16 July 2013

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RE: Cover letter addressing reviewer comments

The cover letter addressing issues raised by the reviewers and the revised manuscript has been reviewed and approved by all listed authors. We look forward to hearing from you in the near future.

Reviewer 1

Major Compulsory Revisions

1. The abstract results could include more details about the concepts/themes that emerged from the community conversations.

Page 4: We have made the following amendments to the Results section of the Abstract:

Results: The on-line survey was completed by 2 members of the Collaboration (71%). Consumer and community participation was considered important and essential, worked well, and was integral to the success of the project. The 32 women attending the Community Conversations generated 500 statements that made reference to prevention, how information and messages are delivered and appropriate support for women. Nearly all the attendees at the Community Conversations (93%) believed that they had an opportunity to put forward their ideas and 96% viewed the Community Conversations as a positive experience.
2. *The community conversations using “world café processes” was conducted. Invitations were placed on websites, emailed to consumer organisations, reference groups, and women known to the collaboration. Can the authors discuss the potential selection bias?*

We have revised the Community Conversation section under Methods (page 10) to include the following:

Invitations to participate in a Community Conversation seminar on alcohol and pregnancy were placed on websites and emailed to a network of consumer and community organisations, reference groups and women living in Perth and Cairns and known to members of the Collaboration. Consumer organisations contacted were broad and not restricted to child health issues. We acknowledge that the participants are unlikely to be representative of the broader population, particularly with respect to people who do not have access to electronic communication and high risk populations.

3. *Characteristics of the women who participated in the community conversations could be summarised in a table.*

We have revised the Community Conversation section under Results (page 14) to include the following:

Participants were women of child bearing age and included women with and without children and some who were pregnant. We did not collect demographic details from individual participants.

4. *The community conversations were recorded and transcribed. Did the authors use software to code the data?*

We have revised the Community Conversation section under Methods (page 11) to include the following:

Following the philosophy of the Community Conversation and world café process, conversations were not recorded and field notes were not taken. The 500 participant statements were entered into a spreadsheet using word processing software and coding was performed by two authors using hard copy records.

5. *Were observations and field notes taken to assess the level and nature of interaction of participants?*

No formal field notes were taken to assess the level and nature of interaction of participants. We followed the philosophy of the Community Conversation and
the structured world cafe process which uses small groups guided by a facilitator to monitor and promote participant interaction. We acknowledge that field notes may have provided valuable additional information.

6. Providing a selection of participant quotations would enable the reader to assess the dependability of the study, as well as the types/nature of opinions women contributed to the discussions.

Thank you for raising this issue. We have amended the Community Conversations section under Results (pages 14/15) as follows:

The selected statements that follow are indicative of the issues raised by attendees. Many attendees noted that prevention and need to take the message to the whole community, including men is a priority. One participant stated “Educate women so it isn’t just another thing she can’t do – put on TV, everyone sees it” and another commented “Not just mother – whole family system”. Other attendees also referred to the use of television and social media with statements “More emphasis on national recognition of FAS rather than putting sole responsibility on the GPs to deliver education on alcohol consumption eg more info via TV, radio etc” and “Using websites ie headspace, my space, facebook, bebo”. Educating young people was also highlighted by participants “Educate young people about the effects of drinking on babies. Focus on the positives of how to have a healthy baby.”

Community Conversation participants also referred to how information and messages are delivered to women. Participants supported the use of a standard set of questions for all women, with one attendee stating “Health professionals can tell you it’s a standard question they ask everyone so you don’t think you are being singled out. Also only have someone with people skills to ask the question (not someone who will look horrified if you say yes)”. Of particular importance was how to ask the question about alcohol consumption in pregnancy, the language used and training for health professionals to ask the question. Women wanted questions asked “In a non-accusatory manner. People will clam up (go into denial) if confronted in a way that makes them feel to blame for their child’s condition”. Women also commented that “The health professional should be confident in asking the questions – not hiding behind language” and that health professionals should “Be aware of language issues – break down big words so people understand”.

It was important to women attending the Community Conversations that health professionals recognise the feelings and anxieties when asking women about alcohol use in pregnancy. These concerns were reflected in statements such as “Embarrassed (shame factor) ‘I am not a drunk’” and “Fear, guilt, panic – what irreversible decision have I made?” While another participant stated “Should be made to feel proud if you don’t drink”. One woman commented “Ask but at the same time offer solutions. Hard to offer up information if you are feeling there’s
nothing being given in return ie this information will help people in the future but it won’t necessarily help your situation”.

Several attendees expressed concern about the need for cultural sensitivities with statements such as “Intergenerational trauma and legislation for Aboriginal people” and “Assumption about culture that comes across as patronising”. However another participant stated “This is about the child & their difficulties, not about their culture”.

Some statements reflected concern about the name ‘Fetal Alcohol Spectrum Disorder’ and that FASD is not curable. One participant stated “Rename the syndrome coz FASD just points the finger at the mother, whereas some generic name like learning-blah-blah disorder doesn’t let others know the mum was at ‘fault’”.

Minor Essential Revisions

1. The FASD collaboration results could be presented as key themes or concepts reflecting the members’ perspectives on consumer and community participation.

We have reviewed this section. The evaluation included four questions specific to consumer and community participation in the FASD Project which resulted in 30 statements. We have separated this section into two paragraphs for clarity and added further detail to describe the range of comments from members of the Collaboration on page 13.

In particular members commented on two aspects of the impact of consumer and community participation in the FASD Project: community voice and inclusiveness.

2. Some aspects of the larger FASD Project were reported elsewhere. It is unclear if these sections were re-reported in this paper. For example, the Delphi Survey results are referenced.

Results are not re-reported in this paper however we cite one finding from the Delphi survey on page 12.

Page 8:
We report here the consumer and community contributions to the FASD Project; findings from the Delphi study component have been reported separately [25-27].

Page 11:
The modified Delphi process is described in Watkins et al [27].
The workshop methods are described in Watkins et al [32].
Delphi Study – this section cites one finding from one question in the Delphi survey which was posed by attendees at the Community Conversations and used in the Delphi survey and the outcome. “Of the 103 health professionals who completed the study, 92% agreed with this statement [27].”

The three FASD Project published papers [References 25-27] do not report on consumer and community participation in the FASD Project.

Reviewer 2

1. I am not entirely sure if it is correct to describe the Delphi method as a form of a survey. I would suggest that this is looked into by the authors.


Page 8: We have made the following amendment:
The FASD Project consisted of: a systematic literature review; Community Conversations; a Delphi study; a consensus development workshop and diagnostic and consumer subgroup meetings.

Page 11: We have made the following amendments:

**Delphi Study**

Data from the systematic literature review and the key issues from the Community Conversations were reviewed by the Collaboration to develop questions for the survey of health professionals. The modified Delphi process is described in Watkins et al [27]. Members of the Collaboration were asked to identify individuals known to have expertise or experience in the screening or diagnosis of FASD for recruitment to the Delphi study panel.

**Consensus Development Workshop**

All members of the Collaboration were invited to participate in the two-day workshop to review the evidence from the systematic review of the literature, feedback from the Community Conversations and results from the Delphi study, and develop the diagnostic instrument for FASD in Australia.
Page 16: We have made the following amendments

**Delphi Study**

Of the 220 health professionals invited to participate, 28 were recruited by consumer representative members of the Collaboration and women attending the Community Conversations. One of the key issues evolving from the Community Conversations was that a routine question about alcohol use should be asked of all pregnant women. This was included in the survey as follows: “Alcohol exposure should be assessed alongside other lifestyle factors including diet, physical exercise and smoking”. Of the 103 health professionals who completed the survey, 92% agreed with this statement [27].

2. **NICE has recently changed its name from the National Institute for Health and Clinical Excellence to that of the National Institute for Care Excellence, so this should be revised.**

Page 16: We have made the amendment to National Institute for Health and Care Excellence on page 18 and updated Reference 35

Yours sincerely

[Signature]

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