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

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ABSTRACT

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Introduction Patient engagement and integrated knowledge translation (iKT) processes improve health outcomes and care experiences through meaningful partnerships in consensusbuilding 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.

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.

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/begjr

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

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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.²³ 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.¹⁷⁻¹³ 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 consensusbuilding 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.^{28–3035 41–47}

Existing gaps in organisational directives and training on knowledge user engagement have led to inconsistent and inadequate patient engagement in consensusbuilding 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

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The objective of this scoping review is to identify and synthesise patient engagement and iKT approaches, methods, and strategies that have been used for consensusbuilding 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, get the scoping review can clarify and map key concepts on 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 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 method-ology to enhance reporting quality.^{61 62} We have engaged Reviews and Meta-Analyses extension for Scoping Reviews knowledge users in the scoping review as outlined in 5 guidance by Pollock *et al.*⁶³ The protocol for the scoping review has been registered with the Open Science Framework (https://osf.io/begjr/).

Patient and public involvement

data min 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. 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) 664 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 handsearched 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, patientcentred, 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 Covidence⁶⁷ 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

Protec 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 g (eg., publication title, study aims), (b) study methodology 8 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 ğ pilot tested and refined with at least two members of uses related 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

to text Abstracted data from this scoping review will be analysed quantitatively into numerical counts (eg., geographical an 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, d including their roles, responsibilities, associated strate- > gies 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 given in the proposed scoping review aims to summarise

identify patient engagement approaches, methods and $\overline{\mathbf{g}}$ 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.

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 rev processes for our larger project or indicators to support the transition of	iew will inform iKT a prioritising quality of youth with chronic 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

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.

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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

Although our scoping review will adhere to well-known methodological frameworks, it will not be without limita-5 tions. Studies may be missed given the conflation of terms text 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 **B** the healthcare context. Additionally, consensus studies may be excluded due to lack of explicit detail on the use 9 of patient engagement strategies, despite heavily involving **≥** patients throughout the process. Moreover, while no uning, 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 interrater reliability, robust application of screening criteria will be supported by shared, transparent documentation nough group consensus. Notably, this proposed review has several strengths. These clude searching non-empirical and grey literature sources reduce publication bias.⁸⁵ To further ensiveness, we will 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.

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

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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 Sick-Kids Research Symposium, Annual Children's Healthcare Canada Transitions to Adulthood Conference and National Health Council: Science of Patient Engagement.

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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.

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