Author's response to reviews

Title: Quality of family history collection with use of a patient facing family history collection tool.

Authors:

R Ryanne Wu (ryanne.wu@duke.edu)
Tiffany L Himmel (tiffany.himmel@duke.edu)
Adam H Buchanan (adam.buchanan@dm.duke.edu)
Karen P Powell (klpowel2@gmail.com)
Elizabeth R Hauser (elizabeth.hauser@dm.duke.edu)
Geoffrey S Ginsburg (geoffrey.ginsburg@duke.edu)
Vincent C Henrich (vchenric@uncg.edu)
Lori A Orlando (lorlando@duke.edu)

Version: 2 Date: 24 January 2014

Author's response to reviews: see over
Dear Esteemed Editors:

We appreciate your review of our article, “Quality of family history collection with use of a patient facing family history assessment tool.” We have sought to address the reviewers’ comments below and within the manuscript.

Reviewer 1:

Compulsory revisions:
1. Describe, briefly in the introduction, the family history tool used. What is MeTree?

_We have added to the second paragraph of the introduction to further explain what the family history tool, MeTree, is._

2. The main objective of this manuscript is to assess the quality of the pedigrees collected with MeTree. The authors list 8 criteria to define this quality. However, the use of these criteria throughout the manuscript varies and it is hard for the reader to follow the variations. For example, the abstract (page 3) lists 8 criteria; the same criteria are listed in the methodology (pages 6-7) but they are immediately reduced to 5 criteria (page 7) for pedigrees with no deceased relatives. On page 8 the authors state that when a relative was affected by two or more conditions, the quality of reporting will be evaluated for just one of the conditions. On page 11, the authors talk about high-quality relatives and how their numbers affect the quality of the family history collected. It would be better if the authors address all the quality related issues in just one section of the manuscript or a table.

_We have further explained the variation in number of quality criteria. There are 8 overall criteria assuming probands have at least one dead relative (2 criteria apply only to deceased relatives.) One criteria is only briefly mentioned (“an up-to-date FHH”) as it is inherent to completion of the MeTree tool. This is why the total is reduced to 7 (or 5 if no deceased relatives are present.) We have sought to make this clearer within the body of the paper._

_We are unable to place all discussion of quality criteria in one section of the methods as we needed to introduce certain definitions (“data aggregated by proband” and “data aggregated by individual”) prior to continued discussion of the quality criteria. We hope that be further clarifying the criteria in the paper, it will make more sense overall._

Minor essential revisions
1. Indicate the response rate: 1,184 patients entered their FHH; how many were invited?
We have now addressed this at the beginning of the results section.

2. Given the constant change of denominators, the authors should report both numerator and denominators in the percentages, particularly for those not reported in the tables. They do it in a few cases but should do it consistently for all cases.

We have now reported numerators and denominators consistently throughout the manuscript.

3. Tables and figures should be self-contained; i.e., title and footnotes should be comprehensive and the reader should not need to go to the text to interpret the results (include the meaning of abbreviations and concepts in titles and footnotes; for example, what ‘baseline’ means in table 2?). Also, be consistent with the numbers reported. Table 1 reports N and % in one column but not in the other. According to the authors, figure 2 reports percentages (range 0–100) but the figure actually reports proportions (range 0–1).

We have made adjustments to the tables and figures to address the reviewers concerns.

4. In two places (pages 8 and 15) the authors state that their population is generalizable. Generalizable are the findings not the sample of a population. By the way, the sentence regarding generalization on page 15 repeats ‘that’ unnecessarily.

We have corrected the misstatements mentioned.

5. Probably the reference number 31 on page 14, regarding risk stratification, should be changed to 32.

We have addressed this concern. The reference was correct but it was Health Heritage we were referring to, not Family Healthcare.

6. A sentence on page 16 states that some probands may not know the FHH history of a grandparent. I believe that what the authors mean is the ‘disease status’ or ‘vital status’ of a grandparent, not the family history.

We have corrected this in the manuscript.

Discretionary revision

1. The axis in figure 1 would look better if they were not detached from the histogram.

We have made adjustments to Figure 1 based on the above comment.

Reviewer 2:
Minor Essential Revisions:
1. The authors might consider adding the term “assessment” into the Title and throughout the manuscript, as the MeTree tool does more than just “collect” family health history.

   This is an excellent point and we have changed the wording in the title and manuscript.

2. Is there a copyright on the MeTree program? If so, this should be acknowledged when using this term through the manuscript.

   There is no copyright on the MeTree program.

3. It is unclear in the Methods section if the patient participant completed a paper worksheet with their family history information, which the investigators then entered into MeTree to generate a pedigree, or if the patient used the MeTree program to enter their family history information – what is the purpose of the worksheet? This should be clarified, and if there was no patient self use of the program, reasons provided as to why.

   Participants used the worksheet to collect data that they then entered into MeTree directly. We have clarified this in the methods section.

4. As there is mention and discussion of the patient educational intervention, and how this impacted their findings, it would be helpful to learn more about what information was provided in the patient brochures – how these materials were designed, etc. Also, does the MeTree program provide guidance to the user as to definitions on the 48 diseases that can be collected? Also, if the user has a family member with more than one cancer type, is there information as to primary versus secondary cancers, etc.

   We have added further detail about the educational materials in the methods section.

5. Terms such as FDR and SDR should be defined prior to use in the Discussion section as the general reader may not be familiar with these acronyms.

   FDR and SDR are defined in the results section. To aid the reader, we define FDR and SDR again in the discussion section.

6. Page 9: the Section on “Perceptions of FHH Knowledge” needs some work. Seems a sentence or two is either incomplete or missing?

   We have added some more information to this paragraph as requested.

7. Further define what specific hereditary cancer syndromes are analyzed by the MeTree algorithms as the percentage of 0.21% (page 14) seems quite low, and further discussion may be necessary.
On further evaluation of our data, we had mistakenly entered the incorrect number. This is now corrected such that individual prevalence levels are now accurately reported as 0.91%.

8. Define PCPs – be consistent with use of either PCPs or the term “physician” throughout.

We have changed the wording so that only the term PCP is used and is clearly defined.

9. In the Discussion section there is mention of “the amount of data and the quality of the data were sufficient to perform risk stratification on the vast majority of patients…” Please further define “risk stratification” in the context of this study.

We have clarified this within the discussion section. Risk assessments were made on patients based on currently published clinical guidelines.

10. Check punctuation throughout. For example, p. 12, second paragraph there is a period missing after “no data relatives. Parentheses missing on p. 9, extra spaces btw words, etc

We have reviewed and corrected the manuscript for typographical errors.

11. For Table 1, what is this asterisk text associated with: * previously published: Orlando LA, Hauser ER, Christianson C, et al. Protocol for implementation of family health history collection and decision support into primary care using a computerized family health history system. BMC health services research. 2011;11:264.

Table 1 was originally published in the article cited.

We hope that our changes to the manuscript and our comments above satisfactorily answer the reviewers’ concerns. Please let us know if there are further clarifications that can be made. We appreciate the opportunity to publish in BMC Family Practice.

Sincerely,

R. Ryanne Wu