Reviewer's report

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

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Reviewer: Silke von Esenwein

Reviewer's report:

Summary
This manuscript describes the development of an ePHR for patients with severe and persistent illnesses. The authors incorporated feedback from clinicians and patients in three developmental stages: 1. Focus groups and interviews with clinicians and patients to identify needs and concerns. 2. Preliminary testing of the developed model and 3. Preliminary implementation. In the process of developing and implementing the ePHR, the authors developed four considerations for future ePHR development: appeal, construction, ease of use, and implementation. This manuscript addresses the needs of an underserved population that is at risk for not reaping the benefits of new and progressive health information technologies, and thus is an important contribution to the field. This reviewer has some concerns about the incorporation of patient feedback, the validity of the implementation phase feedback, and the lack of references for fact statements and non-original conclusions. The recommendation is to address the concerns and resubmit for further review.

Major Compulsory Revisions

2. Stage 3: Preliminary implementation, Procedure

a. 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.

3. Results

a. 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.

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.
   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.
      - “An ePHR could act as a hub to connect services, placing the patient at the centre.”
      - “However, for mental health service users these records could be especially useful.”

      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.”
   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.
   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.

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.

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.

3. Results

a. 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?

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?

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 ePHR, or how the authors are planning to increase the appeal.

2. Construction

a. “Such issues are particularly important to people who may suffer stigma and discrimination concerning their diagnosis. “

Please provide references for this statement.

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.
3. 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.

4. Implementation

a. “Implementing ePHRs in clinical practice will require a shift in attitudes.”

Please provide references for this statement.

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 to be unsubstantiated. Please provide confirmation of this claim. Furthermore, there is no substantiation as to why the authors believe further training would be beneficial.

Discretionary Revisions

1. Stage 1, Procedure

a. It would be helpful if the authors described how they define “appetite” for the technology in this population. Is it “usefulness”?

2. Stage 2, System Overview

a. Last sentence is missing a period.

b. If possible, it would be illustrative to see screenshots of the ePHR portal so readers can see the “look and feel” of the ePHR.

3. Discussion, Implementation

a. “It is worth noting that ePHRs differ from online banking because they necessitate an attitudinal shift from two groups: service users and clinical staff.”

Did ATM banking not necessitate an attitudinal shift from two groups: bankers and bank customers?

b. “We believe that success with the four considerations outlined above can be achieved through the involvement of stakeholders.”

Editorial edit: This is a bit clunky. Define the considerations and the stakeholders.

**Level of interest:** An article whose findings are important to those with closely related research interests

**Quality of written English:** Acceptable
**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:**
I declare that I have no competing interests.