Author's response to reviews

Title: Collaborating with consumer and community representatives in health and medical research in Australia: results from an evaluation

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Author's response to reviews: see over
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The Editors-in-Chief
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Dear Editors-in-Chief

Collaborating with consumer and community representatives in health and medical research in Australia: results from an evaluation

Thank you for inviting us to respond to the reviewers’ reports and to submit a revised manuscript.

Response to reviewers’ reports

Reviewer’s report: Jonathon Boote

This is a very interesting paper reporting a formative evaluation of consumer involvement within an Australian health research project. There are very few such evaluations reported in the literature, making this paper a useful contribution. The methods are appropriate and soundly used, generating a range of qualitative and quantitative data that are accurately reported in my view. The authors are right to state that no standardised measurement tool currently exists to evaluate the impact of consumer involvement on health research processes and outcomes. However, it was positive to see the authors making use of previously published principles of successful consumer involvement in their evaluation. The paper is very well written and easy to read.

Minor essential revisions

I think there is an error on the second to last line of the conclusion: should CCRs read CCRs?

This has been corrected and now states “CCRs”

Discretionary revisions

I think the paper’s introduction could be improved if reference was made to developments in consumer involvement in research in countries other than Australia (such as the USA and the UK) and if the authors could outline other arguments in support of consumer involvement apart from it being a policy imperative (i.e. epistemological, moral and effectiveness/consequentialist arguments).

We have now provided additional background information that is required by the second reviewer as part of her compulsory revisions.

Reviewer’s report: Carla Saunders

Major Compulsory Revisions

Background

It is important that early in background a statement on the evidence base and/or rationale for consumer involvement in health research is provided to place the current work within a more robust context.

We have provided additional information about the rationale for consumer involvement in health and medical research to place the current work in a more robust context. This is placed in the background, where new paragraphs one and two have been added.

Some clarification needs to be made about the requirement of the NHMRC for research applicants to describe community/consumer participation i.e. does this ultimately influence funding decisions under a scientific merit review process? How much weight is given to consumer involvement?

Although the NHMRC Model Framework for Consumer and Community Participation in Health and Medical Research cited in the paper states that “grant applicants will be asked how consumer and community participation will be involved in proposed research”[1], in their current advice to NHMRC Project Grant applicants [2] they ask “does this research involve
consumer and/or community participation?" If the answer is 'yes', they then ask further questions about consumer and community participation. We have therefore deleted from the background, paragraph 3, last 2 lines the statement "It then became a requirement for applicants to the NHMRC for research funding to state how consumers and communities would participate in research" as we think this is now an equivocal statement. Therefore, we have not addressed the question about how this may influence funding decisions under a scientific merit review process, and how much weight is given to consumer involvement as we consider this is outside the remit of this paper.

We also wish to clarify that consumer and community participation in this research project was not a condition of our funding, we were funded by the Health Promotion Foundation of Western Australia and not the NHMRC. To clarify this point we have changed the statement in the background, paragraph 8, lines 1-3 “…we committed to collaborating with consumer and community representatives (CCRs) in research to comply with NHMRC requirements …” to “…we committed to collaborating with consumer and community (CCRs) in research, not as a condition of funding, but to comply with the NHMRC statement on consumer participation in research [3], and to conduct good research practice [4, 5].”

NHMRC requirements are stated to be the primary driver of consumer involvement in this project and that it was also anticipated that the participation would add value, does this mean that this is the first time consumers have been involved in the research of this group? If so please state and briefly describe past successes / challenges with consumer involvement in your research. If not please indicate whether there was any initial investigation of consumer involvement to inform the approach described in this paper.

The NHMRC requirements stated in the Statement on Consumer and Community Participation in Health and Medical Research [3], a Model Framework for Consumer and Community Participation in Health and Medical Research [1], and Resource Pack for Consumer and Community Participation in Health and Medical Research [6] were the primary drivers for consumer and community involvement in this project. Two of these documents were published in 2005 and were used by us in 2006 to guide consumer and community participation in the Alcohol and Pregnancy Project. We also received guidance from the consumer research liaison officer at our research organisation. We now describe this process in the background, where new paragraph 6 has been added. To accommodate this, we have deleted in paragraph 7, lines 1-3 and inserted revised lines 1-2.

Furthermore, although some members of our research group had collaborated with consumers in the past, this was the first time they had collaborated formally with consumers and conducted an evaluation. We have changed the sentence “This was the first time that these researchers involved in the project had collaborated with CCRs in research” to “This was the first time that the researchers involved in the project had formally collaborated with CCRs in research” in the methods, under the second heading titled “Establishing consumer and community participation”, first paragraph, last 3 line2.

The background states an evaluation was conducted on the impact of CCP – this should be changed to read researcher and consumer perceived impact of CCP

In the background, last paragraph, lines 12-13, we have replaced “we conducted an evaluation of the process” with “we conducted an evaluation of researchers’ and CCRs’ perceptions of the process”. In the abstract, objective, lines 2-4, we have changed “…and evaluate the process, context and impact of their participation” to “…and evaluate researchers’ and consumer and community representatives’ perceptions of the process, context and impact of consumer and community participation in the project”.

What is the research question?

We have addressed this in the background, last paragraph, lines 12-13. We have replaced “we conducted an evaluation of researchers’ and CCRs’ perceptions of the process” with “we conducted an evaluation to answer the question: what were researchers’ and CCRs’ perceptions of the process”

Methods
The first sentence in the methods section which describes the Alcohol and Pregnancy Project needs to be placed in the Background section.

We have moved this sentence to the background, last paragraph, commencing at line 5. We have deleted in the methods, the first heading “The Alcohol and Pregnancy Project” and replaced it with “Establishing the Steering Committee for the Alcohol and Pregnancy Project”.

There are currently insufficient details provided to replicate this work. It is stated that advice was obtained with regard to setting up the 2 reference groups – this advice needs to be further clarified. Similarly the reason for omitting the word consumer needs to be explained.

We have now provided information on setting up the two reference groups and explained the reason for omitting the word consumer in the Aboriginal Community Reference Group. These changes appear in the methods, under the second heading titled “Establishing consumer and community participation”, first paragraph, lines 1-6 were deleted, and 17 new lines have been inserted. In the revised paragraph 2, lines 1-2 have been deleted as these are now included in the revised paragraph above.

Some of the governance and information tools such as the TOR/Project Summary etc should be provided as appendix to this paper to support replication and guidance for other researchers.

We have attached as an appendix, the Information for the Community, Project Summary, and Terms of Reference for the Consumer and Community Reference Group.

Evaluations of CCP have been undertaken - see:


In the methods, under the fifth heading titled “Evaluating consumer and community participation”, we have changed “A search of the literature did not reveal any evaluations of CCP in health and medical research” to “A search of the literature did not reveal a suitable form of evaluation of CCP in health and medical research”.

More information needs to be provided on the development of the questionnaire used to assess the process, context and impact of involvement i.e. was there any validation process such as piloting and refining etc? The open ended questions need to be provided in Table 1. Results should also be provided i.e. rates of responses etc

As explained in the paper in methods, under the fifth heading titled “Evaluating consumer and community participation” there were 22 questions in the questionnaire (and 23 for the Aboriginal Community Reference Group). For the first 16 questions (17 for the Aboriginal Community Reference Group) we sought agreement or disagreement with statements that were stated from (1) the project Terms of Reference that were established at the commencement of the project and agreed by CCRs and researchers and affirmed at every CCR meeting; and (2) Telford’s principles of successful involvement in National Health Services research [7]. We did not seek to pilot or refine these statements. We have not changed the text in the paper.

The remaining four questions were paraphrased from Hanley’s briefing notes [4] where she states in the section “Involving the public in evaluating the research process “…reflect on what went well during the research, what did not work so well and what they would do differently if they were to do the research again”. We have not changed the text in the paper but the four open-ended questions are now stated in Table 2.

The consumer research liaison officer and a researcher commented on the questionnaire before it was distributed to CCRs and researchers.

Telford principles need to be briefly described for the benefit of readers.
Telford’s principles of successful involvement are stated in Table 1. We have not included a further description of these but in the methods, under the fifth heading titled “Evaluating consumer and community participation”, paragraph 2, line 4 we have now added “Table 1” to the following “… assessed Telford’s principles of successful involvement in National Health Service research (Table 1)”.

Results

The results need to include examples of tangible input/advice from consumers that led to positive changes. Rather than just describing researchers' opinions about working with consumers generally, the actual input that led to improvements in research design / tools / approaches etc is needed for this paper to add to the existing evidence base otherwise it is simply describing a general view rather than the value that involving consumers added. Tangible examples under each heading of input from consumers that led to change and would not have been available without consumer involvement is required. A table highlighting the actual contributions of consumers would be useful to demonstrate the merit and importance of involvement.

We appreciate the reviewer’s comment and agree it is important to obtain tangible examples of CCRs’ input that led to change that would not have been available without the involvement of CCRs. In the methods, under the fourth heading “Consumer and community representatives’ contribution to the project” we list five areas of CCRs’ contribution to the project. For this paper, we are not able to offer in the results section, tangible examples of input from consumers that led to change that the reviewer has requested as we did not specifically collect these data other than those listed in the methods (described above). Also, the focus of the paper and our results is to report the researchers’ and CCRs’ perceptions of the process, context and impact of CCP in the project. Nevertheless, we have noted that it is important to record examples of input and advice from consumers that led to changes, and indeed, this has since occurred. We have now mentioned this in the discussion, paragraph 6, lines 11-13.

Discussion

This paper needs to focus more on the ‘so what’ that is above and beyond that of satisfying a funding application requirement.

We have clarified above (and in the background, paragraph 8, lines 1-3) that the research was not to satisfy a funding application requirement and have also noted the reviewer’s comment on ‘so what’. We have revised the discussion and added some further points as follows:

Paragraph 4, lines 6-7 have been added that previously comprised the last paragraph in the discussion, and lines 8-10 have been revised;
Paragraph 5, lines 1-4 in this paragraph have been moved to lines 7-11 in revised paragraph,
lines 5-8 in this paragraph are now lines 1-4 in revised paragraph,
new lines 4-6 and 12-16 have been added; and
Paragraph 6, lines 6-13 have been added.

Conclusion

We have revised the conclusion to accommodate the revisions in the manuscript in paragraph 1, lines 1-11.

We are pleased to submit our revised manuscript and responses to the reviewers’ comments.

We thank the reviewers for their valuable comments on the paper.

Yours sincerely
References


