Author’s response to reviews

Title: Engaging Patients and the Public in Health Research: Experiences, Perceptions and Training Needs among Manitoba Health Researchers

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Engaging Patients and the Public in Health Research: Experiences, Perceptions and Training Needs among Manitoba Health Researchers

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We would like to thank the Reviewers for their constructive comments and suggestions. We have endeavored to respond to each comment (in italics) below and make the necessary changes to the manuscript. Please note that all page and line numbers referenced correspond to the manuscript containing track-changes.

Reviewer reports

Rachel Matthews (Reviewer 1): Major Revision

Thank you for submitting this interesting work about the experiences, perceptions and training needs among Manitoba Health Researchers. You have obviously considered the challenges of supporting researchers to involve patients and the public and designed a method to understand local issues in more depth. I assume the findings will be used to design suitable and acceptable training and developmental opportunities.
I offer these reflections which may lead you to revise and reframe or place emphasis differently to strengthen the manuscript.

Thank you for your feedback.

1. Contribution to the literature

Internationally, there is already a reasonable amount of literature which describes the difficulties and anxieties experienced by researchers when contemplating PPI and you do reference recent publications. My concern is that your findings may have the most resonance locally in your province. You could revisit the findings and consider if there is anything that you have uniquely uncovered that will be of interest to a wider audience. Without this, I felt I was not learning anything particularly new.

Thank you for your comment. Although we appreciate the breadth of research available in this area, there are few studies that examine the training needs of health researchers with regards to engaging patients and the public in health research. We also know from knowledge translation and patient engagement theories (for example: see the knowledge-to-action [KTA] framework) the critical importance of local context in addressing gaps and developing interventions, such as training, supports and resources, highlighting the importance of a provincial based study. Additionally, given the importance of replication in scientific methods, we believe that this study plays a vital role in growing our understanding of the topic under study and its evolving nature alongside growth within the field itself. Therefore, we believe that our contributions are two-fold: (1) this study expands the literature base relating to training and resource needs of health researchers, and (2) provides a better understanding of the local context.

2. Background

The background could be strengthened by considering how you use the literature to introduce your research. The paragraph starting at line 34 on page 6 seems to really speak about what you are getting at and I wonder if that's worth bringing in earlier? I like the point about policy outpacing evidence. I wanted to know more about that as I would agree that there is a disconnect between evidence, policy and practice development. Perhaps you could expand and explain further? I would also revisit your explanation in the paragraph staring at line 9 on page 7 of what the research is attempting to do. I was confused wondering are you seeking to identify needs or working out what could address the gaps? Your manuscript title suggest you are collecting data about three different aspects which doesn't align with this paragraph or perhaps you are saying something different at this point.
Thank you for your suggestion. We have noted this discrepancy throughout (ie. Relating to consistency between the title and the organization of the paper under such titles) and have updated accordingly. Additionally, we have re-arranged and clarified numerous aspects within the introduction section to better reflect the overall purpose of the paper.

3. Methods

I can see that you spent time designing a lengthy questionnaire. I wasn't completely certain whether you had used or adapted existing validated tools? The questionnaire is divided into sections to address the 3 main areas of knowledge and experience, perceptions, needs and strategies. Your recruitment strategy could be summarised in a table by phase. This could help to clarify your target sample and the changes you made in your recruitment strategy. Descriptive statistics is not my area of expertise, however in taking advice from data analysts in my team, I might question whether your comparatively small numbers necessitated the statistical analysis you used. Other reviewers may be able to comment further.

Our survey was developed specifically for this project and informed by existing validated tools. This has been clarified by updating several descriptions in the section titled “Questionnaire Instrument” as reflected on page 9 line 16 which states: “A custom questionnaire was developed for the study” and page 10 line 4-6 which states: “Survey development was informed by adapting aspects of both the….”

It is also stated in the limitations section. See page 24 lines 21-23.

We agree that a table summarizing our recruitment strategy would be helpful. Unfortunately, our paper is already at the maximum table and figure allowance.

As noted on page 11 lines 1-3, we conducted a power calculation during the design phase of the study to set a target range of responses needed to ensure that we reviewed adequate power to be confident in our results and reduce measurement imprecision. Given the low response rate of researchers who had no experience engaging patients and the public in health research, we combined those with no or little experience into one group, while we combined those with some or extensive experience into the second comparison group to achieve a better balance between the two groups. We did not run statistical tests for sample sizes less than 5, and otherwise, followed established principles.
4. Data interpretation

I was intrigued that you involved the Patient and Public Engagement Collaborative Partnership to ‘validate the findings and outline future directions’. I wondered if there would be a fundamental difference in perspective and perception? I wanted to know if they were involved in the initial idea and design of the study as well as this stage? A table showing the timelines of the project could be helpful. Their input described on p16 contains some really useful clues about what might need to change especially the reflection on p17 line 58 which suggested learning together. This for me links back to the policy-evidence- practice gap you mention earlier in the manuscript. In my experience learning together offers real rewards.

Thank you for your comment. We agree that their involvement was a highly beneficial component of this study. Unfortunately, at the time that this survey was developed and distributed, our Patient and Public Engagement Collaborative Partnership did not yet exist. We recognize that their involvement from the initial stages of idea formation, design and throughout the entire study would have been ideal. This is a lesson that we will and have taken forward for future studies. This has been clarified in the methods section (page 12 lines 5, 18-19) and is also mentioned in the results (page 19 line 3) and discussion (page 23 line 16). Furthermore, we recognize that engagement of the Partnership in only one phase of the study is a study limitation, which we acknowledge on page 25 lines 2-6.

5. Discussion

In the discussion I would reconsider the points you want to draw out from your findings. There is unlikely to be a one size fits all solution so your findings point to an experience specific menu which takes account of the stage people are at in their career. Involvement is very experiential, how could that be supported? Could more experienced researchers act as peer support? Is there scope for joint training?

We agree with your comment that this is a potential strategy that could be explored. For example, during our centres “lunch time learning series”, we include invite a number of researchers and patient partners to share their experiences and expertise, which acts in some ways as a “peer support” approach. The strategy of mobilizing the expertise of more experienced researchers is drawn out a bit further on page 22 lines 12-16 as per your input.
6. General Comments

Overall, you have conducted a comprehensive piece of work that provides a local benchmark. However, greater explanation, focus and clarity in the text and the presentation of some information in tables might help. I'd be interested to know if you could repeat the exercise following training interventions or whether co-designing and co-evaluation training/development/support might provide better real time data about what helps build capacity and confidence and if that converts to better practice and more involvement at different levels.

Thank you for your comments – we have tried to adapt the language used throughout to make the article more clear and accessible. We are certainly interested in conducting future studies relating to the above noted points.

Thank you for your helpful feedback.

Dawn E Moser, MBA (Reviewer 2): Accept

Very interested in this topic and think it is certainly beneficial for stakeholder and patient engagement. Thank you for publishing.

Thank you for your comments and interest in this article.

Zarah Monfaredi, MSc (Reviewer 3): Minor Revision

Overall, a really interesting study with some really valuable findings! Congratulations, just a few comments below. In addition to the comments below, I would suggest a thorough read through to correct some awkward sentences and grammatical issues.

Thank you for your feedback.

Page 4, line 15: I suggest being more specific, rather than saying "varying" stages and levels of involvement, please be specific about exactly which stages and levels of involvement.

We agree with this comment. Unfortunately due to word count limitations in the abstract, we are unable to go into further detail relating to research stages and levels of involvement. We updated this line to instead read: “Participating Manitoba health researchers engaged patients and the public in health research at multiple, but typically lower levels of involvement” (see abstract – page 5 lines 5-7).
Page 5, line 36: The spectrum reference (Reference #3) is not specific to research and the highest level is "empower", not "patient-directed" as noted in the manuscript. Consider explaining how this spectrum has been modified for research purposes.

Thank you for pointing this out. Here at our Manitoba SPOR SUPPORT unit, we use the term patient-directed to refer to the highest level of the IAP2 spectrum, as we find it resonates more with our Partnership group and in providing training.

Page 5, line 48: Please add a reference to the statement: "However, engaging with patients and the public requests... compassion and self-awareness".

In revising the language throughout the manuscript, we have changed this sentence thus not needing an accompanying reference. This sentence now reads: “Achieving authentic, meaningful and inclusive engagement at any level with patients and the public requires distinct knowledge, attitudes and skills, and may represent a new paradigm for some health researchers.” See page 7 lines 1-7.

Page 6, lines 16-21: This comment applies to the entire manuscript. Please be explicit about the meaning of "involvement" and "engagement". Are these terms being used interchangeably or are they referring to different types of patient/public activity? Please provide a definition for each term, be consistent with wording, and be clear if these terms are being used to refer to the same type of activity.

Thank you for this comment. Given the terminology used in the IAP2 spectrum, which includes “involvement” as a level of engagement, we have updated all terminology to “engagement” to reflect the overarching process of engagement regardless of the level that they are engaged.

Page 6, line 55: You refer to "contributors"- who are these contributors? Patients? Public? Please elaborate.

This line has been clarified and now states: “A recent qualitative study examining the views of both researchers and patients and the public found mixed views on researchers needs for training in the field.” Please see page 8 lines 6-8.
Page 7, line 10: "This study aimed to address these gaps..." You have identified many gaps in the paragraph above, please be specific about which gaps this study will address.

This sentence has been updated to reflect the overall themes of the gaps and purpose of the paper: “The current study aimed to address the above noted gaps relating to experiences, perceptions, and training needs in the context of the Canadian province of Manitoba.” (see page 8 lines 18-19).

Page 7, lines 17-20: Another example of "engaging" and "involving" being used seemingly interchangeably. Please be specific/consistent.

As noted in a previous comment, we have updated our terminology throughout to consistently use one term.

Page 9, line 55: "the phases of discover, dream, design, and destiny" Please provide further explanation here. For a reader unfamiliar with the appreciative inquiry approach, this doesn't serve to explain the method used.

Thank you for your comment. We removed the details of this approach, shortening the sentence to “This process was guided by an appreciate inquiry approach” as we believe that further details can be explored by the reader by visiting the attached reference, which is open access.

Page 14, lines 12-14: "The type of support that health researchers responded a desire to receive..." This line is very wordy and confusing, consider being more concise, for example: "Health researchers reported needing advice or guidance..."

We agree. This sentence has been updated as per your suggestion – see page 16 lines 11-12.

Page 17, line 19: "...we move along the spectrum of engagement levels" this sentence is confusing, please revise. Also, specify that the "spectrum" referenced is the IAP2 spectrum.

This has been updated to read: “We found most researchers engaging at the lower levels of inform consult or involve, which increasingly do not fulfill requirement of funding agencies and journals, and fewer engaging at the levels of collaborate or patient-directed.” Please see page 22 lines 6-9.
Page 20, line 15: "its appropriateness" Unclear, is this the appropriateness of involvement/engagement? Please clarify

Please see page 23 lines 10-11. The appropriateness refers to when it is appropriate to engage patients and the public within the research process.

This has been updated to:” ….. the appropriateness of patient and public involvement based on level of involvement, stage of involvement in the research process….. (page 16 lines 4-6)

“However, researchers views on when it is appropriate to engage patients and the public within the research process, and other factors such as time, practicality and geographical limitations.” (page 23 lines 10-13)

“Basic and biomedical research was one area where researchers were unsure of the appropriateness of engaging patients and the public.” (page 23 lines 14-15)

Page 20, line 22: "within this growing movement" Unclear, which movement? Patient engagement? Please clarify

This sentence was updated to read: “Basic and biomedical research was one area where researchers were unsure whether or not it was appropriate to engage patients and the public.”

Please see page 23 lines 14-15.

Page 20, line 32: "For example, the definition of a health research" a typo, I believe it should be "health researcher".

Thank you for identifying this typo.

Page 20, line 51: "...practices are meeting this criteria" Unclear, which criteria? Please specify.

This line has been updated to: “Furthermore, the partnership discussed the concept of meaningful engagement and the need for additional methods, such as interviews, to truly capture whether patients and the public are being meaningfully engaged within the research process.” Please see page 24 lines 2-6.

Page 22, line 22: Based on your findings, it is not clear to me how this will facilitate further development of training. Perhaps it is more fitting to inform decisions surrounding the availability of support/resources.
This final line has been updated accordingly and now reads: “These results are critical to inform decisions surrounding the availability of supports and resources for health researchers in Manitoba”. Please see page 25 lines 21-23.

Mary Newburn (Reviewer 4): Major Revision

This paper addresses and interesting and important subject but I feel uses an inadequate methodology and the questions addressed are too narrow. A realist approach asking questions along the lines of 'What matters (and/or is valued or useful) to whom, why and in what circumstances?', would have been better. This rather limited mainly quantitative approach to the question seemed inadequate to really exploring the issues in a way that would make a substantial contribution to knowledge.

Thank you for your constructive feedback and reflection. At the time that this study was developed, no research had examined the current landscape of patient engagement within the province and few had formally examined it within Canada. While we fully appreciate the need for additional methods (ie. Interviews, focus groups) and methodologies, this is an area for future research which will compliment and strengthen our understanding and the practice of patient engagement among health researchers. For now, these findings have allowed our support unit to identify a number of areas requiring further attention and has enabled us to inform decisions surrounding the availability of supports and resources provincially.

At one point the authors suggest that researchers early in their career may be preoccupied by the need for 'publication, productivity and tenure'. I felt that this paper was might be influenced by the same preoccupations, rather than a genuine interest in PPI in research. The authors refer to 'theoretical domains framework' and a 'determinants of implementation behaviour' questionnaire, which sounds impressive, but was not referred to in the results of discussion sections in relation to the (design) or analysis of the collected data. There was a tantalising reference to appreciative enquiry and 'discover, dream, design, destiny', but little evidence of how this was applied and reflection on its utility.

Thank you for your comments regarding the lack of explicit reflexivity within the manuscript itself. The study was designed and conducted by a multi-disciplinary team. However, given word limitations but the recognized need to be transparent and reflexive, we have included a short description within the text to highlight the research team:

“The study investigators are affiliated with the Strategy for Patient Oriented Researcher (SPOR) and include a patient and public engagement lead, a knowledge broker and trainee, a director and early career investigator, and a clinician scientist, all with expertise and experience in knowledge translation and patient engagement from a trauma-informed intersectional lens.” (page 9 lines 9-13)
While both the TDF and appreciative inquiry were referenced, aspects of these were used to help inform the development of our questionnaire (TDF) and appreciative inquiry was used to help in planning for our meeting with the Partnership team. We’ve clarified their use in the study by stating that the TDF was used to help us create a custom non-validated questionnaire (page 9 paragraph titled “Questionnaire Instrument) and have updated the sentence regarding the appreciative inquiry approach to read “Planning for the engagement process within this study was guided by an appreciative inquiry approach”, removing the text regarding the specific phases.

1) I would have liked to know who these researchers were. What were their academic disciplines? Were they doctors (if so of which branch of medicine), nurses, midwives, psychologists, health service researchers, social scientists)? While their length of service may be on interest, so is the background and the values /methodologies of their discipline.

As above, we had included a line broadly outlining our roles outside of this study and thus, subsequent interest in conducting this study given our positions within a Manitoba SPOR SUPPORT unit.

2) I would equally have liked to know much more about the PPI in this study. The Patient and Public Engagement Collaborative Partnership was not explained, yet this is surely of central interest to an article exploring PPI in research. Who set it up? Who funds it? Who are the PPI participants? How did they get involved in PPI in research? What health areas are they experienced in? Had they had generally positive or mixed experiences of being engaged and involved in research, or not? Were they 'experts by experience’? I would like to hear some of their words verbatim.

Given word limitations, we were not able to go into detail about the Partnership team, however, we have included a line describing the overall role of this committee. Similarly, we do not feel that it is appropriate to include their words verbatim in this circumstance, as it was not part of our intention/approach in engaging them and shifts to viewing them as data sources rather than engagement partners.
3) The plain English summary needs to be re-drafted. For example, 'IAP2 spectrum' is a far cry from plain English. I cannot believe that there was serious PPI involvement in writing and/or refining the summary. (It was ungrammatical in sentence 2; and the phrase 'research process' was used twice not really clear what this was adding; the last sentence was not well crafted and clear.

Thank you for your feedback – we agree that the plain English summary should be written in more accessible language. This has been updated. Please see pages 2-3.

4) The English was rather clumsy throughout. It would be helpful to have a native speaker who is committed to accessible language to edit it further so that service users, non-native English readers and the public generally (researchers, funders, non-researchers, etc) can read it with ease. All research should be written in accessible English. In particular I picked out as needing refinement/simplification: 'the need for adequate resources to embed patients and the public early on in the research process'. (Services users don't want to be 'embedded'. This is not respectful language. It shows insufficient awareness and reflexivity (and/or poor use of English). Primary research 'pillar' meant nothing to me and was irritating because obscure. The word 'disinterested' was used incorrectly. For 'lack of interest in'. The sentence on p21 beginning 'The basic and biomedical realm was an area in question by health researchers…' was unclear. Later on, 'applicable to apply for competitive funding' should have been 'eligible'. What is 'good merit'? What are 'supports' (plural)? Support is a collective noun. There was a good deal of jargon that was unhelpful. For example, can 'a number of modalities' not be explained in a more direct and straightforward manner?

Thank you for your feedback. We have gone through the manuscript in attempts to make the manuscript more clear, accessible and easy to read. Regarding your specific comments noted above:

- Use of the term “embedding” patients and the public: these were terms used within the particular study that we were referring to, but recognize the nuances in using this language. We have updated these terms to “engaging”, which is more consistent with the terms used throughout. This has been updated (see page 7, lines 16-19).

- Use of the language “primary research pillar”: while the terminology ‘primary research pillar’ is used by the Canadian Institutes of Health Research, we recognize that this language may be obscure to non-health researchers. Given that this is the term recognized by researchers and how it was described within the survey itself, we have left the term as “primary research pillar” but have included a definition clarifying what this means (see page 11 lines 9-11).

- “Disinterested”: this sentence has been updated to use language that is more direct and clear.
Basic and biomedical: this sentence has been updated to read “Basic and biomedical research was one area where researchers were unsure whether or not it was appropriate to engage patients and the public.” (see page 23, lines 14-15)

Competitive funding: language has been updated as suggested (see page 23, line 20-21)

The term “good merit” was used twice in quotes by respondents (as seen in table 3 and table 4), which is why that term was used within the manuscript. Given that this was a survey, we are unable to clarify the exact meaning of this word by respondents, though could speculate. Please let us know if you would like us to speculate and elaborate further.

Support(s) could mean a number of things: consult/advice/guidance from a patient engagement expert, peer-to-peer support, facilitator, etc.

The term “modalities” has been updated to “approaches” (see abstract) throughout

It would be helpful to say more about ‘patient directed’ research. It is insufficient to simply refer to patients doing ‘final decision making’. This part of the paper suggested to me that the authors were not very familiar with the literature and debates around involvement/codesign and patient-led research.

We appreciate your comment. While we appreciate the critical importance of patient-directed research and the wealth of research in this area, we cannot fully elaborate on one aspect of the IAP2 spectrum without elaborating on all aspects. Furthermore, given that our purpose was to gain a concrete understanding of the landscape of patient and public engagement from the perspective of health researchers within the province – and our findings suggesting that very few researchers are engaging at the patient-directed level – expanding on this area is not a central focus of this paper. However, this is certainly a further area of study that could be explored in a subsequent project which explores the experiences of health researchers and patient/public partners engaging in patient-directed engagement.

We have updated our brief definition of “patient-directed” (see page 6, line 23-24) from merely having final decision-making power to actively controlling, direct and managing the entire research process.

I was puzzled by the power calculation. I'm not convinced that this was necessary or appropriate. If it was, it needed better explanation. If there was a hypothesis informing the power calculation, this was unclear.
Thank you for your comment. The power calculation was informed by a published piece of work (referenced in the section outlining the power calculation), which indicates the minimum number of respondents needed to be confident in our results and reduce the margin of error. Although sample calculations are not required or appropriate in qualitative research, the survey based quantitative approach used a power calculation to: (1) set our target sample size before sending out the survey, (2) to help determine the smallest sample size that is suitable to detect effects and run statistical tests, (3) reduce type II error, and (4) to ensure that we were getting useful information from enough people for the study to be useful.

7) The point about PPI being used most by mid-career researchers doing mixed methods research was really interesting. Those who use mixed methods often explore both what and why/how questions. It seems likely to be no coincidence that mixed methods researchers value and practice PPI in research. This could usefully be explored a little, explicitly, in this paper.

Thank you for your reflections. Yes, we completely agree that this finding was not surprising given the approach and values of mixed-methods researchers. Given that this finding was not statistically significant, we did not want to place much weight on these findings, but rather highlight the general trend. We have included wording as suggested which now reads as: “Again, the findings suggest that the majority of those who had engaged were mid-career researchers conducting mixed-methods research, a trend which has been reported previously (21) and is not surprising given the emphasis on both the what and how/why among mixed-methods researchers.” (page 23 lines 1-4)

8) This study (research subject) would be improved by a full commitment to a mixed methods approach and asking a broader, more holistic range of related questions.

Thank you for your comment. While we completely agree with taking a mixed-methods approach, the overarching purpose of this particular study was to explore the general landscape of patient and public engagement from the perspective of health researchers, including the knowledge, experiences, perceptions and training needs, to support the development of appropriate responses to their needs. A mixed methods approach asking a broader and more holistic range of questions and that builds on this initial study is an area for future research that would certainly be helpful as we move forward.

Thank you for your thorough feedback.