

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Co-developing patient and family engagement indicators for health system improvement with healthcare system stakeholders: A consensus study
AUTHORS	Santana, Maria-Jose; Ahmed, Sadia; Fairie, Paul; Zelinsky, Sandra; Wilkinson, Gloria; McCarron, Tamara; Mork, Mikie; Patel, Jatin; Wasylak, Tracy

VERSION 1 – REVIEW

REVIEWER	Lachman, Peter Royal College of Physicians of Ireland, Quality
REVIEW RETURNED	26-Sep-2022

GENERAL COMMENTS	<p>Thank you for the well conducted participatory research. It would be interesting to see how the research mets all 18 criteria.</p> <p>Another paper has recently been published in the journal - a Delphi study on engagement in hospital , also from Cansda and it would be good if you could reference the paper and possibly include a comment for the reader on differences and similarities approach etc. (Anderson NN et al. Consensus on how to optimise patient/family engagement in hospital planning and improvement: a Delphi survey. BMJ Open. 2022 Sep 20;12(9):e061271. doi: 10.1136/bmjopen-2022-061271.</p> <p>It would also be good to comment on the move from engagement to coproduction where power is shared in an equal partnership.</p>
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REVIEWER	Usher, Susan Université de Sherbrooke, Centre de recherche Charles-Le-Moyne
REVIEW RETURNED	05-Oct-2022

GENERAL COMMENTS	<p>The authors have rigorously undertaken an effort to arrive at indicators for patient and family engagement in the work of SCNs. Selection of the PPEET in Phase 1 is followed by an interview phase and 3 rounds of Delphi consensus building.</p> <p>My main reservations concern the clarity of the presentation of the methodology (and its results).</p> <p>I feel confident, in proposing Minor revisions, that it is not the methodology itself but rather the presentation of various stages of the study that creates ambiguity and uncertainty.</p> <p>The presentation of the methodology, results and tables requires review to ensure readers understand the nature and connection between each phase. Attention is required throughout to use of the</p>
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words "selection" and "development" regarding indicators. The process of adapting indicators is under-described. Use of terms PPEET (to refer to original measures from survey) and PFE-I (adapted for SCN) should be examined carefully.

I remain especially unclear about Phase 2: I understand that participants complete the PPEET questionnaires (with the reduced number of questions, i.e. 33). They are then interviewed on barriers and facilitators of engagement (line 22, p. 6). How is the interview connected to the initial undertaking of the questionnaires? The purpose of the interviews is left unclear and needs to be specified. Results presented pages 12-14 and Table 2 reflect thematic analysis of views on barriers and facilitators, and not the relevance of indicators. There is a gap here that needs to be filled to allow readers to follow the logical progression between phases. How then do these themes relate to Delphi rounds prioritizing and adapting measures to be used in SCNs? The analysis of interviews appears to become a selection criteria in the Delphi rounds. This needs to be described.

Delphi round 1 states "rank each of the PFE-I criteria: have the PPEET measures been modified before this stage? if so how? Line 7 page 7 refers to "new" indicators. Round two, p. 7, line 6: workshop participants noted areas of disagreement indicated by the ratings. Line 9 refers to "modifications to the indicators" Round three describes "refining PFE-I" and voting on overall importance.

We are given no information about how and why indicators were modified, nor the potential relation between interviews and these modifications.

Table 3 requires a paragraph in the text to explain table entries and statistics: what does "not developed" mean? what does "Newly developed derived from previous (Working Together, Resources for Patient Engagement) mean? what does N/A mean? How were evidence sources (PPEET, interviews, consensus meeting) introduced and weighed?

Participants

Line 18, p. 6 "After completing the online survey, respondents were invited to interview" Are participants at each phase drawn from the same pool? i.e. did all those participating in interviews also complete the questionnaire? did all those participating in the Delphi process participate in interviews? A flow chart of participation, including the breakdown of staff, PFA and leadership would be helpful. It would be nice if Table 3 also included the % vote (by PFA and hc stakeholders) to discard the remaining 15 indicators.

Appendix II presents the number of positive responses and denominators. Can you specify that they are answering the question: Is the indicator about (...) important? It currently reads as people's answer to the question itself.

Background

The purpose of the study is to develop indicators of PFA engagement in SCN work across the AHS, starting with the PPEET, narrowing down to the most important measures, and adapting indicators to the SCN context.

To fully understand this objective, I would appreciate information on how PFA engagement has been measured up to now in SCN work (referred to p. 5 line 30) (i.e. AHS Advisory Council Member Experience Survey)? What shortcomings in existing practice

	<p>motivated the development/selection of indicators? This would make the gap the authors seek to fill more evident.</p> <p>Discussion Indicators are meant to improve the quality, in this case of patient and family engagement. The background refers to (Bombard et al 2018) driving system improvement and improving service delivery as the "outcome" of the exercise. However outcome measures are left aside from the start in the indicator selection/refinement process. There are increasing calls in the engagement literature to attempt to move from process to outcomes. Recent systematic reviews find that evaluations of engagement activities are mostly designed to assess engagement activities and not outcomes. (Boivin et al 2018, Dukhanin et al 2018). Others recognize that process indicators are not sufficient to understand the pathway of impact (Vat et al 2019, Usher & Denis 2022). Given the interest expressed in this paper's introduction in driving system improvement, the neglect of outcome indicators warrants discussion and could be introduced as a limitation to the study.</p> <p>Additional material The COREQ only provides page numbers; it is more helpful if it includes the information as well.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Dr. Peter Lachman, Royal College of Physicians of Ireland

Comments to the Author:

Thank you for the well conducted participatory research. It would be interesting to see how the research meets all 18 criteria.

RESPONSE: Thank you for your comments. We utilized the COREQ checklist for reporting of qualitative studies and added more detail on the reporting checklist.

Reviewer Comment: Another paper has recently been published in the journal - a Delphi study on engagement in hospital, also from Canada and it would be good if you could reference the paper and possibly include a comment for the reader on differences and similarities approach etc. (Anderson NN et al. Consensus on how to optimise patient/family engagement in hospital planning and improvement: a Delphi survey. *BMJ Open*. 2022 Sep 20;12(9):e061271. doi: 10.1136/bmjopen-2022-061271.

RESPONSE: Thank you for the reference to the Anderson et al. paper. We have added the reference to the discussion, and compared with our study (lines 606-611, page 17).

Reviewer Comment: It would also be good to comment on the move from engagement to coproduction where power is shared in an equal partnership.

RESPONSE: We have utilized the Canadian Institutes of Health Research Patient Engagement Framework to guide this work, using the four guiding principles of engagement: inclusiveness, supports, mutual respect, and co-build, and therefore for consistency used those terms. We've added more description on how our work aligned with those four principles in the discussion section (lines

591-599, page 17).

Reviewer: 2

Dr. Susan Usher, Université de Sherbrooke

Comments to the Author:

The authors have rigorously undertaken an effort to arrive at indicators for patient and family engagement in the work of SCNs. Selection of the PPEET in Phase 1 is followed by an interview phase and 3 rounds of Delphi consensus building.

My main reservations concern the clarity of the presentation of the methodology (and its results).

I feel confident, in proposing Minor revisions, that it is not the methodology itself but rather the presentation of various stages of the study that creates ambiguity and uncertainty.

The presentation of the methodology, results and tables requires review to ensure readers understand the nature and connection between each phase. Attention is required throughout to use of the words "selection" and "development" regarding indicators. The process of adapting indicators is under-described. Use of terms PPEET (to refer to original measures from survey) and PFE-I (adapted for SCN) should be examined carefully.

RESPONSE: Thank you for the careful review of the methods section. We have added some clarity on phase 1 of this work, where the PPEET was selected by the AB4HR council members to measure patient engagement (Line 305-310, page 8). Phase 1 was prior to the development of indicators for patient and family engagement, and therefore indicators were not adapted. We've reviewed the paper for consistency in wording.

Reviewer Comment: I remain especially unclear about Phase 2: I understand that participants complete the PPEET questionnaires (with the reduced number of questions, i.e. 33). They are then interviewed on barriers and facilitators of engagement (line 22, p. 6). How is the interview connected to the initial undertaking of the questionnaires? The purpose of the interviews is left unclear and needs to be specified. Results presented pages 12-14 and Table 2 reflect thematic analysis of views on barriers and facilitators, and not the relevance of indicators. There is a gap here that needs to be filled to allow readers to follow the logical progression between phases. How then do these themes relate to Delphi rounds prioritizing and adapting measures to be used in SCNs? The analysis of interviews appears to become a selection criteria in the Delphi rounds. This needs to be described.

RESPONSE: We have provided some clarification in the methods section on phase 2 of this work, and how the interviews are connected to the overall aim (line 234-242, page 5). The purpose of the interviews was to expand on responses from the survey, to expand on participants' patient engagement experiences working within the SCNs, and to gain an in-depth understanding of the barriers and facilitators to engagement in health research and system transformation. PFE-Is were drafted from the PPEET survey and qualitative interviews for the consensus process. Therefore, the themes from the interviews helped to develop additional indicators not captured by the PPEET survey. (line 250)

Reviewer Comment: Delphi round 1 states "rank each of the PFE-I criteria: have the PPEET measures been modified before this stage? if so how? Line 7 page 7 refers to "new" indicators. Round two, p. 7, line 6: workshop participants noted areas of disagreement indicated by the ratings. Line 9 refers to "modifications to the indicators"

Round three describes "refining PFE-I" and voting on overall importance.

We are given no information about how and why indicators were modified, nor the potential relation

between interviews and these modifications.

Table 3 requires a paragraph in the text to explain table entries and statistics: what does "not developed" mean? what does "Newly developed derived from previous (Working Together, Resources for Patient Engagement) mean? what does N/A mean? How were evidence sources (PPEET, interviews, consensus meeting) introduced and weighed?

RESPONSE: Thank you for your comments. To clarify, the PFEIs were drafted based on the PPEET survey and qualitative interview, and they were not modified prior to round 1 of voting. We have added more description on how indicators were modified in round 2 (line 533-539, page 14) in the results section. The table has been modified for improved clarity. For instance, N/A= voting not required/applicable as PFE-I accepted in previous round. Certain indicators were developed based on previous indicators (description included in line 551-557), some indicators were developed from the consensus rounds and then introduced again for voting in the next round.

Reviewer comment:

Participants

Line 18, p. 6 "After completing the online survey, respondents were invited to interview" Are participants at each phase drawn from the same pool? i.e. did all those participating in interviews also complete the questionnaire? did all those participating in the Delphi process participate in interviews? A flow chart of participation, including the breakdown of staff, PFA and leadership would be helpful. It would be nice if Table 3 also included the % vote (by PFA and hc stakeholders) to discard the remaining 15 indicators.

Appendix II presents the number of positive responses and denominators. Can you specify that they are answering the question: Is the indicator about (...) important? It currently reads as people's answer to the question itself.

RESPONSE: Participants are drawn from the same pool for all the phases, however since the survey is anonymous we did not confirm with all interview respondents or Delphi consensus participants whether they completed the survey. A description of study participants are included in the methods section (Lines 160-172, pg. 4). In the results section, we have indicated how many participants were involved (lines 314, 372). Table 3 only includes the indicators that were accepted in the final round. Round 2 of the consensus process was an online discussion with the Delphi participants therefore we do not have a breakdown of how many PFA, SCN staff participants excluded the indicators, as each indicator was discussed until consensus was reached and a final anonymous vote (on zoom) was taken when disagreements arose. We have included a table of the indicators that were discarded in APPENDIX II with the reasons for discarding.

APPENDIX II displays how the indicator would be measured, and Delphi consensus participants rated each indicator using the criteria (overall importance, impact, actionable interpretability, and relevance). In the future, for implementation of the indicators they would be measured using the numerator and denominator. For instance, the indicator "enough information about the role" would be measured by taking the "Number of PFAs who responded agree or strongly agree to having enough information about their role" divided by the "Total number of PFAs responding to this question".

Reviewer Comment:

Background

The purpose of the study is to develop indicators of PFA engagement in SCN work across the AHS, starting with the PPEET, narrowing down to the most important measures, and adapting indicators to the SCN context.

To fully understand this objective, I would appreciate information on how PFA engagement has been measured up to now in SCN work (referred to p. 5 line 30) (i.e. AHS Advisory Council Member Experience Survey)? What shortcomings in existing practice motivated the development/selection of indicators? This would make the gap the authors seek to fill more evident.

RESPONSE: Thank you, we have included context in the background section on the gaps that led to this work (line 107-112, page 3)

Reviewer Comment:

Discussion

Indicators are meant to improve the quality, in this case of patient and family engagement. The background refers to (Bombard et al 2018) driving system improvement and improving service delivery as the "outcome" of the exercise. However outcome measures are left aside from the start in the indicator selection/refinement process.

There are increasing calls in the engagement literature to attempt to move from process to outcomes. Recent systematic reviews find that evaluations of engagement activities are mostly designed to assess engagement activities and not outcomes. (Boivin et al 2018, Dukhanin et al 2018). Others recognize that process indicators are not sufficient to understand the pathway of impact (Vat et al 2019, Usher & Denis 2022).

Given the interest expressed in this paper's introduction in driving system improvement, the neglect of outcome indicators warrants discussion and could be introduced as a limitation to the study.

RESPONSE: Thank you for raising this important point. We have revised the discussion section to include the discussion on process and outcome indicators (lines 647-646, pg.18)

Reviewer Comment:

Additional material

The COREQ only provides page numbers; it is more helpful if it includes the information as well.

RESPONSE: We have added more details to the COREQ checklist

VERSION 2 – REVIEW

REVIEWER	Usher, Susan Université de Sherbrooke, Centre de recherche Charles-Le-Moyne
REVIEW RETURNED	12-Jan-2023
GENERAL COMMENTS	The authors have satisfactorily responded to the concerns raised in my initial review.