Author’s response to reviews

Title: Learning from older peoples' reasons for participating in demanding, intensive epidemiological studies: A qualitative study

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"Learning from older peoples' reasons for participating in demanding, intensive epidemiological studies: A qualitative study" (BMRM-D-17-00251)

Dear Editor and Reviewers,

Thank you for your reviews and comments. We have addressed each query one by one detailing our response in the table below for clarity.

Editor

1. You note that the data were analyzed using “Framework” (line 110), but you do not provide a description of this method, which is not likely to be familiar to many of our readers. Please describe “Framework” in more depth

Thank you for this suggestion. We have added a description of the method: page 8, line 131-142

2. In line 150 you refer to “an MOT.” Please define this term the first time it appears in the manuscript.

We have now defined the term “MOT” on page 10, line 181-182
3. Your results regarding altruistic reasons for participation parallel findings in the field of survey research regarding reasons people offer for willingness to respond to a survey request. For example, Porst and von Briel (1995) used an open-ended question to find out why people would be willing to participate in a future survey interview. Reasons fell into three categories – altruistic reasons, egoistic reasons, and factors related to the characteristics of the study (see too results from Couper et al. 2008, 2010; Singer 2003). We recommend integrating some of these results into your discussion in order to strengthen the generalizability of your findings. Thank you for these suggestions. Please see the responses regarding particular articles below.


Thank you for this suggestion but since the article is in German we are unable to include it.


Thank you for this suggestion but we feel that this article does not relate well to our study as it is exploring how the risk of disclosure of sensitive data and the potential harmful effects of that disclosure, together with sensitivity of the topic influences survey participation. In our study, we have not investigated whether our participants were concerned about risk of disclosure or sensitivity of the topic. Certainly, this was not an issue brought up by any of our interviewees.


Similarly, this article explores all the above in association with willingness to participate (in contrast to true participation). These two papers do not concern specifically older people in the context of intensive health research and they concentrate on disclosure risk and sensitivity of the topic which were not our focus areas.


This paper was helpful, thank you. We have incorporated this study in the discussion – see page 17, line 373-376

Reviewer 1
1. This qualitative research interviewed a series of older people who participated in a demanding research study involving physician screening, long travel, and a muscle biopsy. The people were highly motivated and do not represent typical research participants. For this reason, it is unfortunate that the researchers were unable to interview older adults from the parent cohort who declined to participate. Would their motivation for participation in research differ? An interesting question is what level of motivation is needed for participating in studies that differ in invasiveness, discomfort, and commitment. Still, the conclusions from the research seem reasonable: barriers to participation can be substantially lowered with careful outreach and accessibility. Thank you for this comment.

We agree that interviewing those who did not participate in HSS would add more depth to this qualitative study. However, as mentioned in the paper, we were unable to interview non-participants as we did not have ethical approval to do so.

We agree that the difference between levels of motivation required to take part in different studies would be interesting to explore in more detail and would require a broader type of study. Thank you for the comment that our study can provide a range of methods that other researchers could use to improve participation of older people.

Reviewer 2

1. This qualitative study aims to explore the motivators and concerns of older people in participating in an intensive epidemiological study. The study aim is plausible, since it is a common struggle among researchers to recruit enough participants in gerontological/epidemiological studies and knowledge on the motivators of older people to participate in such studies might help researchers in their recruitment efforts and lead to higher participation rates and thus to increased representability of studies. The manuscript is well written, scientifically sound and well suited for the readers of BMC Medical Research Methodology. Therefore, I have only minor comments to the manuscript.

Thank you for your comments on the usefulness of this qualitative study and insightful suggestions for revising the manuscript.

2. In the beginning of the introduction, issues related to clinical trials are brought up. This, clearly, relates to this study, but, since the current study is based on an epidemiological setting, I feel it may be a bit misleading to begin with discussing clinical trials. Therefore, I would recommend the authors to slightly revise the introduction such that it is clear from the beginning that this study does not involve a clinical trial, and take this into account also in the abstract.

We agree with this comment and have now altered the abstract and introduction so as to better represent the content of the paper. Addressed in the abstract page 3, line 4-5 and introduction page 5, line 52-67

3. In the methods section, I would recommend the authors to report the reasons for not participating in the study (out of 1521 those 1247 who were not recruited to HSS).
4. Furthermore, it would be nice to know how long the interviews lasted in average and which assessments had been completed before the interview. Since the assessments that were completed after the interview are not reflected in the participants' answers, the authors should take notice of this in the discussion.

Thank you for this suggestion which has been addressed on page 7, line 115-117

5. Since the assessments that were completed after the interview are not reflected in the participants' answers, the authors should take notice of this in the discussion. This point has been clarified on page 20, line 447-451

6. The participants of this study did not have significant health problems. Therefore, the study cannot enlighten the problem stated in the beginning of the introduction/abstract of multi-morbid older people not being represented in clinical trials/epidemiological studies, since the results represent only the views of healthy older people. This issue should be discussed in the limitations of the study.

We have now revised the abstract and introduction as in comment 2. We have also included this as a limitation of our study in discussion, on page 18, line 435-438.

7. Further, while revising the introduction, the authors should be careful not to build expectations on this study giving answers to how could multi-morbid people be motivated to participate in studies.

Thank you for this suggestion which has been addressed on page 6 (see comment 2)

8. Similarly, the fact that the participants were highly active, and therefore probably more likely to participate also in studies, should be noticed in the discussion.

Thank you and we have now included this point in the discussion on page 20, line 447-451

9. Page 7, line 110: I do not understand the first sentence of the data analysis section - what is meant by 'Framework'?

This point has been highlighted by the Editor (Please see editor comments) and we have now explained the method in more detail.

10. Page 7, lines 126-127: I think that this notion of the interviews being conducted until no more information was emerging should be placed in the methods section and not in the data analysis section.

Thank you for this helpful suggestion. We agree and we have made the proposed change.