Author’s response to reviews

Title: Co-building a patient-oriented research curriculum in Canada

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Author’s response to reviews:

We very much appreciate the time and effort all reviewers put into reviewing and providing recommendations for this work. We think these suggestions have strengthened the manuscript and we are pleased with the result. Please see the responses to each reviewer comment below (which have been numbered).

Reviewer 1:

1. Comment: "In don’t think involvement and engagement are interchangeable words, while involvement may have a deeper and more meaningful contribution, allowing patients to actively participate across the different phases of a given Project, the term "engagement" usually stands (in practice) for having patients inputs but not necessarily taken into account to shape the final learnings."

Response: Thank you for this note. We completely agree that terms carry a wide range of meaning in both theory and practice. Within SPOR, the definition and intent for the term ‘patient engagement’ implies the in-depth, meaningful contribution as a partner, and this is specified in the manuscript. There is actually a whole section in the curriculum about defining patient engagement in the context patient-oriented research.

The point is well taken and a small note has been included at the end of the disclaimer (where it is indicated that the term PE can be used interchangeably with PPI for the purpose of this article) to
recognize that there are a range of understandings of what PE means.

Note: The terminology differs depending country and setting. For example, in the United Kingdom, patient and public involvement is used for active partnership between patients and the public and researchers in the research process, while in Canada the word ‘engagement’ is used to refer to active partnerships. In the UK context, ‘engagement’ refers to information and knowledge sharing about research. Participation is often referred to as taking part in a research study, for example people being recruited to take part in a clinical trial, while in the Netherlands patient participation in research refers to active partnership between patients and researchers.

2. Comment: "Everytime you mention "other stakeholders", specially at the beginning of the article, it is not clear to me the range or scope, who and what for may be useful to understand better from the beginning and align expetations."

Response: Much appreciated. All instances where the term ‘other stakeholders’ was mentioned was either clarified or removed. In many cases, the term ‘relevant stakeholders’ is used and is defined within the document as including researchers, patients, health care professionals and policy makers (that is, health system administrators, decision-makers, etc.).

Reviewer 2:

3. Comment: "Page 4, Line 58
Add a citation to the sentence: "Furthermore, researchers and patients should learn together"."

Response: This has been completed; citation [7] was inserted at the end of this sentence.

The first few lines of this page discuss the benefits of training for patient partners. Is there any literature that you can include here that reports the benefits of training for researchers?"

Response: Good point. There is limited literature that specifically reports benefits for researchers. However, we have included a few benefits for researchers and included citations.

5. Comment: "Page 5, Line 10
Add a citation to the sentences: "Training needs reported by researchers..." and "Learning needs of patients include..."

Response: This has been completed; citation [11] was inserted at the end of this sentences.

6. Comment: "Page 6, Line 40
Please clarify: Did the themes identified through the two focus groups (as described on page 8) lead to the development of the learning outcomes? It is not clear to me how the focus groups related to the content of the modules."

Response: Author response: Thank you for this comment. The focus group sessions were post mortem discussions following the conclusion of the curriculum development and pilot process. These discussions produced key themes to inform this research article and were not part of the curriculum development or piloting process.
The focus group was comprised of individuals who had previously participated in various roles during the development and pilot of the curriculum. Some of the focus group members were developers who had also participated in the early stages of conceptualizing and creating the learning outcomes. There were also focus group members who participated as facilitators or patient co-facilitators.

The updated “Sample and recruitment” section in the Methods section better summarizes these points.

7. Comment: Page 6, Line 56
In the last paragraph, you mention "17 different locations". Were these locations spread across Canada? Might be worth including this information here."

Response: We have included the phrasing "spread across Canada" to the sentence in question.

8. Comment: "Page 7, Line 6
Please revise the following sentence to include the word "the" as follows: "... but it should be noted that THE ratio..."

Response: Thanks for this. This edit has been made to the sentence in question.

If possible, please include the surveys mentioned here in the additional files."

Response: Great suggestion. We have added these documents as Additional file 3 and made reference to this supplementary material in the sentence in question.

10. Comment: "Page 7, Line 20
For this paragraph, please insert a fraction (in brackets) next to the corresponding percentage to show the total number of surveys this is based on."

Response: This has been done for the three percentages given in this paragraph.

11. Comment: "Page 9, Line 17
Please change the following sentence to include the word "be": "...also something that could not BE predicted..."

Response: Thank you for catching this. This edit has been made.

12. Comment: "Page 9, Line 21
Consider placing all verbatim quotes in the results section into a table"

Response: We appreciate this suggestion. However, after looking at these specific ‘highlight quotes’ in table format, we felt that this disrupts the flow and creates a redundancy with the main results table (Table 2). For this reason, we have left these highlight quotes integrated within the narrative part of this section.

Were healthcare providers and decision-makers/policy-makers represented at the Train-the-Trainer session? It may be worth discussing how this affected uptake and buy-in among these stakeholder groups. Or perhaps this is a limitation to be addressed by future POR curriculum."
Response: Individuals with these backgrounds were present at the Train The Trainer session, although their primary role was typically a staff member in some training capacity within their SUPPORT Unit or Network, or as a patient within the SUPPORT Unit jurisdiction or Network community.

This said, further upstream in the development process, health care professionals and decision-makers were part of both the original reference group and the consensus building workshop (to establish the curriculum learning outcomes). We have tried to make this more explicit in the Introduction on page 5, paragraph 2.

Unfortunately, the affect of the specific presence of any stakeholder group in stages of the development process was not discussed explicitly during the focus group sessions, and thus was not included in the Results.

The conclusions are not aligned with the objectives stated in the Methods section. The conclusion refers to the evaluation and demonstrated feasibility, while the objectives were to describe the process and explore the experience. Please revise to ensure clarity and consistency."

Response: Thanks for raising this point. We have clarified this opening sentence in the Conclusion to: “The perspectives brought forward from this study suggest that the Foundations development process has demonstrated the feasibility and added value of co-developing and piloting a curriculum in PE and POR on a national level.”

Reviewer 3:

15. Comment: "The introduction is perhaps a bit lengthy and I wonder if there is a way to make it more concise. Would it make sense to put more of the development of curriculum section in with the additional files perhaps?"

Response: We appreciate this suggestion. We state in the Methods section that the curriculum development process is the key 'object' being studied in this paper, and we feel strongly that the information about this development process is crucial to understand and to be able to reference back to while reading the full text. For this reason, we prefer to keep this section intact within the main body of the manuscript.

Reviewer 4:

16. Comment: "While the Foundations process was clearly strong on involving patients in design, delivery and refinement of the curriculum it is not clear if the demand or need for the training was identified by professionals on patients' behalf.

The rationale for developing the training is described but as stated above does not discuss to what extent there was any "bottom up" patient/service-led demand if any, and if there was how this was expressed or channelled."

Response: We are thankful this observation. We’ve made the following edit on page 5, paragraph 1 to clarify this point: “In the early stages of SPOR, both researcher and patient communities directly expressed a clear need for training on PE. This was a recurrent gap that was voiced at various meetings,
including a national workshop to develop the SPOR Patient Engagement Framework [14].”

17. Comment: "I would have liked more detail on the process for recruiting the advisory reference group - were patients recruited already involved/co-opted or was the call put out more widely?"

Response: Thank you for noting this. We have updated page 5 paragraph 1 to clarify how recruitment was completed for the original reference group for the curriculum.

18. Comment: "The discussion section highlights the aim for Foundations to dovetail into "further training or real-world POR opportunities through SPOR SUPPORT Units or SPOR Networks" but no timescale is given for this, or examples of if this has happened. If the timescale since the pilots were run and evaluated is too soon to say the authors should state this, and say that such further training and opportunities are still an aspiration at this stage."

Response: This is a great observation. We have added a paragraph a new paragraph in the Discussion section (page 18, paragraph 5) to describe this statement in better detail.

19. Comment: "The conclusion section highlights that the initiative has "built capacity for POR" but as above does not state if this has been quantified in any way or harnessed yet."

Response: This phrase and the rest of the sentence is referring to the increase in knowledge and skills as well as the change in understanding that occurred within the study participants as a result of undertaking the co-development process. The aim of the study was not to quantify the capacity change within the individuals, but to explore their experiences and perceptions of the process. We have added a new paragraph in the Discussion to describe how the curriculum has been leveraged for further training and real-world research opportunities. We also state in the Introduction that 26 facilitators were trained through the national train-the-trainer workshop during the process.

20. Comment: "Although laypeople/patients/public are thanked and acknowledged there were none as co-authors, so a paper written exclusively by professionals and practitioners. While a patient/public co-author would not be necessary in itself, or for its own sake, the lack of lay co-authors is at odds with the genuine co-production and close collaboration with patients/public in the rest of the initiative."

Response: Thank you for raising this since it is a critical aspect of this manuscript. Multiple patients were co-authors of this document; this was not originally explicitly stated in the article, but rather in the GRIPP2 long form.

An explicit note to this effect has been added in the Methods section under ‘Reporting’. We’ve also included the GRIPP2 long form as an additional file.

Associate Editor Feedback:

21. Comment: "Page 9 Line 49 is not clear: “The constant comparison method was used to inductively develop themes from of the transcript [22].”"

Response: Much appreciated feedback. There was an extra ‘of’ in the original sentence, which has been removed. Some clarifying edits have been added throughout this paragraph to improve clarity and add more detail about the process.
22. Comment: "I agree with reviewer 4 that detail about recruitment of participants is needed."

Response: In response to reviewer feedback item #17 above, we better described the recruitment of the initial reference group in the Introduction.

It was not clear from this comment whether the reviewer may also be asking about participant recruitment for this study, so we have also added a clarification for this in the Methods section under ‘Sample and recruitment’.

23. Comment: "There is also a lack of methodological detail regarding how the coding was applied to the data."

Response: Thanks for raising this. More detail has been added to the sixth paragraph of the Methods section.

24. Comment: "In reporting the results it would be good practice to include unique identifiers with quotes, e.g. “Participant E (Patient Co-facilitator)”"

Response: Great suggestion. This has been updated throughout the Results section. Note that we have also shuffled the original letter-assignments for each study participant in Table 1 (this is because the original lettering followed the exact order of authors on this paper). The new lettering makes it less possible to predict who may have said what comment.

25. Comment: "PPI: Patient and Public Engagement” needs correcting to Patient and Public Involvement."

Response: Thanks. Edit made.