Author's response to reviews

Title: Novel open-source electronic medical records system for palliative care in low-resource settings

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Author's response to reviews: see over
Dear Professor Chang,

Thank you for considering our manuscript “Novel open-source electronic medical records system for palliative care in low-resource settings” by R. Richards-Kortum et al. for publication in *BMC Palliative Care*. Please find enclosed our revised manuscript with changes made in accordance with the reviewers’ comments and the editorial request elaborated in the email dated June 26, 2013.

Referee 1:

1. Major Compulsory Revisions: None

   [No changes recommended.]

2. Minor essential revisions: Page 3, background, 3rd paragraph 4th line should have a semi colon rather than colon in the punctuation.

   The colon in the third paragraph of the Background (now the second paragraph of the Background) was replaced with a semicolon.

3. General comments: Thank you for the opportunity to review this article. I found it interesting, well written and it highlights important issues for palliative care in developing nations. My only comments are that I found the labelling of the figures to be a little confusing. Otherwise the background is presented well and the article reads well throughout. I have looked at the software, which is freely available as stated by the authors. It appears to be easy to use and addresses the task as intended by the authors. The article clearly explains the need for such software as well as describing how the software is implemented and on what systems the software can be run. The discussions and conclusions of the article are well balanced and support the data.

   The labeling of the figures has been significantly revised for clearer comprehension.

Referee 2:

1. The core message of why DataPall was developed still remains a bit fuzzy to me. Is it about organizing administrative data, creating a patient registry (the authors use the term database but registry may be more appropriate), aid in clinical decision making, tracking the same set of common data elements across locations, obtaining funding? All of the above? Whatever the answer, I think it should be explicitly stated from the outset (e.g. DataPall was developed to 1). Blah blah blah; 2). Blah blah blah). I would caution the authors in overstating the aim of its development, since it doesn’t seem to have any capabilities for clinical decision support and has not yet been proven to provide data for conducting research or building the evidence base. Research-level data and clinical-level data are not necessarily the same. Several experiences in the US echo that there are important challenges applying clinical data for robust research. The so-called rapid learning health care system proposed by the Institute of Medicine aims to do exactly that, but its development is still in its infancy. Maybe if the authors alluded to what types of research or evidence base development they have in mind this would help the readers.
We added a sentence to the section under the “Use of DataPall” subheading in the Implementation section to clarify why DataPall was developed. Additionally, changes have been made throughout the manuscript to clarify that DataPall tracks clinical-level data as opposed to research-level data in accordance with this point.

2. We know that the largest barrier to implementation of any new health information technology solution is not understanding and conforming to the inherent workflow of a clinical environment. I would like to see the authors refer to the natural workflow of a busy clinic/hospital in Malawi and cite (maybe within Table 1) what challenges/opportunities existed and how these were addressed. As it reads now, this is a large missing piece of the story.

   A new Figure 1 has been added to document the clinical workflow in a palliative care unit.

3. I think it would be helpful to refer to either current (e.g. St. Gabriel’s hospital) or future planned feasibility/pilot studies. How will the authors define success as institutions continue to use DataPall? Are those users currently being evaluated for levels of satisfaction, barriers to use, and logistical issues?

   We added a sentence to enumerate the authors’ definition of success in the pilot sites. It is the final sentence of the section under “Sites for Field Assessment” subheading in the Implementation section.

4. Regarding how the manuscript is organized, there seems to be a lot of mixing between methods, results, and discussion throughout the whole paper. For example, the first sentence of the second paragraph of the results puts your findings into context based on historical experiences. This should be in the discussion to demonstrate the importance of your findings. This is not data that was collected in this protocol and should not be reported in the results. Another example: the challenges because of language barriers are presented in the last paragraph of the Results section. This should be in the discussion.

   The Results and Discussions sections have been restructured to avoid mixing between the two. Specifically, all discussion of the results that was previously under Results has been moved to the Discussion section.

5. I am not sure it is statistically prudent to use “mean” for such a small sample size of 10 and 7 participants. I would suggest reporting and performing analysis on the data assuming it is non-parametric.

   We switched to a non-parametric Wilcoxon rank sum test in place of the parametric two sample difference of mean t-test to assess the significance of our findings.
6. As is usually presented in a manuscript, I would like to see the authors review the findings of their study in the first paragraph of the Discussion section.

   Two short paragraphs summarizing the findings were added to the beginning of the Discussion.

7. For the SUS, how does one define success? What do other papers shows? Is the SUS you found good, bad, or in the middle? This should be discussed.

   The result of the SUS test is contextualized in the second paragraph of the Discussion.

8. The Methods section should also explicitly state what statistical analyses will be performed.

   The final paragraph of the Methods section indicates that we used a Wilcoxon rank sum test to assess significance.

9. The second paragraph of the Background seems unnecessary. True, more palliative care is needed in Africa. Your project doesn’t address that which makes this paragraph seem largely interesting to read, but not related to your methods or aim.

   The second paragraph of the Background was eliminated.

10. I would like to see a little bit more discussion about core informatics principles throughout the manuscript. The authors could refer to data standardization (can different sites customize data elements?), data governance, element interoperability, or data security. Though this may seem a bit complex for the average reader, it remains important for the reader to understand that these principles were remembered throughout the development of DataPall.

    A discussion of the core informatics principles was added to the Discussion (see the penultimate paragraph of the Discussion).

Additionally, the Acknowledgement section has been rewritten to match the format stipulated by BMC Palliative Care.

Thank you so much for your consideration of this manuscript. Please do not hesitate to contact us with any additional questions or concerns.

Sincerely,

Rebecca Richards-Kortum