Author’s response to reviews

Title: Global Health in Preconception, Pregnancy and Postpartum Alliance: Development of an International Consumer and Community Involvement Framework.

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Dear Sophie and Richard,

We would like to thank the reviewers for their constructive comments and thank you as Editors for your time and effort on this paper.

We have responded to the reviewers’ comments and revised the manuscript accordingly.

Below we outline how reviewers’ comments have been addressed.

Yours sincerely,

Helen Skouteris

C=comments; R=responses

Reviewer 1

C1. The focus on translation priorities as well as research was encouraging and the attempt to address a gap in literature for women in your target group is helpful.

R1. We thank the reviewer for the encouraging feedback.

C2. I would have liked more on cultural difference, especially given the international pedigree of the authors and the focus on flexibility and adaptability in the framework. For example, the term 'consumer' seems to indicate a particular cultural preference which may not be universal and indeed the observations about disadvantaged groups provides further evidence of diversity in perspective and experience, yet it was not clear how this should be addressed. The limited extent of involvement in the framework did not allow this to be developed as much as it warranted.
R2. We have reviewed the manuscript and believe that the international perspective to date is reflected in our collaborations and authorship (representing five continents) as shown in the text below.

“Thirteen international experts in the fields of women’s preconception, pregnancy and postpartum health, two consumers and six early career researchers attended a CCI workshop in September 2018[11]. Five continents were represented. The consumers (LJ and HiS) were invited from established non-governmental women’s health and consumer representative organisations and had received training through these organisations regarding involvement as consumer experts in research activities.” Page 11.

We have provided additional details to reflect that one of the consumers recruited in Australia was from a culturally and linguistically diverse background:

“….we recruited six consumers (five women and one male partner) via a playgroup based in Melbourne, Australia, word of mouth and professional contacts with Aboriginal women’s health advocates/midwives. One of the consumers was born in Venezuela and spoke English as a second language; her experiences of perinatal care were through the Australian health system.” Page 16.

We have also clearly stated that the paper describes the co-development of the framework to date: “Our strategy acknowledges the importance of local and cultural context and we have held preliminary discussions with women from Aboriginal and Torres Strait Islander communities in Australia; we will continue to work on adapting the framework as these partnerships and others develop.” Page 24.

Our international and diversity foci are limited at this point, that is to be expected with this being the nascent period for such an innovative program. Publishing this paper will help to get the word out as will concerted efforts by those currently involved to reach out widely to their networks, both consumer and professional.

Regarding the use of the term Consumer, we understand that different terms can be attached to a range of meanings depending on the country or group of “consumers” involved. Indeed, cultural differences across the use of terms has been noted as making literature reviews quite challenging (Manafo et al. 2018) Hence we had acknowledged in the paper that different terms are used across different countries:

“These countries apply different nomenclature such as patient engagement (US) and patient-researcher engagement (CA), patient and public involvement (UK) or consumer and community involvement (AUS).” Page 9.

We have also updated the description of the term Consumer to provide further clarity around its use:

“A consumer (also referred to as a member of the public, patient and stakeholder in other countries) is historically the term used widely throughout Australia as reflected in title of National Health and Medical Research Council’s Statement on Consumer and Community
Involvement (2016) and has become the term that people relate to in Australia to describe any person affected by the research, such as those with a lived experience of a health condition and/or a recipient of research knowledge/health and community services” Page 8.

C3. References to practices which may be of interest to readers, like 'playdates' and 'yoga for bump,' could be further developed. I suspect that a further search of grey literature (eg in England from Public Health England or the Maternity Transformation Programme or the Prevention Programme) would have identified additional insight as well as significant examples of co-production with women.

R3. We agree with the reviewer that there will be other approaches being implemented for involving women in research that are relevant to HiPPP’s agenda. As such we believe that the reviewer has picked up on the point that we are making in the paper regarding the lack of accessible information describing the “how to” and hence part of the rationale for reporting our framework development. Even after reviewing the suggested programs via electronic methods, it was clear that CCI/PPI work is being conducted in this field, but we were not able to identify any such information beyond engaging individuals at the “participant/patient” level. This research gap has now been expanded on in the discussion:

“Furthermore, our grey literature search was limited to the peak bodies that had emerged during discussions with researchers and other experts working in the field at the time, meaning that other valuable resources may have been omitted. Indeed, following the co-development of the framework we have become aware of women’s health programs and services that are likely to implement innovative methods for involving consumers in research and co-production activities, but even then have not been able to identify accessible resources outlining the pragmatic approaches implemented to facilitate meaningful CCI.” Page 23.

C4. Some of the data may need refreshing. For example younger women were cited as the population group at highest risk of obesity but the reference dates from 2016 and it was not clear if this finding remains valid. Also clarity on whether this is a global figure and whether again regional differences are significant.

R4. We have now clarified that the global figure refers to low, middle and high-income countries and have included additional references, dated more recently than 2016, to support this statement:

“Maternal obesity is evident across low, middle and high income countries (Stephenson et al., 2018), however obesity prevalence is growing faster among communities experiencing socio-economic challenges (Kumanyika, 2019; Perez-Escamilla et al., 2018).” Page 7.

C5. It was also not clear whether the importance given to obesity by HiPPP and the way these life stages were seen as ‘key obesity prevention windows’ were shared by the women in the study.

R5. Thank you for highlighting this important omission. We have updated this section as follows:
“During initial discussions about the project, most consumers volunteered information about their own experiences relating to attempts to engage in healthy lifestyle practices, including detailing challenges in maintaining optimal dietary intake, physical activity levels and weight management in preconception pregnancy and postpartum. In addition to noting the relationship between their perinatal eating and weight patterns and current weight status, most consumers stated that they wished they had known earlier that un/healthy lifestyle behaviours before, during and after pregnancy could adversely impact their future child’s health and weight trajectory. As such, consumers viewed HiPPP’s research agenda as a public health priority.” Page 16.

Reviewer 2

C1. This article is very informative, I enjoyed reading it. I was particularly interested in how the team have carried out this work as I have a strong interest in ethics, maternal health and more generally in obesity reduction initiatives at a public health level. Having published a framework on ethics myself and continuing on this piece of work, I was able to fully understand how to make this piece stronger.

R1. We are delighted to read that the manuscript has been informative and may be useful to others working to strengthen frameworks or solve similar public health problems. We thank reviewer 2 for comments on how we may strengthen our own work presented in the manuscript.

C2. Title 1. Should avoid using the CCI acronym.

R2. We have removed the acronym from the title. Page 1.

C3. Abstract 2. Not clear what the acronym CCI is.

R3. We have added “consumer and community involvement” before the acronym, which is now presented within brackets: “The aim of this paper is to outline our strategy for the development of the HiPPP Consumer and Community (CCI) Framework, with consumers…” Page 5.

C4. Introduction 3. Clear and easy to read and understand but would need an edit to reflect changes suggested below.

R4. Thank you, please see responses to each separate comment.

C5. Peer reviewed literature 4. Literature searching has not included the search terms ‘service user’ and ‘action research’ can the team offer a sentence or two about why these key terms were omitted or what impact that may have on the overall piece of work? I can however see that participatory research was picked up through the articles yielded in the search.

R5. We agree that there the range of terms used across different countries that we may not have been aware of when reviewing the literature and have now acknowledged this in the discussion:
We also note that our peer reviewed literature search may not have captured all relevant studies as a wide range of terms are used across the CCI literature (Manaf et al.). Furthermore, our grey literature search was limited to the peak bodies that had emerged during discussions with researchers and other experts working in the field at the time, meaning that other valuable resources may have been omitted.” Page 22.

C6. Grey Literature search 5. Can a justification be offered about why the five leading body's CCI frameworks were identified and not others? For example the World Health Organisation has its own global strategy concerning involvement and collaboration too: https://www.who.int/healthsystems/strategy/everybodys_business.pdf?ua=1

R6. We agree that there will be resources that were not aware of when reviewing the grey literature and have now acknowledged this in the discussion as per our response to C5. Page 22

C7. Targeted community involvement 6. Increasingly we are being asked to reflect on the type of involvement we adopt in our own work to help add knowledge and information on reporting to journals (see GRIPP2). The kudos of reporting this information brings an element of transparency and some reassurance to the readership that there was some thought offered to why involvement happened in a particular way and within a given budget.

R7. We had initially intended to use the GRIPP2 Short Form to report on future HiPPP research initiatives implementing the co-developed CCI framework; however, following the reviewer’s helpful feedback we can see how its application will strengthen the current paper and contribute toward addressing the CCI/PPI research gap. Page 11, Table 2.

C8. I do wonder if the type of involvement you described has been used by others and if it has, then maybe, the team could reference it as an example? I am thinking how the six people were found (the justification for their lived experience is fine - nice and clear but its the other details that are missing). Particularly why was this a the better method over other methods for example placing an advert to find people. This information might be useful for the journal readership, also especially given the nature of the article and its focus being CCI values related.

R8. We have updated this section to acknowledge there are a range of methods for effective CCI as our intention is not to suggest that our approach might be a better method than another: “Finally, research evidence[45] suggests that to date, there is not any one particular method of choice to support effective CCI[16, 45]; hence there may be a range of other approaches, including how consumers are recruited (e.g., via professional networks; advertising) that may be just as useful, and we would emphasise that overarching project’s goals, resources, and who may be the best people for the project will be key in guiding those decisions.” Page 23.

C9. Method/process of presentin - this will help to bring out originality 8. Can each of the five values be grounded in references where these points have been made/listed before in the literature. If this is too tricky, how about having a short discussion about how each value base is applied within the literature of a values based framework?
R9. In addition to the frameworks/guidelines described in the grey literature section of the manuscript (see pages 14-15), we have now provided more explicit references to other value frameworks that informed the values included in the framework and included corresponding references:

“…the values adopted by our framework aligned well with values that informed the development of the Alberta SPOR Unit Patient (in Canada the term patient refers to a person/consumer with lived experience of a health issue or their informal caregiver, such as a relative or friend) Engagement Platform[23], which were shared with us by one of the international CCI experts (VVW) on the team (e.g., Guidelines on Compensation[43]; Ethical Guidelines for Engaging with Patients as Researchers[44])”. Page 21.

We have also included references to other CCI values in the manuscript:

“Yet, lessons learned during the developmental phase of our CCI framework supported other research findings showing that underpinning CCI values are rarely made explicit[42]…” Pages 20-21.

“For example, an intervention designed for women in the general population who are engaged with perinatal health services may not be as relevant to women from vulnerable populations or those living in remote communities. This requires CCI to be undertaken with a deep understanding of historical, cultural and social complexity of specific local or regional contexts[45]; values that benefit all. Building the mutually respectful relationships needed to carry forward this work will take time.” Page 22.

C10. Can a short discussion be offered about whether the five values have reached saturation/are exhaustive before proposing an evaluation?

R10. We have reviewed the manuscript and we feel that the paper clearly states that the described framework will continue to be adapted and evolve as the diversity of included voices expands. As such, the values described in the current framework represent what has been offered to date and are not necessarily seen as an end point. Ongoing evaluations and reflective practices will continue to inform how the framework evolves, including the values it encompasses.

Some examples are provided below:

“Given the need to adapt local contexts and the evolving nature of the field, we focus on progress to date and acknowledge that this work will continue to evolve in response to the needs of consumers, researchers, health professionals and other stakeholders as well as the HiPPP objectives and opportunities.” Pages 10-11.

“It is acknowledged that further international consumer involvement is needed. Our strategy acknowledges the importance of local and cultural context and we have held preliminary discussions with women from Aboriginal and Torres Strait Islander communities in Australia. We will continue to work on adapting the framework as these partnerships and others develop.” Page 24.
C11. An overarching theory or logic model might be helpful to tie the three tables together in one diagram. So that the users of this framework to see its robustness.

R11. We appreciate the suggestion regarding using a model to better demonstrate the framework’s robustness and have now incorporated: Table 1 to tie the three tables together, summarising the co-development process and a logic model showing how the framework is intended to work (Figure 1). We believe these graphical representations have provided a clearer way for readers to understand the aim of co-developing the framework, processes involved as well as anticipated outcomes. Page 11.

C12. Discussion 11. A huge amount of work is going on in reproductive health within the UK and globally in the 'preconception' stage using assisted technologies (e.g. egg freezing, IVF, sperm donation etc) and I wonder why this school of work is not mentioned or discussed? I imagine bringing this back into the discussion allows the readers to remember that the framework proposed is broad enough to consider across the spectrum. Maybe give examples of the variety of health issues at preconception pregnancy and postpartum stages where health problems could be solved in the real world with this framework's help.

R12. Our research is specifically focused on lifestyle health in preconception, pregnancy and postpartum and we view it as being relevant to any discipline/service wishing to involve women/consumers in research associated with reproductive health/perinatal life stages. Supplemental Table 3 acknowledges that women/consumers in preconception may be using fertility services. We have now re-iterated its relevance to broader contexts in the discussion section:

“Furthermore, we have discussed preconception, pregnancy and postpartum life stages from a broad perspective, however the framework may be applicable to other research areas that are relevant to these life stages, such as Polycystic Ovary Syndrome, Gestational Diabetes and assisted reproductive technology.” Pages 22-23.

C13. Conclusion 12. The team make an important point about adapting this framework to local contexts. I wonder if more can be discussed about the challenges/opportunities of its applicability. Maybe the international conversation needs to be brought in here too?

R13. We have reviewed the manuscript and we believe that the authorship team and method highlight the international contributions that have been incorporated in these vital early steps to launch the co-development of the framework. The paper also clearly states that it describes the work that has been conducted to date and emphasizes that the framework will continue to be adapted and evolve as the diversity of included voices expands (locally and internationally). We expect that we will be able to report on challenges and opportunities that arise as we move through the next phases. In the discussion, we now include some insights into what might be needed to reach the next phase:

“However, we envisage that these too will be adapted in response to the voices of consumers with experiences from varied backgrounds and contexts, including consumers from Indigenous
and culturally and linguistically diverse backgrounds. For example, an intervention designed for women in the general population who are engaged with perinatal health services may not be as relevant to women from vulnerable populations or those living in remote communities. This requires CCI to be undertaken with a deep understanding of historical, cultural and social complexity of specific local or regional contexts[45]; values that benefit all. Building the mutually respectful relationships needed to carry forward this work will take time”. Page 22.

Reviewer 3.

C1. This is a very interesting paper that describes a framework for engaging with people who in my own experience can be quite difficult to even just identify as many are not currently service users. The lack of evidence identified on CCI in pre-conception care is sadly not surprising.

R1. Thank you. We appreciate the feedback.

C2. I would be interested to know more about some of the approaches used. Specifically, 'playdates' and 'yoga for bump'. Were the playdate sessions attended by multiple consumers with children or was it the researchers' own children and did they participate in the yoga? From the way it is worded I am not clear so some clarification around that would be helpful.

R2. We have updated the section describing the play date, which now states: “On two occasions, meetings were held as “playdates” involving two parents (the researcher and consumer) and their two toddler children at a time, as this format was preferred by some of the consumers who wished to attend with their young children. In these instances, age-appropriate snacks and toys were provided so that consumers could comfortably supervise their children while workshopping the HiPPP CCI Framework.” Page 17.

We have now added references for ‘yoga for bump’ and provided some further details to provide clarity around what the PPI initiative in the UK entails: “For example, in the UK, CCI researchers organised free ‘Yoga for Bump’ (antenatal yoga) sessions, held in a disadvantaged locale, to engage women in maternity-related discussions with a researcher and Q&A. As with a midwife[38, 39]. The main aim of the initiative was to create more accessible opportunities for consumers from a range of backgrounds to be involved in research. The initiative also sought to address competing time demands that often prevent pregnant women from being involved in research by organising an activity that they might enjoy taking part in and instead of expecting women to travel to the research institution, they held sessions in a more convenient location. Yoga for Bump Sessions were promoted through flyers, posters, social media and the group website[39].” Page 19.