Author’s response to reviews

Title: Patient and Public Engagement in Integrated Knowledge Translation Research: Are we there yet?

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Author’s response to reviews:

Response to reviewers

Thank you for the constructive and detailed comments provided by the reviewers. These have been very useful as we have worked to strengthen this paper, I am confident that that manuscript is better because of this feedback. Many thanks, Davina and team.

Reviewer 1:

This is an interesting area of work but the case for patient involvement, inclusion and at what level is not strongly made and should be evidenced from the literature. There is stronger supporting evidence and some of it is already in the reference list just not always considered in the right places or contexts

Thank you, we have added further descriptions of key studies to strengthen the messages around patient and public engagement.
There are other reviews and papers, in the area of public and patient involvement worthy of mention, such as the work of Sophie Staniszewska (Warwick UK) and Ocloo (Kings College London, UK) (e.g. Ocloo, J., & Matthews, R. (2016). From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. BMJ Qual Saf, bmjqs-2015.). Also, the UK and European patient voice in research campaign 'No research about me without me' could have been mentioned.

The World Health Organisation also considers that patient involvement is important, and could have been mentioned as part of the justification (World Health Organisation (2006) Ninth futures forum on health systems governance and public participation. http://www.euro.who.int/document/e89766.pdf)

Thank you for these suggestions. We have reviewed and included these important sources in our manuscript. We have also included statements about the WHO recommendations and ‘nothing without me’ movement.

As with many areas of health care, public involvement has its own taxonomy and country specific terminology; this could have been mentioned with explanation early in the paper.

This is addressed in the opening section of the paper and revisited in the later section on patient engagement.

Arguments for the benefits of service user / patient involvement are made but these are not always clearly stated or substantiated. There are important points to be made and some which need clarification, much of the literature to support this is in the reference list but not always clearly articulated or cited in the text. I think this paper should be reworked to be a stronger and more succinct, synthesis of the evidence of the benefits of service user involvement.

Thank you for this valuable feedback. We have addressed this and worked to ensure that key evidence is leveraged in our discussions around the benefits of patient and public engagement.

Thank you very much for your comments. These were very helpful in enabling us to advance the quality of our manuscript.

Reviewer 2:

RIE is an international journal with an international readership, and the issues raised are relevant internationally, but at the moment the focus appears too narrowly on the issues in a Canadian context. Specifically, the authors focus on patient engagement and IKT, which is a Canadian
conceptualisation of the more general issue of how to have more effective research translation into policy and practice. The authors briefly mention on p 7 that IKT is only one of a 'plethora' of approaches to the issue globally, but then only focus on IKT and do not consider what the implications of their thinking are for KT in other global contexts.

Thank you, this is a very valid and important comment. In order to address this, we have strengthened our descriptions of IKT and how this relates to other collaborative research approaches internationally. That being said, our paper specifically addresses IKT as a distinct approach and we have stated this more clearly in the opening section and later in the manuscript.

I think the discussion on p 7 needs to be expanded to contextualize IKT more fully, and then the international implications of their conceptual linkage of patient engagement and IKT needs to be more fully explored in the later discussion and conclusions.

As per the comment above, we have now addressed this at multiple points in the paper.

The terminological and conceptual challenges of the term 'patient engagement' (and related terms like involvement and participation) are not addressed until the bottom of p 12 whilst the term is used unproblematically before then. Who counts as a 'patient' and what about members of the public who are not now patients but are potential patients, or carers of patients? I think there needs to be a much earlier definition of terms and discussion of the conceptual challenges, not least because the term 'engagement' has very different meanings in different international contexts.

Thank you for this valuable feedback. We have revised the earlier sections to ensure that these terminological and conceptual challenges are highlighted and addressed.

It is clear from the paper that in practice, patients have not usually been treated as one of the key stakeholder/knowledge users in IKT. This is of course one of the issues the authors are trying to address but the handling of this issue is awkward. In the definition of IKT on patients (but not the wider public) are listed as one of the groups of knowledge users, but later in the paper the phrase 'knowledge users and patients' appears, suggesting implicitly that the latter are not included in the category 'knowledge users'.

We have clarified the terminology around patient and public engagement, as previously mentioned. Furthermore, we have clarified that the term ‘knowledge user’ is an inclusive term. As per the IKT approach, this may include patients, members of the public, family members, friends, caregivers and community organizations.
Then in considering where patient engagement is in IKT, the authors report how poorly patient engagement is in practice, and use a new term 'community members' which has not been previously used. Not only does this again raise definitional issues, but this also raises the question of how extensive or real any philosophical commitment to patient/public engagement really exists in IKT at all.

Thank you for these suggestions, we have revised our manuscript to use more consistent language and have further clarified our messages about the gaps and opportunities for patient engagement within IKT research.

On p 17 it is stated that IKT is conceptually designed to address the power imbalances between patients and researchers/professionals through a commitment to co-leadership and co-production, but this does not seem to be the case at all from the evidence the authors themselves have just cited above. I would like to see a more robust assessment of whether there is any meaningful commitment to co-production/addressing power imbalances in the IKT approach.

In this paper, we begin to examine contrast the theoretical linkages and tensions that exist between IKT and patient engagement. We have strengthened our arguments about the gaps and opportunities that exist, as well as providing a more wholesome discussion of power and diversity. We hope you will find that this is much clearer in the current version.

The discussion of representation seems very dated and professionally focused. In my experience patient/public contributors never claim to represent others; they are there to give an alternative lived experience perspective. It is professionals who worry about representativeness, and often as a device to delegitimize patient perspectives. I think a much more nuanced discussion is needed here.

Thank you very much for this important point. We agree with this comment and have reworked our section to include a more nuanced and up-to-date overview of issues related to representation, diversity and legitimacy. This comment was particularly helpful and I believe it has really added to the messaging in our manuscript.

Need to double check use of abbreviations/acronyms. Some are used before being define, e.g. KT used on p 4.

Thank you for this, we have addressed this in our revised manuscript.

Some specific points/quotes end with a citation of multiple sources, making it unclear which the specific source is.
Thank you, we have addressed these.

Page 13 - what is meant by 'engagement of patient engagement'?

Apologies, this was a typographical error. We have fixed this.

Best to avoid 'it could be argued' (p 15) and 'This may be' (p 19) - anything could be or may be - need to be more definitive in what you are claiming.

Thank you for this comment, we have edited the manuscript to ensure more definitive lines of argument, as well as ensuring greater clarity for content where there is less certainty.

'Equitable' has several possible meanings, and not clear what you mean on p 16 and later when you refer to 'equitable partners'. Do you mean 'fair' or 'equal' or something else. Certainly, researchers and patients are never equal in terms of the power/voice they have in decisions.

Thank you very much for this feedback. Upon reflection, we can see the challenge with this kind of language and have adapted this accordingly.

Thank you very much for your constructive and useful comments.

Reviewer 3:

What about the involvement of patients organizations? it would be relevant specially for very young patients or patients with vital prognosis who cannot be involved in research.

Thank you for this comment, we have included a section which speaks to the special role that patient organizations may have within IKT research, particularly for populations that may face multiple barriers to engagement.

page 5, line 27: those impacted by the research, does it include family?

We have clarified our terminology to reflect the wider meanings of patient engagement.
page 6 IKT Research: I would add the empowerment of patients and the willingness of patients organizations to be involved in all discussions "nothing about us without us"

Thank you, we have addressed this in our manuscript.

page 23, lines 4 to 48: the conclusion should end on a topic which would be more linked to the content of the article

We have revised the conclusion section to provide a clearer overview of the key messages of the paper.

Add difficulties to get the point and to clearly understand the outcome of the article

We have edited the paper to develop clearer lines of argument.

Thank you very much for your comments.

FROM THE CO-EDITORS-IN-CHIEF:

This is an interesting discussion piece but we have some concerns that much of the discussion is not based on cited evidence, given the number of generalizations in the paper. For example, on the second page the author states there is 'growing awareness of the need to include patients within research' but this is not substantiated, and we suggest that this "awareness" may not replicate across all nations, all funders and all researchers? The next sentence 'These collaborative and patient-orientated research approaches...' begs for further detail which is not forthcoming, here or later in the paper. Are collaborative and patient-oriented the same things; can one have the latter without the former?

Thank you for this feedback. We have clarified the tensions and relationships further in the revised paper to produce a clearer message.

There is a very good list of references for the paper, and perhaps the manuscript needs closer linkage rather than more references, but nevertheless our feeling is that the paper needs major reworking to ensure the reader understands the background, context and potential benefits of patient/carer/service-user involvement, and that in particular, that the context is clearly defined - if it is specifically Canadian we can accept that, but it needs to be stated early on (and probably restated later too).
Thank you, we have addressed this in our revised version by clarifying key concepts and anchoring our discussions more specifically within the evidence-base for both IKT and Patient engagement. We have further addressed the Canadian specific nature of IKT but have made links to how this may resonate with international models of patient engagement and collaborative research.

Many thanks,

Davina