Author’s response to reviews

Title: Collaborative development of an electronic Personal Health Record for people with severe and enduring mental health problems

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Author’s response to reviews: see over
Dear Editor

Thank you for considering our paper and please pass on our thanks to the reviewers for their suggestions. We have accommodated all of the mandatory recommendations and many of the discretionary comments. We now believe the manuscript to be clearer, and citations have been added where comments were considered unsubstantiated. Please find below a point-by-point response to the reviewers.

Reviewer 1

Major compulsory revisions

1. Stage 3: Preliminary implementation, Procedure

The authors state that a number of instruments were added after the clinician focus groups. However, it is not clear if those suggestions were then shown to potential consumers of the ePHR. Since ePHRs are patient centered and patient driven, it seems counterproductive to not elicit further feedback from patients. What if they do not want those measures or find them bothersome? Please describe how you arrived at the decision of incorporating these changes without further patient input.

Whilst we understand the concerns of the reviewer, there is a degree to which clinicians must have an input into the ePHR in order that the service users who choose to engage with myhealthlocker will derive the most benefit. There are two main reasons for this: 1) A key feature of myhealthlocker is that it is connected with healthcare providers’ systems, allowing easier communication and greater collaboration between services and service users. This function will achieve maximum utility if clinicians also engage with myhealthlocker. Clinicians must feel involved if they are to engage with the system, so we felt it important to consider their views. Research with failed systems such as HealthSpace showed that when systems are “deployed” without consideration of the end user, take up is likely to be low. It could be demoralising for service users to engage with a system which their clinicians do not add to. 2) Certain outcomes are collected routinely within mental health services. So the outcome measures chosen by clinicians are those which service users are routinely completing anyway. The service user may well complete these outcomes at each visit to the clinician with pen and paper. So the addition of these outcomes in myhealthlocker just gives service users a different method to complete the questionnaires. We have added information to the paper to make this clearer (p7).

2. Results

It is not clear from the result section how many times users accessed the ePHR. In order to evaluate the usability ratings, it would be useful to know how many times people dropped in to use the site, how many accessed it through the internet or their mobile devices, or if there was a difference between those that reported being confident or not confident with computers. While some of these issues are pointed out in the discussion section, the reviewer is of the opinion that the usability ratings are meaningful unless at least some of the basic user statistics, and how they relate to the ratings, are presented. Furthermore, the number of patients surveyed is low to be able to draw any kind of conclusion. While it is interesting to read about the development of the ePHR, it would be far more interesting to read about one that is well-received for a wider audience, or at least if it was
explained what groups of patients responded well to it. The authors are encouraged to solicit more patient feedback, provide more relevant detail about the characteristics of the patients that respond well, or not, to the ePHR, and what the implications are for this specific ePHRs, other ePHRs, and other health IT interventions.

We felt that the fairly low number of participants did not really justify any formal analysis, but this is now included (p8). We have now added demographic data and how these characteristics relate to the scores.

Thank you also for your suggestion to collect more data. Of course this is an ongoing process and we are currently preparing a separate paper which will contain a far more powerful analysis following some further implementation. The main purpose of the current paper is to detail the development of myhealthlocker.

Minor essential revisions

1. Background

a. First paragraph: It would be useful for readers to have the authors define what the difference is between an ePHR and a patient portal, which are not mentioned in the article at all. Both are accessed online and contain clinical records. Clearly define the unique features of an ePHR in comparison to patient portals.

The patient portal is simply the front end through which patients can access their personal health record. We have made this clear page 3.

b. Throughout: There are a number of fact statements that have no reference associated with it, giving the impression that the authors are expressing original thought. Some examples:

- Every sentence in the first paragraph. We have added references now.

- “An ePHR could act as a hub to connect services, placing the patient at the centre.” Reference added

- “However, for mental health service users these records could be especially useful.” This statement is linked to the following sentence, which is supported with a reference.

Please review carefully for needed citations.

2. Methods

a. Stage 1, Identifying needs and Priorities

Needs reference:

“This is because there is little information on readiness to use technology for people with psychosis, who may have had educational opportunities limited by the early onset of their symptoms.”

Reference added page 4.
b. Stage 1, Results

The authors state that “people from black and other minority ethnic groups might need extra support when engaging with online health-related information.”

However, none of the chosen quotes illustrate this finding. Please relate any data that confirms your statement.

It is the Ennis et al reference which suggests that black and ethnic minority groups might need extra support. Quotes were extracted from separate focus groups. We have now edited to make this clearer (page 4)

c. Stage 1, System Overview

Confidentiality statement: For readers non familiar with British data protection and information governance regulations, it would be useful to either describe them more in detail or give the reader a reference for further details.

We have decided to provide a reference since the content is somewhat technical and longwinded. (p5).

d. Stage 2, Table 1

The table is missing the scoring scale, nor are the results interpreted adequately. Are the scores good, excellent, poor? “Whilst there were no areas which were seriously lacking” is too vague.

We have added the scale to the table (page 7). We have also given a more precise sentence on the same page.

e. Stage 3: Preliminary implementation, Procedure

- The authors state that some attendees were lent mobile devices, but there is no discussion about if attendees received any training in regards to potential data safety issues and how to avoid them. Please describe if and how attendees were training in any additional security procedures.

Page 5 “Service users who were lent a device were given an information sheet about online safety.”

3. Results

The authors report that almost 40% of users did not feel confident using a computer prior to using myhealthlocker. However, it is not discussed if or how users were using the ePHR. Did they receive additional training?

Service users who required skills training such as using a mouse and keyboard were provided with ad hoc training by the drop in session facilitators. This has been included p8.

4. Discussion

a. Appeal: The authors state that “Our ePHR, myhealthlocker, has demonstrated some appeal to service users, shown by the high scores for “attractiveness” and “user-friendliness”. However,
appealing to a larger number of users remains a challenge.” It would be helpful to elaborate on the last sentence and to rework the second paragraph. “Appealing” how? Which were the measures that scored lower? Why? In the result section, the authors state that none of the measures scored badly. Why pick these two?

We have reworked the first and second paragraph to make it more precise – the emphasis now is on improving uptake specifically, which is what we meant by “Appeal”. We have also picked out the lowest scoring measure. (p9)

b. The second paragraph could use another try. There are some good suggestions given (without all the references, however), but they do not provide a comprehensive sense of the existing literature on electronic user appeal or increased functionality. Thus, this section does not provide a good plan for the PHR, or how the authors are planning to increase the appeal.

We now think this section much improved, with more references added and a more precise account of key features which we are working on.

5. Construction

a. “Such issues are particularly important to people who may suffer stigma and discrimination concerning their diagnosis.” Please provide references for this statement

Reference provided

b. Given that the “technical and ethical processes of building a social networking function into myhealthlocker are unresolved,” the authors do not elaborate on how they are planning to proceed on this issue.

Page 10: We have added a couple of lines about a potential option and mentioned that we are currently in talks with information governance officers.

6. Ease of Use

a. “People with severe and enduring mental health problems may lack experience and confidence with computers.” Please provide references for this statement.

Reference added

8. Implementation

a. “Implementing ePHRs in clinical practice will require a shift in attitudes.” Please provide references for this statement.

Reference provided

b. The second paragraph could use another round of thought and editing. What is the evidence that engagement and adding more PROMS will make the ePHR more appealing? While there is a large literature on the first claim (none cited), the second claim seems be unsubstantiated. Please provide
confirmation of this claim. Furthermore, there is no substantiation as to why the authors believe further training would be beneficial.

We have reworked this paragraph with added references.

Discretionary revisions

1. Defining the word “appetite” – Actually the definition of “appetite” is “a strong desire or liking for something” and so we feel that this word is the correct one.
2. Insert full stop end of last sentence stage 2 “overview” – done
3. Comparison with banking – we have now removed this sentence
4. Clunky sentence – now defines the four considerations and the stakeholders

Reviewer 2.

1. In the abstract the authors report that 133 stakeholders were collaborated with. I failed to find out where this number came from. On page 4, line 171 it is mentioned that 121 services users were interviewed. Who were the 12 other at stage 1?

This is the combined number of stakeholders from the 121 interviews and the focus groups.

2. The 121 cases were interviewed. Obviously using open-ended questions? How was the analysis of responses analysed (thematic content or another way?) so that the authors came up with five themes?

Actually the interviews were structured – the quotes on p4 were taken from focus groups. We have now made this clearer by stating that the focus groups were separate. We have also termed the structured interviews “surveys” for clarity.

3. What kind of measures were used for self-monitoring? Could, perhaps, the Worrying Tree described in an appendix?

The worry tree has now been incorporated as an appendix.

4. On page 8, line 21, the authors report that some respondents had problems with text size. Does this mean the amount or size of the fonts?

We mean the font size – apologies for not making this clearer.

5. How was data security/privacy ensured in this system?

Page 5 line 20 now details how security was maintained.