Author’s response to reviews

Title: Improving health information systems during an emergency: lessons and recommendations from an Ebola Treatment Centre in Sierra Leone

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Author’s response to reviews:

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Dear Dr. Duftschmid and BMC Medical Informatics and Decision Making editorial board,

Thank you for reviewing our research article and allowing us to submit a revision. We would also like to thank the reviewers for their helpful comments regarding how we can strengthen our paper. We are pleased that several reviewers thought this work was interesting and useful.

We have tried to respond to all of the editor and reviewer comments in detail, and have revised the manuscript and supplementary material accordingly. With this revision, we have included
both a clean version of the revised manuscript (with track changes incorporated) and a track-changed version. Below, we have provided our responses to the comments from the editor and each reviewer.

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Editor comments

1. "Even though the paper refers to reference [11] on several occasions for detailed descriptions of various aspects addressed in the current paper, there still seems to be a significant overlap between the 2 papers. It is essential that you remove any redundancy with [11] in your current paper (e.g. fig. 4 is identical in both papers). Further, I would recommend that you already refer to [11] earlier in your paper (maybe end of section "Background") and clearly explain, what your current paper adds to [11]."

We believe that these two papers are substantially different. Reference [11] is focused very specifically on how the OpenMRS-Ebola software was built and implemented in the ETC environment, with technical explanations about software development and hardware choices. The current paper is a higher-level paper describing the processes of how we tried to systematically design the overall HIS structure, whether for an EHR or PMR. We had originally included some redundancy so that the current paper could be fairly comprehensive. However, we understand that we should remove any such redundancy, including from the text and figures. We have edited the paper accordingly (including removing figure 4). We kept figure 3 (IV fluid monitoring/ordering) so that readers can have a sense of what the EHR looked like and because this figure was not included in the main text of [11]. However, we can further delete figure 3 from this paper if desired. As per your suggestion, we have included a clearer explanation of what the current paper adds to the literature, and how the papers are different, at the end of the background.

2. "The paper should be shortened. Several corresponding suggestions (e.g. remove descriptions of well-known aspects of agile software development) were made by the reviewers."

We agree that this is a long paper and have now shortened it substantially. We added text in some places based on reviewer comments asking for more details about various processes and lessons. We believe their requests reflect the unavoidable fact that setting up an HIS requires getting an enormous number of details right. Our purpose in writing this paper is to help guide
anyone considered setting up an HIS, so we preferred to be detailed instead of speaking in vague
generalities. We believe we have now made the overall text more concise while only adding
more details where requested by reviewers. We believe this allows us to have a balance between
readability but also specificity for those who need it. We have reduced the word count
(including tables) from around 11,400 to a little under 6,900.

3. "The methods section should be revised to improve clarity and linkage to the results section. A
suggestion for a corresponding organisation of the methods and results section was made by
reviewer 5."

We have made the change recommended by reviewer 5 and agree that this improves the clarity
of both the methods and results sections. We appreciate this suggestion.

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First reviewer

1. "While there is excellent discussion comparing a full HIS to paper records, it would be helpful
to understand why a full EHR like OpenMRS was chosen versus other approaches, such as
simple ODK forms or simple apps, was selected…Consideration of the latest data would
improve the timeliness and relevance of the piece."

We chose to use a full EHR because the most important challenge we identified (through
feedback from clinicians) was communication of essential but complex patient information from
the Red to Green zone. In particular, accurate drug ordering was deemed to be a top priority for
the EHR because it was needed for both patient care and safety. IV fluid monitoring was another
such area. These priorities ruled out simpler electronic approaches since basic forms and apps
are not designed to handle complex processes like drug ordering. Indeed, a very easy-to-use
tablet-based drug ordering module that was suitable for the Red zone even required innovation
for a system like OpenMRS. We have included more information on why we chose a full EHR
in the supplementary file (particularly section A3 of Additional file 1) and how our approach is
pertinent when a more complete EHR is needed. As far as we know, what we have said here is
relevant to the current Ebola outbreak in the DRC.
2. "The piece would benefit from the discussion of user workflow. Was the exact same workflow used for the PMR and the EHR? Where exactly was double entry required etc.? Were both the PMR and EHR used in the red and green zones? Maybe a simple workflow diagram would help?"

Thank you for this suggestion. We have updated the paper to include more information about these areas, particularly to the following sections: 1) “clinical workflow” and “how errors are minimized” in Table 1 and 2) section A4 in Additional file 1. We thought a bulleted list, such as the one we added in Additional file 1, provided more detail than a simple workflow diagram could about these processes.

3. "It appears that the methodological discussion could be much shorter as many described aspects are well-known characteristics and methodologies of agile software development, which the authors mention later. I view this as optional and just mention for consideration as it may improve the article flow and readability."

We agree that this paper, including the methods section, is too long. We have substantially reduced the text, including descriptions of Agile methods where we identified them in the paper.

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Second reviewer

1. "…however I found that although this manuscript had been revised, it lacked focus, and was far too long."

We wanted to clarify that this is our first real revision. The previous edits were only to clarify a couple of questions from the editor’s office, and not related to the actual body of the text. However, we agree that the manuscript is very long. We have shortened it to improve clarity and focus.

2. "As there was only management of cases with Ebola, the term Ebola Management Center is the more appropriate term and should be used throughout."
The terms used for these centres in the West African outbreak were “Ebola Treatment Centre” in Sierra Leone and “Ebola Treatment Unit” in Liberia. These terms were the ones used by the governments and organizations like the WHO, CDC, and others. Thus, we have chosen to keep Ebola Treatment Centre in this paper as that was the commonly used term.

3. "Abstract is too long, particularly the background (pg 2 sentences beginning on line 28-32 can be deleted). Also, the methods section doesn't link with the results section, as I was expecting to find findings from the questionnaires the personnel answered. So, the methods sections needs to be much clearer and focus more on what was done to develop the HIS. Conclusion should be shortened and the last sentence needs to be edited, the language is poor."

Thank you for these suggestions. We have edited the abstract to improve the content within it, including better linking the methods and results sections. We have also reduced text in the background and conclusions sections and reworded the final conclusion sentence. We think the abstract is an acceptable length because it is under the journal’s 350 word limit.

4. "Background is far too long and repetitive (line 63 and line 92 have the same message). Too much detail in paragraph beginning line 91 - would delete. Overall, please make this section more concise."

We agree and have shortened the background section of the paper. Regarding these specific comments, we have deleted the sentence starting line 63 and have shortened the paragraph beginning with line 91.

5. "Methods section is far too long. The authors need to consider what is actually relevant for the reader to understand improving a HIS during an outbreak. A paragraph (line 153 onwards) dedicated to information about the patient and health worker population is completely irrelevant and could be summarized into two lines."

We had originally included some of this information to give context about the environment in which the HIS was built and used, including constraints such as languages spoken amongst the patient and health worker populations as this is important for an HIS. We have edited the methods section to remove information that may be deemed less relevant, including shortening
the paragraph starting line 153. We have retained information that we believe is necessary for understanding the context for this HIS.

6. "Lines 167-169: I would prefer to read a concise reason why an EHR was set up in parallel to a PMR. The rest of this paragraph really needs to be shortened."

We have shortened this text as suggested. We have included a brief explanation about the decision to set up an EHR in parallel, with more detail in the supplementary file. We have restructured the methods section so this information is now in the section on determining the inputs and outputs.

7. "Lines 175-180: Again, this paragraph could be shortened to two lines e.g. To design the HIS, we sought input from staff on data needs and restrictions due to infection, prevention and control (IPC). We then piloted and adapted the HIS over the course of xx months."

Other reviewers actually asked for more detail about this section, and we have thus both reduced the text to be more concise and added some additional information, as requested, to this section. We did this as part of a general restructuring of the methods and results sections to improve flow and have the methods better link to the results.

8. "Lines 182-191: This paragraph is repetitive and needs to be edited. This level of detail is not necessary as you already stated in the earlier paragraph that you sought input from staff."

Similar to our response above, we have added some more detail as requested by other reviewers to this section. But we have also tried to remove any repetition.

9. "Lines 209-358: Again, this level of detail is not necessary. It would be much wiser to adapt panel 1 and incorporate some of that information rather than having six pages of text."
As part of the restructuring of methods and results, we have moved much of this to the results section. We have taken your suggested to remove this from the main text, and have now added this information to Table 1 instead.

10. "Line 365: Repetitive sentence. You have already said in line 166 that MSF gave advice. In general, this paragraph could be shortened."

We have removed this paragraph from the methods section and have incorporated relevant parts into the discussion section on sharing.

11. "Line 404: quite surprised to see that the comparison of using the PMR with the EHR was published before describing how these HISs were developed. Why have you included an evaluation competent, when it has already been published? It makes me question what this paper adds? Also, I noticed that you have used some of the same figures as in the published manuscript. Why?"

Please see our response to the editor’s first comment above for an explanation about the different scope of these two papers. Regarding the evaluation, different aspects of the evaluation are discussed in the two papers, corresponding to the different focus of each paper. In [11] we included a specific comparison of drug ordering and registration errors as that paper was focused on the technical details of the EHR (and went into much greater detail about the drug ordering module, for example). Such a technical comparison was not relevant to our goal for this paper (i.e. describing the broader strategic approach we used). We focused on the survey responses related to the EHR in [11], and have not done that in this paper. Here we include responses from respondents on how well they believed the PMR was functioning as this is relevant to several of the points discussed in this paper. In addition, the evaluation is a minor part of this paper, so we are confused about the question asking what this paper adds. Regarding overlap with the previous paper, as explained above we had included a bit of overlap with the previous paper (e.g. figure 4) to make this paper more self-contained, and identified these overlaps by citing the previous paper. We have removed such overlap now, including figure 4.

12. "Lines 563-619: much was covered in your previous publication. Why have you included it here? In general, the discussion is far too long. A 17 page discussion, with much repetition, is highly unacceptable."
We had included this text to have a more comprehensive discussion, and tried to have it not be repetitive with the previous paper. However, we have moved most of this text to the supplementary file. We have also substantially reduced the discussion section and tried to get rid of any repetition.

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Third reviewer

1. "My major comment is that the length of the manuscript could be reduced. There is much excellent information here, but there is a fair amount of redundancy between methods, results and discussion. I realize this is in part because descriptive methodology papers don't fit well into the traditional "methods-results-discussion" framework, but I would suggest to the authors that they can still condense some of the information presented in the methods and discussion sections particularly, which will also help the flow of the paper through the three sections."

We agree that this paper is too long. We have now made substantial edits to reduce the text, including in the methods, results, and discussion sections. We have also re-organized the methods and results to improve flow, using a suggestion from another reviewer on restructuring these sections.

2. "My other major comment is that I would like to know more about lessons learned as the HIS was built and revised. I would see this as a key component of the "results". The authors state that an iterative process was undertaken, but it would be valuable for readers to know what did *not* work and why. Not every iteration is required to be described, but highlighting some of the major changes made would strengthen this paper."

We agree that this is a valuable addition to the paper. We have included a section in the results now on revisions during implementation, with additional details in “Additional file 1; section A7”. In this supplementary file, we provide some examples of things that failed as well. We had originally included some examples of failures in the discussion section as well, which we have retained there.

3. "Line 183: Can the authors describe how they obtained the opinions of stakeholders regarding inputs? Was this informal or via a formalized process? Interviews? Surveys? Workgroups?"
Due to this work being done within an emergency response, we did not have time for a formalized process. Instead, we tried to use a systematic process to put together our inputs/outputs, and then had informal semi-structured interviews with people we identified as stakeholders. We have now included more details about the input/output process in the methods section, including how we developed the inputs/outputs, identified stakeholders, and conducted the interviews.

4. "Line 498: I believe there is a typo here, as it currently reads as if the average LOS for all Ebola-positive patients was 3 days and the LOS for the subset of survivors was 9 days. I assume the 3 day LOS is supposed to be for Ebola-positive patients who died?"

Thank you for pointing out this typo. We have corrected this to now correctly state that the 3 day LOS was for those who died.

5. "Line 511: It seems like a small number of clinical staff completed the survey? How many total clinical staff were at the ETC at the time of the survey? What proportion completed the survey? Also, more exact data about the survey responses would be preferred, as it would make this section more robust than simply saying "many" or "most"."

Thank you for this point. We have add a denominator now (~70 clinical staff), and an explanation for why it was difficult to get more to complete the survey. We have also added numbers to the survey responses as suggested.

6. "Figure 1: I would introduce this much earlier in the paper since the concept of "red" and "green" zones is talked about right away in the introduction, and knowing the flow of people helps visualize the challenges to the flow of information. Also, the figure is missing most of the green zone - where were the green zone areas like the clinician workspace and the pharmacy relative to the red zone? The authors may additionally want to show the flow of providers in and out of the red zone, as it is actually more important than the flow of patients for the purposes of this paper."

Our purpose for Figure 1 is to show the restricted flow of people (including providers) and equipment in the Red zone. We have clarified the title of the figure to explain that this was not
only patient flow, but overall “people” flow within the Red zone (including of providers). It is only intended to be a schematic, and not as a map of the overall ETC. However, we appreciate your suggestion and have now included an annotated map of the Kerry Town ETC based on an aerial photo taken of the site during its operations in section A1 of Additional file 1. We have also included more information about user workflow in the methods and results of the main paper (e.g. “clinical workflow” section of Table 1), as well as in section A4 of Additional file 1.

7. "Figure 5: The patient ID number at the bottom of this figure would generally be considered a medical record number and thus protected health information that should be blacked out. Related to that, stating the ID numbers of the first five patients within the paper would also likely be considered protected health information and the authors should probably provide hypothetical example numbers instead."

This is a very good point. We have blacked out the ID number in this figure, and have removed ID number descriptions in the paper. Thank you for noting this.

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Fourth reviewer

1. "The utility of an EHR has face value, and so are its potential advantages over paper-based system during a public health emergency. Some of the work contrasting the development and practical shortcomings of a paper documentation system to that of a purpose-built EHR has already been published (reference 11). Many meaningful outcomes of EHR implementation remain (e.g. speed/accuracy/completeness of medical care documentation, risk/prognostic model development, efficiency of supply chain/personnel management, data sharing and analyses across levels of care and locations etc). However, none are defined or measured here. As such, the work outlined in the manuscript does not rise to the scientific level."

If published, our paper would be the only publicly available documentation that we are aware of on how to set up an HIS that addresses the many challenges posed by outbreaks like Ebola. While ideally we would have liked to more rigorously evaluate our system, it was not realistic during the 2014-16 epidemic to carefully measure all of the relevant performance metrics. Thus, relative to the existing state of knowledge on this topic, we think that our paper offers valuable perspectives to anyone who faces the challenge we did; namely, systematically setting up an HIS during such an emergency. For a more general reader interested in understanding how an HIS
could be created for such circumstances, we believe our paper would also be informative and novel. A key goal of this paper is to make establishing such systems easier and less time-consuming during emergencies, hence increasing the likelihood that there would be time for more thorough evaluations as well. To this point, we have tried to provide guidance on how to better incorporate evaluations into emergency HIS planning.

We believe this comment also focuses on the EHR and not the HIS. We commented above (in our response to the editor comments) on how this paper broadly addresses the issue of setting up an HIS (possibly including an EHR) while Ref [11] focuses more specifically on the technical issues involved in building the EHR.

2. "The steps to develop and evolve software are well known, including the "Agile" development/implementation cycles used here. What is novel is the challenging set of conditions under which this development has now proven feasible. Of particular interest are requirements and implementation issues related to low human/material/power resources and stifling infection control measures (PPE, ETC zoned structure). The manuscript is at its best when it transparently describes practical problems and needed compromises, or when it makes sensible recommendations on how to build a basic EHR that can be rapidly adapted to the specific needs of future outbreaks/emergencies."

We have tried to shorten the paper substantially, including Agile development descriptions. While shortening the paper, we have tried to retain our specific examples and recommendations, as we agree that such details are useful given the goal of this work.

Fifth reviewer

1. "I suggest that you write the method and results in a 3 stage approach. Stage 1 - determining input/outputs, stage 2 - implementing, and stage 3 - evaluation."

Thank you for this very helpful suggestion. We have now updated the paper to reflect this change, with those subsections now in both the methods and results sections.
2. "The section from line 209 on page 9 to line 363 on page 15 is really results not method and this should be moved to the start of the results section."

We agree with this. We struggled with the placement of this text initially as well, and do believe the paper flows better now with your suggested change of methods/results headings and moving this to the results section. We have placed most of this text into Table 1 of the results section. We are happy to move it back into the main text of the results section if that is preferred, however, for readability.

3. "...the abstract will need to be reworked to reflect the changes. In particular the methods section of the abstract is very weak and does not adequately describe the actual method using any methodological terms. There are so many questions raised when reading this section of the abstract for example: how did you develop the key questions? Was there any validation process? What was the selection process for determining your 'relevant personnel'? Did you use interviews or focus groups or survey? In the results section of the abstract you do not actually describe any results except usage, which is not what the method section describes."

We have updated both the abstract and the text within the body of the paper to explain the methods that we used when developing these questions, interviewing personnel, etc. We were severely restricted in terms of time when designing and implementing the HIS, and thus tried to develop systematic processes that were rapid and feasible during an emergency as we had to build the HIS almost from scratch (we tried to build off of previous work but found little documentation that could help us). As such, we used informal but semi-structured interviews, and were unable to validate the questions. One goal of this paper is to save time for others in similar situations by documenting the systematic approach and time-saving tactics we found useful, thereby hopefully freeing up some of their time for things like rapid validation or more complete evaluations. Additionally, we have re-organized the methods and results sections as per your recommendation for better linkage between the two. We agree with you that these changes have improved the flow of the paper.

4. "line 67-68 this sentence need a reference or expansion on how EMRs make patient care more efficient and accurate."
We wanted to clarify that our sentence here is not about EMRs, but about medical record systems (paper or electronic) in general. We have added a citation for the more general case of medical records improving efficiency and accuracy.

5. "line 76 in the final sentence you state clinical trials cannot be started without high quality medical records - this needs justification as we know clinical trials have been occurring for a long period of time without such records."

This is a good point. During our time working on this epidemic, there were clinical trials that we were unsure would be able to start because the patient data was not adequate for conducting a trial. But you are correct that trials have been conducted in such settings. We have removed this sentence, and modified an earlier sentence in that paragraph to include clinical trials but without reference to the data needing to be high-quality. That sentence now reads (with the change in bold): “Second, for diseases with a scant evidence base such as Ebola, patient data are essential for clinical trials and understanding the prognostic factors related to demographics, epidemiological risk factors, and clinical outcomes…”.

6. "line 183 onwards - you need to explain the actual methods used…”

We have edited this section to include further details on how we developed the inputs and outputs, how we selected the relevant stakeholders, and how we asked them for answers to the inputs.

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Thank you again for the consideration of our manuscript and we look forward to your feedback. Please let us know if there is any other information you need from us.

Yours sincerely,

Shefali Oza (on behalf of the other co-authors), London School of Hygiene and Tropical Medicine