Author's response to reviews

Title: A telephone survey of factors affecting willingness to participate in health research surveys

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Author's response to reviews: see over
Reviewer’s report:
1. Is the question posed by the authors well defined?
Yes. This paper investigates the willingness of various groups (general population, members of an occupational cohort, and cases and controls in a disease study) to participate in health research and factors that affect that willingness. As participation rates in research continue to plummet, it is very worthwhile to discover why, and how to encourage participation.
*No change required.*

2. Are the methods appropriate and well described?
Yes, in general they are, though more on the following would make it more complete:
- the reasoning for including the cohort and case-control study participants is not explicitly stated, nor is the rationale for the sizes of samples selected for those groups compared to each other and compared to the general population sample.
- there is no indication of the number of call backs made.
- the size of the cohort study is indicated in the methods, but there is no comparable data given for the number of cases and controls in the other study.
- lines 98 and 99 don’t clearly indicate what the initial approach was for those without addresses.

To address this we have added to the introduction:
“We also undertook the telephone survey in a sample of participants from an existing cohort and a previous case-control study to identify the willingness of known study participants to take part in another health study and to identify differences in their views compared to those who had not previously participated in such a study eg on the role of Ethics Committee.”

We anticipated a lower non-response rate and a higher participation rate among the previous cohort and case-control study participants so that a smaller number of participants were approached in these samples.

We did not ask potential participants to call us back. We state in the Methods that “Up to ten attempts to contact the potential participant were made…..”

To clarify the approach for those without addresses, we have added (lines 108 and 109):
“Where no address was available the potential participant was called without a prior introductory letter.”

3. Are the data sound?
They appear reasonable. There does appear to be an error in Table 1. The figure “2,197” for non-contactable in the no letter general population sample must not be correct. - The number of refusals doesn’t seem to be reported in Table 1.

Did 49.6% of those contacted actively refuse or are there other reasons for not participating?

Table 1 has been corrected. The refusals have been added with a footnote to indicate the reasons they were considered to be refusals.
Refusals included those who actively declined or claimed to have already done the survey, those who made but did not keep an appointment, those who terminated during the survey, those who said that they did not know the named person and those who asked to be removed from the list.
Table 4 doesn't indicate if the results are for the full study (all 3 groups) or the general population only.

The heading for Table 4 now reads:

"Table 4 Australian general population sample preference for length of study explanation, and survey method by sex and age group (% by column)"

4. Do the figures appear to be genuine, i.e. without evidence of manipulation?
Yes.
No change required.

6. Are the discussion and conclusions well balanced and adequately supported by the data?
Yes. It would be useful to discuss the value of the cohort and case-control samples. It occurs to me that one possible avenue for future studies would be through occupational cohorts. There was excellent participation in the original study, and this group expressed greater willingness for further study participation, so this seems a promising avenue for research in the future.

To address this in the Discussion we have added:

"There may be value in ensuring that all study participants are canvassed at set up as to their willingness to participate in future studies, as was done in the WABoHS study, and these individuals may provide a pool for future study recruitment."

7. Are limitations of the work clearly stated?
Yes, the main limitation - the low participation of the population sample is indicated up front. Ironic and worrying in a study trying to gauge determinants of participation. If there were no call backs, this may have contributed to low participation. This should be explained (and the reason for no call backs explained).

The recruitment protocol included up to ten phone call attempts to contact participants. Our statement in the submitted paper Methods that “Up to ten attempts to contact the potential participant were made at different times of day and days of the week.” has been clarified as phone call attempts.

8. Do the authors clearly acknowledge any work upon which they are building, both published and unpublished?
It appears so.
We have added a recently published paper Fritschi et al (reference 13)

9. Do the title and abstract accurately convey what has been found?
Yes.
No change required.

10. Is the writing acceptable?
Yes, generally clear. - Title of table 1 is not quite right. - explanation in footnote a of table 1 is not clear. Is this all about mobiles? Were people not recontacted if there was a busy signal? –
Table 1 title now reads: Study population and participation rates by study sample groups.
People were recontacted and up to ten attempts were made to contact them. This was stated in the method and has been clarified as phone attempts. We state in the Methods that “Up to ten phone attempts to contact the potential participant were made at different times of day and days of the week ….”
The footnotes to the table have been expanded to clarify who was covered in each group:
Non-contact: a Includes no answer, engaged, answering machine, those under 18, those with language difficulty and too frail/old/ill
Eligible population: b Excludes non-contacts
Refusals c Includes those who actively declined or claimed to have already done the survey, or made but did not keep an appointment, or terminated during the survey, or said that they did not know the named person or who asked to be removed from the list.

Table 2 needs a definition of ATSI
Added

Reviewer 2
Reviewer’s report:
Major Compulsory Revisions
1. Is the question posed by the authors well defined?
The background and introduction while concise and frames the big-picture well, it does not describe how they sought to answer their research questions and what resources will be used to do so, therefore once they jump into describing the different cohorts, general public and case-control samples, there is no context by which to go by. The findings of this study are very consistent with previous studies regarding survey participation and methods.
We have added the following to the end of the Introduction:
“ To this end, we organised a telephone survey of a random sample of Australians to identify their willingness to take part in health research.
We also undertook the telephone survey in a sample of participants from an existing cohort and a previous case-control study to identify the willingness of known study participants to take part in another health study and to identify differences in their views compared to those who had not previously participated eg on the role of Ethics Committee.”

2. Are the methods appropriate and well described?
My major concern with this study is the study design. Methods are overall well-described; however, the very nature of the study design is biased by the problem they are trying to study/address- they still are only surveying individuals who have agreed to participate in the survey about participation in survey research. It is a bit circular, but I am not sure that this the best method/approach for addressing their research aims.
We have added the following to the Discussion:
“ This form of research clearly involves some circularity, in that those who took part are, de facto, willing to participate. However, it is difficult to see how we can explore
people’s views without asking them and there were informative differences in rates of willingness associated with different questions and different subgroups of participants. Interviewees were advised about the content of the study before giving consent to participate and it might be that hearing the topic might have induced them to participate when ordinarily they would not have agreed.”

How is non-response bias adjusted for in their sample and how might this affect the study results?
We did not know anything about non-responders so we could not adjust for non-response. We have added the following to the Discussion
“We have no information about the individuals who did not answer the telephone or who answered but did not take part in the study. The telephone numbers were obtained from a commercial list without such information. In view of this we cannot assess any non-response bias. We have compared the demographic descriptors of our general population sample to those of the general population to assess how different they are to the general population however.”

Also, gender is a known modifier affecting research participation and yet the authors chose a cohort of 90% men to study willingness to participate in a cohort study. This is evident in their own differences in female participation rates compared to total Australian population,, and this was even more evident in the study results when asking those surveyed regarding participation in health surveys. “For the general population sample, greater willingness to participate was reported by women 160 than men (61% vs 58% p = 0.047), “ Results do not discuss these data limitations at all in the discussion.

Many occupational health research cohorts are largely male, and the industrial cohort was the cohort available to the research group. The high willingness of these men underlines their continued interest in taking part in health research. We have added the following to the Discussion
“In the case of the largely male cohort, the responders continued to be willing to take part in research in contrast to the usually lower interest than among women, as was evidenced in the general population group.”

3. Are the data sound?
Despite concerns regarding bias in interpretation and the results, the data seem fine. No change required.

4. Do the figures appear to be genuine, i.e. without evidence of manipulation?
There should be some confidence interval or p-value showing significant differences in table 2,
Done

Table 4 should include references to chi-square tests corresponding to p-values, similar to Table 3.
Done
5. Are the discussion and conclusions well balanced and adequately supported by the data?
The discussions and conclusions do not discuss the issues of inherent bias and potential for reporting bias in their own work as a limitation to the overall study. We say in the limitations:
“Those who refused to take part in our study may also be unwilling to take part in other health research and/or might have taken part if it had not been a telephone survey.”

As stated above we have added the following about non-response bias to the Discussion.
“We have no information about the individuals who did not answer the telephone or who answered but did not take part in the study. The telephone numbers were obtained from a commercial list without such information. In view of this we cannot assess any non-response bias. We have compared the demographic descriptors to those of the general population to assess how different they are to the general population however.”

We have added the following paragraph to the conclusions.
“Our survey only includes those willing to take part in a survey, but it is encouraging that those who have already taken part in health research are highly responsive and very willing to take part in another study.”

We added the following to the discussion:
“Some questions such as education level or long term disability may have been subject to reporting bias but the remoteness index and SEIFA were coded from area measures and are not likely to be biased.”

6. The limitations of the work are not clearly stated, please see above.
Response: In the revised manuscript we have now more clearly stated the limitations. As addressed in the reply above.