Author’s response to reviews

Title: Barriers to cervical screening among older women from hard-to-reach groups: a qualitative study in England

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Reviewer 1:

Major Compulsory Revisions

1. The beginning sentence in on page 4, line 2, while it is good to provide the statistics for England, it would be good to relate to the statistics providing a global perspective. For instance, if each 3000 women are diagnosed annually what is that ratio with regard to global rates?

We have now added the global incidence statistics for cervical cancer.

2. Relatedly, in the background section it would be good to provide statistics and information related to the deaths or fatalities of Human papillomavirus (HPV). What is the magnitude, is it a problem in the country? Such information would perhaps explain why women feel scared or uncomfortable to have the screening results. Also it would be good to know the resulted statistics for some that have been screened in the country or global statistics whether they have been negative or positive.

We have also added the global mortality statistics for cervical cancer. The number of women who die of cervical cancer in England is low relative to other countries, this is largely because of the cervical screening programme in England which has been in existence since 1988.
3. Please double check if the reference numbers should be after the full stop. Throughout the document this needs to be checked if is agreeable with the journal then you can proceed. Otherwise, on page 4, onwards Line 53 and 57 where do the reference belong, is it with the new sentence or the sentence that is completed with a full stop (.)?

The reference format has now been edited and is consistent with a format acceptable to the journal.

4. What study design was used for this research? In the methods section there is no mention of the study design apart from indicating the method - of data collection that is the focus group discussions. You begin with the recruitment of the study participants. Use the standard format used by the journal requirements in the presentation of the methods sections.

We have now added a sub-heading for design at the beginning of the methods section and explicitly stated that the study uses a qualitative design.

5. What is the justification for the selection of only 6 focus groups? how did you identify/determine that you reached saturation during the data collection process.

We have now added more detail to the methods section about our original plan regarding the number of focus groups to be carried out.

6. Please include page numbers on your document, which are lacking all through. Also follow the journal guidelines for further review and editing for improvement of this manuscript. https://bmcwomenshealth.biomedcentral.com/submission-guidelines

Page numbers have been added and the manuscript has been edited in line with journal guidelines.

7. While the title shows attitudes to cervical screening among older women, the researchers did not classify whether all the submissions were attitudinal, negative or positive attitudes.

The reviewer seems to be highlighting that not all of the themes identified in the data relate to attitudes, i.e. knowledge and practical barriers are also identified. In line with this, we have edited the title to say “barriers” instead of “attitudes” and we feel this now reflects the aims and findings more appropriately and addresses the reviewers point.
Minor Essential Revisions

Abstract

1. The use of poor knowledge: what was the classification for knowledge? What justification or measure did you use relating to the qualitative findings? Who had good or higher knowledge? What is poor knowledge as defined in your study?

Knowledge was not objectively assessed, rather ‘poor knowledge’ was something women described subjectively. We have tweaked the wording in the abstract to try and clarify this.

Methods

1. What is the justification for the selection of the 50-60 year olds non white British? The explanation for the ethnic minority non white British group does not seem to come out well.

Women aged 50-64 years are classified by the National Screening Committee as being in the ‘older’ of the two screening age cohorts in England and are invited every 5-years (women aged 25-49 are invited more frequently). We therefore used this age range for selection. We have now explained this in the recruitment section. We have also added further detail about how were defined ‘ethnic minority’.

2. What was the composition of the focus group discussions? What is the number of participants per group?

The number of participants and the characteristics of participants in each group is shown in Table 1.

3. What languages were used during data collection? Where it required say for interpreters during data collection and moderation, were other languages used other than English?

We feel that the procedure for interpreting and translating has been clearly described in the methods section and the second sentence of the results. The languages spoken in each group had been described (“Four of the groups were in English or mostly English, one group was in Sylheti and one group was in Arabic/Somali”). This has however now been moved to the procedure subsection in line with one of the reviewers other comments.
4. How did you control for bias given the multiplicity of ethnic groups/languages represented from the different countries highlighted as indicated on page 6, line 34-37 referring to "were from a range of ethnic backgrounds including Bangladeshi, Pakistani, African, Caribbean and White British"

The aim of this study was to explore the range of beliefs about cervical cancer and cervical screening that are discussed by women from hard-to-reach groups. We did this using qualitative methodology and so controlling for the multiplicity of ethnic groups/languages was not possible. We had stated this as a limitation: “Since we did not focus on one specific ethnic group, we cannot see in-depth insights into one specific ethnicity”, but we have now expanded on this limitation and have suggested how we think future quantitative research might be used to establish this.

Results

Information regarding the languages used in the data collection should be transferred to the section on focus group discussion.

This has been moved.

Did it matter the duration the participants had spent in England from the time they had moved there to the time of the survey? Could this have had an influence on the results in any way or not?

Length of time in England may be a relevant factor in women’s perceived barriers and facilitators to screening. Unfortunately we did not assess this. We have now mentioned this as a limitation.

Would be good to know the number of times / frequency or if the theme identified was running through all the focus group discussions. For instance, for the findings on line 6, discomfort and embarrassment, was it from all the 6 FGDs?

Since the research is qualitative, the aim was to identify the range of themes that are mentioned and not to quantify these (if we wanted to do this then a quantitative survey design and a representative sample would have been better). We would therefore argue that including details about the exact number of women mentioning each theme is not meaningful.
Nothing is mentioned if the FGD participants were in agreement with the submission of one participant in the group. Line 11 to 12 show one of the participants mentioned "It's a very sensitive area, the private area, for every woman", (P6, group 6).

See above comment.

On a lighter note, extreme negative experiences-Line 26 presents well the magnitude of the problem as highlighted in Line 26, Page 10. It would be good to have similar presentations in some of the write up and quotations made.

See above comment.

Page 9, line 22 there are typos, please correct them.

I think the typos that are being referred to are within the quotes. Since the quotes were transcribed verbatim some of the language is colloquial and may appear as a typo, but is in fact reflective of what exactly the participant said.

In the discussion section, it would be good to show how why this study is unique and very important for the study population with regard to other studies that have been done elsewhere. Would we have had different findings if the methodologies changed? Say if we used quantitative methods?

We have edited the first paragraph of the discussion to say more specifically why this study is unique and important for the study population. We have also added a paragraph after the limitations section suggesting how future research using quantitative methods may be useful since it would help quantify the themes identified in the current study and would allow exploration of potentially confounding variables.
Reviewer 2:

The authors state that they used advertisements and recruited the aid of community groups as well as of a market research group. Women were offered 25 pounds sterling to participate. In spite of all of these efforts the study recruited only 38 women, 4 of who were over the age targeted by the study. The authors did not offer data regarding how women were contacted, how many women were contacted or what percent agreed to participate. This data is essential in order to determine how representative this group was of the targeted population. The lower the rate of agreement to participate, the more likely that the population is biased. Data regarding percentage of women from the different focus groups would be essential for the reader to know.

The aim of the present study was to use qualitative methodology to explore the views of women from hard-to-reach groups. Our aim was to identify the key themes that are identified during discussion in relation to this topic. Samples for qualitative studies are not expected to be representative of all women in the target group, rather they are expected to include a range of participants to ensure a range of views. Data on the number of women that were contacted and the number that agreed to participate (i.e. what would usually result in a response rate or participation rate for quantitative studies) is not deemed appropriate or necessary for qualitative studies. We have added a bit more detail about the methodology used and its strengths and limitations to clarify this for the reader.

The Results section was entirely descriptive and in such general terms that there is no ability to find distinction between focus groups. Although this reviewer would have predicted from the low numerator in each group that significance would be difficult to attain, the authors did not even attempt to quantify differences in responses between focus groups. One item of interest discussed in the Discussion section did mention that one focus group didn't even discuss sexual behavior, a fact that would lead one to believe that this issue is of importance to the knowledge and attitudes regarding cervical cancer risks. However the authors failed to mention in which focus group this occurred, leaving this rare point of useful knowledge of little practical value to the reader.

As mentioned above the aim of this qualitative study was to identify key themes that arise in open discussion about cervical screening and not to try and quantify these. While we have done this occasionally (where it was surprising that something was not mentioned at all/mentioned frequently), placing numerical value on the themes is not within the remit of this methodology. We have now explicitly stated this in the analysis section and mentioned the limitations of qualitative work more generally.
As a matter of research protocol, the authors discuss in page 13 lines 5-12 that while some women responded initially not having knowledge of cervical cancer screening, once shown photographs (presumably of the procedure) that they acknowledged having knowledge of it. The authors did not describe this in the Methods section (an essential component if this work is to be reproduced), nor did they provide the reader with data regarding how many women changed their response after being shown photographs or in which focus groups they were found. This would again represent useful data for the reader.

We have mentioned the use of the photograph in the procedure sub-section of the methods “A photograph was also used to help women understand what the screening procedure involved.” Re: quantifying women’s responses, please see our responses to the previous two comments.

Acknowledging that the topic of cervical cancer is difficult to approach, the questions designed by the authors and discussed did not seem designed to yield quantifiable data. The reader cannot assess if the majority of women felt this way, if only a vocal minority opined on the issues. The manuscript is entirely descriptive with no way for the reader to assess the likely accuracy or relevance of the authors opinions. An example of this is found in page 12, Discussion Section, beginning in line 59. The authors state that a "number of erroneous beliefs" held by the women (unknown number/percentage) were uncovered where "improving knowledge and debunking beliefs" would "help". The erroneous beliefs are not specified. This is critical since although some beliefs and misconceptions can be changed with education, it is well documented in the cervical cancer screening literature that certain beliefs and behaviors are difficult if not impossible to change in these populations.

Again, the study is qualitative and therefore not expected to be representative of the population. The frequency of the responses has been described using terms like ‘a few’, ‘several’, and ‘some’. This is to avoid suggesting to the reader that we were making a statement about the whole community and is a common way to report qualitative results. We hope our edits to the methods and limitation sections help to clarify this. We have removed the sentence referring to erroneous beliefs.

Finally, in the Introduction Section the authors state that "drawing from 22 studies" and then listed a series of barriers to screening that are identical to the conclusions of the current study. The authors need to effective advocate why their study of 38 women contributes to the body of literature on the topic.

We have now added to the discussion how we think our study adds to the literature.
Reviewer 3:

Material and methods: This study was a flow online sampling. There are two ways of recruitment. P.5, Line 18 "Four focus groups with ethnic minority women were organised through community groups. Community groups indicated their interest in helping with the research after seeing an advert describing the project that was posted on an online community group network page. Community leaders were asked to recruit women and were offered a financial donation for helping to do this. Two focus groups with women from lower socio-economic backgrounds were organised by a market research company." Are the people characteristics different due to the different ways of sampling? For example, those people who may more frequently access to the network page or the social media. The sampling number is relatively small in qualitative study; thus, the possibility of specific characteristics and the bias resulting from the way of sampling should be clearly described.

We purposefully used two different routes to recruitment because we wanted to identify women from ethnic minority backgrounds (expected to be reachable through community groups) and women from lower SES groups (most easily identifiable through a market research company where detail on SES is held on record). The numbers included are similar to other studies and take into account the aims and scope of the study. We have edited the methods to clarify these points.

Results: In table 1, why is the nonresponse (unanswered) rate higher in group 6? Owing to the data of self-reported screening history, there should be a recall bias according to the normal or abnormal pap smear result. Do you collect the data of pap smear result from the patient? What do you think are the reasons for the discordance of "currently up-to-date" and "will go in future"?

- One participant in group 6 did not complete the questionnaire. Unfortunately, we are not sure why this is.

- We did not collect data on previous cervical screening results, but acknowledge that this may influence women’s views and have now mentioned this in the discussion.

- Some women may have decided not to go in the future (despite having been before and being up-to-date – the two are not mutually exclusive).
Result: In "Knowledge of cervical cancer risk factors", it included sexual behavior, age, and others. As we know, HPV infection is an important risk factor to cervical cancer, but only one woman mentioned about HPV infection. Is the poor awareness of HPV particularly in these group of people?

Previous research has suggested that awareness of HPV is lower in ethnic minority and low SES groups. However, awareness of HPV is also low in the general population. We have now added a sentence that touches on the importance of being aware of HPV, particularly in light of a move to primary HPV testing (planned from 2019 in England).

Results: In "Knowledge of cervical screening", since you have mentioned "Reasons for poor knowledge". P.9, Line 7, "One woman in this group discussed a common 'myth' that cervical cancer was a disease people got as a result of having 'done bad things'." Do you collect the information of religion?

Unfortunately we did not collect data on women’s religion. We have now mentioned this in the limitations section.

Results: P.10, Line 39, should be female genital mutilation

This has been changed

Discussion: There is in-depth interpretation of the awareness to cervical cancer and barriers to cervical screening in low SES and minor ethnicity women. Can you more distinctively identify the association between non-up-to-date and non-intend to future screening? In other words, are more up-to-date women decide to be screened in the future or the non-up-to-date women will attend future screening? Probably, the barriers of the three types of people: never-screened, non-up-to-date, and not intend to be screened are variant despite all of which led to the decreased rate of cervical screening. According, I suggest the barriers in the three types of people should be analyzed and discussed respectively.

The reviewer seems to have interpreted these three items as indicating mutually exclusive groups. We apologise for the confusion and have edited Table 1 to make it clear that these are three different questions that women answered and do not represent mutually exclusive groups. We have also described these more clearly in the methods section. We do agree that there are different groups of non-attenders and that barriers vary between them and while in theory, we could develop a typology within this sample (Overdue intenders; Overdue non-intenders; Never screened non-intenders etc) this wasn’t the aim of the study. We were simply aiming for a heterogeneous sample with respect to screening experience/intention and this means the sample size doesn’t allow us to draw out such differences.
Discussion: Limitation should include sampling bias, reliability of self-reported screening history, such uncomfortable or distressful experience and abnormal result may cause recalled bias.

We thank the reviewer for highlighting these limitations and we have now discussed them in the limitations section.

In Conclusions, health professional attitude may have more impact on the low SES and minor ethnicity group due to their poorer knowledge or understanding to the purpose of cervical screening. The detailed explanation and well-informed in advance could ease their anxiety during the procedure and improve the barriers for future screening.

We thank the review for suggesting this as a discussion point and have now included it.