Author's response to reviews

Title: An analysis of online health information on schizophrenia or related conditions: a cross-sectional survey

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Author's response to reviews: see over
Dear BMC Medical Informatics and Decision Making Editorial Team,

Thank you very much for providing us with the opportunity to revise our manuscript entitled “An analysis of online health information on schizophrenia or related conditions: a cross-sectional survey”. The manuscript has been modified based on the reviewers’ important comments and the revised manuscript has been approved by all co-authors. Below every comment, you will find our answers.

I confirm that this manuscript has not submitted elsewhere and it has not been published elsewhere.

I hope to find it worthwhile for publication and I am looking forward hearing from you.

On behalf of all the authors,

Best regards,
Christina Athanasopoulou

Reviewer 1 (Lian van der Krieke)

Minor essential revisions:
Introduction:
1. On page 5 you state “a thorough promotion for the use of web-based health information in different countries is needed”. This statement might be too strong and a bit premature. The aim of your paper is to see what information is provided on websites and to find out whether the quality is sufficient. At the same time, I do agree with your point that internet access and access to proper online health information is a basic right. Perhaps you can reformulate your sentence, focusing more on the priority that should be given to this topic, instead of promoting the use of online health information sites.

Authors’ answer: We thank the reviewer for that comment and have made the following change: on page 6, the statement “a thorough promotion for the use of web-based health information in different countries is needed”, was replaced by “priority should be given ensuring the availability and universal accessibility of high quality online mental health information [35,36,37]”.
Results

2. Please explain what a HON certification is (last sentence, page 11).
Authors’ answer: The HON certification is first mentioned on page 9. The following text was corrected: ‘Three additional characteristics were added including other languages available, provision of online services (e.g. video-conferencing), and presence of the Health On the Net (HON) code [53] which is an ethical standard certification of the trustworthiness of a specific health and medical website’

Discussion

3. What I miss in the discussion section is a discussion of your findings related to the difference in ICT context in Finland and Greece. In the introduction, you explain the differences in ICT context, and why it is relevant to take these two countries. But, you do not come back to it (only in the Conclusion, which is too late). Could you please elaborate on this in the Discussion? What do the differences that you found between Greece and Finland mean in the context of their different ICT climates? What are the implications? For instance, do the results indicate that top internet countries do not produce top websites? That countries in which the internet penetration rate is less high do not produce worse websites?
Authors’ answer: We thank the reviewer for her comment and have amended the manuscript by adding the following on page 16: ‘Although compared to Greek citizens, Finnish citizens are much more likely to seek health information online [62], and to have greater access to the internet [30], and more advanced ICT skills [29,31], our study found no evidence that the first-returned Finnish websites providing schizophrenia-related information were of better quality than Greek websites. This finding does not exclude the possibility that there are high quality Finnish and Greek mental health websites, but it does demonstrate that if high quality sites exist they are not among the first 20 results when a schizophrenia-related Google search is performed.’

4. Could you elaborate on how to improve mental health websites (for people with schizophrenia) in the future? Who should be involved? What needs to be taken into account?
Authors’ answer: This is discussed and further elaborated in the ‘Implications’ (page 20) section.

Discretionary revisions: Introduction

5. This sentence, especially the first part, I find difficult to understand: “While the Web can be accessed by a variety of populations [17], consumers may apply to their own lives the online information they read [18], which in turn may support their empowerment and understanding of the disease [19, 20].” Do you aim to focus on ‘consumers’ as a specific subgroup of ‘a variety of populations’? Or do you want to say that, because all the information on the web accessible for everyone, all consumers have the opportunity to look for free information that is
relevant to them (an opportunity that they did not have before, no longer solely dependent on professionals?
Authors’ answer: We thank the reviewer for her comment and have amended the manuscript by correcting paragraph 2 on page 4 (Background): ‘Advances in technology allow psychoeducation to be delivered conveniently through the Internet [15]. Such technology is now frequently used by members of the public to access health information online [16] with a substantial percentage of all online health searches being for mental health information [17]. Internet users visit medical websites primarily to acquire information about a health condition, its treatment, symptoms, and to obtain health advice [18].’

6. On page 4, where you discuss computer-based psychoeducation, I would suggest to also mention the Cochrane Review about computer-based psychoeducation recently published by your research group.
Authors’ answer: Thanks to the reviewer we have incorporated the following sentence (page 5): ‘In addition, web-based psychoeducation for people with schizophrenia shows some promise as a means of improving mental state, providing social support, and supporting medication compliance [20].’

7. On page 6, the sentence “However, a limited number of similar studies were conducted in countries like Finland or Greece, which differ in population, internet access and, Information and Communication technologies (ICT) use and attitudes” can be reformulated into a more informative sentence. To me, it is not clear whether previous studies were conducted in Finland and Greece, or in countries like Finland and Greece (in that case, how were they similar?). Furthermore, it is not clear to me what the findings of these studies were. Perhaps you can reformulate the sentence into something like: “Only two studies have been conducted in Finland and Greece that showed that .... They had a broad focus, including a variety of populations. The objective of this study is to assess....”
Authors’ answer: This sentence has now been amended, as suggested, as follows (page 6): ‘Four studies of the quality of online health information have been conducted in Finland [40,41], and Greece [42, 43]. Only one of these was related to mental health. It found that Finnish websites providing information about antidepressants did not cover all aspects of treatment [40]. These two European countries differ in population, Internet access and, Information and Communication Technologies (ICT) use and attitudes [29-31]. The objective of the current study was to assess, describe and compare Finnish and Greek websites that first appear after performing an online search concerning schizophrenia or related condition.’

Methods
8. On page 6, I would replace “one” by “a search” to make the sentence more
clear: “Search terms in Finnish and Greek language were chosen with the aim of
generating a list of websites that might to a search produced by....”
Authors’ answer: Corrected (page 7).

9. On page 7, you explain your hypothesis for four most probable search terms. I
was wondering, did you check the validity of your hypothesis with some random
service users?
Authors’ answer: This is discussed in the Limitations section (page 18), as follows: ‘Second,
there are no studies on how Finnish and Greek people diagnosed with schizophrenia
retrieve online mental health information. Hence, they may use a search engine other
than ‘Google’ or use different search terms or methods to acquire online health
information about their illness.’

10. Regarding inclusion criterion 1) on page 8: did you focus on adults in general
or adults with schizophrenia or related disorders (as is stated in your introduction)?
Authors’ comment: We thank the reviewer for this comment and we have clarified the
objective of the study as follows (page 6):
‘The objective of the current study was to assess, describe and compare Finnish and
Greek websites that first appear after performing an online search concerning
schizophrenia or related condition.’

11. Regarding exclusion criterion 8: by ‘parents’, do you mean ‘parents of people
with schizophrenia’?
Authors’ answer: This was replaced in the revised manuscript as follows (page 8): ‘8) or
provided health information for a non-adult population (e.g. for children or adolescents, or
their parents).’

12. About the selection process: can you add information about reviewers (e.g.
two independent reviewers), and possibly inter-rater reliability?
Authors’ answer: Thank you for raising this point. This question is now discussed
fully in the final paragraph of the section ‘Coding system and instrument’ (page 11),
while in the Limitations section (page 19) we have added that: ‘Last, inter-rater
reliability was only calculated for content of webpages, since it was the only indicator
assessed from two same language raters. However, the coding of the other indicators
was discussed for all data, between the Finnish and the Greek rater.’

Results
13. Page 12: About the correlations/associations: you report that there is no
significant correlation between accountability and interactivity. But, why would
you expect a correlation between these two factors? I would suggest to motivate the
associations that you are investigating in the analysis section.
Authors’ answer: Thank you for your excellent point. In previous studies
correlations/associations were made among indicators, but not for the ones we mentioned in
this manuscript. Thus, after your comment we judged it was better to delete this part of the results section.

14. Page 13: Interactivity of the website. I would suggest to start reporting the results about incorporated evaluation questionnaires. To me, this is a more ‘typical’ characteristic of interactivity than the provision of email addresses of web masters.
Authors’ answer: Thank you for this comment. We have revised the text on page 14 as follows: ‘Five websites (9%) incorporated evaluation questionnaires, for example, to enable the user to provide feedback about the website or to evaluate his/her health status. About three-quarters (74%, n = 43) of all websites provided the e-mail address of the webmaster and two-third (62%, n = 36) provided an intra-site search engine.’

Discussion:
15. Page 14: Perhaps you can make the first sentence more specific by underlining the fact that your focus was on websites intended for people with schizophrenia or a related disorders.
Authors’ answer: We have revised the first sentence of the Discussion section (page 15) as follows: ‘This study was designed to assess, describe and compare Finnish and Greek websites appearing first on ‘Google’ when using a search term on schizophrenia or related conditions.’

16. In the discussion, you seem to discuss the results of all indicators, except for Characteristics of the website.
Authors’ answer: We have added the following text on page 16 (third paragraph of Discussion): ‘This is supported by the finding that service promotion was more common on the Greek websites than on Finnish websites’ and ‘There were no significant differences between the Finnish and Greek websites with respect to other characteristics of websites such as scope, country and whether a drug company was involved.’

17. About accountability and ownership (page 15): could you explain why you think information about accountability and ownership is important? Could you speculate about a possible ‘best’ and a ‘worst’ owner?
Authors’ answer: The accountability measure used was based on the items proposed by Silberg as representing evidence of high website quality. Subsequently such criteria have been cited by authorities as important indicators of quality. Whether a website reports ownership is one of the Silberg items. We could have empirically investigated if ownership type was associated with overall Silberg quality but we have opted instead to focus on comparison between the Finnish and Greek websites.

18. Page 15: I don’t understand the relation between these two sentences: “Not
many governmental websites appeared in our online searches. Governmental bodies, patient associations and other official organizations participated in the development process of reliable health information to citizens.”

Authors’ answer: We have now omitted this section of the text.

19. Page 15: Relying on ... higher quality scores”. What do you mean with higher quality scores? Are you thinking about the content of websites?
Authors’ answer: This sentence has now been omitted.

20. Page 16: “In the current study it was found... health or mental health websites”. Aren’t you only focusing on mental health websites?
Authors’ answer: We thank the reviewer for this comment and have amended the sentence (page 17): ‘In the current study it was found that this information was typically not available within the first webpage of the included websites.’

21. Page 16: “Additionally, it was assessed... might have been inadequate”. I would suggest to move this sentence to the limitations. Also, ‘was’ should be deleted.
Authors’ answer: This sentence has been moved to the limitations section, and rephrased as follows: ‘Additionally, only the presence or absence of specific content was assessed (diagnosis, treatment, patient associations, clinics), without evaluating the accuracy or comprehensiveness of the provided information. Thus, even when the webpage achieved a positive rating on the current scoring system, the content of the webpage might have been of low evidence-based quality.’

22. Page 16/page 17: I don’t understand the function of the paragraph starting with “In the analysis, ‘wikis’ were scrutinized.” Why do you pay special attention to wikis in the discussion section? To me, it does not seem to logically follow from the previous paragraphs.
Authors’ answer: We thank the reviewer for his comment. The sentence ‘In the analysis, ‘wikis’ were scrutinized’ has now been replaced by: ‘In our study we included ‘wikis’ in the analysis, although their use as a reliable health resource has been criticized [70, 71].’

23. You could consider adding to your limitations some critical remarks related to the measurements that you used. I was a bit surprised to find out that ‘Aesthetics’ did not include the use of pictures or video material, whereas I think this can be crucial in information sites for people with psychotic problems.
Authors’ answer: We agree. The following text was added ‘Fourth, the quality indicators of this study could potentially consist of more items. For example, the aesthetics indicator did not measure the presence or not of images or video or other media (only diagrams) in our included webpages, although such material has the potential to assist people to better understand the text they read (74).’
Reviewer 2 (Nicola Reavley)

Essential revisions

Methods

P7 para 2. How were the random web pages chosen and how sure can we be that these random pages were adequately representative?

Authors’ answer: The sentence: We thank the reviewer for his comment and in the revised manuscript the sentence ‘Additionally, from every website, five random webpages were saved.’ (page 7) was replaced by the sentence: ‘Additionally, within every website five webpages were collected, applying convenience sampling. After opening and saving the first webpage that appeared from Google results, then four additional randomly selected webpages were saved which were linked to the initial page. Convenience sampling was preferred for the selection of webpages because of their convenient accessibility and proximity (51).’ In addition in Limitations section (page 18) the following was added: ‘In addition, the convenience sampling method used for the selection of five webpages for each website, does not ensure that someone could access and read the specific five webpages’

P9. Please include some more information on “the questions frequently generated by people with psychiatric disorders”. I see that there is a reference but it would be helpful to include details of such questions along with some information about how decisions about which questions to include were made.

Authors’ answer: Thank you. The sentence: ‘Lastly, the content of the provided online information was evaluated based on the availability of answers to health-related enquiries frequently generated by people with psychiatric disorders[52]’ was rephrased in the revised manuscript as (page 9): ‘Lastly, the content of the provided online information was evaluated based on the availability of answers to health-related enquiries frequently generated by people with psychiatric disorders, such as information about diagnosis, treatment options, and medication side-effects [55].’

It would also be useful to provide some assessment of inter-rater reliability and a discussion of how differences were resolved.

Authors’ answer: As noted above, information about inter-rater reliability and discussion of how differences were resolved has now been incorporated into the last paragraph of the ‘Coding System and Instrument’ section (page 11).

Minor revisions:

Introduction

The introduction jumps about a bit. It might be improved if the first part of para 2 and para 3 were better integrated. The beginnings of both those seem to cover similar territory. Could the authors say something specific about why internet health info is particularly useful for those with schizophrenia to link the first para with the rest of the introduction?
Authors’ answer: The paragraphs in question have now been restructured and rewritten (see paras 2 and 3 of revised manuscript).

In addition, paragraph 3 in the Background section (of the original manuscript) which read:
‘On the other hand, online health information can be easily misinterpreted [23] and consumers may be exposed to contradictory online medical advice and opinions [24]. Further, deficits in attention, concentration, visual perception and interpretation are commonly associated with schizophrenia [1,9]. As a consequence, it is particularly important that these websites, intended for people with schizophrenia, provide simple but high quality and understandable information, in design format that takes into account the above difficulties [25,26].’
has been rephrased as follows:

‘Schizophrenia is commonly associated with deficits in attention, concentration, visual perception and interpretation [1,9]. At the same time, online health information can be easily misinterpreted [21] and online health seekers may be exposed to contradictory medical advice and opinions [22]. As a consequence, it is particularly important that websites providing information about schizophrenia should present simple but high quality and understandable information, in a design format that takes into account the above difficulties [23,24].’

The authors could briefly expand on other studies of Finnish or Greek internet health information (mental health or, if not then more general information) to help set the scene for investigation of internet info on schizophrenia?
Authors’ answer: As noted in response to Reviewer 1, this section has now been rewritten to address this comment. See page 6: ‘Four studies of the quality of online health information have been conducted in Finland [40,41], and Greece [42, 43]. Only one of these was related to mental health. It found that Finnish websites providing information about antidepressants did not cover all aspects of treatment [40]. These two European countries differ in population, Internet access and, Information and Communication Technologies (ICT) use and attitudes [29-31].’

Results and Discussion
One difficulty with knowing whether the conclusions are appropriate to the data is in the definition of ‘inadequate’. I think the authors need to give us more idea of what an ‘adequate’ score is on some of these scales. Perhaps this could be done by comparing with other studies that have used similar scoring system, particularly if these have shown that the information is of reasonable quality (some for depression in English at least I believe).
Authors’ answer: We thank the reviewer for this comment. We have now used the term “low” rather than the term “inadequate”. This term reflects the fact that few of the Silberg criteria, on average, were satisfied.” See also page 15: ‘It seems that first-appearing Finnish and Greek websites, providing mental health-related information were of low quality
(reflecting the fact that few of the Silberg criteria, on average, were satisfied) with respect to the assessed indicators.'

As the authors note, there has been a growth in wikis in recent years, along with quite a bit of debate about the quality of the information on such sites. While they mention wikis in the discussion, there is no information on the quality of such sites as they compare to more ‘traditional’ sites. It would be interesting to know if these sites rated more or less highly on some of the scales used.

Authors’ answer: We thank the reviewer for her comment. A consideration of the relative quality of blog compared with other sites is beyond the scope of the current study. However, we have now incorporated the following sentence in the discussion section: ‘However, future research should consider investigating comparative quality across these different types of resources including wikis.’