Author’s response to reviews

Title: Exploring the perspectives of community members as research partners in rural and remote areas

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Author’s response to reviews:

Re: Response to Reviewers for manuscript RIAE-D-19-00047

Dear Editors and Reviewers,

Thank you for your time in reviewing our submission. We particularly appreciate how each reviewer has taken the time to understand our project and place it within the context of current literature in the field. Below you will find a detailed response to each comment presented by the reviewers and a revised manuscript with changes highlighted.

We look forward to your decision and thank the RIAE community for its ongoing support of patient and public engagement in research.

Sincerely,
Chelsea Pelletier (on behalf of all authors)

Reviewer #1: I feel it would be helpful to explain in the title that the article refers to northern and rural areas of British Columbia in Canada. As the publication is aimed at an international audience it will support a better understanding. I would suggest that the title might be more appropriately constructed to explain some of the characteristics of the populations of such areas, perhaps by describing the areas as small communities which are relatively remote, for example. This would also facilitate those searching for articles on similar or different types of location, or communities.

Response – Thank you for this comment and we appreciate that the term “northern” does not necessarily have relevance to regions outside of Canada. We have revised the title to reflect “rural and remote” areas. Throughout the text, we have also revised the language to reflect rural and remote communities (eg, distance to larger centres), but clarified that this work takes place in the context of northern British Columbia, Canada, with likely implications for other rural and remote geographies/regions.

Abstract: I experienced a little confusion around the inclusion of community members as research
partners and the exclusion from authorship of community members. It would appear that the authors are the academics and 'knowledge users'. I think it would be helpful to explain at the outset that this is an article which is focused on what would be required in order to facilitate the involvement of community members as research partners and not that it is an example where community members have been involved in co-producing the research or the article.

Response – As you have indicated, our team included researchers and knowledge users. The purpose of this project was to better understand how we could add community members to our research team, so we have not included community members as part of the authorship team and did not have community members as research team members. It is our intention that future projects would involve co-production of research articles, based on the knowledge gained with this project.

We have clarified this in the conclusion section of the abstract (page 4, line 100 – 103):

Although this project did not include community members as research team members or in the co-production of this research article, we present guidelines for research teams interested in adding a patient or public perspective to their integrated knowledge translation teams.

We have also added this to the limitations section (page 20, line 500 – 504):

A limitation of this project is that we did not include a community member partner on our research team. While this would have presented an opportunity for co-production, ultimately the inclusion of patient or public team members is the next step in our research, guided by the outcomes of this project as described in our framework.

I liked the emphasis on the characteristics of rural, fairly remote, populations and the challenges of involving such communities as authentic partners in research. I was glad to see mention of the challenges of confidentiality in such localities where members are often very locally connected, thus where confidentiality can be a prime concern. I feel the comparison is well made with those residing in urban environments in close proximity to universities, with easy access to services and facilities and often with pre-existing or on-going relationships with researchers. There are now many publications around 'hard to reach' populations but I feel that despite the small size of the current study it does offer relevant insights to researchers, health and social care practitioners and policy makers. The research is focused on making health interventions most relevant and therefore beneficial to local populations, and makes the case that real involvement of community members in identifying, designing and advising on delivering are important ways in which to improve the impact of health interventions. Although these are not novel ideas the emphasis on tailoring the participation of community members to suit the contexts of their lives and the desire to explore this via this particular study is useful and well timed. The methods are appropriate and although sample size is small the findings resonate with other much larger studies.

The finding that community members are particularly motivated to participate in research which they feel benefits their communities and themselves surprised me most. The claim that community members were most frustrated by frequent research participation with no real involvement and no information about outcomes or impact is unfortunately one of the most frequent complaints of public or patient partners in research, even where involvement is claimed to be a central value in a project.

I think the framework of guidance is useful, however I am well aware that both research projects and health interventions share a constraint of cost effectiveness and are often needed to be delivered to pre-
determined time deadlines. It is an accepted fact that authentic co-production, whether in research or health interventions depends on sustaining relationships and trust, both of which take time and emotional effort from all team members but which may not be adequately resourced in research or health delivery costs. I do believe, however, that steps towards improving authentic partnership working between researchers, patients and members of communities, such as the guide suggested in this paper, even when they may be less than perfect in translation into practice, must be supported and shared.

Response – Thank you for your comments on our work and for placing it in the context of the broader field and literature. We agree about the need to balance feasibility and authenticity is a challenge faced by researchers and the health system alike. We hope this work can contribute to the ongoing conversation and can help others who are interested in taking the first steps toward this process.

Reviewer #2: This paper focuses on providing an increased understanding of how to include community members from northern and rural areas as partners on research teams. The paper raises a number of interesting points such as ways factors that could be an enabler or barrier to involvement, recommendations for different stakeholders etc.

Overall, I felt the paper would benefit from more structure, including: a definition and explanation of knowledge user partners, more clarity regarding what data was collected and why; and a more considered exploration of the findings. The following points highlight more specifically how I think this paper could be improved:

Response – thank you for your time and thoughtful review of our paper. We have provided a response to each of your comments below.

Introduction

From a discussion around frameworks, it shifts to knowledge translation, and participatory approaches, it would be useful to add a sentence to make the link. Lines 130 to 134- How is this different from participatory approaches (e.g. community members are involved in community-based participatory approaches)? A more detailed explanation of how, if at all, this work fills the health inequalities gap/addresses those issues given that this is discussed in the paper in different sections. No mention of PPI in the global context, would be good to add a sentence on this. There is also a need for consistent use of terminology (involvement/engagement/participation). It does not matter which term the authors use as long as it is not used interchangeably, but it would be good to clarify that they mean working 'with' as research partners. The author could also place greater emphasis on what their study adds to what is already known and could provide better links around how this research builds on what is previously known. This is discussed to some extent in the discussion section but seems missing from the introduction. A more structured introduction could strengthen the author's argument and clarify how the study hypotheses were developed.

Response – We have revised the introduction substantially based on your feedback. We have revised the entire manuscript for consistency of the use of engagement. This includes mention of patient and public engagement in in the international context, page 5, line 124 – 129:

There are several national-level organizations that support and provide frameworks for integrated or engaged research approaches including the Strategy for Patient-Oriented Research (SPOR) from the
Canadian Institutes for Health Research (1), the Patient-Centred Outcomes Research Institute (PCORI) in the United States (2), and National Institute for Health Research (NIHR) INVOLVE in the United Kingdom (3).

We have also expanded on the second paragraph (page 5, line 135-140) to define knowledge users, explain that community members/patient/public partners are one type of knowledge user, and why it is important to study community member engagement in research specifically as it is understudied (and the public is less commonly engaged in research).

Integrated knowledge translation is a research approach that advocates the co-production of research with knowledge user team members, typically defined as people or organizations that are likely to benefit from or who may use research findings in practice or to guide decision making (6). Knowledge users may include but are not limited to research funders, health care providers, health system decision makers, advocacy organizations, patient groups, and/or members of the public (6,7).

Methods

Restructure methods section (flip the first two paragraphs for better structure). A reflection or discussion around who they involved and why in their research would be useful. Why emails were used, and only those from existing networks were contacted? Were any other approaches used? Given a discussed regarding underserved groups, inequality and people being left out, this does not seem to be an inclusive approach even in the context of participation, which is fine but would be useful to discuss limitations and strengths of such an approach. There is no mention of obtaining consent or how this was done.

Response – We have flipped the first two paragraphs as you have suggested. Participants were recruited through our existing network to account for feasibility challenges (grant funding timelines). Similarly, as this project was focused on people who are engaged in physical activity leadership in their communities, we specifically aimed to contact people who met that criteria. We agree that this approach may have excluded some people from participation, although recruiting participants around a specific topic (physical activity) did provide more of a direction for discussion and enabled specific examples that were relevant to participants. We have added more detail regarding this issue in the limitation section (page 20, line 506-510).

Although pragmatic, our recruitment method involved circulating an email through the existing physical activity networks of knowledge user team members. This strategy may have excluded some community members with divergent perspective from participating; however, it did enable a more robust and directed discussion with participants around a specific concept.

Written consent was obtained from participants who were interviewed in person. For people who were interviewed over the telephone, a consent/information form was sent via email prior to the interview and then verbal consent was obtained. This has been clarified in the manuscript, page 10, line 252-255:

All participants provided informed consent. For in-person interviews, written consent was obtained. In the case of telephone interviews, the participant information and consent form were sent via email prior to the scheduled interview and verbal consent was obtained.
Moreover, there is reference made to a recruitment matrix, what do they mean by this (an example would be useful).

Reference – Our recruitment matrix was structured as a table based initially on age and community size. As each participant was recruited, we plotted each participant on this table and monitored our recruitment to ensure diversity. We have added additional information about the use of our recruitment matrix to track representation, page 8, line 209-212:

Recruitment was guided using a recruitment matrix that plotted participants on a table based on community size and age. As participants were recruited and completed the interviews, we tracked representation back to our original targets and sought participants who met specific lenses or criteria as needed.

Lines 207-208 refer to the importance of anonymization. It is essential ethically to do this when undertaking research, so not sure what this sentence adds. Unless this was an issue and the researcher had to reassure them about this in order to elicit an open discussion and recording of the interviews.

Response – We have mentioned the importance of anonymization of data particularly from the perspective of rural communities as the small population size may make it easier for participants to be identified and we were particularly sensitive to the level of identifying information provided. For example, in several small northern BC communities there may only be one physician or nurse. For this reason, we have not identified specifically what community participants live in or their occupations and have chosen quotes that may not accidentally reveal any of these detailed (e.g., landmarks, events).

Lines 212 to 216 could be combined into a sentence, or the author can review this and present it more succinctly.

Response – As addressed in your following point (and other reviewers), we have expanded this section to describe the questions included in the interview schedule, page 9, line 226-232:

Participants were invited to share their understanding of and any past positive or negative experiences with health research. The interview schedule also included questions and prompts to encourage participants to explain how researchers could best include community members as partners on research teams and what supports would best facilitate their engagement.

Line 220 emerged from the data.

Response - This has been revised.

Were knowledge users involved in data analyses provided any training on how to undertake qualitative analysis?

Response – One of the knowledge user team members (A. Pousette) has experience with qualitative data analysis through previous work and education. Other team members were provided training by the researcher team members and were mostly sought for their opinions and perspectives on the ideas identified.

It would be useful if the author could provide more information about the content of the interviews and the method of analysis. For example: What topics did the interviews cover? Was data analysis
concurrent with data collection, and was the interview schedule modified based on emerging findings? Why only 12 participants? Did they reach thematic or data saturation? The participant characteristics table has no information regarding ethnicity and experience of research.

Response – Data analysis was completed after data collection. The interview schedule was revised slightly after piloting of interviews; however the questions were not changed substantially, rather additional prompts were added and some questions clarified. We have addressed and expanded on the participant information provided in the results section (detailed below). We have also added more information to describe the topics discussed in the interviews (above).

Findings

It could be useful to present some information regarding the participant characteristics and if this influenced their views (e.g. any similarities or differences) to provide context for the subsequent findings. This could enhance the richness of the findings section as currently, it is descriptive.

Response – We have added a sentence at the beginning of the results/findings section that summarizes the demographic information of the participants, Page 11, line 263-270:

The majority of participants (58%) were in the age category of 35-54 years and female (58%). Half of participants (50%) reported completing post-graduate education. Six participants (50%) were currently working and six (50%) were retired but still actively engaged in their community through volunteer roles. Participants reported living in northern BC for anywhere from 5-52 years (average: 36.3 years), with many having grown up in the region. Six participants (50%) reported prior research experience, ranging from coordinating patient groups, assisting in participant recruitment, as a research team member, as a research participant, and as a component of their health professional degree program.

The authors present the qualitative findings under three thematic sub-headings. However, I do not think that the conceptual names for the themes adequately represent the range of data presented within these sections. While there is better clarity of codes etc. in Table 2, this does not come through in this section. Perhaps the authors could review these conceptual names, and potentially make use of the language used by the participants. For example, the authors discuss the relevance, but this is at three different levels: research, personal and community. It would be good to draw this out a bit more and make it explicit in this section.

Response – We have revised the results (findings) section to reflect the codes and sub-themes described in the Table 2. We have added additional language throughout this section to better represent the range of data represented under each theme.

Data presented in the third theme appears to be related to building relationships and partnerships and training. I am not sure how this is around empowering participation. If through adequate training, they equip individuals to enable and encourage participation, then yes it covers empowerment. However, no such links have been made. Did anyone discuss training as a means for capacity building? While there is light-touch discussion around the need for understanding community needs, it feels like a missed opportunity as it is not explored further. Moreover, issues presented here seems more generic to involvement than for underserved groups, would be worth discussing specific and generic issues and distinguish them.

Response – We have added some clarification to our description of the third theme, empowering
participation. This theme also includes points raised about understanding and valuing community members for their expertise, which in turn would make them feel empowered and welcomed to participate in the project more fully. We have clarified this point in the first paragraph of this section (page 14-15, line 376-378):

By forming an authentic partnership, providing adequate training, and identifying community members as subject matter experts, research teams can empower research engagement by patient and public partners.

We have also specified in this section how there are specific issues with fractured or inauthentic relationships for rural and remote communities, page 15, line 380-382:

This issue of researchers ‘helicoptering’ into communities to collect data appears to be particularly relevant for engagement with rural and remote communities

Discussion

In the discussion and the methods section, the authors refer to the framework. It would be useful to know and understand what it adds to what is known. Lines 417 to 428 do not seem relevant as I don't think this is mentioned elsewhere in the paper. Further emphasis on the strengths of the study and an explanation of how the findings build on what is already known and the limitations of the study should also be noted. Moreover, there is a lot of discussion around barriers and ways to address health inequities; however, this seems to be the missing link in the findings section.

Response – We have removed one paragraph from the discussion that you mentioned, page 16, line 410-428. Some comments have been added to the following paragraph. You are correct that this language issue was not an explicit goal of the project and was not something mentioned by participants.

We have added a limitations section to our discussion (page 20, line 502-510).

A limitation of this project is that we did not include a community member partner on our research team. While this would have presented an opportunity for co-production, ultimately the inclusion of patient or public team members is the next step in our research, guided by the outcomes of this project as described in our framework. Although pragmatic, our recruitment method involved circulating an email through the existing physical activity networks of knowledge user team members. This strategy may have excluded some community members with divergent perspective from participating; however, it did enable a more robust and directed discussion with participants around a specific concept.

Further, the authors have not explicitly stated what the study adds. It would be useful to think about restructuring the discussion section. I am unclear on how GRIPP 2 is used to report the findings here and whether it is relevant in this situation. Some explanation in the text to clarify this would be helpful.

Response – Upon reflection, we have decided to remove mention of the GRIPP 2 checklist for this paper as it appears to have created confusion. Our research team included researchers and knowledge users, although knowledge users are an important non-researcher group, we recognize that those included on our research team are not considered patients or members of the public under traditional definitions.

It would be helpful if the authors could provide a more detailed description of the implications of this
research for policy and practice and highlight what evidence gaps remain and what gaps the current work has filled.

Response – This project adds to the growing field of research on understanding patient and public engagement in research, particularly from the perspective of rural and remote communities. We have added some language to reflect this at various points throughout the discussion, conclusions, and in the implications section where we suggest strategies for researchers and knowledge users based on the process of completing this project and the findings.

Reviewer #3: I found this an interesting and well written article which had some novel elements exploring barriers and motivators for rural communities being involved in the research process. I have a few comments which I would suggest need addressing.

1. The title does not make it clear where in the world the Northern and Rural communities are. It also isn't clear why Northern is the key aspect of this research. Is it not more a reflection of the distance from the centres of population and government? If so I would suggest changing the wording of the title to "remote and rural communities". If the authors feel the research only applies to those in northern and rural Canada then I would suggest leaving the term northern and adding Canada to the title instead.

Response – We appreciate that the term “northern” may only have relevance in our Canadian context. For clarity, we have revised the title to reflect “rural and remote areas” and in the text have changed reference to northern and rural to “rural and remote in the region of northern British Columbia.”

2. To my knowledge the term 'knowledge user' is not a commonly used term in the UK setting so could do with further clearer explanation on first appearance in the manuscript. Are you including members of the public in this group? If so I would prefer this to be clearer - see my point 3 below.

Response – A knowledge user is typically defined as “an individual who is likely able to be able to use research results to make informed decisions about health policies, programs and/or practices.” This can include a health care practitioner, policy maker, decision maker, health care administrator, community leader, individual charity, patient group, etc. (http://www.cihr-irsc.gc.ca/e/49505.html). We have revised the first paragraph, page 5 line 135 – 140 to define knowledge users and integrated knowledge translation.

Integrated knowledge translation is a research approach that advocates the co-production of research with knowledge user team members, typically defined as people or organizations that are likely to benefit from or who may use research findings in practice or to guide decision making (6). Knowledge users may include but are not limited to research funders, health care providers, health system decision makers, advocacy organizations, patient groups, and/or members of the public (6,7).

3. I was concerned at the lack of any documentation of patient and public involvement (PPI) in the research as distinct from the actual research itself which was conducting qualitative research 'on' members of the public to find their perspectives on PPI. Given the research is highlighting the important considerations for PPI in research, I would have expected the researchers to have considered public views when planning, conducting, analysing and reporting the results. The GRIPP2 checklist highlights that there has been PPI in these aspects but it is not clear in the methods. I would suggest the authors explain what public involvement they had in the methods more clearly in the main manuscript and not confuse this with the data obtained in the qualitative research.
Response – Upon reflection and for clarity, we have decided to remove the GRIPP2 checklist form our paper. Although our research team does include two knowledge user team members (Anne Pousette and Gloria Fox) who do not have research roles, this likely does not meet traditional PPI definitions as typically defined and we apologize for this confusion. This is a definition/clarification that our team has been struggling with, particularly as we tend to work in areas of preventive public health, where patients and carers are essentially members of the public, we recognize that these team members likely fall outside of what is typically considered patients and members of the public (as they work in public health or health care). We have clarified this at several points throughout the manuscript, including the abstract, methods, and limitations.

4. The development of the framework is not explained in the methods. How was this derived? Were public partners involved in the development of the framework or the plain language summary.

Response – as addressed above, our team did not include public partners but did include researcher/knowledge users, which is typically described in an integrated knowledge translation approach. All team members were involved in analysis, framework development, and the creation of the plain language summary. We have added two statements to the methods section to reflect the specific role of knowledge users in this project.

Page 8, line 194-198:

All study protocols and materials, including the recruitment strategy, inclusion/exclusion criteria, recruitment matrix, interview schedule, research ethics application, data analysis, and knowledge translation outputs, were co-produced by researcher and knowledge user team members through regular in person meetings and circulated via email for approval until consensus was reached.

Page 10, line 240 – 246:

Identified themes, ideas, and experiences shared by participants were used to create a framework for community-partnered research to portray factors that should be considered by research teams interested in patient and public engagement. In addition, based on the learnings from both completing this integrated knowledge translation project and in our discussions with community members, our research team co-produced a set of principles and takeaway messages for both researchers and knowledge-users when partnering on research teams (presented as implications & future directions).

5. In table 1 I would like to see all the demographics which were used in purposive sampling as described in line 193-196- eg. Ethnic group/indigenous peoples etc. The previous experience of participants is not clearly documented in the results so this could also be added to the table or in text. Age needs a unit (years) in table 1.

Response – Table 1 has been revised. We have also added additional demographic information to the results section, page 11, line 263-270:

The majority of participants (58%) were in the age category of 35-54 years and female (58%). Half of participants (50%) reported completing post-graduate education. Six participants (50%) were currently working and six (50%) were retired but still actively engaged in their community through volunteer roles. Participants reported living in northern BC for anywhere from 5-52 years (average: 36.3 years), with many having grown up in the region. Six participants (50%) reported prior research experience,
ranging from coordinating patient groups, assisting in participant recruitment, as a research team member, as a research participant, and as a component of their health professional degree program.

6. I felt the results section was not very long or detailed and a there was a lot of emphasis in the discussion to elements not highlighted explicitly in the results for example: What is the rationale for using the terms identified in line 427. Was this one of the findings of the research? If so, please include in the methods and results.

Response – This statement regarding how to define patient partners in research (line 427) has been removed as you are correct it was not discussed by participants in this study. We have revised the results section to better match with the themes and subthemes described in Table 2.

7. What do the authors believe are the limitations of their research?

Response – We have added a limitations section at the end of the discussion, page 20, line 503-510:

A limitation of this project is that we did not include a community member partner on our research team. While this would have presented an opportunity for co-production, ultimately the inclusion of patient or public team members is the next step in our research, guided by the outcomes of this project as described in our framework. Although pragmatic, our recruitment method involved circulating an email through the existing physical activity networks of knowledge user team members. This strategy may have excluded some community members with divergent perspective from participating; however, it did enable a more robust and directed discussion with participants around a specific concept.

8. Were community partners involved in developing the implications and future directions?

Response – The implications and future directions was co-produced by researcher and knowledge user research team members based on our experience working as a team and in our discussions with community member/patient partners that were interviews. We have added a sentence to the methods section to clarify this point (page 10, line 243-246):

In addition, based on the learnings from both completing this integrated knowledge translation project and in our discussions with community members, our research team co-produced a set of principles and takeaway messages for both researchers and knowledge-users when partnering on research teams (presented as implications & future directions).

9. As highlighted in point 3 the GRIPP2 checklist may need updating

Response – upon reflection and reviewer comments, we have decided to remove the GRIPP2 checklist from this paper. Although this paper did include partnership between researchers and non-researchers, the partners included are likely not considered patient or public partners by most definitions and likely created some confusion.

10. On page 14 line 376 is rather a strong statement as the authors did not consider study design, data collection, analysis and interpretation in this study - or if it was considered it was not clearly documented

Response – We have revised this statement as follows, page 16, line 421-425:
We present a co-produced framework that considers the three themes identified in analysis placed within a rural and remote community context. We also present our learnings from conducting this project following an integrated knowledge translation approach that includes researchers and knowledge users as full partners in study design, data collection, analysis, and interpretation.

11. I do not have great expertise in qualitative research however I would expect to see more details in the methods section regarding the methods used for the telephone interview, any topic guide, how this was developed, any methodology used to develop this and implement it.

Response – we have elaborated in the methods on the topics and questions included in the interview schedule. Page 9, line 226-229:

Participants were invited to share their understanding of and any past positive or negative experiences with health research. The interview schedule also included questions and prompts to encourage participants to explain how researchers could best include community members as partners on research teams and what supports would best facilitate their engagement.

12. There is clearly cross over between this manuscript and another manuscript highlighted concerning physical activity. It would be helpful to make it clearer what the relevance of physical activity (as stated for example in line 400) was in selecting and including participants in this reported research. Or if this is a limitation to the research that the group may not have experience of research.

Response – This project was conducted in the context of our physical activity research program to increase our understanding of how to engage with community members as team members for future projects. We agree this does present some limitations to the research as being engaged in community physical activity promotion or leadership was an inclusion criterion. On the other hand, it was more pragmatic to focus on a single topic for both recruitment purposes and also to enable more concrete examples of research activities for participants to engage in (this was especially helpful when participants did not have a clear idea of what kind of research they could be involved in). We have added this to the limitations section, page 20, line 503-510:

A limitation of this project is that we did not include a community member partner on our research team. While this would have presented an opportunity for co-production, ultimately the inclusion of patient or public team members is the next step in our research, guided by the outcomes of this project as described in our framework. Although pragmatic, our recruitment method involved circulating an email through the existing physical activity networks of knowledge user team members. This strategy may have excluded some community members with divergent perspective from participating; however, it did enable a more robust and directed discussion with participants around a specific concept.

Assistant co-editor comments: Really interesting submission. The above reviewers comments should help direct you with the revision. In particular we would appreciate clarification about the reason for your team not involving patients or carers in your write up.

Response – Thank you for this feedback. We did not include patient partners as typically defined in the completion of this project as the objective of the project was to better understand how to include community member (or patients/carers/families) on our research teams for future projects. Our team includes research along with knowledge users (research end users). To clarify, we have removed mention of the GRIPP reporting checklist in the paper, as we realize this was designed and focused on reporting of patient inclusion in research projects and reporting and may be confusing to readers.