Author's response to reviews

Title: Moving Towards a More Inclusive Patient and Public Involvement in Health Research Paradigm: The Incorporation of a Trauma-Informed Intersectional Analysis

Authors:

Carolyn Shimmin (cshimmin@exchange.hsc.mb.ca)
Kristy Wittmeier (kwittmeier@exchange.hsc.mb.ca)
Josée Lavoie (Josee.Lavoie@umanitoba.ca)
Evan Wicklund (EWicklund@disabilitystudies.ca)
Kathryn Sibley (Kathryn.Sibley@umanitoba.ca)

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We would like to thank the Reviewers for their constructive comments and suggestions. We have responded to each comment below and made the necessary changes to the manuscript. Changes to the manuscript text have been noted in the paper in yellow highlight.

Reviewer #1: To the authors, I want to start by saying that I am proponent of patient engagement and appreciate your proposed re-framing as public involvement in health research. I am starting here because, while there are aspects of your manuscript that I think are worthy of further discussion, I want to be clear that I find this work to be worthy of publication. This contribution is well written and, more importantly, may serve to extend the range of discussion and considerations when it comes to the implementation of patient engagement in health research.

I had two initial responses upon reading this manuscript. (1) This is terrific and important. The other, which occurred simultaneously was, (2) I know very few people who are ready to incorporate trauma-informed intersectional thinking into patient engagement efforts; we are still building a case for patient engagement and continue to circle the outstanding question of how to measure impacts empirically.

Authors’ Response: Thank you so much for your feedback. We definitely understand and agree that incorporating a trauma-informed intersectional analysis to public involvement approaches may challenge some, even many, health researchers. Upon this suggestion, we have added a
sentence on page 7 highlighted in yellow to recognize this. Acknowledging this challenge, we would argue that this is, in fact, the most auspicious moment — as we “build a case for patient engagement” — to incorporate a trauma-informed intersectional analysis in order to ensure: that the conceptualization, practice and evaluation of public involvement in health research is wholly inclusive, allowing spaces and opportunities for voices traditionally less heard in research, and that it doesn’t continue to privilege the more dominant voices and discourses.

We agree with your thoughts about building the case for patient and public involvement, and as we continue to “circle the outstanding question of how to measure impacts empirically”, we believe the questions in Table 5 around evaluation are quite relevant and need to be addressed, as impact with regard to patient and public engagement can be seen as three fold: 1) impact on the research outcomes; 2) impact on the researchers themselves; and 3) impact on public research partners. This will require looking at a number of items that are presently missing from patient and public engagement evaluation frameworks but which we propose in this paper such as: 1) how conflict between researchers and public research partners is addressed (we would argue that conflict is actually something to be valued as it demonstrates that different perspectives and lived experiences are being given space and respect); 2) how often there were opportunities to challenge ideas and renegotiate power imbalances within research teams (seeing the renegotiation of power imbalances as a valuable process for both researchers and public research partners); 3) how we came to decide upon participatory approaches that do not further re-traumatize, actively working to address historical and present-day trauma; 5) how we work to actively dismantle cultural stereotypes and biases; and 6) how we worked to leverage the healing value of traditional cultural connections.

Reviewer #1: Having said that, I have several colleagues who I think would find the perspective you offer useful and I look forward to this work taking a form that can be shared.

I find this work admirable and appreciate that you are in an environment that supports thinking about the patient engagement in health research as "a matter of health equity and social justice" and is able to address the considerations associated with participation of First Nations and indigenous populations. Again, this strikes me as forward thinking and reaching in an important direction. I want these ideas to be incorporated in the literature on patient engagement. I also want to push you to think about two things: the proposed disruption of the patient and researcher identities, and the role of incrementalism in paradigm shift.

First, I am not sure that disruption of the patient / researcher identities is the goal. Rather, each role as distinct and as conventionally defined is valuable. I personally struggle with the effort to train "patients" to be "researchers" problematic. In part this is because a strength and value of the public involvement lies in the viewpoint not indoctrinated into a research way of thinking.

Authors’ Response: Thank you again for this feedback. We definitely agree with you that one of the strengths and values of public involvement “lies in the viewpoint not indoctrinated into a research way of thinking.” We see the focus of this paper as looking at the myriad of intersecting social locations in which we inhabit that are part of identity formation — of both public research partners and researchers — as opposed to roles (see page 2 of the manuscript). We argue that the
way in which the patient identity is “conventionally defined” is problematic, as it is through a normative and dominant lens (i.e. white, hetero, middle/upper class, able-bodied, well-educated) and in turn, excludes voices traditionally less heard. In incorporating an intersectional analysis, looking at the complex interplay between identity formation and systems of power and oppression, we can begin to disrupt the conceptualization of the identity of “patient” as simply a homogenous group, acknowledging the reality that individuals’ economic, political, cultural, subjective and experiential lives intersect in intricate and multifarious ways. In advocating for discursive and embodied reflexivity, we also call for disruption of the identity of researcher as an objective entity, and call for the acknowledgement that researchers, too, inhabit many different social locations which has an impact on partnership building with public research partners.

Reviewer #1: I do agree that reflexivity is a useful and meaningful path the understanding the dynamics involved in these collaborations. It is also often overlooked or unacknowledged that researchers are also patients, at least some of the time.

Second, at this time I feel entrenched in the pragmatics of the process involved in patient engagement and, quite frankly, I am not sure if either the engaged patient participants or the researchers would see the relevance of several proposed questions. Again, it is not that I think these are unimportant questions to consider, but rather, I invite you to think about how relevance may vary in different settings and the importance of applicability and priority. Are there incremental steps that you can see that might help move both researchers and engaged members of the public (patients) in the direction of the paradigm you propose?

Authors’ Response: Thank you again for this feedback. This is an important question. We acknowledge that currently in the pragmatic realm of patient/public engagement in health research, the focus is on the practical utilization and evaluation of participatory approaches to involve voices of lived experience in health research decision-making. What we argue in this paper is that in order to ensure that the practical aspects of participatory approaches lead to more inclusive, meaningful and authentic involvement then it is integral to incorporate questions at the beginning of any patient/public engagement endeavour that: 1) challenge both researchers and public partners to think about the numerous intersecting social locations in which they inhabit and how that might affect the way they perceive the research topic; b) make the research team explore how both geographical and systemic barriers (systems of power and oppression) may affect access to health care services and experiences of health care, and hence ensuring that participatory approaches include ALL these different perspectives; and c) have the research team thinking about the impact of trauma on health and how to create safe spaces for all voices to be heard. So by ensuring the pragmatics of participatory approaches in patient/public engagement also includes a trauma-informed lens and critical reflexive practice (by way of the questions we outline), then we can arm research teams with skills and abilities to open spaces and opportunities for resistance and renegotiation of power imbalances and create spaces where diverse perspectives feel safe to engage with researchers.

We definitely agree though, that some, even many, research teams (including public research partners) may feel more comfortable in taking incremental steps towards the incorporation of a trauma-informed intersectional analysis. We have added a sentence and highlighted it in yellow on pg. 7. to recognize this and also let readers know that the tables of questions build one upon
the other: from beginning with a more general research team exercise encouraging discursive reflection (pg. 8), to questions around framing and prioritizing the research question (pg. 11), to understanding different populations affected (pg. 11), to deciding on the engagement strategy (pg. 12), and evaluation of public involvement in health research (pg. 13). We encourage researchers and public research partners who may find it challenging to incorporate all, to perhaps begin with the general reflexive practice, and then depending on level of comfort and phase/stage of research, to gradually incorporate one at a time. Excitingly, and this may further address the reviewer’s question, we are currently in the process of validating the framework with people who represent voices traditionally less heard in health research and in the future, intend to validate the framework with health researchers as well.

Small bits: I did not know what the "60s scoop" references, so for non-Canadian readers this seems an important reference to make understood.

Authors’ Response: Thank you for pointing this out. We have added a description on page 6 which we have highlighted in yellow.

Thank you for the opportunity to review your work.

Reviewer #2: Comments to the Author

This is an excellent and thoughtful paper that can advance the current dialogue on patient/public engagement, particularly in a North American context. I think the paper can be published as it stands. One area where I would have liked to see some more discussion (no doubt influenced by my own research interests) would be to dig into the differences between patient and public (or citizen) engagement. There is a passing reference to this on page 4, but no significant discussion of work taking a public engagement framing. There is probably enough here for an entirely different paper, but for example: what would intersectionality look like within models of engagement such as Citizens Juries, which have been used more extensively in Australia? Is the invocation of the "citizen" itself problematic given colonial histories and ongoing violence/discrimination against indigenous peoples, or could it function restoratively? Also, models of public engagement often think about the role of lived experience differently than patient engagement, and both consider membership in collectivities, but perhaps in different ways. Are the techniques listed in the tables (which are potentially very helpful to readers, I think) the same for "public engagement," or are they slightly different? The authors seem familiar with the relevant literature which would make it relatively easy to comment on some of these issues.

Authors’ Response: Thank you for your feedback. This is an interesting question, and though a fulsome analysis of the difference between patient and public engagement and the incorporation of a trauma-informed intersectional analysis may go beyond the scope of this paper, we propose that the way in which we have laid out the argument on pg. 3 that: there is a need to look at the complex interplay between systems of power and formation of identity of ‘patient partners’; as well as the movement towards the utilization of “public involvement” versus “patient engagement”; point to the idea that by disrupting the identity of “patient,” means that we are
looking at lived experiences of health of families, friends, informal caregiver, communities and public. Therefore, like the reviewer suggests, we believe the questions outlined on pages 8, 9, 11, 12, and 13, could very easily be adapted for use in the engagement of the general public in health research and we have added a sentence recognizing this on pg. 7 highlighted in yellow.

We believe that whether the chosen participatory approach to the engagement of the public is Citizen Juries, World Cafés or Revolving Conversations, research teams, including public research partners, can always use the general discursive reflection questions (pg. 8) at the beginning of a participatory activity, or they may want to delve into the questions around the framing and prioritizing of the research question (pg. 11) and understanding different populations affected (pg.11). Or perhaps before choosing the participatory approach, the research team (including members of the public) could go through the deciding on the engagement strategy questions (pg. 12) or the team may commit to using the evaluation questions on pg. 13 following the participatory approach. As suggested by the reviewer, we believe that the tables of questions can easily be integrated into participatory approaches that aim to engage the larger general public in health research, and in fact, will make them far more inclusive and representative of the diverse perspectives that make up the general public by opening up spaces that are safe, allowing for differing ideas, and enabling the resistance and renegotiation of power.