BMJ Open

Patient, caregiver and other knowledge user engagement in consensus-building healthcare initiatives: a scoping review protocol

Sarah E. P. Munce ,[1,2] Elliott Wong,[3,4] Dorothy Luong,[1] Justin Rao,[3] Jessie Cunningham,[5] Katherine Bailey ,[3,6] Tomisin John ,[4] Claire Barber ,[7] Michelle Batthish,[8] Kyle Chambers,[9] Kristin Cleverley ,[10,11] Marilyn Crabtree,[9,12] Sanober Diaz,[9,12] Gina Dimitropoulos,[9,13] Jan Willem Gorter ,[14,15] Danijela Grahovac,[16,17] Ruth Grimes,[18] Beverly Guttman,[12] Michèle L Hébert,[19] Megan Henze,[9,20] Amanda Higgins,[9,21] Dmitry Khodyakov,[22] Elaine Li,[9] Lisha Lo ,[23] Laura Macgregor,[9,24] Sarah Mooney,[9,25] Samadhi Mora Severino,[9,26] Geetha Mukerji ,[27] Melanie Penner ,[9,28] Jacklynn Pidduck,[9,21] Rayzel Shulman,[3,29] Lisa Stromquist,[9,30] Patricia Trbovich ,[6,31] Michelle Wan,[9] Laura Williams,[9,32] Darryl Yates,[4,9] Alene Toulany [3,33]

To cite: Munce SEP, Wong E, Luong D, *et al*. Patient, caregiver and other knowledge user engagement in consensus-building healthcare initiatives: a scoping review protocol. *BMJ Open* 2024;**14**:e080822. doi:10.1136/bmjopen-2023-080822

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (https://doi.org/10.1136/bmjopen-2023-080822).

Received 12 October 2023
Accepted 10 April 2024

For numbered affiliations see end of article.

Correspondence to
Dr Sarah E. P. Munce;
sarah.munce@uhn.ca

ABSTRACT

Introduction Patient engagement and integrated knowledge translation (iKT) processes improve health outcomes and care experiences through meaningful partnerships in consensus-building initiatives and research. Consensus-building is essential for engaging a diverse group of experienced knowledge users in co-developing and supporting a solution where none readily exists or is less optimal. Patients and caregivers provide invaluable insights for building consensus in decision-making around healthcare, policy and research. However, despite emerging evidence, patient engagement remains sparse within consensus-building initiatives. Specifically, our research has identified a lack of opportunity for youth living with chronic health conditions and their caregivers to participate in developing consensus on indicators/benchmarks for transition into adult care. To bridge this gap and inform our consensus-building approach with youth/caregivers, this scoping review will synthesise the extent of the literature on patient and other knowledge user engagement in consensus-building healthcare initiatives.

Methods and analysis Following the scoping review methodology from Joanna Briggs Institute, published literature will be searched in MEDLINE, EMBASE, CINAHL and PsycINFO databases from inception to July 2023. Grey literature will be hand-searched. Two independent reviewers will determine the eligibility of articles in a two-stage process, with disagreements resolved by a third reviewer. Included studies must be consensus-building studies within the healthcare context that involve patient engagement strategies. Data from eligible studies will be extracted and charted on a standardised form. Abstracted data will be analysed quantitatively and descriptively, according to specific consensus methodologies, and patient engagement models and/or strategies.

Ethics and dissemination Ethics approval is not required for this scoping review protocol. The review process and findings will be shared with and informed by relevant knowledge users. Dissemination of findings will also include peer-reviewed publications and conference presentations. The results will offer new insights for supporting patient engagement in consensus-building healthcare initiatives.

Protocol registration https://osf.io/beqjr

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This review will identify and synthesise patient engagement approaches in consensus-building initiatives across healthcare settings.
- ⇒ Knowledge user engagement throughout the design and conduct of the review will support the identification of knowledge gaps, and health service and research priorities that are reflective of their needs and experiences.
- ⇒ Application of a well-established methodological framework from the Joanna Briggs Institute will support the production of this high-quality review.
- ⇒ To reduce publication bias and enhance comprehensiveness, data extraction will include literature from all languages across multiple databases, including grey literature sources.
- ⇒ Although patient engagement is broadly defined in this review, we may miss studies in our search given the wide use of terminology describing knowledge user engagement methods in consensus-building healthcare initiatives.

INTRODUCTION

Integrated knowledge translation (iKT) is an engagement process that supports the ongoing relationship between researchers and knowledge users as active participants in research.[1] 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.[2 3] 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 on equity, trust, humility, and shared partnerships that incorporate the knowledge and care experiences of patients/caregivers.[3–5] Unsurprisingly, within the past decade, patient engagement and iKT have tripled in citations within the scientific literature.[6] 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.[1 7–13] Despite emerging evidence on patient engagement and iKT on closing the gap between research and application,[14 15] there is a lack of guidance on how to implement and evaluate patient engagement in research.

With the growing attention and recognised benefits of meaningful engagement,[3–5 7 8 16–21] there is wider consideration for involving knowledge users in consensus-building healthcare initiatives.[22–30] Consensus-building approaches are participatory frameworks for engaging a range of knowledge users, including patients, caregivers/family, health advocates, healthcare staff and leadership, to co-develop and support a solution in the best interest of the group where no single correct solution exists.[31 32] Building consensus with key knowledge users and maintaining meaningful engagement throughout the entire research process is essential to guide strategic and significant decisions in healthcare.[7 23–27 29 30 33–44] Indeed, a commitment to high-quality interdisciplinary consensus approaches, grounded in the perspectives of patients/caregivers, is needed to inform priorities, processes and outcomes of healthcare initiatives. In doing so, healthcare initiatives will be driven by consensus to effect change that reflects the priorities and needs of those receiving care and most affected by health research outcomes.[28–30 35 41–47]

Existing gaps in organisational directives and training on knowledge user engagement have led to inconsistent and inadequate patient engagement in consensus-building initiatives in healthcare.[15 48–51] Consequently, consensus-building efforts are often unintentionally tokenistic, biased and inflexible, with power dynamics further bridging the divide between researchers and patients/caregivers.[15 48–51] Ultimately, poorly conducted engagement results in undue frustration or distress in patients and caregivers who feel unheard, unsupported and powerless to advocate for change.[46 48–52] This may lead to barriers such as lack of motivation and retention from patients and caregivers, which in turn leads to unclear expectations and poor communication between researchers and these knowledge users.[53–55] Thus, there are missed opportunities to build consensus towards improved health outcomes important to patients and caregivers.[48 49]

The objective of this scoping review is to identify and synthesise 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 prioritise previously identified quality indicators applicable across chronic health conditions through consensus building.[45]

METHODS

This scoping review will be conducted in accordance with the Joanna Briggs Institute scoping review methodology.[56] A scoping review methodology is appropriate given the broad nature of the overall research objective on patient engagement and consensus-building strategies. Moreover, the scoping review can clarify and map key concepts on a specific topic in the literature, thereby helping identify gaps or priorities in research on patient engagement and consensus.[57–59] It will be further guided by the best practice guidance and reporting items for the development of scoping review protocols.[60] Moreover, the review will adhere to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews guidelines and involve experts on scoping review methodology to enhance reporting quality.[61 62] We have engaged knowledge users in the scoping review as outlined in guidance by Pollock *et al*.[63] The protocol for the scoping review has been registered with the Open Science Framework (https://osf.io/beqjr/).

Patient and public involvement

This scoping review will include engagement with knowledge users including patients/youth, caregivers, healthcare providers, and health system leaders through an iKT panel in collaboration with the research team. Panel members will be recruited using the research team's pre-existing relationships with key knowledge users, including leading organisations in child and youth health in Canada. They will provide key search terms that will enhance the depth and scope of our search strategy, contribute to the article screening process and be involved during the interpretation and dissemination phases of this project.

Eligibility criteria

Inclusion criteria: (1) all consensus study designs that employ commonly used methods (eg, nominal group technique, Delphi, RAND/UCLA Appropriateness Method, modified Delphi); (2) within the healthcare context and across patient populations of all ages, settings of care and health condition(s)[6 64] and (3) explicitly describe patient engagement outcomes, strategies, methods or approaches. No restrictions will be placed on date or language of publication.[64]

Exclusion criteria: we will exclude all non-primary studies (eg., systematic reviews, scoping reviews, protocols, meta-analyses, editorials, commentaries, perspectives or opinion articles and conference proceedings). However, we will scan the reference lists of relevant non-primary studies to ensure all eligible studies are captured.

Search strategy and information sources

To identify relevant peer-reviewed studies, our research team and information specialist (JC) will develop a comprehensive search strategy with experts from the patient engagement and consensus fields (AT, SEPM). The search will be conducted in MEDLINE (Ovid) and Medline (Ovid) Epub Ahead of Print, In-Process and Other Non-Indexed Citations, CINAHL (EBSCO), EMBASE (Ovid) databases and PsycINFO (Ovid) from inception to 19 July 2023. No language limits will be applied. Patient engagement-specific publication venues (eg., Health Expectations, Research Involvement and Engagement) and grey literature will also be hand-searched in specialised databases like OpenGrey, Grey Literature Report and GreyNet International; platforms like arXiv, bioRxiv and SSRN and databases like ProQuest Dissertations and Theses.

Search terms will include the three main concepts 'patient OR knowledge user engagement', 'public and patient involvement', 'consensus' and 'consensus building'. This is based on published reviews and search strategies using medical subject headings and text related to consensus, public and patient engagement, patient-centred, knowledge user and iKT.[3 16 47 65] The complete search strategy for MEDLINE is provided in online supplemental appendix I and for CINAHL in online supplemental appendix II.

The search strategy will be peer-reviewed using the Peer Review of Electronic Search Strategies (PRESS) checklist by an information specialist .[66] Moreover, networks of the research team will be consulted to ensure all relevant data and information sources will be obtained.

Study selection

Following the search, all identified references will be saved in Covidence[67] and duplicates removed. A pilot test of the level 1 screening form based on the criteria outlined above will be conducted on a random sample of 25% of identified articles. The descriptions of the eligibility criteria will be revised to improve the consistent application of the selection criteria, if deemed necessary by the team or if a low agreement (ie, <70%) is observed. Level 1 and level 2 screening will occur in duplicate by two independent reviewers. For level 1 screening, reviewers will screen the titles and abstracts for inclusion using the screening form. For level 2, the full text of potentially relevant articles will then be collected and screened to determine final inclusion. Similarly, a pilot test of the level 2 screening form will also be performed on approximately 25% of the articles, followed by the calculation of inter-rater reliability for included studies.[68] Discrepancies will be resolved by discussion between the two reviewers and when necessary, a third reviewer will be available to resolve conflicts. Studies excluded during the screening phases will be documented in Covidence, along with the rationale for their exclusion.

Critical appraisal of literature sources

Assessment of the methodological quality of included studies is not a requirement of scoping reviews.[56 69] As such, quality and risk of bias will not be assessed, nor will studies be excluded based on quality assessment.

Data items and charting process

Data from included literature will be extracted using a standardised abstraction form developed in Microsoft Excel. The form (table 1) will capture abstracted data within the following categories: (a) study information (eg., publication title, study aims), (b) study methodology and demographics (eg., population, equity diversity inclusion principles, gender, ethnicity, culture, language)[70] and (c) patient engagement activities (eg., framework used, tools and strategies, frequency of engagement, facilitation, degree of involvement). Additional categories may be identified through discussions with the research team and iKT panel. The data abstraction form will be pilot tested and refined with at least two members of the research team. To ensure transparency of reporting, inter-rater agreement and reliability will be determined by calculating a Cohen's κ and percentage agreement.[68 71]

Data analysis and synthesis

Abstracted data from this scoping review will be analysed quantitatively into numerical counts (eg., geographical origin of studies, consensus methodology) and qualitatively using content analysis (eg., patient engagement models, strategies, client characteristics, healthcare programme).[72] Data will be analysed, coded manually and then summarised into: (1) how knowledge users were engaged throughout the consensus-building process, including their roles, responsibilities, associated strategies and patient population; (2) use of patient engagement models, values/principles, theories, frameworks and (3) the overarching consensus-building approach. Depending on the included articles, subgroup analyses may be considered for example, by sex, gender-related variables as well as other characteristics (eg., race, ethnicity, culture, language, education, income).[70]

DISCUSSION

The proposed scoping review aims to summarise and identify patient engagement approaches, methods and strategies that have been used for consensus-building in the healthcare context. Results will inform best practices for engaging knowledge users in consensus-building research projects. They could potentially be used to inform existing reporting guidelines such as the Core Outcome Set-STAndards for Reporting and the ACcurate COnsensus Reporting Document.[73 74] For example, it may provide a rationale for including checklist items for reporting patient involvement beyond being participants.

Table 1 Information to be extracted from included studies

Category	Data to be extracted
Study information	▶ Publication title ▶ Author ▶ Year of publication ▶ Country of origin (study location)
Study methodology and demographic	▶ Population (including health conditions, age, gender and race) ▶ Sample size ▶ Study aims and objectives ▶ Consensus methodology (eg, RAND, Delphi, Consultation, e-Portal, informal process) ▶ Stakeholder groups (including numbers of patients, family/caregivers, health providers, decision-makers) ▶ Recruitment strategy (including equity diversity inclusion principles)
Patient engagement	▶ Framework, methodology, policy or guide for patient engagement ▶ Types of shared documentation (eg, educational material) ▶ Tools and strategies (eg, interactive website or mobile apps) ▶ Frequency of engagement (eg, quarterly) ▶ Length/Duration of patient engagement ▶ Leaders/Facilitators of patient engagement ▶ Online versus in-person patient engagement ▶ Degree of involvement (eg, stage of process) ▶ Challenges, barriers and/or facilitators of engagement ▶ Evaluation and outcomes of patient engagement

Additionally, the results of this review will inform iKT processes for our larger project on prioritising quality indicators to support the transition of youth with chronic physical, mental or developmental disabilities into adult care.[45] Our systematic review identified 169 quality indicators, with most being developed without involving affected youth or caregivers.[45 75–82] To bridge this gap, we are conducting a national multiknowledge user initiative to actively engage youth and their caregivers, healthcare providers and health system leaders in prioritising quality indicators for benchmarking and supporting transition. An iKT panel includes these knowledge users as collaborators on the larger project to help inform national policies for supporting transition. To that end, this review will optimise and tailor our approach to knowledge user engagement.

It is clear that thoughtful and carefully planned processes for engaging specific patient partners are central to spearheading meaningful practice and policy change.[43–45 80 83] This was demonstrated by Healey *et al*[83] who used a robust consensus-building approach with well-deliberated patient engagement strategies to inform health policy on heart donation and transplantation across Canada.[83] As such, our scoping review will summarise the available consensus-building methodologies applied within the healthcare context. Moreover, our review may offer insights on specific consensus approaches to help prioritise the perspectives and needs of youth with chronic health conditions. This may include a multimodal approach composed of a blend of discussions, panels and small-group activities, videoconferences, anonymous surveys and regular contact prior to, during and following consensus-building meetings.[83 84] Beyond optimising our research, our findings have the potential to offer guidance for future research to effectively engage and build consensus with relevant knowledge users.

Although our scoping review will adhere to well-known methodological frameworks, it will not be without limitations. Studies may be missed given the conflation of terms relating to patient engagement (eg., knowledge user involvement, co-design, co-production), and its models, theories and frameworks. To mitigate this, we have broadly defined patient engagement to encompass commonly used search terms for describing patient engagement in the healthcare context. Additionally, consensus studies may be excluded due to lack of explicit detail on the use of patient engagement strategies, despite heavily involving patients throughout the process. Moreover, while no language restrictions were applied in the search strategy, foreign studies may be lost in translation and missed due to differing terminology for patient engagement and consensus. To account for differences in reviewer inter-rater reliability, robust application of screening criteria will be supported by shared, transparent documentation of the inclusion criteria. This will be further mitigated by pilot testing the screening criteria, as well as regular team meetings to evaluate articles and resolve conflicts through group consensus.

Notably, this proposed review has several strengths. These include searching non-empirical and grey literature sources to reduce publication bias.[85] To further maximise comprehensiveness, we will manually search reference lists of relevant non-primary studies, to identify articles not previously identified in our search. Additionally, all phases of the review will be conducted in duplicate to ensure consistent application and adherence to the prescribed methodology. Finally, the search strategy has been peer reviewed using the PRESS to enhance quality and comprehensiveness.[66]

Ethics and dissemination

Ethics approval is not required as this scoping review will synthesise findings from published literature. We will disseminate the study results using traditional strategies, such as symposia, conference presentations and publication in a peer-reviewed journal (eg, *BMJ Open* or *Research Involvement and Engagement*). Additional dissemination strategies will be informed by our iKT panel. This will contribute to the relevance, quality and appropriateness of reporting. Doing so will help increase the reach and sharing of our findings across various non-academic settings. We aim to dialogue directly with knowledge users through presentations across local, national and international conferences, including the SickKids Research Symposium, Annual Children's Healthcare Canada Transitions to Adulthood Conference and National Health Council: Science of Patient Engagement.

Author affiliations
[1]KITE Toronto Rehabilitation Institute, University Health Network, Toronto, Ontario, Canada
[2]Rehabilitation Sciences Institute, University of Toronto, Toronto, Ontario, Canada
[3]University of Toronto Temerty Faculty of Medicine, Toronto, Ontario, Canada
[4]The Hospital for Sick Children, Toronto, Ontario, Canada
[5]Hospital for Sick Children Research Institute, Toronto, Ontario, Canada
[6]University of Toronto Institute of Health Policy Management and Evaluation, Toronto, Ontario, Canada
[7]Medicine, University of Calgary Cumming School of Medicine, Calgary, Alberta, Canada
[8]McMaster University, Hamilton, Southern Ontario, Canada
[9]Integrated Knowledge Translation Panel Member, Toronto, Ontario, Canada
[10]Centre for Addiction and Mental Health Queen Street Site, Toronto, Ontario, Canada
[11]Lawrence Bloomberg Faculty of Nursing, University of Toronto, Toronto, Ontario, Canada
[12]Provincial Council for Maternal and Child Health, Toronto, Ontario, Canada
[13]Faculty of Social Work, University of Calgary, Calgary, Alberta, Canada
[14]CanChild Centre for Childhood Disability Research, Department of Pediatrics, McMaster University, Hamilton, Southern Ontario, Canada
[15]Department of Rehabilitation, Physical Therapy Science & Sports, Wilhelmina Children's Hospital University Medical Centre, Utrecht, The Netherlands
[16]National Health Hub in Transition, Children's Healthcare Canada, Hamilton, Southern Ontario, Canada
[17]CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, Southern Ontario, Canada
[18]Canadian Pediatric Society, Winnipeg, Manitoba, Canada
[19]Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, Alberta, Canada
[20]Surrey Place Centre, Toronto, Ontario, Canada
[21]IWK Health Centre, Halifax, Nova Scotia, Canada
[22]RAND Corp, Santa Monica, California, USA
[23]University of Toronto Centre for Quality Improvement and Patient Safety, Toronto, Ontario, Canada
[24]Martin Luther University College, Waterloo, Ontario, Canada
[25]Stollery Children's Hospital, Edmonton, Alberta, Canada
[26]School of Health Policy and Management, York University, Toronto, Ontario, Canada
[27]Department of Medicine, Women's College Hospital, Toronto, Ontario, Canada
[28]Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario, Canada
[29]Division of Endocrinology and Department of Paediatrics, University of Toronto, Toronto, Ontario, Canada
[30]National Health Hub in Transition, Children's Healthcare Canada, Ottawa, Ontario, Canada
[31]Patient Safety and Quality Improvement, North York General Hospital, Toronto, Ontario, Canada
[32]University Health Network, Toronto, Ontario, Canada
[33]Division of Adolescent Medicine, The Hospital for Sick Children, Toronto, Ontario, Canada

X Sarah E. P. Munce @drsarahmunce, Jan Willem Gorter @Dr_Gorter and Sarah Mooney @sarahmooney21

Acknowledgements The authors wish to sincerely thank Quenby Mahood, a reference librarian at the Hospital for Sick Children, for peer-reviewing the search strategy using the PRESS checklist.

Contributors AT, SEPM and DL conceptualised the design and methods of this scoping review, revised the manuscript and approved the final manuscript as submitted. EW synthesised the literature, drafted the initial manuscript, revised the manuscript and approved the final manuscript as submitted. All authors provided input and guidance on study design, approved the final manuscript as submitted and agreed to be accountable for all aspects of the scoping review.

Funding This work was supported by the Canadian Institute of Health Research (CIHR) through the CIHR Transitions in Care (TiC) Team Grant (Funding Reference Number: FBD-507043).

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the 'Methods' section for further details.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

ORCID iDs
Sarah E. P. Munce http://orcid.org/0000-0002-0595-8395
Katherine Bailey http://orcid.org/0000-0001-6486-4818
Tomisin John http://orcid.org/0009-0004-4588-3633
Claire Barber http://orcid.org/0000-0002-3062-5488
Kristin Cleverley http://orcid.org/0000-0002-2822-2129
Jan Willem Gorter http://orcid.org/0000-0002-3012-2119
Lisha Lo http://orcid.org/0000-0002-3875-4372
Geetha Mukerji http://orcid.org/0000-0002-6477-9848
Melanie Penner http://orcid.org/0000-0002-8376-9768
Patricia Trbovich http://orcid.org/0000-0002-8120-5926
Alene Toulany http://orcid.org/0000-0003-1238-7049

REFERENCES

1 Canadian Institute of Health Research. Knowledge translation. 2016. Available: http://www.cihr-irsc.gc.ca/e/29418.html#2
2 Jull JE, Davidson L, Dungan R, *et al*. A review and synthesis of frameworks for engagement in health research to identify concepts of knowledge user engagement. *BMC Med Res Methodol* 2019;19:211.
3 Nguyen T, Graham ID, Mrklas KJ, *et al*. How does integrated knowledge translation (IKT) compare to other collaborative research approaches to generating and translating knowledge? Learning from experts in the field. *Health Res Policy Sys* 2020;18:35.
4 Leggat FJ, Wadey R, Day MC, *et al*. Bridging the know-do gap using integrated knowledge translation and qualitative inquiry: a narrative review. Qual Res Sport Exerc Health 2023;15:188–201.
5 Smith B, Williams O, Bone L. The moving social work co-production collective. co-production: a resource to guide co-producing research in the sport, exercise, and health sciences. *Qual Res Sport Exerc Health* 2023;15:159–87.

6. Higgins T, Larson E, Schnall R. Unraveling the meaning of patient engagement: a concept analysis. *Patient Educ Couns* 2017;100:30–6.
7. Gifford W, Adams D, Gray E, *et al*. Developing and implementing culturally safe cancer survivorship strategies with first nations peoples. In: Kothari A, McCutcheon C, Boland L, et al, eds. *How We Work Together: The Integrated Knowledge Translation Casebook*. Ottawa, ON: Integrated Knowledge Translation Research Network, 2020: 2. 10–3.
8. Liddy C, Moroz I, Joschko J, *et al*. Using an integrated knowledge translation (IKT) approach to enable policy change for electronic consultations in Canada. *Healthc Policy* 2018;14:19–29.
9. Dunn S, Reszel J J, Weiss D D, *et al*. The experience of using an integrated knowledge translation approach to develop, implement and evaluate an audit and feedback system in Ontario maternal-newborn hospitals. In: Kothari A, McCutcheon C, Boland L, et al, eds. *How We Work Together: The Integrated Knowledge Translation Casebook*. Ottawa, ON: Integrated Knowledge Translation Research Network, 2020: 2. 2–6.
10. Gainforth HL, Athanasopoulos P, Casemore S, *et al*. Using IKT to translate the spinal cord injury physical activity guidelines in a community-based organization. In: McCutcheon C, Kothari A, Graham ID, eds. *How We Work Together: The Integrated Knowledge Translation Research Network Casebook*. Ottawa, ON: Integrated Knowledge Translation Research Network, 2019: 1. 45–50.
11. Graham ID, Kothari A, McCutcheon C, *et al*. Integrated knowledge translation research network project L. Moving knowledge into action for more effective practice, programmes and policy: protocol for a research programme on integrated knowledge translation. *Implement Sci* 2018;13:22.
12. Forsythe LP, Ellis LE, Edmundson L, *et al*. Patient and stakeholder engagement in the PCORI pilot projects: description and lessons learned. *J Gen Intern Med* 2016;31:13–21.
13. South A, Hanley B, Gafos M, *et al*. Models and impact of patient and public involvement in studies carried out by the medical research council clinical trials unit at university college London: findings from ten case studies. *Trials* 2016;17:376.
14. Zaheer R, Morassaei S, Hitzig SL, *et al*. A roadmap to engaging patients in research: the experience of a large academic research hospital in Canada. Patient Exp J 2023;10:155–63.
15. Crockett LK, Shimmin C, Wittmeier KDM, *et al*. Engaging patients and the public in health research: experiences, perceptions and training needs among Manitoba health researchers. *Res Involv Engagem* 2019;5:28.
16. Bombard Y, Baker GR, Orlando E, *et al*. Engaging patients to improve quality of care: a systematic review. *Implement Sci* 2018;13:98.
17. Lofters A, Virani T, Grewal G, *et al*. Using knowledge exchange to build and sustain community support to reduce cancer screening inequities. *Prog Community Health Partnersh* 2015;9:379–87.
18. Murphy L, Wells JS, Lachman P, *et al*. A quality improvement initiative in community mental health in the republic of Ireland. *Health Science Journal* 2015;9:1–11.
19. Reeve C, Humphreys J, Wakerman J, *et al*. Community participation in health service reform: the development of an innovative remote aboriginal primary health-care service. *Aust J Prim Health* 2015;21:409–16.
20. Acri M, Olin SS, Burton G, *et al*. Innovations in the identification and referral of mothers at risk for depression: development of a peer-to-peer model. *J Child Fam Stud* 2014;23:837–43.
21. Thomson A, Rivas C, Giovannoni G. Multiple sclerosis outpatient future groups: improving the quality of participant interaction and Ideation tools within service improvement activities. *BMC Health Serv Res* 2015;15:105.
22. Dodd S, Gorst SL, Young A, *et al*. Patient participation impacts outcome domain selection in core outcome sets for research: an updated systematic review. *J Clin Epidemiol* 2023;158:127–33.
23. Al Wattar BH, Tamilselvan K, Khan R, *et al*. Development of a core outcome set for epilepsy in pregnancy (E-CORE): a national multi-stakeholder modified delphi consensus study. *BJOG* 2017;124:661–7.
24. Almoajil H, Hopewell S, Dawes H, *et al*. A core outcome set for lower limb orthopaedic surgery for children with cerebral palsy: an international multi-stakeholder consensus study. *Dev Med Child Neurol* 2023;65:254–63.
25. Forget P, Patullo C, Hill D, *et al*. System-level policies on appropriate opioid use, a multi-stakeholder consensus. *BMC Health Serv Res* 2022;22:329.
26. Finger ME, Karcz K, Schiffmann B, *et al*. Prioritizing risk factors and identifying target areas to address with interventions to improve sustainable employment of persons with a brain injury or a spinal cord injury - a multi-stakeholder consensus process. *Front Rehabil Sci* 2023;4:1049182.
27. Shorter GW, Heather N, Bray JW, *et al*. Prioritization of outcomes in efficacy and effectiveness of alcohol brief intervention trials: international multi-stakeholder e-delphi consensus study to inform a core outcome set. *J Stud Alcohol Drugs* 2019;80:299–309.
28. Graffigna G, Barello S, Riva G, *et al*. Fertilizing a patient engagement ecosystem to innovate healthcare: toward the first Italian consensus conference on patient engagement. *Front Psychol* 2017;8:812.
29. van der Scheer JW, Woodward M, Ansari A, *et al*. How to specify healthcare process improvements collaboratively using rapid, remote consensus-building: a framework and a case study of its application. *BMC Med Res Methodol* 2021;21:103.
30. Dixon-Woods M. How to improve healthcare improvement-an essay by Mary Dixon-woods. *BMJ* 2019;367:l5514.
31. Waggoner J, Carline JD, Durning SJ. Is there a consensus on consensus methodology? Descriptions and recommendations for future consensus research. *Acad Med* 2016;91:663–8.
32. Cary MA, Plamondon K, Banner-Lukaris D, *et al*. Building consensus in research partnerships: a scoping review of consensus methods. *Evidence & Policy* 2023;19:485–511.
33. Madden JA. A practical guide for consensus-based decision making. 2017. Available: https://www.tamarackcommunity.ca/latest/a-practical-guide-for-consensus-based-decision-making
34. Jones J, Hunter D. Consensus methods for medical and health services research. *BMJ* 1995;311:376–80.
35. Harvey N, Holmes CA. Nominal group technique: an effective method for obtaining group consensus. *Int J Nurs Pract* 2012;18:188–94.
36. Van de Ven AH, Delbecq AL. The nominal group as a research instrument for exploratory health studies. *Am J Public Health* 1972;62:337–42.
37. Fitch K, Bernstein SJ, Aguilar MD, *et al*. *The RAND/UCLA Appropriateness Method User's Manual*. Santa Monica: Rand Corp, 2001.
38. Brook RH. Assessing the appropriateness of care—its time has come. *JAMA* 2009;302:997–8.
39. Dalkey N, Helmer O. An experimental application of the delphi method to the use of experts. *Management Science* 1963;9:458–67.
40. Landeta J. Current validity of the delphi method in social sciences. Technol Forecast Soc Change 2006;73:467–82.
41. Cleverley K, McCann E, O'Brien D, *et al*. Prioritizing core components of successful transitions from child to adult mental health care: a national delphi survey with youth, caregivers, and health professionals. *Eur Child Adolesc Psychiatry* 2022;31:1739–52.
42. O'Cathain A, Croot L, Duncan E, *et al*. Guidance on how to develop complex interventions to improve health and healthcare. *BMJ Open* 2019;9:e029954.
43. van C, McInerney P, Cooke R. Patients' involvement in improvement initiatives: a qualitative systematic review. *JBI Database System Rev Implement Rep* 2015;13:232–90.
44. Shen S, Doyle-Thomas KAR, Beesley L, *et al*. How and why should we engage parents as co-researchers in health research? A scoping review of current practices. *Health Expect* 2017;20:543–54.
45. Bailey K, Lee S, de Los Reyes T, *et al*. Quality indicators for youth transitioning to adult care: a systematic review. *Pediatrics* 2022;150:e2021055033.
46. Philp F, Freeman R, Stewart C. An international survey mapping practice and barriers for upper-limb assessments in movement analysis. *Gait Posture* 2022;96:93–101.
47. Roche P, Shimmin C, Hickes S, *et al*. Valuing all voices: refining a trauma-informed, Intersectional and critical reflexive framework for patient engagement in health research using a qualitative descriptive approach. *Res Involv Engagem* 2020;6:42.
48. Aarden E, Marelli L, Blasimme A. The translational lag narrative in policy discourse in the United States and the European Union: a comparative study. *Humanit Soc Sci Commun* 2021;8:107.
49. Richards DP, Cobey KD, Proulx L, *et al*. Identifying potential barriers and solutions to patient partner compensation (payment) in research. *Res Involv Engagem* 2022;8:7.
50. Richards DP, Poirier S, Mohabir V, *et al*. Reflections on patient engagement by patient partners: how it can go wrong. *Res Involv Engagem* 2023;9:41.
51. Richards DP, Strain K, Hawthornthwaite L, *et al*. Storytelling at board meetings: a case study of co-developing recommendations. *Patient Experience Journal* 2023;10:173–80.
52. Arakawa N, Bader LR. Consensus development methods: considerations for national and global frameworks and policy development. *Research in Social and Administrative Pharmacy* 2022;18:2222–9.
53. Buck D, Gamble C, Dudley L, *et al*. From plans to actions in patient and public involvement: qualitative study of documented plans and

the accounts of researchers and patients sampled from a cohort of clinical trials. *BMJ Open* 2014;4:e006400.
54 Preston J, Nafria B, Ohmer A, *et al*. Developing a more tailored approach to patient and public involvement with children and families in pediatric clinical research: lessons learned. *Ther Innov Regul Sci* 2022;56:948–63.
55 Preston J, Biglino G, Harbottle V, *et al*. Reporting involvement activities with children and young people in paediatric research: a framework analysis. *Res Involv Engagem* 2023;9:61.
56 Peters MDJ, Godfrey C, McInerney P, *et al*. Chapter 11: Scoping reviews (2020 version). In: Aromataris E, Munn Z, eds. *JBI Manual for Evidence Synthesis: JBI*. 2020.
57 Munn Z, Peters MDJ, Stern C, *et al*. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Med Res Methodol* 2018;18:143.
58 Munn Z, Pollock D, Khalil H, *et al*. What are scoping reviews? Providing a formal definition of scoping reviews as a type of evidence synthesis. *JBI Evid Synth* 2022;20:950–2.
59 Nyanchoka L, Tudur-Smith C, Thu VN, *et al*. A scoping review describes methods used to identify, prioritize and display gaps in health research. *J Clin Epidemiol* 2019;109:99–110.
60 Peters MDJ, Godfrey C, McInerney P, *et al*. Best practice guidance and reporting items for the development of scoping review protocols. *JBI Evidence Synthesis* 2022;20:953–68.
61 Tricco AC, Lillie E, Zarin W, *et al*. PRISMA extension for scoping reviews (PRISMA-SCR): checklist and explanation. *Ann Intern Med* 2018;169:467–73.
62 Khalil H, Peters MD, Tricco AC, *et al*. Conducting high quality scoping reviews-challenges and solutions. *J Clin Epidemiol* 2021;130:156–60.
63 Pollock D, Alexander L, Munn Z, *et al*. Moving from consultation to co-creation with knowledge users in scoping reviews: guidance from the JBI. *JBI Evidence Synthesis* 2022;20:969–79.
64 Pieper D, Puljak L. Language restrictions in systematic reviews should not be imposed in the search strategy but in the eligibility criteria if necessary. *J Clin Epidemiol* 2021;132:146–7.
65 McCarron TL, Moffat K, Wilkinson G, *et al*. Understanding patient engagement in health system decision-making: a co-designed scoping review. *Syst Rev* 2019;8:97.
66 McGowan J, Sampson M, Salzwedel DM, *et al*. PRESS peer review of electronic search strategies: 2015 guideline statement. *J Clin Epidemiol* 2016;75:40–6.
67 Innovation VH. Covidence systematic review software. Melbourne, Australia,
68 Cohen J. A coefficient of agreement for nominal scales. Educ Psychol Meas 1960;20:37–46.
69 Page MJ, Shamseer L, Altman DG, *et al*. Epidemiology and reporting characteristics of systematic reviews of BIOMEDICAL research: a cross-sectional study. *PLoS Med* 2016;13:e1002028.
70 O'Neill J, Tabish H, Welch V, *et al*. Applying an equity lens to interventions: using PROGRESS ensures consideration of socially stratifying factors to illuminate inequities in health. *J Clin Epidemiol* 2014;67:56–64.
71 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res* 2005;8:19–32.
72 Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277–88.
73 Kirkham JJ, Gorst S, Altman DG, *et al*. Core outcome set-standards for reporting: the COS-STAR statement. *PLoS Med* 2016;13:e1002148.
74 Gattrell WT, Logullo P, van Zuuren EJ, *et al*. ACCORD (accurate consensus reporting document): a reporting guideline for consensus methods in biomedicine developed via a modified delphi. *PLoS Med* 2024;21:e1004326.
75 Alashkar F, Aramayo-Singelmann C, Böll J, *et al*. Transition in sickle cell disease (SCD): a German consensus recommendation. *J Pers Med* 2022;12:1156.
76 Alenezi S, Alyahya AS, AlKhalifah SM, *et al*. Saudi expert consensus-based autism spectrum disorder statement: from screening to management. *Children (Basel)* 2022;9.
77 Quartermaine JR, Rose TA, Auld ML, *et al*. Participation measures that evaluate attendance and involvement for young people aged 15 to 25 years with cerebral palsy: a systematic review. *Disabil Rehabil* 2023;1–17.
78 Coulston F, Spittle A, McDonald C, *et al*. We are a unique breed": strategies to enhance physical activity participation for preschool-aged children born extremely preterm, a mixed-methods study. *Disabil Rehabil* 2023;45:4111–21.
79 Bailey K, Lee S, de Los Reyes T, *et al*. Quality indicators for transition from paediatric to adult care for adolescents with chronic physical and mental illness: protocol for a systematic review. *BMJ Open* 2021;11:e055194.
80 Sun HL, Breakey VR, Straatman L, *et al*. Outcomes indicators and processes in transitional care in adolescents with haemophilia: a delphi survey of Canadian haemophilia care providers. *Haemophilia* 2019;25:296–305.
81 Sobota AE, Shah N, Mack JW. Development of quality indicators for transition from pediatric to adult care in sickle cell disease: a modified delphi survey of adult providers. *Pediatr Blood Cancer* 2017;64.
82 Suris JC, Akre C. Key elements for, and indicators of, a successful transition: an international delphi study. *J Adolesc Health* 2015;56:612–8.
83 Healey A, van Beinum A, Hornby L, *et al*. Patient engagement in a Canadian consensus forum for heart donation after circulatory determination of death. *Can J Anesth/J Can Anesth* 2020;67:1738–48.
84 Baines RL, Regan de Bere S. Optimizing patient and public involvement (PPI): identifying its 'essential' and 'desirable principles using a systematic review and modified delphi methodology. *Health Expect* 2018;21:327–35.
85 Paez A. Gray literature: an important resource in systematic reviews. *J Evidence Based Medicine* 2017;10:233–40.

Appendix I: Medline Search Strategy

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations and Daily <1946 to July 18, 2023>

#	Searches	Results
1	Delphi technique/ or (Delphi or "modified-delphi").tw,kf.	18356
2	((concordance* or agreement* or concurrence*) adj2 (reach* or setting* or arriv* or process*)).tw,kf.	2658
3	consensus*.ti,kf. or consensus*.ab. /freq=2	57800
4	or/1-3	70456
5	(("PPI" or "patient and family" or "patient partner$" or "PFE-I$") adj2 engag*).tw,kf.	355
6	("patient and public involv*" or "Public and Patient Engagement").tw,kf.	1563
7	((online or internet or "web-based" or virtual*) adj2 (engage* or particip* or collab* or involv*)).tw,kf.	7415
8	(("lived experience" or "first-hand" or perception* or "patient experience*" or "personal experience*" or experience*) adj3 (ill* or disease* or chronic* or condition* or "health-related")).tw,kf.	42303
9	Professional-Family Relations/ or "Patient-Centered Care"/ or "Translational Science, Biomedical"/ or (("Patient-Centered*" or "patient-centred*" or "patient-centric" or "child-centered*" or "child-centr*" or "person-centred" or "person centric" or "family-centric" or "family centred" or "family centered*" or "user centric" or "client centric" or "client centred" or "client centered" or "person-centered" or "user centered" or "user centred" or "knowledge user*" or "co-design*" or "co-creat*" or "co-produc*" or "RAND/PPMD") adj2 (iKT or "integrated knowledge translation" or "integrated knowledge transfer*" or "disseminat*")).tw,kf.	38221
10	*Patient Participation/ or ((patient$ or child* or youth* or adolescen* or teen* or "patient and family" or "PFE" or "patient/caregiver" or caregiver$ or carer$ or guardian* or family* or families or parent* or mother* or father* or stakeholder$ or client* or "care partner*") adj2 (particip* or partner* or engag* or perspective* or advisor* or activat* or empower* or involv* or collab* or consult*)).tw,kf.	281432
11	or/5-10	360201
12	4 and 11	2885
13	(conference abstract or editorial or comment or letter or newspaper article).pt.	2193101
14	12 not 13	2860
15	("case reports" not "review").pt.	2204126
16	14 not 15	2845
17	remove duplicates from 16	2836

Appendix II: CINAHL Search Strategy

CINAHL Plus search strategy from 1947 to July 19, 2023

#	Query	Limiters/Expanders	Last Run Via	Results
S1	(MM "Delphi Technique") or TX (Delphi or "modified-delphi")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	16,478
S2	TI (consensus*) or AB (consensus*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	55,685
S3	TX ((concordance* or agreement* or concurrence*) W2 (reach* or setting* or arriv* or process*))	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	4,343
S4	S1 OR S2 OR S3	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	70,395
S5	MM Consumer participation or TX ((patient# or child* or youth* or adolescen* or teen* or "patient and family" or "PFE" or "patient/caregiver" or caregiver# or carer# or guardian* or family* or families or parent* or mother* or father* or stakeholder$ or client* or "care partner*") W2 (particip* or partner* or engag* or	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	244,018

	perspective* or advisor* or activat* or empower* or involv* or collab* or consult*))			
S6	TX (("PPI" or "patient and family" or "patient partner$" or "PFE-I#") W2 engag*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	603
S7	TX ((online or internet or "web-based" or virtual*) W2 (engage* or particip* or collab* or involv*))	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	7,860
S8	TX ("patient and public involv*" or "Public and Patient Engagement")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	2,040
S9	MH Physician-patient relations or MH Patient centered care or MM Translational Medical Research or TX (("Patient-Centered*" or "patient-centred*" or "patient-centric" or "child-centered*" or "child-centr*" or "person-centred" or "person centric" or "family-centric" or "family centred" or "family centered*" or "user centric" or "client centric" or "client centred" or "client centered" or "person-centered" or "user centered" or "user centred" or "knowledge user*" or "co-design*" or "co-creat*" or "co-produc*" or "RAND/PPMD") W2 (iKT or "integrated knowledge translation" or "integrated knowledge transfer*" or "disseminat*"))	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	68,359

S10	TX (("lived experience" or "first-hand" or perception* or "patient experience*" or "personal experience*" or experience*) W3 (ill* or disease* or chronic* or condition* or "health-related"))	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	32,870
S11	S5 OR S6 OR S7 OR S8 OR S9 OR S10	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	330,359
S12	S4 AND S11	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	7,928
S13	PT (conference abstract or "Case Reports" or editorial or comment or letter or newspaper article)	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	719,499
S14	S12 NOT S13	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	7,854
S15	S12 NOT S13	Limiters - Peer Reviewed; Exclude MEDLINE records Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen -	838

			Advanced Search Database - CINAHL Plus with Full Text	