “helpful” in guiding users of Web 2.0 platforms towards trustworthy health information. However, 37% did not know whether the platform they use applies ethical guidelines or not. The results of this survey have shown that the users have a need to be better informed about the guidelines used on Web 2.0 platforms. The webmasters of health websites play a key role in fulfilling this need, and the HONcode certification is a tool that can be used to assist in this task.

Key words: Medical Informatics; Health Surveys; Web 2.0

Introduction
The HONcode is a set of eight principles covering principal ethical aspects to ensure the transparency of online health information and its production process. The HONcode certification for websites with health-related content was initiated by the Health On the Net Foundation (HON) in 1996. HON’s mission is to guide users of the Internet towards transparent and trustworthy online health information. The means of fulfilling this mission is to educate webmasters via the HONcode certification which aims to improve transparency of health websites.

The HONcode certification process is updated based on the evolution of the Web and more specifically the impacts of this evolution on the health domain on the Internet. In 2008, following the continuous evolution of the Web, HON collaborated with the French National Authority for Health (Haute Autorité de Santé, HAS) to create the first version of the Web 2.0 guidelines for HONcode certified websites [1]. These guidelines were designed to describe how to implement the eight HONcode principles on Web 2.0 platforms, such as forums, blogs and wikis. Taking into account the experience gained in the previous four years as well as the increasing number of HONcode certified websites with Web 2.0 platforms, HON decided to update its Web 2.0 guidelines. The increase of websites in English with Web 2.0 platforms was from 10% to 16% in the period of 2008 to 2012. During May of 2012, a survey was conducted to identify current trends in using Web 2.0 platforms for health purposes among users and webmasters, and to collect feedback on the proposed (new) HONcode guidelines for Web 2.0 platforms.

This paper, the focus is on the users of Web 2.0 platforms, their ways of using these platforms for health purposes, and their perceived need to establish guidelines for Web 2.0.

Method
An online survey was conducted between the 3rd of May and the 31st of May, 2012. Two different questionnaires were prepared: one for users of Web 2.0 platforms and one for webmasters [2; 3]. The questionnaires were available in both English and in French. The survey was promoted in both languages on the HON website, in the HON newsletter for webmasters of HON-code certified websites, and via social media channels, such as Twitter, Facebook and LinkedIn. In addition, the webmasters were asked to promote the user questionnaire on their website by displaying a ready-to-use banner. Halfway through the field time, the survey was re-promoted by sending a reminder to the webmasters of HON-code certified websites. The first page of the online questionnaire featured a filter question that was designed to exclude respondents who were not in the focus group of the study, which meant those who do not use Web 2.0 platforms related to health. The actual questionnaire included 23 questions of which 17 were close-ended and 6 were open-ended or partially open-
ended questions. On average, completing the questionnaire took 6.5 minutes.

Once the survey was closed, the quantitative analysis was done by using PASW Statistics 18. Only the questionnaires that had been fully completed (100%) were taken into account in the analysis, which comprised mainly of descriptive statistics, such as frequencies and cross tabulations. These results are presented in tables and in graph form. The answers to the open-ended questions were divided into categories which revealed some main trends. These results are presented as comments.

Results

A total of 115 users of Web 2.0 platforms fully completed the questionnaire, with 85 in English and 30 in French. A total of 156 respondents did not finish the questionnaire and were thus excluded from the final results.

Of the respondents 61 were women and 54 were men. All age groups were well represented, with the largest number of participants from the age group 50 to 60 years old (28%), and the second largest from the age group 18 to 29 years old (23%). When asked about their health, the vast majority reported to be generally healthy (58%). A third reported to having “a long-term, chronic health condition” (32%), and 10% reported “a specific health problem”. A total of 47% said that they are using Web 2.0 platforms for themselves, 6% for a person they care about, and 41% for both. In addition, 6% reported that their use was based on something else, such as their profession.

When asked about their activities on Web 2.0 platforms, 49% of the respondents reported to only reading, and 51% to reading and writing messages/comments. A total of 55% said they check a Web 2.0 platform dedicated to a health topic of their interest “every day” or “every week”, 31% reported to doing this “not regularly, but when needed”.

The respondents reported to using mostly forums (46%), personal health management platforms (23%) and blogs (16%). Nonetheless, when asked whether they prefer websites with Web 2.0 platforms over websites without platforms, over half of the respondents (52%) chose the option “no opinion / don’t know”. Only 4% answered “no”, and 44% answered “yes”. In the comments, the users mentioned several reasons behind their preference for websites with Web 2.0 platforms. The most common reasons were interacting and collaborating with other users, and user-friendliness.

According to the respondents, their main purposes of using Web 2.0 platforms were to get health-related information (42%), and to communicate with peers about health-related issues (34%). When asked whether they trust the health-related information found on Web 2.0 platforms, almost half of the respondents (49%) reported that they usually check the information by comparing it with other health websites. A total of 26% of the users reported that when in doubt regarding the trustworthiness of the health information, they normally verify it with peers or physicians on the Web 2.0 platform.

In the user questionnaire, the respondents were asked to answer simplified questions regarding their use of Web 2.0 platforms for health purposes. These questions were based on the proposed (new) HONcode guidelines for Web 2.0 platforms. In total, 78% of the respondents felt that it is important to have Web 2.0 platforms moderated. 13% reported that this is not important for them, and 9% had no opinion or did not know.

When asked if they find it important that “a clear statement is provided that the information on the Web 2.0 platform is to support, and not to replace, the physician-patient relationship”, 76% replied “yes”. 14% felt that it is not important, and 10% had no opinion or did not know.

A total of 86% participants reported that they would like to know how their personal information is used when it is collected by Web 2.0 platforms. Only 6% said that they did not want to know, 8% had no opinion or did not know.

Of the respondents, 78% reported that they would like to have the option to consult / be redirected to the original document/source of the health information found on Web 2.0 platforms. Only 4% said that they did not need this option, but 18% said that they had no opinion or didn’t know.

In total, 59% reported to noticing false or misleading health information at least “every now and then” on the Web 2.0 platform(s) they use. A total of 41% said that they have seen this “almost never” or “never”.

When asked if they find it important to be able to communicate with the moderator of the Web 2.0 platform (e.g. for user support), 64% said “yes”. However, 24% said that this is not important for them, and 12% had no opinion or did not know.

Furthermore, when asked if they think it is important that the Web 2.0 platform they are using fulfills its purpose in respect to its mission, only 57% answered “yes”, and 20% replied “no”. Almost every 1 in 4 users (23%) said that they had no opinion or did not know.

In total, 83% of the respondents felt that, for them, it is important to be informed whether the moderator has a conflict of interest. Only 8% said that this was not important, and 9% had no opinion or did not know.

When asked if they find it important to be able to easily distinguish advertisements on the Web 2.0 platforms from the
users’ contributions, 86% answered “yes”. Only 5% said that this was not important, and 9% had no opinion or did not know.

In total, 81% of the respondents felt that a set of ethical guidelines would be very helpful or helpful in guiding users of Web 2.0 platforms towards trustworthy health information.

When asked if the Web 2.0 platform they are using applies any guidelines, 51% said “yes”, and 12% “no”. However, 37% of the respondents did not know whether or not the platform they use applies ethical guidelines.

Discussion and conclusions

In recent years, Web 2.0 platforms have shown to be very useful and important in managing day-to-day issues related to one’s health. Over half of the participants of the survey presented in this paper reported to checking a platform dedicated to a health topic at least every week (55%), and to being active members of these platforms (51% reading and writing messages/comments). Their main purposes of using Web 2.0 platforms were to get health-related information (42%) and to communicate with their peers about health-related issues (34%).

A total of 81% of the respondents felt that a set of ethical guidelines would be “very helpful” or “helpful” in identifying transparent, health-related Web 2.0 platforms. Although 37% of the users did not know whether the platform they use applies ethical guidelines. These results can be interpreted as alarming in the sense that the users might not be informed or aware of how the information on the platform is managed, and whether the information is transparent and trustworthy, regarding for example the confidentiality policy used on the platform.

On the other hand, a total of 59% reported to noticing false or misleading health information at least “every now and then” on Web 2.0 platforms. In case of doubt, almost half of the respondents (49%) reported to usually checking the health-related information they find on platforms by comparing it with other health websites. These results might be a sign that some users tend to critically evaluate and judge the information they find on Web 2.0 platforms. However, this number of respondents who show a critical approach to evaluating health information is still too low.

Ideally, all medical and health-related information should be verified by comparing it to other trustworthy sources. Furthermore, before taking action that could have a direct impact on an individual’s health, the information should be discussed with a physician.

Due to the highly dynamic nature of the Web, no one can prevent misleading information from appearing on Web 2.0 platforms. The Health On the Net Foundation’s mission is to guide users towards trustworthy and transparent health information by collaborating with webmasters of health websites and Web 2.0 platforms.

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References

1 Current HONcode guidelines for Web 2.0 platforms: ht tp://www.healthonnet.org/HONcode/Webmasters/Conduct.html

Graph 1

“What kind of Web 2.0 platforms do you give preference to?”
Graph 2

“Have you noticed false or misleading health information on the Web 2.0 platform(s) you use?”

- All the time: 5.22%
- Often: 17.39%
- Every now and then: 37.39%
- Almost never: 30.43%
- Never: 9.57%
Do you think a set of ethical guidelines would be helpful in guiding users of Web 2.0 platforms to trustworthy information?