PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Patient, caregiver and other knowledge user engagement in consensus-building healthcare initiatives: a scoping review protocol
AUTHORS	Munce, Sarah; Wong, Elliott; Luong, Dorothy; Rao, Justin; Cunningham, Jessie; Bailey, Katherine; John, Tomisin; Barber, Claire; Batthish, Michelle; Chambers, Kyle; Cleverley, Kristin; Crabtree, Marilyn; Diaz, Sanober; Dimitropoulos, Gina; Gorter, Jan Willem; Grahovac, Danijela; Grimes, Ruth; Guttman, Beverly; Hébert, Michèle L.; Henze, Megan; Higgins, Amanda; Khodyakov, Dmitry; Li, Elaine; Lo, Lisha; Macgregor, Laura; Mooney, Sarah; Severino, Samadhi Mora; Mukerji, Geetha; Penner, Melanie; Pidduck, Jacklynn; Shulman, Rayzel; Stromquist, Lisa; Trbovich, Patricia; Wan, Michelle; Williams, Laura; Yates, Darryl; Toulany, Alene

VERSION 1 – REVIEW

REVIEWER	Caroline Sanders University of Northern British Columbia, School of Nursing
REVIEW RETURNED	20-Nov-2023

GENERAL COMMENTS	This article presents a scoping review protocol on approaches to engaging knowledge users in consensus building healthcare initiatives. The proposed review will be a valuable contribution to the research field on knowledge user engagement and integrated knowledge translation. Overall, this is a well-designed scoping review protocol. Upon review I recommend acceptance with some suggestions for minor revisions. Comments to the Authors: Introduction - Pg 3 line 34-37: As a reader this sentence defining knowledge users is confusing. I expect the authors are trying to say that knowledge users include patients and caregivers but is not limited to just them and also includes clinicians, decision makers etc. I feel it would be clearer to describe that Knowledge Users are any individual who is able to use research findings to make decisions and then list examples of who. This is done later on in the article and is clearer so would recommend that here as well. - Pg 3 General question. Researchers and knowledge users, does this also have space for the work within a quality assurance framework, that can inform decisions and change, you note quality care (since QA can lead to changes within the quality cycle – that may not be primarily research drives?). - Pg 3-4 Question - If a critical aspect of high-quality decisions that supports positive outcomes, is inclusive, responsive, and timely is consensus decision-making, evidence of new power within a

	framework of change? What I am asking is whether, through consensus, there is a shift in power, and if this needs to be considered considering the limited evidence of the 'how' to implement and evaluate engagement, and it is 'new power'? Methods - The proposed methods for this scoping review are comprehensive and align with standardized approaches for scoping reviews. - The authors highlight that knowledge user engagement throughout the design and conduct of the review is a strength. Within the Methods under patient & public involvement, it would be helpful to identify how knowledge users have been identified (recruited) to participate in the panel with the research team. Is this through an existing iKT panel? Are they receiving compensation/honorarium as partners? What training and support will they receive to foster meaningful engagement in this work as collaborators? It is also unclear within the protocol if and how knowledge users have been engaged in the development – what is their role in this protocol? - The authors provide sufficient detail on the search of academic literature; however, there is a limited description of how the grey literature search will be conducted. Will the authors conduct targeted searches of websites for health organizations, quality networks, patient networks, etc. (e.g., https://patientvoicesbc.ca/) or just google scholar? Given that the authors state there is no established framework for systematically searching the grey literature on patient engagement in consensus-building approaches as a limitation, it would be helpful to identify how they intend to go about it and to document this process to assist those who may be undertaking similar work in the future. - For study selection, it would be helpful to clarify how the pilot test numbers for the screening form use were determined. For level 1 it says approximately 100 articles and then Level 2 says 1%. It may be more appropriate to use a proportion for both. Also is 1% sufficient for piloting at level 2? - With the large team how will agreement be reached and the responsibilities divided? - In the table I was curious if there would be a secondary follow up to support the position of evaluation, for example if the user engagement resulted in a tangible outcome – is the duration and impact level of the outcome being reported / is there any opportunity to reconnect with the primary source to determine if this was sustained or amplified or lost since the publication? It is a bigger ask outside of the review (maybe) but its such an interesting perspective when, as a reader, I sit in a place of clinical, knowledge user involved in work in such areas and researcher. Additional minor edits: - Please spell out the word "and" throughout the article rather than using the & symbol in the body text. - Typo on pg 2, line 22 – two words are combined, should say "or is"

REVIEWER	Jan van der Scheer THIS Institute - University of Cambridge
REVIEW RETURNED	15-Dec-2023

GENERAL COMMENTS	Thank you for the opportunity to review this protocol. I applaud and am excited to read how the authors aim to advance these important methodological areas around engagement and consensus-building. It's methodologically an excellent piece. It's very richly referenced - if the Editor supports keeping this extensive referencing, it would

make for a rich source of information for readers. Rationale and aim/objectives could do with some further clarity (the current abstract provides a helpful structure/flow for this). The number of authors and their role may need some justification or reconsideration, also subject to the Editor's views. I've provided a larger number of smaller suggestions or considerations - some very detailed and some more about structure or need for clarification. These reflect my support of the paper, and my hope of helping to further strengthen it. I look forward to reading the findings of the review when it's completed.

Abstract
- Type error: "oris"
- Suggested rephrasing: "despite this emerging evidence" --> "despite emerging evidence"
- Suggested rephrasing: "patient engagement is inconsistent or lacking..."

Strengths and limitations
- What is meant with "comprehensively synthesize"? Please consider rephrasing
- Suggested rephrasing: "support" instead of "promote"
- I'm not sure iof "non-empirical" is clear - I suggest to stick to "grey literature sources"
- Suggested rephrasing: "Although patient engagement is broadly defined..."
- Reconsider comma use after "consensus building"

Introduction
- Definitions of key terms are references in the methods, but are not specifically provided in the text. I suggest considering a table with key definitions, such as "patient engagement" and "consensus-building initatives" early in the introduction. This would not need to serve the purpose of defining the terms for the purposes of the lit review itself, just to help navigate the reader from the start - not in the least considering the diversity of terminology used in this area. It may help help reduce word count of the introduction, which is rich in information but feels a little long - mostly since as a reader I'd like to know more rapidly what the problem and proposed solution is. I do appreciate that this could be a matter of taste/style.
- What is meant with "emerging" in the second sentence - is iKT not already fairly established, at least within the Canadian context?
- The first paragraph feels a little long, perhaps because it does not state a problem - although the iKT findings and are important, I'm not sure if the readers need to be provided with these details at the start. As a reader, I'd be looking in the first paragraph for a broad outline of a problem. It may also suggest that the paper is mainly about iKT, even though that does not come to foreground in, for example, the search terms.
- Paragraph 3 - patient engagement and iKT are used here next to each other. Are they exclusive or is one a function of the other? From paragraph 1, I take that the authors see iKT as a patient engagement process. Perhaps this can be clarified. This would also help with the specified objective (last paragraph).
- The first sentence of the last paragraph reads like a key sentence, also considering its extensive associated referencing. Please consider moving it into one of the early paragraphs.
- Reference 40 could be replaced with: https://pubmed.ncbi.nlm.nih.gov/33975550/
- Has the COMET handbook been referenced? If not, please

	consider it - especially in the context of selecting outcome domains and/or quality indicators. - I'm not sure if "In fact" is a logical follow-up from the preceding sentence. How are these linked? Please clarify. - Given that the eventual focus of the work is on improving care for/with youth with chronic health conditions, please consider providing a couple of sentences of context. Perhaps this is possible if the preceding paragraphs are shortened, with some of the information brought to the discussion. For example, I wonder if the link for doing this type of mapping through a scoping review to improving engagement with youth with chronic health conditions can be strenghtened. Why is this broad scoping review needed to solve the identified problems in the previous "systematic review" (ref 67)? - Is reference 67 indeed a systematic review? I did not identify that from a brief scan of the reference (https://pubmed.ncbi.nlm.nih.gov/33025456/). Should this be reference 9? Methods - The first paragraph highlights some of my points above about rationale and aim of the work? Is this review about mapping gaps in patient engagement in consensus-building building more generally, is it about informing engagement strategies around quality indicators for healthcare transitions of youth with chronic conditions, or both? - There is reference to "research question", but this has not been specified - perhaps rephrase to "objective" - Definitions in paragraph 2 - please see my comment at the introduction. - The involvement of the knowledge users is understandably limited - in this case to youth and caregivers. If the scope of the review is broader than this area, should ideally the group of patients/caregivers also be more diverse? Perhaps this can be clarified with more specifically defining the aim/objective of the review. - What are "robust activities or processes" in relation to consensus study designs? Would this exclude consensus-building meetings? - Exclusion critiera: "scan the reference lists of relevant studies" - is this of the non-primary studies that are excluded or are these the reference lists of included studies? If the latter, the sentence should be moved elsewhere. - What does "hand-searched" mean in relation to Google Scholar and particular journals? - If there is no quality appraisal of the studies, which I understand and would support in light of the nature of a scoping review, how would the information then inform the future research of the authors (and others)? This is likely related to scope/rationale - if the mapping is meant to highlight gaps, what are we then to do with that? If we don't know if the studies are of good quality, how would we then know if we'd like to use the findings of those studies or not? Perhaps consider addressing this in the introduction and/or discussion. - Are the three specified topics (last para of Methods) guiding for the generation of codes and/or themes, i.e. is this a somewhat deductive process? Discussion - The first paragraph highlights what is not clear to me - is the previous work (ref 9) informing the current scoping review? Or is the scoping review informing the larger project? Some if not all of the text in this first paragraph would be very helpful in the Introduction.

	- Paragraph 2: if there are already robust approaches available such as used by Healey et al, why do we need then need a scoping review to inform the quality indicator project for youth with chronic health conditions? The authors clearly already have a robust approach in mind - what / how will the review add to that? - Paragraph 3 feels a little redundant - it highlights interesting findings, but they are more about iKT practices than specifically about patient engagement in consensus-building. The last sentence of the paragraph seems similar to the point made in the last sentence of paragraph 2. - There are methodological frameworks for grey literature searches, so why is it a limitation that we don't have that specifically for "patient engagement in consensus-buidling approaches"? - If it's not necessary to assess study quality for the purposes of this review, I would not see it or stipulate it as a limitation. Even if this is proposed as limitation, I cannot see how the iKT panel would help address that (especially since they have a background embedded in but limited to youth and caregiver experiences around chronic health conditions). - The hand-searching of reference lists is not completely clear - please see my comment for the Methods. - I don't think it's needed to re-explain or further elaborate on the inter-rater relability mitigation strategies - that seems more fitting for the Methods. Ethics and dissemination - Although there is a lot of evidence for the strengths of iKT approaches, it might be a bit too bold to state that in and of itself the approach will "ensure" the "relevance, quality and appropriate direction" of the project. - I'm not sure if "end-of-grant" components is understood by all readers. Author contributions - Consider the long author list, perhaps the contributions could be further specified, e.g. using CREDIT taxonomy and/or by linking the initials of un-specified author to specific activities. If this is not possible, perhaps an authorship group should instead be considered for those involved in the design or future conductance of the review but not having a significant role in this manuscript in accordance with ICMJE criteria. The PRISMA checklist is currently empty - is that intended?

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Dr. Caroline Sanders, University of Northern British Columbia

Comments to the Authors:

Introduction

- *Pg 3 line 34-37: As a reader this sentence defining knowledge users is confusing. I expect the authors are trying to say that knowledge users include patients and caregivers but is not limited to just them and also includes clinicians, decision makers etc. I feel it would be clearer to describe that Knowledge Users are any individual who is able to use research findings to make decisions and then list examples of who. This is done later on in the article and is clearer so would recommend that here as well.*

RESPONSE: We have modified the definition based on this suggestion, to now state “Knowledge users are defined as all individuals who are involved in knowledge production in studies, who may benefit from or be affected by the research and/or who are active healthcare system users.”(See lines 108 – 111 of the tracked version)

- *Pg 3 General question. Researchers and knowledge users, does this also have space for the work within a quality assurance framework, that can inform decisions and change, you note quality care (since QA can lead to changes within the quality cycle – that may not be primarily research drives?).*

RESPONSE: Thank you for this interesting suggestion. The objective of the proposed scoping review is to understand how knowledge users have been engaged within consensus-building studies and not necessarily quality assurance frameworks that can inform decisions and change in other contexts.

- *Pg 3-4 Question - If a critical aspect of high-quality decisions that supports positive outcomes, is inclusive, responsive, and timely is consensus decision-making, evidence of new power within a framework of change? What I am asking is whether, through consensus, there is a shift in power, and if this needs to be considered considering the limited evidence of the ‘how’ to implement and evaluate engagement, and it is ‘new power’?*

RESPONSE: We agree that this is a really important consideration when engaging knowledge users. The models/theories/frameworks we will discover in the scoping review will undoubtedly incorporate constructs of power and power shifts. We aim to discuss these findings further in the subsequent scoping review manuscript.

Methods

- *The authors highlight that knowledge user engagement throughout the design and conduct of the review is a strength. Within the Methods under patient & public involvement, it would be helpful to identify how knowledge users have been identified (recruited) to participate in the panel with the research team. Is this through an existing iKT panel? Are they receiving compensation/honorarium as partners? What training and support will they receive to foster meaningful engagement in this work as collaborators? It is also unclear within the protocol if and how knowledge users have been engaged in the development – what is their role in this protocol?*

RESPONSE: Thank you for this excellent suggestion. Information about how the iKT panel will be recruited has been added. We plan to compensate patient and family members for time spent in the scoping review process and that information will be included in a subsequent manuscript. Training and support will be provided as needed, and support will be tailored according to the panel members’ needs; this information will also be provided in the final paper. The details about the iKT panel involvement were discussed with the members, to determine their proposed level of involvement that is presented here in this protocol. Additionally, the members have been provided with the protocol paper to review.

- *The authors provide sufficient detail on the search of academic literature; however, there is a limited description of how the grey literature search will be conducted. Will the authors conduct targeted searches of websites for health organizations, quality networks, patient networks, etc. (e.g., https://patientvoicesbc.ca/) or just google scholar? Given that the authors state there is no established framework for systematically searching the grey literature on patient engagement in consensus-building approaches as a limitation, it would be helpful to identify how they intend to go about it and to document this process to assist those who may be undertaking similar work in the future.*

RESPONSE: Additional information on our grey literature search strategy has been included “gray literature will also be hand-searched in specialized databases like OpenGrey, Grey Literature Report, and GreyNet International; platforms like arXiv, bioRxiv, and SSRN; and databases like ProQuest Dissertations and Theses" (see lines 232 – 235 of the tracked version).

- *For study selection, it would be helpful to clarify how the pilot test numbers for the screening form use were determined. For level 1 it says approximately 100 articles and then Level 2 says 1%. It may be more appropriate to use a proportion for both. Also is 1% sufficient for piloting at level 2?*

RESPONSE: We have updated the manuscript to reflect pilot testing of 25% of identified articles for both level 1 and 2 screening (see lines 252 – 253 & 260 of the tracked version).

- *With the large team how will agreement be reached and the responsibilities divided?*

RESPONSE: Responsibilities for screening are divided based on the amount of time individuals have to dedicate to supporting the review. A dedicated research coordinator will be assigned to one set of screening and extraction, while the second set will be distributed among the research team members. These details will be provided in the final manuscript.

- *In the table I was curious if there would be a secondary follow up to support the position of evaluation, for example if the user engagement resulted in a tangible outcome – is the duration and impact level of the outcome being reported / is there any opportunity to reconnect with the primary source to determine if this was sustained or amplified or lost since the publication? It is a bigger ask outside of the review (maybe) but its such an interesting perspective when, as a reader, I sit in a place of clinical, knowledge user involved in work in such areas and researcher.*

RESPONSE: We agree this would be a very interesting perspective. Unfortunately, it is outside of the scope of this review.

Additional minor edits:

- *Please spell out the word "and" throughout the article rather than using the & symbol in the body text.*

RESPONSE: This change has been implemented throughout the article.

- *Typo on pg 2, line 22 – two words are combined, should say "or is"*

RESPONSE: This error has been corrected on line 58 of the tracked version.

Reviewer: 2

Dr. Jan van der Scheer, THIS Institute - University of Cambridge

Comments to the Author:

Abstract

- *Type error: "oris"*

RESPONSE: This error has been corrected on line 58 of the tracked version.

- *Suggested rephrasing: "despite this emerging evidence" --> "despite emerging evidence*"

RESPONSE: The suggested rephrasing has been applied.

- *Suggested rephrasing: "patient engagement is inconsistent or lacking..."*

RESPONSE: The sentence has been changed to “patient engagement remains sparse…”

Strengths and limitations

- *What is meant with "comprehensively synthesize"? Please consider rephrasing*

RESPONSE: We have deleted the word comprehensively to clarify the sentence.

- *Suggested rephrasing: "support" instead of "promote"*

RESPONSE: This suggested rephrasing has been implemented.

- *I'm not sure iof "non-empirical" is clear - I suggest to stick to "grey literature sources"*

RESPONSE: We have deleted the word “non-empirical”.

- *Suggested rephrasing: "Although patient engagement is broadly defined..."*

RESPONSE: This suggested rephrasing has been implemented.

- *Reconsider comma use after "consensus building"*

RESPONSE: This suggestion has been incorporated.

Introduction

- *Definitions of key terms are references in the methods, but are not specifically provided in the text. I suggest considering a table with key definitions, such as "patient engagement" and "consensus-building initatives" early in the introduction. This would not need to serve the purpose of defining the terms for the purposes of the lit review itself, just to help navigate the reader from the start - not in the least considering the diversity of terminology used in this area. It may help help reduce word count of the introduction, which is rich in information but feels a little long - mostly since as a reader I'd like to know more rapidly what the problem and proposed solution is. I do appreciate that this could be a matter of taste/style.*

RESPONSE: All key terms are now defined in the introduction section and their references have now been removed from the methods (see lines 103 – 114 of the tracked version).

- *What is meant with "emerging" in the second sentence - is iKT not already fairly established, at least within the Canadian context?*

RESPONSE: The word “emerging” has been removed from the sentence (see line 106 of the tracked version).

The sentence now reads as follows, “Integrated knowledge translation (iKT) is an engagement process that supports the ongoing relationship between researchers and knowledge users as active participants in research.”

- The first paragraph feels a little long, perhaps because it does not state a problem - although the iKT findings and are important, I'm not sure if the readers need to be provided with these details at the start. As a reader, I'd be looking in the first paragraph for a broad outline of a problem. It may also suggest that the paper is mainly about iKT, even though that does not come to foreground in, for example, the search terms.

RESPONSE: We agree and have made changes to the first paragraph to address this and clarify the problem at the outset. We have also made this section of the introduction more succinct, as seen from lines 103 to 133. The first paragraph of this section reads as follows.

"Integrated knowledge translation (iKT) is an engagement process that supports the ongoing relationship between researchers and knowledge users as active participants in research. Knowledge users are defined as all individuals who are involved in knowledge production in studies, who may benefit from or be affected by the research and/or who are active healthcare system users. They may include patients, caregivers, families, clinicians, decision-makers, and policymakers. By actively involving knowledge users at every stage of the research process, iKT generates knowledge and solutions built upon equity, trust, humility, and shared partnerships that incorporate the knowledge and care experiences of patients/caregivers. Unsurprisingly, within the past decade, patient engagement and iKT have tripled in citations within the scientific literature. This coincides with increasing evidence that iKT accelerates the clinical application/adoption of impactful research outcomes that drive health system change and improve health outcomes for patients and families. Despite emerging evidence on patient engagement and iKT on closing the gap between research and application, there is a lack of guidance on how to implement and evaluate patient engagement in research."

- *Paragraph 3 - patient engagement and iKT are used here next to each other. Are they exclusive or is one a function of the other? From paragraph 1, I take that the authors see iKT as a patient engagement process. Perhaps this can be clarified. This would also help with the specified objective (last paragraph).*

RESPONSE: The terms patient engagement and iKT are used next to each other within the context of this scoping review because iKT is a broader term and is not exclusive to patients in research. This sentence has now been moved to the first paragraph (see lines 124 – 126) to improve the flow and readability of the Introduction section.

Secondly, the definition of iKT has been modified (see lines 105 – 108 of the tracked version) to provide further clarity. The definition now reads as follows. "Integrated knowledge translation (iKT) is an engagement process that supports the ongoing relationship between researchers and knowledge users as active participants in research."

- *The first sentence of the last paragraph reads like a key sentence, also considering its extensive associated referencing. Please consider moving it into one of the early paragraphs.*

RESPONSE: The first sentence of the last paragraph has been moved to the second paragraph (see lines 140 – 142 of the tracked version). The section now ends with a clear paragraph with the objective of the scoping review.

- *Reference 40 could be replaced with: https://pubmed.ncbi.nlm.nih.gov/33975550/*

RESPONSE: We have included this reference in addition to the existing reference (see line 147 of the tracked version).

- *Has the COMET handbook been referenced? If not, please consider it - especially in the context of selecting outcome domains and/or quality indicators.*

RESPONSE: We have not referenced the COMET handbook as the primary purpose of the proposed study is to identify the use of patient engagement in consensus-building. Our search will not be limited to clinical trials.

- *I'm not sure if "In fact" is a logical follow-up from the preceding sentence. How are these linked? Please clarify.*

RESPONSE: This sentence has been removed from lines 167 -171 of the tracked version.

- *Given that the eventual focus of the work is on improving care for/with youth with chronic health conditions, please consider providing a couple of sentences of context. Perhaps this is possible if the preceding paragraphs are shortened, with some of the information brought to the discussion. For example, I wonder if the link for doing this type of mapping through a scoping review to improving engagement with youth with chronic health conditions can be strenghtened. Why is this broad scoping review needed to solve the identified problems in the previous "systematic review" (ref 67)? Is reference 67 indeed a systematic review? I did not identify that from a brief scan of the reference (https://pubmed.ncbi.nlm.nih.gov/33025456/). Should this be reference 9?*

RESPONSE: We are sorry that this was not clear. This scoping review has a different objective than the previously referenced systematic review (previously ref 67) and does not solve the identified problems from that review. Our goal is to better understand how patient engagement can be implemented in consensus-building initiatives. We have clarified this in the section.

We have made edits to this section to make it more clear. It now reads “The objective of this scoping review is to identify and synthesize patient engagement and iKT approaches, methods and strategies that have been used for consensus-building in the healthcare context. This scoping review will inform best practices for engaging knowledge users in research. We plan to use the results in a study engaging youth, caregivers and other knowledge users to prioritize previously identified quality indicators applicable across chronic health conditions through consensus building.” (See lines 163 – 178 of the tracked version).

Methods

- *The first paragraph highlights some of my points above about rationale and aim of the work? Is this review about mapping gaps in patient engagement in consensus-building building more generally, is it about informing engagement strategies around quality indicators for healthcare transitions of youth with chronic conditions, or both?*

RESPONSE: While we plan to use the results for a broader study which aims to prioritize a core set of quality indicators for youth with chronic conditions transitioning to adult care, the overall goal of the scoping review is to map out the gaps in patient engagement in consensus-building studies.

- *There is reference to “research question”, but this has not been specified – perhaps rephrase to “objective”*

RESPONSE: This suggestion has been implemented as seen on line 183 of the tracked version.

- *Definitions in paragraph 2 - please see my comment at the introduction.*

RESPONSE: This paragraph has been removed from lines 195 – 199 of the tracked version.

- *The involvement of the knowledge users is understandably limited - in this case to youth and caregivers. If the scope of the review is broader than this area, should ideally the group of patients/caregivers also be more diverse? Perhaps this can be clarified with more specifically defining the aim/objective of the review.*

RESPONSE: In the Introduction section, we have now clarified that knowledge users are not limited to patients and caregivers with the following statement “They may include patients, caregivers, families, clinicians, decision-makers, and policymakers” following the definition of knowledge users. Under patient and public involvement, we have also included the other knowledge users who are part of the iKT panel.

- *What are "robust activities or processes" in relation to consensus study designs? Would this exclude consensus-building meetings?*

RESPONSE: We have changed the terminology to be clearer and more accurate which now states "All consensus study designs that employ commonly used methods (e.g., nominal group technique, Delphi, RAND/UCLA Appropriateness Method, modified Delphi)." (see line 205 of the tracked version).

- *Exclusion criteria: "scan the reference lists of relevant studies" - is this of the non-primary studies that are excluded or are these the reference lists of included studies? If the latter, the sentence should be moved elsewhere.*

RESPONSE: The word "non-primary" has been included to provide clarity.

- *What does "hand-searched" mean in relation to Google Scholar and particular journals?*

RESPONSE: More details on our grey literature search have been included on lines 225 to 228 of the tracked version). Hand-searched means using keywords on specific databases and manually reviewing title results.

- *If there is no quality appraisal of the studies, which I understand and would support in light of the nature of a scoping review, how would the information then inform the future research of the authors (and others)? This is likely related to scope/rationale - if the mapping is meant to highlight gaps, what are we then to do with that? If we don't know if the studies are of good quality, how would we then know if we'd like to use the findings of those studies or not? Perhaps consider addressing this in the introduction and/or discussion.*

RESPONSE: The process of conducting quality appraisals on identified studies is not a requirement in the PRISMA-ScR reporting guideline. However, this review will include the *critical* appraisals of identified studies to synthesize the information available on knowledge engagement in research. The study objective has been modified to provide clarity on the use of our findings, in which we hope to use the study results (i.e., identification of relevant engagement models/theories/frameworks) to navigate how we engage knowledge users (youth, caregivers, healthcare providers and health system leaders) in a broader project the team will be conducting.

- *Are the three specified topics (last para of Methods) guiding for the generation of codes and/or themes, i.e. is this a somewhat deductive process?*

RESPONSE: The three specified topics will guide the data extraction variable and not the coding process.

Discussion

- *The first paragraph highlights what is not clear to me - is the previous work (ref 9) informing the current scoping review? Or is the scoping review informing the larger project? Some if not all of the text in this first paragraph would be very helpful in the Introduction.*

RESPONSE: We have made some edits to better clarify the objective to now state "The objective of this scoping review is to identify and synthesize patient engagement and iKT approaches, methods and strategies that have been used for consensus-building in the healthcare context. This scoping review will inform best practices for engaging knowledge users in research. We plan to use the results in a study engaging youth, caregivers and other knowledge users to prioritize previously identified quality indicators applicable across chronic health conditions through consensus building". (see line 297 of the tracked version).

- *Paragraph 2: if there are already robust approaches available such as used by Healey et al, why do we need then need a scoping review to inform the quality indicator project for youth with* *chronic health conditions? The authors clearly already have a robust approach in mind - what / how will the review add to that?*

RESPONSE: While this one study has been identified, we want to understand and map the range of consensus-building studies that have used engagement models/theories/frameworks across a diverse set of knowledge users in research and study designs.

- *Paragraph 3 feels a little redundant - it highlights interesting findings, but they are more about iKT practices than specifically about patient engagement in consensus-building. The last sentence of the paragraph seems similar to the point made in the last sentence of paragraph 2.*

RESPONSE: We agree that there is a lot of redundant information highlighting interesting findings. We have made this section more concise to improve readability (see lines 330 – 343 of the tracked version).

- *There are methodological frameworks for grey literature searches, so why is it a limitation that we don't have that specifically for "patient engagement in consensus-buidling approaches"?*

RESPONSE: Based on your comment, we have removed this as a study limitation (see lines 354 – 361 of the tracked version).

- *If it's not necessary to assess study quality for the purposes of this review, I would not see it or stipulate it as a limitation. Even if this is proposed as limitation, I cannot see how the iKT panel would help address that (especially since they have a background embedded in but limited to youth and caregiver experiences around chronic health conditions).*

RESPONSE: This statement has been removed.

- *The hand-searching of reference lists is not completely clear - please see my comment for the Methods.*

RESPONSE: This sentence has been clarified to now state "To further maximize comprehensiveness, we will manually search reference lists of relevant non-primary studies, to identify articles not previously identified in our search." (see lines 368 – 369 of the tracked version).

- *I don't think it's needed to re-explain or further elaborate on the inter-rater 12eliability mitigation strategies – that seems more fitting for the Methods.*

RESPONSE: This sentence has been deleted, as it has already been mentioned in the Methods section.

Ethics and dissemination

- *Although there is a lot of evidence for the strengths of iKT approaches, it might be a bit too bold to state that in and of itself the approach will "ensure" the "relevance, quality and appropriate direction" of the project. I'm not sure if "end-of-grant" components is understood by all readers.*

RESPONSE: We have incorporated your suggestions into this section for more clarity.

Author contributions

- *Consider the long author list, perhaps the contributions could be further specified, e.g. using CREDIT taxonomy and/or by linking the initials of un-specified author to specific activities. If this is not possible, perhaps an authorship group should instead be considered for those involved in the* *design or future conductance of the review but not having a significant role in this manuscript in accordance with ICMJE criteria.*

RESPONSE: This is a helpful suggestion. All authors did meet ICMJE criteria. We will explore using CREDIT taxonomy for subsequent publication for our author group. 16 co-authors were integrated Knowledge Translation panel members, and this is shown in affiliation number 8.

- *The PRISMA checklist is currently empty - is that intended?*

RESPONSE: The completed version of the PRISMA-P Checklist has been uploaded.

VERSION 2 – REVIEW

REVIEWER	Caroline Sanders University of Northern British Columbia, School of Nursing
REVIEW RETURNED	09-Feb-2024

GENERAL COMMENTS	This is a paper that has been enhanced with the changes. Thank you.

REVIEWER	Jan van der Scheer THIS Institute - University of Cambridge
REVIEW RETURNED	24-Feb-2024

GENERAL COMMENTS	Thank you for the careful consideration of the reviewers' suggestions and comments. I am happy to endorse publication, subject to one last consideration as described below - the Editor may wish to adjudicate. I would not want to unnecessary delay publication of the article The authors state in their responses that the COMET handbook and metholodogy is not referenced, as the focus is not on clinical trials. They have indeed now clarified that the results are aimed to inform a larger project on prioritizing quality indicators to support the transition of youth with chronic physical, mental or developmental disabilities into adult care. However, I do still think that consideration of Core Outcome Set development methodology is relevant - at least in terms of how the results of the scoping review might inform improvement of such methodology. As Kirkham et al (2016, doi:10.1371/journal.pmed.1002148) for example explain, "COS are being developed for settings other than clinical trials [...] The reporting checklist is relevant regardless of the consensus methodology used in the development of the COS and can be applied to COS developed for effectiveness trials, systematic reviews, or routine care." The COMET handbook has helped emphasise and improve standardisation of consensus-building methodology that should include patients and/or members of the public when developing Core Outcome Set, which - with a broad view on its applicability - should also be applied to developing/consensus-building a set of quality indicators as the authors refer to. In addition, I see relevance in referring in the discussion to the very recently published ACCORD guidelines for consensus-building reporting: https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pm

	ed.1004326. For example, the authors could discuss in a sentence if they think the results of the scoping review could inform future work around reporting of consensus-building, such as specifying an item about PPI (as many journals, such as BMJ Open, require for any study, including justification if PPI was not employed).

VERSION 2 – AUTHOR RESPONSE

Reviewer: 1

Dr. Caroline Sanders, University of Northern British Columbia

Comments to the Author:

This is a paper that has been enhanced with the changes. Thank you.

Reviewer: 2

Dr. Jan van der Scheer, THIS Institute - University of Cambridge

Comments to the Author:

Thank you for the careful consideration of the reviewers' suggestions and comments. I am happy to endorse publication, subject to one last consideration as described below - the Editor may wish to adjudicate. I would not want to unnecessary delay publication of the article

The authors state in their responses that the COMET handbook and metholodogy is not referenced, as the focus is not on clinical trials. They have indeed now clarified that the results are aimed to inform a larger project on prioritizing quality indicators to support the transition of youth with chronic physical, mental or developmental disabilities into adult care.

However, I do still think that consideration of Core Outcome Set development methodology is relevant - at least in terms of how the results of the scoping review might inform improvement of such methodology. As Kirkham et al (2016, doi:10.1371/journal.pmed.1002148) for example explain, "COS are being developed for settings other than clinical trials [...] The reporting checklist is relevant regardless of the consensus methodology used in the development of the COS and can be applied to COS developed for effectiveness trials, systematic reviews, or routine care."

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In addition, I see relevance in referring in the discussion to the very recently published ACCORD guidelines for consensus-building reporting: https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1004326. For example, the authors could discuss in a sentence if they think the results of the scoping review could inform future work around reporting of consensus-building, such as specifying an item about PPI (as many journals, such as BMJ Open, require for any study, including justification if PPI was not employed).

RESPONSE: Thank you for this excellent suggestion. Although the study's primary objective is to contribute to a broader project aimed at prioritizing quality indicators to facilitate the transition of youth with chronic physical, mental, or developmental disabilities into adult care, its focus diverges from informing the design of the consensus protocol. Instead, this scoping review delves into the utilization of patient/knowledge user engagement within such projects. We are systematically gathering data on various aspects of patient engagement activities, including frameworks employed, tools and strategies utilized, frequency of engagement, facilitation methods, and the extent of involvement. These findings will inform the implementation of patient/knowledge user engagement strategies within our larger project, adopting an integrated knowledge translation approach. Furthermore, in the discussion section, we have addressed how the results of this scoping review could be integrated into existing reporting guidelines (such as COS-STAR and ACCORD), proposing, for instance, the inclusion of a checklist item focusing on the extent of patient involvement beyond their role as mere participants.