Author's response to reviews

Title: Evidence-based health information from the users' perspective - a qualitative analysis

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Author's response to reviews: see over
Authors’ response to Editor’s comments and Reviewers’ reports

First, we would like to thank the Associate Editor and the Reviewers for their very helpful and constructive comments and for the opportunity to rework the manuscript. Our resubmitted version addresses all the points raised. The article was also proofread by a native English speaker. In the following we respond to the comments of the Associate Editor and Reviewers.

Additional notes to the Editor:

We would like to thank you for your suggestions for revising the manuscript. Our comments on your advice are included in our responses to the Reviewers’ reports.

Besides, we note the following:
1) We added the following acknowledgement of sponsorship by the German Research Foundation as requested: "We acknowledge the financial support of the German Research Foundation (Deutsche Forschungsgemeinschaft, DFG) for open access publication." We further noted the funding received from the IQWiG.

2) We would like to ask you to display tables 6 and 7 in the article itself, and not just as additional links to the PDF files, if at all possible.

Thank you very much.

Best regards - on behalf of all authors
Irene Hirschberg
Reviewers' reports

Version: 3 Date: 26 March 2013
Reviewer 1: Zachary Munn

Reviewer's report:

A very interesting and worthwhile paper. I particularly found the section on 'dealing with research evidence' very useful.

Major Compulsory Revisions
None

Minor Essential Revisions
Page 8, first paragraph - missing " after disinterest, 'the statements were multiply coded' - reword to 'the statements were coded multiple times'

Authors' response: We have corrected it in the revised version.

Discretionary Revisions
I would like to see, if possible, an example document - perhaps a snapshot of the front page of one of these consumer sheets would be useful?
I think the discussion should include some reference to similar studies (if there are any), and how the findings of this study relate to these studies.

Authors' response: The evaluated consumer information cannot be shown since they were pre-versions or drafts tested by order of the IQWiG within their usual production and evaluation process. As we added in the Methods section, the tested informational texts were provided in a defined layout (legible font size and line distance, place for notes). They were either unpublished or they were already published and under revision for an update of the text. The user comments were acknowledged within IQWiG's revision of the texts. The final revised informational texts can be accessed at http://www.gesundheitsinformation.de or http://www.informedhealthonline.org.
I think the area of study is of interest and has some practical implications. I was disappointed in the study however, as it did not seem to add a great deal to our understanding of user reaction to this type of information.

Major Compulsory revisions

1. All points in conclusion to be illustrated with a quote from the focus group data
   
   **Authors' response:** We included quotes mainly in the Results section, in particular in the subsection "Dealing with research and evidence". Further, all reaction patterns are described and underlined with 1-2 quotations in tables 4 and 5. (We also made other changes to table 4.) We did not include more quotations in the main text, but referred to the tables for better readability. The main conclusions are acknowledged in tables and text. (See also below response to question 4 (Does the manuscript adhere to the relevant standards for reporting and data deposition?), reviewer's comment 1)

2. Participants should be described in the main text
   
   **Authors' response:** We now describe participants in the results part in a new paragraph "Test readers of the study", and refer also to table 2 for a more detailed description of the readers' characteristics. Besides, we addressed the test readers' characteristics age, gender, nationality, and education in comparison with the German population as the following:
   
   "The test readers were recruited from a pool of registered people who were interested in participation, primarily participants in the MHH patient university. Eight of the 94 analysed test readers participated twice in the user testing. The gender distribution in the group was roughly three women to two men. The average age was 51 years (median: 57 years, range 15-82 years). 39.4% of the participants suffered from a chronic condition and 8.5% took part in a self-help group. More detailed descriptions including education, profession and nationality are shown in table 2. In comparison with the German population, the test reader population had a higher proportion of women (51% vs. 62.8%) and fewer participants from other nations (8.8% vs. 3.2%). Besides, there were differences in the age structure (more elderly test readers over 45 and from 15-25 years old) and the educational level (more test readers with a higher level of education) between the test population and the wider German population."

   We referred to that in the limitations:
   
   "...In further user testings we have increased efforts to recruit and include test readers with a low level of education and from younger age groups in particular...."

3. the information products should be described in the method section and the reasons for choosing these products should be given
   
   **Authors' response:** We revised the manuscript accordingly. See also below response to question 2 (Are the methods appropriate and well described), reviewer's comment 1.
4. Greater clarity to the aim of the research and the connection to the method and findings - particularly concerning the issue of 'expectation'.  
Authors' response: We revised the manuscript accordingly; please see the manuscript and responses to question 1 (Is the question posed by the authors well defined?) and 4 (Does the manuscript adhere to the relevant standards for reporting and data deposition?), reviewer comments 1.

5. More information about the conduct of the focus groups, with information about data storage, consent of participants and support for them to take part.  
Authors' response: We revised the manuscript accordingly, complementing the part on the user testing as the following:  
"After voluntarily announcing their interest at the patient university's office, the potential participants received an informational letter on the test procedure and conditions. Besides, they were asked to fill in a short questionnaire on characteristics such as age, gender, nationality, their education and profession, as well as health issues (membership of a self-help group, whether they suffered from a chronic illness or disability). Balanced groups of five participants were then chosen considering these characteristics and personal relevance on the health issues addressed by the informational materials (Table 2). A week prior to the focus groups, the texts were sent to the selected test readers. They were instructed to read the information carefully and note any open questions, unclear wordings or problems understanding the text. The test readers were told just after the whole discussion process that the IQWiG was the author of the evaluated texts. The focus groups took place in the rooms of the patient university and lasted between two and three hours. The participants received an allowance of €60.  
The focus group discussion started with a brief introduction of the moderator and the participants, followed by information on the testing procedure, the recording conditions, which ensured confidentiality. The participants were then again asked for their consent to take part in the discussions. Afterwards, the texts were intensively discussed on the basis of a structured discussion guide (Table 3). The focus groups were moderated by one of the authors (GS or MLD) who also took some notes and recorded the discussions with a digital recorder. Afterwards the audio data were transcribed by the moderators. A transcript of each discussed product was typically six to eight pages long, with anonymised original statements as well as paraphrased passages. The data were stored on the secured computer server of Hannover Medical School."

6. Revision of conclusions with greater explicit linkage between the findings and their practical implications  
Authors' response: We tried to foster this linkage by adding inter alia to the conclusions:  
"There is a need for further research that investigates how to acknowledge the following factors in the development of EBHI: 1) potential user reactions as outlined in our category scheme, and 2) how users understand EBHI and EBM."

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**Question 1. Is the question posed by the authors well defined?**  
**Reviewer's comment 1:**  
There is no specific question in the article but the authors do identify an aim in the abstract: 'The aim of our study is to define the spectrum of consumers' reaction patterns to written EBHI to get a deeper understanding of their expectations.'
I think the study does define the spectrum of reactions from consumers, but I don't think it really addresses the issue of their expectations. I am not sure how the word 'expectation' is being used here. I imagined on reading the abstract that I would get an insight into what the consumers expected from the information - they were not asked about this. They were asked about what effect the information would have on subsequent behaviour - an interesting group of questions from their focus group schedule that I did not think was fully explored in their discussion session.

Authors' response: We thank the Reviewer for her constructive and helpful critique. Maybe the use of the word "expectation" was misleading, and not sufficiently explained: it is right that in the underlying user testing we did not explicitly ask for the readers' expectations. The discussion guide focussed on comprehension, structure, readability etc. (table 3). Nevertheless, the issue of readers' expectations, too, could be and indeed was addressed in the analysis of the secondary data, meaning in the described qualitative analysis of a subsample of the discussion transcripts.

Our aim was to analyse readers' reactions, presumptions and expectations, taking into account also their concrete criticisms of the texts and suggestions for improvement. We wanted to explore how potential users react to this particular type of evidence-based health information, also 1) what kind or type of information they expected or wanted, and 2) what assumptions they had reading these texts. The discussion transcripts were quite comprehensive on that, too. We extracted text passages on readers' perceptions, assumptions, and expectations, and on reactions, with a focus on "formal textual criticism" and "dealing with research and evidence" etc., all summarized in a category scheme of reaction pattern.

We revised the text and clarified the wording and aim in the main text and the abstract.

(See also response to question 4 (Does the manuscript adhere to the relevant standards for reporting and data deposition?), reviewer's comment 1)

Further, we agree with the Reviewer that it could be an interesting approach, too, to explicitly ask the readers for their expectations beforehand, or before and after reading the texts. (See also response to question 6 (Are limitations of the work clearly stated))

Reviewer's comment 2:
I would also want a better understanding of their 'consumers'. There was a brief description of the people taking part in the exercise, but not much discussion about them. A large proportion suffered from a chronic illness, and many, particularly men, had had higher educational training. I wondered if these might be particularly sophisticated users of this kind of information, and therefore the most likely to use it. The article would have benefited from being more explicit about this.

Authors' response: We added this information; see also above our response to major revision point 2 (Participants should be described in the main text).

Question 2. Are the methods appropriate and well described?
Reviewer's comment 1:
The methods were adequately described. It would have helped me to have a better understanding of the structure of the different information products that were being
read, and the differences between them. For example did all the products have numbers as data in them? What proportion of them had evidence that was ambiguous? Was there a grading as to the difficulty in interpreting the information? How were these products chosen?

Authors' response: Thanks for this helpful advice. We revised the manuscript accordingly to give more explanation:

"Typically a package of four health information products composed by the IQWiG were assessed per focus group (table 1) [9, 24]. The IQWiG provided test versions of their informational products; the edited final versions are available on their website [16]."

"This process yielded 25 transcripts of 20 groups; the discussed informational products included 14 "fact sheets" and 11 "research summaries". Fact sheets comprise three to six pages of easily understandable information in reference to a comprehensive report from the IQWiG or multiple sources, meant to give a quick overview of a topic. Research summaries are three-page summaries of systematic reviews or health technology assessment reports, meant as a kind of short answer to a scientific question, comparable to a news article [9]. The texts varied in their complexity and the difficulty of interpreting the given information. Most of the texts (88%) included numbers or proportions presenting e.g. study results or frequency of adverse effects or complications. Many texts (76%) indicated that in some aspects there were not sufficient reliable studies available or that the studies used were of partly ambiguous or uncertain evidence, and that therefore no clear recommendations could be given. The topics of the evaluated informational texts ranged from general topics (such as "using dietary supplements" or "expressing breast milk") to specific interventions (such as "epidurals during childbirth" or "cognitive behavioural therapy" or "therapies for migraine")."

Reviewer's comment 2:
Although I accept that the analysis was discussed by all the authors, I would feel more confident of the coding if a few test transcripts were double coded at the beginning.

Authors' response: Indeed, just the first transcript was coded by three authors, the following transcripts were coded mainly by the first author (IH) supported by the co-authors in unclear cases. We revised the methods accordingly as following: "The first transcript was coded independently by IH, DS, and MLD. All other transcripts were initially coded by IH. Unclear cases were solved by discussion with DS or MLD. Validity of the final results was checked by all authors."

Reviewer's comment 3:
I wanted more information about 'supplementary elements' that were excluded in analysis because of 'high variability' - was that high variability in content or quality? Some more information about how the focus groups were conducted, and how people were supported to contribute to the discussion would have strengthened the article.

Authors' response: We expanded the sentence about the exclusion of "supplementary elements" as follows: "Furthermore, the informational product type "supplementary elements" (table 1) were not considered due to their high variability (regarding topic as well
as type of text and material); therefore the transcripts (n=3) of another focus group featuring only two other texts plus a supplementary element were excluded."

Besides, we added to the description of these elements in table 1 as follows: "Supplements to the central products, for example explanatory texts about organs or signs of illness, quizzes or pictorial material"

For the conduct of focus groups etc. please see our response above to major revision point 5 (5. More information about the conduct of the focus groups, with information about data storage, consent of participants and support for them to take part.)

**Question 4. Does the manuscript adhere to the relevant standards for reporting and data deposition?**

*Reviewer's comment 1:*
I thought that quotes should have been used to illustrate the points made in the text. For example on page 13 there was a discussion about the reaction patterns 'activation' and 'doubt' where a complex interaction between these terms was described. It would have helped me to understand the points more if quotes were used and I would be able to see for myself whether the reactions of the participants did in fact match the explanation given.

*Authors' response: As mentioned above, we revised the manuscript accordingly giving additional quotes for illustration. In page 13, we tried to clarify the interaction of "activation" and "doubt" as follows:
"The connection with "doubt" is visible especially in activation to reflect on "the current state of research" or "health information and education"; critical thoughts arise also with respect to the presentation of studies and their research background and credibility. This is demonstrated also by the subcategories in table 6 and 7."

Some of the subcategories also reveal possible readers' expectations or wishes regarding their informational needs as we now address this question in the revised manuscript:
"The subcategories cover the causes and details of the reaction patterns to health information, providing also an indication of readers' expectations and informational needs (tables 6 and 7)."

*Reviewer's comment 2:*
There was no information given about how the data was stored.

*Authors' response: We added to the Methods section that "The data were stored on the secured computer server of Hannover Medical School."*

**Question 5. Are the discussion and conclusions well balanced and adequately supported by the data?**

*Reviewer's comment 1:*
No the data do not address the first sentence from the 'conclusions': 'this study on the assessment of health information from the users' perspective reveals the different expectations and desires that readers bring to the text.' The data were used to define a spectrum of reactions and did not explore expectations or desires - as one would assume that these ideas would have been explored before they were given the texts to read. This was not done. I think without a clearer picture of what the information
products actually were, it is difficult to see how this article would contribute to a clearer presentation of scientific research. The audience for these products remains unclear also.

Authors' response: As we said above, the way we used the word "expectation" might have been misleading. See also the first paragraph of our response to questions 1 and 4, Reviewer comment 2. We revised the manuscript as follows:

"This study on the assessment of evidence based health information from the users' perspective illustrates the range of readers' reactions to and perceptions of the texts. It also partly reveals what the readers' expectations and informational needs are and which aspects could be considered in the production of this information type."

Regarding the audience, we explained in the discussion that "IQWiG's health information is intended for a broad audience." However, this comment suggests that it would be worthwhile to think about different types of EBHI for different target groups; thanks to the Reviewer and Editor for mentioning this important aspect. We therefore added to the Conclusions: "The spectrum of reactions and differences in health and scientific literacy raise the question whether different types of EBHI for different target groups could better meet the informational need of the users: more research is needed here."

Question 6. Are limitations of the work clearly stated?
Reviewer's comment 1:
Yes, they did discuss their sample and that they are not representative. However, I think that if they had thought about the audience and recruited to some identified characteristics - such as the 'expert patient', carer, healthy person, etc - they might have got a better picture of expectations and the different reactions - what kind of information is important to whom?

Authors' response: We revised the Limitations section, reporting also on our current recruitment strategies:

"In further user testings we have increased efforts to recruit and include test readers with a low level of education, and from younger age groups in particular."

Furthermore, we agree with the Reviewer that it could be worthwhile in future to recruit readers with specific characteristics to further differentiate the different informational needs, expectations and reactions. We added in the Discussion: "Additionally, further studies could concentrate on the following aspects: recruitment of test readers with a specific interest in a given topic (e.g. people who are affected by the illness described in the text); explicit questions on e.g. the users' informational needs, their knowledge of scientific research and EBM, or their level of Health Literacy."

Question 8. Do the title and abstract accurately convey what has been found?
Reviewer's comment 1:
I don't think it reveals anything about expectations, as suggested in the abstract and I don't agree with the claim that the study can be used to as a starting point for reflection on editing EBHI, as all it seems to be saying is that people have a range of reactions to the material.
Authors' response: As mentioned above, we tried to specify our aim and the issue of expectations. Certainly we did not mean with the wording "starting point" that our findings are the only basis for reflection on editing EBHI but one important point for discussion considering this facet of the users' perspective apart from other EBHI criteria. We revised the manuscript accordingly:

"There is a need for further research that investigates how to acknowledge the following factors in the development of EBHI: 1) potential user reactions as outlined in our category scheme, and 2) how users understand EBHI and EBM."