Author’s response to reviews

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

Authors:

Leah Crockett (umcrocke@myumanitoba.ca)
Carolyn Shimmin (cshimmin@hsc.mb.ca)
Kristy Wittmeier (kwittmeir@hsc.mb.ca)
Kathryn Sibley (kathryn.sibley@umanitoba.ca)

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Author’s response to reviews:

Engaging Patients and the Public in Health Research: Experiences, Perceptions and Training Needs among Manitoba Health Researchers – 2nd Revision

Leah K Crockett, MSc; Carolyn Shimmin, MWS, BAJ; Kristy DM Wittmeier, PhD; Kathryn M Sibley, PhD

We would like to thank the Reviewers for their constructive comments and suggestions. We have endeavoured to respond to each comment below and make the necessary changes to the manuscript.

Reviewer report – 2nd requested revision

Mary Newburn (Reviewer 4): Major Revision

"I feel that this is the report of a survey of researchers about their PPI experiences that has a meeting with service users added in, but their two elements of the study are not well integrated. The language has been improved since version 1 but thee have not been the major revisions that I feel are required in order to produce a top quality article adding to the literature on PPI in research. Even for a local study, the findings do not really serve the subject and the values of PPI in depth.”
Thank you for providing additional suggestions to further strengthen this manuscript. We agree with your comment and recognize this as a limitation, which we’ve acknowledged within the paper. While we agree that this is not optimal engagement, our level of engagement is consistent with IAP2, a valid and incremental continuum of engagement that is prominently used within the context in which this study was based. Unfortunately, our paper was already in progress prior to the formation of our partnership group. The partnership committee here at our SPOR unit plays many roles and this study was just one small role in which they were interested in participating. Although their engagement occurred later in the study – at the interpretation phase – the partnership committee endorsed the project and findings, and therefore we feel confident with our findings, current SPOR Support unit activities, and future directions for our unit and the partnership committee. As such, the noted disjointment of their involvement is due to the fact that unfortunately they were not engaged from the very beginning of the project. However, as noted, their input helps us to ensure that (a) our current activities are in line with PPI values, and (b) potential future directions. Finally, as previously noted, this study was initiated at a time where nothing was known about researcher experiences, perceptions and subsequent training needs in the province. By producing data to support these aspects, we believe that this study allows us to enhance the quality of PPI in the province and better address the values of PPI.

Funded by the Canadian Institutes for Health Research, Canada’s Strategy for Patient Oriented Research (SPOR) was developed to bridge the gap between academic researchers and those active in PPI, a comment that you’ve made later on in this review. The SPOR initiative (which has SPOR Support units in each province and territory; Manitoba being one of them) have made inroads by funding this type of research, certain journals now have dedicated supplements, and specific funding calls related to PPI research now exist. However, there is still resistance because this requires a fundamental cultural shift for many. This is why we believe that it is so important to do these types of surveys to gain a baseline understanding of current practices, what is needed by our local researchers, and to align out mandate and efforts to fill those gaps. To date, each unit across Canada is trying to advance and fill the gaps, but we would argue that there is still a dearth of evidence in this area.

More detailed comments (not fully revised) are as follows:

(1) Main text

On the whole, I find the drafting clearer. The topic is important and the findings are of interest, but the paper still does not feel ready for publication. I have picked up on some issues including drafting points. There are more fundamental issues about consistency of argument and reporting across all sections of the paper.
I really appreciate the use of shorter, active sentences. However, additional copy editing would improve it further, eg

P6,l9-10 rephrase so as not to use requirements twice in one sentence.

This has been rephrased to: “However, there is ongoing concern that current efforts are often tokenistic [2] and aimed at fulfilling requirements for funding applications and journals, rather than placing a true value on the engagement of patients and the public in the research process.”

P6, 110-11 - the phrase 'meaningful, authentic and inclusive engagement' is a bit overblown. No adjectives are needed as 'the true value' has already been included.

As per above, these adjectives have been removed.

P6, 118-24 - I would suggest that you add something along the lines of: We decided in this study to use the International Association of Public Participation (IAP2) spectrum of engagement. This runs from… (NB - this framework is not much used in Europe - I see that only Italy appears to be a member https://www.iap2.org/page/membership) (No need to say 'internationally-recognised'.)

This is now stated as: “The International Association of Public Participation (IAP2) spectrum is used actively across Canada, Australia, New Zealand, Indonesia, Italy, Southern Africa and the USA to outline levels of engagement and promote best practices in patient and public engagement. The IAP2 spectrum ranges from….”

P6, l23 - You do not a) make explicit, nor b) say why you changed 'empowered' to patient-directed. As you say you are using the IAP2 framework, it would seem to be important to explain changing the language.

Although we use the term “patient-directed” here in our province as we feel that it is more explicit, we have updated it to “empower” within the paper to be consistent with the IAP2 framework.
This has been updated to “or”

P7, l1-2 - I'm not sure why 'authentic, meaningful and inclusive engagement' is used here. Unless the intended meaning of this adjectives is made explicit, it doesn't add clarity. (If you are just informing people about something, can this be exposed to a test of being 'authentic, meaningful and inclusive'? The point of the spectrum is about different levels of engagement. How do authenticity, meaningfulness and inclusivity relate to the spectrum?)

This has been updated to: “Engaging patients and the public at any level of the spectrum requires distinct knowledge, attitudes and skills, and may represent a new paradigm for some health researchers”

P9, l3-5 - I think referring to 'training' explicitly here, rather than 'strategies' would be clearer and therefore more helpful.

Strategies has been updated to “training”

P9, l10 - I think you need to add in 'Canada's Strategy for Patient Oriented Researcher (SPOR). NB - note the typo. The website says 'research' not 'researcher'. Saying something about the SPOR initiative, which I looked up online, would be helpful; might be more useful than quite so much detail on each of the team members. (Did you mean physical trauma or psychological trauma?)

The study design section has been updated to include a brief statement about Canada’s SPOR, fewer details about the study team, and incorporation of a short description about the patient and public engagement group to lead into their more detailed description later in the paper.

“An online cross-sectional survey was developed and distributed to health researchers in Manitoba, Canada using a multi-phase purposive sampling strategy. The study investigators are affiliated with Canada’s Strategy for Patient Oriented Researcher (SPOR), a national initiative between patients, researchers, healthcare providers and decision-makers to promote patient-oriented research, a better healthcare system, and better health outcomes. SPOR Support units exist across all provinces and territories. The study team, including Manitoba SPOR unit patient engagement and knowledge translation leads, and a clinician scientist, were involved in the conceptualization, design, analysis and interpretation phases of the study. Furthermore, a local patient and public engagement group was launched two years later, and therefore, was engaged in the data interpretation phase.”
Regarding the comment about trauma, taking a trauma-informed intersectional approach to PPI is unique to Manitoba/Manitoba has been at the forefront of this, which is spreading to other jurisdictions. For additional information, please see:

https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-017-2463-1

P11,110 - there is a typo in the new text.

The word “includes” has been added to the sentence:

“No changes were made to survey format or questions between phases, with the exception of an additional demographic question exploring respondents’ primary research “pillar”, a categorization system developed by the Canadian Institutes of Health Research (CIHR) that includes biomedical, clinical, population health, and health services research.”

P15, 15 - typo (should be 'Participants'…’)

Updated

P15, 17 - not accurate to say 'all participants overwhelmingly agreed'. Some interpretation would be helpful (later in the paper) as well as noting these positive survey responses.

The word “all” has been removed. Additional text is included in the discussion.

The following finding is important yet you don't really pick it up in the discussion:

- Fewer than half of respondents agreed that patients and the public are being meaningfully engaged in research (36.5%), while only 15.4% of respondents felt that financial reimbursement to researchers by funding agencies was sufficient. Furthermore, just over half of respondents felt their institutions valued engagement in research (51.9%).

- P16, 11-6 - the areas where researchers felt PPI was more problematic. Do you intend to explore this more fully in further research or address this in training? It's not clear how the various parts of the overall SPOR enterprise are being planned.
If the following is the main finding, more should be made of this in the conclusion. This cannot be addressed by training for researchers: 'The most frequently reported systemic barrier was related to insufficient funds and time allocation within grants to appropriately and meaningfully engage with patients and the public.'

Many caveats, doubts and barriers are reported. I would expect to see some analysis at some stage discussing 'ambivalence' or drawing on other literature to see whether these concerns and questions have been overcome by other researchers, or indeed whether PPI is less central to some kinds of research.

Note: Several paragraphs were added to the text to address the above noted statements.

P17, L7 - what is 'it'? I think you mean practice research. Is this research that is published? Are the PPI groups saying that different methodologies are important? (Such as Participatory Appraisal, perhaps?) The article includes lots of little glimpses, but some potentially highly valuable insights are not teased out and explored.

I believe that what there were trying to get at is that there are many “researchers” – or employees who evaluate their programs and services (ie. in community based organizations, healthcare settings etc) who may have more experience engaging, and thus, our definition of a health researcher (in future studies) should not be restricted to those who met our definition in the current study. To attempt to clarify this:

“Notably, they expressed that academic health sciences researchers are often those who struggle most with engaging throughout the research process compared to those who conduct practice-based, and often unpublished research “on the ground” in settings such as northern communities and community based organizations”

This is noted both in the discussion and limitation sections and as an area for future study. Furthermore, the mention of peer-based mentorship among individuals with more experience (often those who use participatory methods) is also mentioned in the discussion.

P19 & 20 suggest there is quite a gulf between (some) academic researchers and those who are active in PPI in research yet this analysis is not spelt out, nor what SPOR might do next.

Please see the initial paragraph following your first comment.
P20, l6-14 this is an interesting point, but there is so much already to draw together. If you need more words for analysis, perhaps this could be removed and looked at elsewhere.

This paragraph has been removed

P21, l9-11 - this sound vague. More precise summing up on specific issues would be better use of limited space/words.

The first paragraph has been shortened:

“Despite the growing practice of engaging patients and the public in health research, few studies have examined the attitudes, experiences, perceptions and training needs of health researchers. This study presents several key findings, information to guide the development of appropriate supports for engagement, and future research directions that will be required to advance patient and public engagement within the local context.”

P21, l12-14 - this would be clearer if shortened: The most salient theme emerging from this study was the considerable demand overwhelming support for more resources and supports to adequately equip provide health researchers with additional skills to meaningfully engage patients and the public in research their work. (The focus is absolutely not ‘their work’, it is all about public health services, surely.)

Updated to: “This study supports an overwhelming need for more resources and supports to adequately equip health researchers to engage patients and the public in research.”

P21, l20 - Is the following a helpful (priority) point to make? 'Many of the desired supports identified in this study were passive, one-on-one, or self-directed in nature, including the ability to consult with an expert for guidance or access to online resources.' The paper seems to lack a coherent argument and story arc.

Removed.
Plain English summary

On the whole, I find the summary clearer. I really appreciate the use of short active sentences. I question a few things:

Suggest: Understanding the experiences, views and education needs of health researchers can help inform the development of training strategies and resources.

This has been updated as suggested.

Authors said in feedback to reviewers that some amends they would wish to make were not possible because of word length limitations. In some places, phrasing could usefully be shortened, for example 'in the research process' can be shortened to 'in research', on some occasions, particularly soon after the longer phrase has been used. (2)

Thank you for your suggestion. We have attempted to shorten phrases where possible.

Suggest: Overall researchers recognized to some extent the importance of engaging patients and the public within the research process. Despite this, we generally found overall low levels of engagement with the public (for example: only "telling" the lay people about their research or asking for their opinion but not fully involving them in making decisions or influencing priorities). (1)

NB - I am puzzled by the inclusion of 'or asking for their opinion', above. I feel it needs further explanation in order to make sense, because it is a positive phrase unless it is qualified in some way. I have made a speculative suggestion, but is this correct?

This corresponds to the IAP2 levels of inform (telling) and consult (asking for their opinion). We’ve included “rather than having them as shared partners” following this statement.

I don't feel that 'Researchers expressed an overwhelming desire (emphasis added) for broad training and support' makes sense coming immediately after a statement that one of the barriers to PPI in research was researchers' (limited) 'motivation'. Would 'further training' be better than 'broad training'? Why 'broad'? Is any qualification of 'training' actually required?
It has been updated to “further training.” The statement “broad training” was first included because researchers indicated wanting training in every area that we asked.

You say: We also got feedback from a local patient research advisory group to help interpret the findings. I don't think you used the PPI group feedback to 'interpret' the findings, very explicitly. They provided an alternative perspective on some of these issues. You go on to say that the PPI group's views gave you further insight, but what insight? I don't see this reported explicitly anywhere.

This has been updated to:

“We also heard from a local patient research advisory group about their perspectives on the findings. Their comments gave us more insight into the study design and findings and suggested topics for future research.”

The further insight is outlined within the text.

I think one needs to 'fill' or 'address' gaps (in training) rather than 'meet' them.

Updated to “fill”

Abstract

The authors are now using 'patient and public engagement' throughout instead of using both engagement and involvement interchangeably or making a distinction between the two. This does not feel adequate in terms of acknowledging the existing literature and contributing something further to knowledge on PPI in research. It would feel more appropriate to use and explore both terms and how they are used and/or understood in Manitoba, as this is the specific setting of the study. As one of the other researchers has said, quoting definitions would be helpful. As there is a reference to research funders, and much is made of the requirement for PPI, actually spelling out what is expected would be helpful. I feel that the Background section of the abstract should explicitly refer to Manitoba (given the background information provided to reviewers). (3)
PPI is typically a term used in the UK. When we first started the study, we debated between the terms, as some existing research uses PPI, while others used patient and public engagement, and others used patient engagement. Patient and public engagement is the term that we use here in Manitoba, is predominant in North America, and is the term that is preferred by our patient engagement group. Furthermore, given that “involvement” is an IAP2 level, we choose to use patient and public engagement.

We agree about the importance of terminology in the field and the need to address this in the paper. However, we feel that perhaps the abstract is not the place for this. Instead, we have added it to the background section of the main text, clarifying that our definition is that of the Canadian Institutes of health research and noting that terminology varies. Given that a number of funders and journals have different requirements for what constitutes PPI and health researchers in Manitoba receive funding from a number of sources, we have not included this.

P4, l4 - the requirements for PPI are not requirements of 'journal publications' but simply of journals (or journal editors/editorial boards).

This has been updated to “journals”

P4,l6 - This study aimed to establish a baseline understanding of the experiences, perceptions and training needs of health researchers in engaging patients and the public in health research.

Suggestion, perhaps it would be better to say: This study aimed to establish a baseline understanding of the experiences and perceptions and training needs of health researchers in engaging patients and the public to inform their training needs in health research."

Thank you for your suggestion. As per the previous comment as well as this one, the phrase has been updated to:

“This study aimed to establish a baseline understanding of the experiences, perceptions and training needs of health researchers in engaging patients and the public in health research in the context of Manitoba”
That concludes the Reviewer's comments. These notes are to explain the numbered notes that Editors have inserted in the Reviewer's text.

(1) The phrase "in making decisions or influencing priorities" is suggested by the Editors, not the Reviewer. Like the Reviewer, we are making assumptions about what the authors may have meant.

Thank you for clarifying this. Here we are referring to the IAP2 levels of inform (telling them about your research) and consult (getting their opinion); however, at these levels, patients and the public don’t necessarily have shared decision making/not fully integrating them in the research.

(2) The Editors support this point. We are relaxed generally about word counts and some published papers have gone beyond our limits, particular where discussion sections have been very broad. We suggest that this paper may benefit from a fresh pair of eyes with the aim of eliminating repetition and unnecessary phrasing, thus reducing the overall word count and improving readability too, which would then allow the authors to explore some of the suggestions of this reviewer. NB We also endorse the Reviewer's opinion that the paper is a more readable version already, but we feel it can be improved further.

Thank you – we have attempted to amend the paper further to reduce repetition and enhance clarity.

(3) This is very necessary; in the UK and elsewhere funders have different requirements about using - and about demonstrating the use of - PPI, and some regard it as a conversation or process, others as an intervention or tool.

Thank you for your suggestion. We do recognize the importance of terminology both in the field of PPI, but also in knowledge translation. However, we feel that the abstract may not be the best place for this and have such, have instead made reference to this within the main text.

We recognise that presenting a review with editorial comments on the review is an unusual way of proceeding. Please be assured that this has been caused solely by circumstance. We share the Reviewer's opinion that the paper is of interest, but that it is not yet ready for publication. We look forward to receiving the next version in due course.

Thank you for considering our manuscript for your journal.