




BMJ Open Patient engagement in the development and implementation of navigation services: a scoping review protocol

Sarah Rabi ¹, Megan Patton,^{1,2} Maria-Jose Santana ^{1,2,3,4},
Karen L Tang ^{1,3,5}

To cite: Rabi S, Patton M, Santana M-J, *et al*. Patient engagement in the development and implementation of navigation services: a scoping review protocol. *BMJ Open* 2024;**14**:e082666. doi:10.1136/bmjopen-2023-082666

► 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-2023-082666>).

Received 30 November 2023
Accepted 19 July 2024



© Author(s) (or their employer(s)) 2024. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

¹Community Health Sciences, University of Calgary, Calgary, Alberta, Canada

²Pediatrics, University of Calgary, Calgary, Alberta, Canada

³O'Brien Institute for Public Health, University of Calgary, Calgary, Alberta, Canada

⁴Alberta Strategy for Patient-Oriented Research Patient Engagement Team, Edmonton, Alberta, Calgary

⁵Medicine, University of Calgary, Calgary, Alberta, Canada

Correspondence to

Ms Sarah Rabi;
sarah.rabi@ucalgary.ca

ABSTRACT

Introduction Patient navigation, a complex health intervention meant to address widespread fragmentation across the healthcare landscape, has been widely adopted internationally. This rapid uptake in patient navigation has led to a broadening of the service's reach to include those of different social positions and different health conditions. Despite the popularity and prevalence of patient navigation programmes, the extent of patient involvement and/or partnership in their construction has yet to be articulated. This scoping review will explore and describe the extent to which patients have been engaged in the development and/or implementation of patient navigation programmes to date.

Methods and analysis This scoping review will adhere to the Arksey and O'Malley framework for conducting scoping reviews. The electronic databases MEDLINE, CINAHL, EMBASE, PsycINFO, SocINDEX and Scopus were searched in September 2023 using terms related to patient navigation and programme implementation. Inclusion criteria stipulate that the studies must: (1) include an intervention labelled as 'navigation' in a healthcare setting and (2) describe patient engagement in the design, development and/or implementation process of said patient navigation programme. To assess study eligibility, two reviewers will independently read through the titles and abstracts, followed by the full texts, of each study identified from the search strategy to determine whether they meet inclusion criteria. Reviewers will then extract data from the included studies, present descriptive study characteristics in tables, and perform qualitative content analysis.

Ethics and dissemination This review does not require ethics approval as data will be collated exclusively from peer-reviewed articles and thesis dissertations. A manuscript summarising the results of the review will be written and submitted to a peer-reviewed journal for publication. The review will map aspects of programme development that have repeatedly utilised patient perspectives and areas where engagement has lagged. This review will also depict how patient engagement varies across programme characteristics.

INTRODUCTION

Patients often encounter significant challenges when accessing or interacting with health systems and providers due to ongoing

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The breadth of this scoping review will permit a thorough mapping of the state of patient engagement in patient navigation programme development, without constraints to one population, disease or programme type.
- ⇒ Adherence to the Arksey and O'Malley framework for scoping reviews, and subsequent Levac *et al* recommendations, will ensure that the scoping review process is rigorous and transparent.
- ⇒ Due to issues of feasibility, a grey literature search will not be conducted, inherently limiting the claims that can be made on the state of patient navigation outside of peer-reviewed articles and thesis dissertations.
- ⇒ This review will examine the *presence* and relative use of patient engagement in patient navigation programme development and implementation; however, an assessment of the *quality* of patient engagement is outside the scope of this review.
- ⇒ This review will exclusively assess the degree of patient engagement employed in 'patient navigation' programme development which may exclude programmes that provide similar services without being labelled as 'navigation'.

system re-engineering, expansion and specialisation.¹⁻³ For instance, patients with chronic conditions tend to receive care from a team of multiple physician specialists and non-physician healthcare professionals in addition to their family physicians.⁴ These numerous providers, contexts and settings of care can result in fragmented, incomplete and potentially unsafe care, particularly in the absence of clear and comprehensive information exchange across healthcare providers and patients.⁵⁻⁷ These issues are even more pronounced when a patient faces multimorbidity, limited health literacy and poor structural support external to the healthcare system (ie, inadequate housing, transportation and food security).^{8,9} As a result, populations with the greatest social vulnerability, a term referring to one's risk and sensitivity to

adverse health events, tend to experience the most significant barriers to accessing and manoeuvring through their care.^{10–12} In an attempt to mitigate the health inequities that stem from such social and systemic differences, the concept of patient navigation (PN) was conceived.¹³

The inaugural PN programme was based in Harlem, New York, and developed by Dr Harold Freeman, who identified the need to mitigate patient barriers to timely breast cancer care.¹³ This community-based programme aimed to increase access to breast cancer diagnostic and treatment services, particularly for local underserved populations (ie, black women facing financial limitations).^{14 15} This pilot programme resulted in a significant reduction in late-stage cancer diagnoses and an increase in 5-year survival rates.^{15 16} Since the first intervention, PN programmes have proliferated, providing personalised care to address patient barriers to health system access.¹⁷ In tandem with its rapid uptake, PN has also evolved and expanded in reach to assist general populations in addition to those experiencing social barriers to care.^{18 19} Furthermore, PN programmes are no longer confined to cancer care, with applications in chronic disease management, emergency care, primary care and paediatric-to-adult care transitions.^{20–24} Today, while a single universally agreed-upon definition of PN might not exist, Freeman and Rodriguez have more recently defined PN as a ‘community-based service delivery intervention designed to promote access to timely diagnosis and treatment of cancer and other chronic diseases by eliminating barriers to care’.¹³

While addressing patient barriers to healthcare access remains central to PN, it is unclear to what extent programmes are actually engaging patients as partners in programme design, development and implementation.^{25 26} This differentiation pertains to the fundamental delineator between programmes that are patient centred and those that are patient oriented; while PN is inherently patient centric, there is limited information to deduce the degree to which PN programmes have been co-built with patients. For instance, while various guidelines have been created to inform PN programme implementation, several of these frameworks make no reference to the need for patient partnership or consultation.^{27–29} While more recent protocols have begun to advocate the need for patient engagement in PN programming,^{30 31} uncertainty persists as to whether this advocacy has translated into practice in the development of truly patient-oriented programmes. Without understanding how patient partners have been included in the development of PN programmes, one cannot know the extent to which PN is useful and relevant to patients themselves.

The integration of patient perspectives into clinical programme design has many benefits and provides important insights to clinical care providers and teams. These advantages include improved access to a diversity of perspectives, increased awareness of end-user values, greater programme uptake, and strengthened trust between care providers and recipients,^{32 33} all of which

are underpinned by the need to ensure that the priorities of decision-makers align with patients’ care goals. Akin to this work, Bate and Robert similarly discuss the need for patient engagement throughout programme development to uphold the pillars of functionality, safety and usability in clinical practices.³⁴ Therefore, beyond recognising current gaps in patient care, the programmes generated by research teams must also be co-constructed with, and rooted in, care recipient perspectives to be authentically patient oriented.³⁵

Despite the importance of engaging patients as partners in the design and development of health services, the extent to which this has occurred in the field of PN remains unknown. Recognising this knowledge gap, this scoping review is intended to explore and describe the current state of patient engagement in the design, development and implementation of PN programmes through a comprehensive search of the literature. The results of this review have the potential to identify areas of strength and areas of improvement in the current construction of PN interventions.

METHODS AND ANALYSIS

The review will be informed by the scoping review methodological framework constructed by Arksey and O’Malley,³⁶ and built on by Levac *et al.*³⁷ This foundational framework for scoping reviews lays out a six-step method of identifying a research question, searching for relevant studies, selecting studies, charting data, presenting data and consulting with stakeholders on the relevancy and meaning of the findings. Reporting of the systematic review will adhere to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR).³⁸ We are actively in the process of conducting the title and abstract review phase of the project, with the plan to submit a manuscript for consideration by a peer-reviewed journal in Winter 2024.

Step 1: identifying the research question

A preliminary, informal search of the literature demonstrated a gap in knowledge on how patient perspectives have been integrated into the co-building of PN programmes. This knowledge gap informed the research question that will guide this scoping review: *What is known, from the published literature, about the extent of patient engagement in the design, development and/or implementation of patient navigation programmes?* The entire continuum of programme development is considered for this review—from initial needs assessments to eventual piloting of programmes.

Step 2: identifying relevant studies

To ensure a comprehensive search is conducted, electronic databases will be searched, and the reference lists of included articles will be manually reviewed. We have also taken the time to assemble a team with content and methodological expertise that will ensure the successful

completion of the review. Due to the feasibility and breadth of the anticipated electronic database search, a grey literature search will not be performed.

The electronic databases MEDLINE, CINAHL, EMBASE, PsycINFO, SocINDEX and Scopus were searched in September 2023. The search strategy included a combination of subject headings, keywords and synonyms for the concepts ‘patient navigation’ and ‘programme development’. Relevant studies were searched in MEDLINE to inform appropriate subject headings and keywords when constructing the search strategy. The search strategy was tested against these relevant (‘seed’) studies to ensure that the search strategy was comprehensive. The search strategies for each electronic database are included in the online supplemental materials. Only studies published from 1990 onwards will be considered for the review, as PN was first conceived as a construct in 1990. There will be no language restrictions.

Step 3: study selection

Due to the current heterogeneity of PN programmes and the lack of a universal PN definition, all studies that identify their programme as ‘PN’, or that claim to provide navigation services, will be included in the review. With that said, given our research objective is to explore the extent of patient involvement in programme development, any programme that is not intended to be patient facing (eg, programmes where navigators work only with providers, with no patient interaction) will be excluded. References to programme development in either peer-reviewed articles or thesis dissertations will be included in the review.

We have also attempted to define the scope of ‘programme development’ for the purposes of this review, with the team’s understanding of programme development directly informed by the National Institute for Health Research and Medical Research Council (MRC) framework for developing and evaluating complex health interventions.^{39 40} These phases include the physical steps of programme construction and/or identification, feasibility assessments and implementation efforts. The activities encapsulated within ‘program development’ provide a valuable reference for the research team, while still recognising that the operationalising of these steps will be

highly context dependent.³⁹ As such, conversations will be held among the entire study team to determine the phases of programme development addressed by each of the included studies. Articles will be included in the review if they address one or multiple of the programme development phases, with one caveat. We will not be including outcome or effectiveness evaluations of PN programmes in this scoping review, as we are focused specifically on the nature of patient engagement in programme development and implementation. This exclusion therefore does not pertain to studies conducting feasibility or implementation evaluations or needs assessments of PN programmes.⁴¹ Due to our desire to measure patient engagement in the construction of PN programmes, not the appraisal of pre-existing services, studies that exclusively detail PN programme evaluation efforts for already established programmes will be removed. This emphasises our interest in understanding the degree to which PN programmes have been ‘co-built’ with patient partners—a key tenet of patient-oriented research.³⁵

The inclusion and exclusion criteria for the scoping review are outlined in [table 1](#).

Following the search, all identified citations were collated and uploaded into Covidence (Veritas Health Innovation, Melbourne, Australia) for subsequent charting and analysis of the dataset.⁴² Throughout this process, two independent reviewers are actively using the inclusion and exclusion criteria to determine which abstracts adhere to the research question. Conflicts between the two reviewers at this stage are resolved through discussions with, and input from, a third reviewer. Following the compiling of all included abstracts, full texts will be pulled and reviewed. The reasoning for exclusion at the full-text review stage will be recorded and information on study selection at each stage will be presented in a PRISMA-ScR flow diagram.³⁸

Step 4: charting the data

All data extraction will be completed in duplicate, whereby one researcher will physically extract article information, and a second researcher will perform a cross-check of the information to ensure accuracy. Disagreements will be resolved through discussion or, in instances

Table 1 Inclusion/exclusion criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> ▶ Peer-reviewed articles and thesis dissertations outlining the development and/or implementation of an original PN programme. ▶ Papers reporting on programmes that are self-labelled or self-reported to be patient navigation, or its synonyms (eg, healthcare navigation, system navigation, care navigation). 	<ul style="list-style-type: none"> ▶ Interventions and programmes that are not described or labelled as ‘navigation’ programmes, or are not patient facing. ▶ Articles providing no description of programme design, development or implementation. ▶ Secondary literature (eg, systematic or scoping reviews). ▶ Studies aimed at modifying previously established PN programmes.
<p>No restrictions will be placed on the type of study design or participant age range that may be included in the review. PN, patient navigation.</p>	

**Table 2** Proposed strategy for data extraction

Categories of interest	Characteristics extracted
Basic study characteristics	<ul style="list-style-type: none"> ▶ Title ▶ Author ▶ Year published ▶ Journal ▶ Country ▶ Study setting
PN programme characteristics	<ul style="list-style-type: none"> ▶ Programme name ▶ Patient population ▶ Programme objectives ▶ Navigator characteristics ▶ Development phases addressed ▶ Mode of patient–provider interactions
Patient engagement characteristics	<ul style="list-style-type: none"> ▶ Patient partner population ▶ Mode of communication ▶ General methods/strategy for engagement (eg, research partnerships, advisory councils/consultative panels, community-based participatory research) ▶ Activities performed by patient partners (eg, research topic prioritisation, study material development, outcome selection, measurement tool selection/design, commenting on research proposals, peer interviewing, data analysis, research training).

where agreement is not reached, the inclusion of a third researcher. Data will be charted onto an Excel spreadsheet using a descriptive analytical approach, outlining any information about study participants, concepts, contexts, study methods and key findings that are relevant to the review question. Charted information will loosely break down into ‘basic study characteristics’, ‘PN program characteristics’, and ‘patient engagement characteristics’, with more granular detail about each of these categories provided in [table 2](#). Data extraction will also be stratified by patient age (paediatric and adult patient populations) given the inherent differences in research approaches and considerations to engaging with these patient populations.^{43 44} The drafted data extraction tool will be modified and revised as necessary. If needed, the authors of papers will be contacted to request missing or additional data.

As the primary intent of this study is to measure the extent of patient engagement taking place in PN programme development, patient engagement will be gauged using the MRC framework for developing and evaluating complex interventions in tandem with the International Association for Public Participation Spectrum of Public Participation.^{39 45} For this research, we are adhering to the Canadian Institutes of Health Research

(CIHR) definition of ‘patient engagement’ to ensure a collective understanding of the term. Per CIHR’s Strategy for Patient-Oriented Research, ‘patient engagement’ will be defined as patients, family members, caregivers and/or community members providing input, guidance or consultation on at least one aspect of the research process.³⁵ Recognising that approaches to patient engagement for programme development may differ from conventional research steps, this operational definition will also be applied to the stages of programme development. This operational definition is critical to the review as it asserts the fact that patient involvement as a research participant does not substantiate patient engagement or patient-oriented research.

Step 5: collating, summarising and reporting the results

Descriptive characteristics will be provided for all included studies and their affiliated PN programmes (ie, targeted populations, countries and study designs), as well as the modes of engagement practised (ie, characteristics of patient partners, engagement approaches, methods of engagement, stages of research where engagement occurred, activities performed by patient partners).

Conventional qualitative content analysis, as described by Hsieh and Shannon, will be used to develop a coding scheme for the documented approaches to patient and public participation in PN programme development.^{46 47} This approach first necessitates immersing oneself into the text to promote adequate utilisation of the hermeneutical circle.⁴⁷ Following data familiarisation, we will begin stratifying and condensing all full-text articles into their respective meaning units, ensuring that the key morsels of information are retained. Descriptive codes will then be generated for each unit and organised into overarching semantic categories that provide a narrative description of the researchers’ approaches to patient partnership. Depending on the nature of the text, latent themes may also be created that indicate any underlying and/or abstract meaning that we pull from the articles. Lastly, as with all preceding research steps, data coding and collation will be done through researcher triangulation to enhance the rigour of our findings.

Throughout the coding process, all researchers will keep a reflexive journal to document their interactions with, and reactions to, the text. This form of note taking will be particularly useful when charting our analytical pathway from meaning units to themes.

Step 6: consultation

Following search completion, review findings will be presented to four patient partners who have experience in navigating the healthcare system for different chronic conditions both inside and outside the context of formal PN services. Through stakeholder consultation, we hope to generate a more comprehensive understanding of the research topic by collating both literary evidence and patients’ lived experiences. For this step in the review process, the patient partners have been recruited

through the provincial body Alberta Strategy for Patient-Oriented Research SUPPORT Unit, which is dedicated to facilitating patient engagement in health research.⁴⁸ The longitudinal relationship these patient partners have with the research team will hopefully help mitigate the effects of power imbalances historically described in this step of the review process.⁴⁹ Virtual consultative meetings will be held once all preceding review steps have been completed. While a meeting agenda will be proposed in advance of each meeting, the conversations will be largely unstructured and guided by the input of the patient partners. All patient partners will be provided with an hourly compensation rate of \$25/hour as per current patient-oriented research guidelines.⁵⁰

Patient and public involvement

While patient and public input was not sought for the construction of this protocol, patient partner consultation in the review itself will be essential to data analysis, finding interpretation and devising research dissemination strategies.

ETHICS AND DISSEMINATION

This review does not require ethics approval as data will be extracted exclusively from published peer-reviewed articles and thesis dissertations. Following completion of the review, all pertinent findings will be presented in a drafted manuscript and submitted for journal publication. We predict the results of this review will capture how patient engagement has been used in PN programme development literature. Specifically, this review will address the aspects of programme development that have repeatedly utilised patient perspectives and areas where engagement has lagged. This review will also highlight whether researchers' affinity for patient engagement is disproportionate based on particular programme characteristics (ie, disease types or navigator tasks and functions). Understanding where patient input has faltered will direct subsequent research efforts to devise truly patient-oriented PN programmes.

X Maria-Jose Santana @MariaJ_Santana

Collaborators Not applicable.

Contributors SR, MP and KLT conceived the idea for the review and the inclusion/exclusion criteria. All authors constructed and contributed to the drafting of the protocol and analysis planning. SR and KLT constructed the search strategy in consultation with a health sciences librarian.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and

responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iDs

Sarah Rabi <http://orcid.org/0000-0002-3682-8016>

Maria-Jose Santana <http://orcid.org/0000-0002-0202-5952>

Karen L Tang <http://orcid.org/0000-0001-9008-2289>

REFERENCES

- 1 Plsek PE, Greenhalgh T. The challenge of complexity in health care. *BMJ* 2001;323:625–8.
- 2 Baker A. Book: crossing the quality chasm: a new health system for the 21st century. *BMJ* 2001;323:1192.
- 3 Shannon V, French S. The impact of the re-engineered world of health-care in Canada on nursing and patient outcomes. *Nurs Inq* 2005;12:231–9.
- 4 Wagner EH. The role of patient care teams in chronic disease management. *BMJ* 2000;320:569–72.
- 5 Walkinshaw E. Patient navigators becoming the norm in Canada. *CMAJ* 2011;183:E1109–10.
- 6 Walkinshaw E. Steering through the medical maze. *CMAJ* 2011;183:1698–9.
- 7 Reader TW, Gillespie A, Roberts J. Patient complaints in healthcare systems: a systematic review and coding taxonomy. *BMJ Qual Saf* 2014;23:678–89.
- 8 Griesel L, Berens EM, Nowak P, et al. Challenges in navigating the health care system: development of an instrument measuring navigation health literacy. *Int J Environ Res Public Health* 2020;17:5731.
- 9 Haggerty JL. Ordering the chaos for patients with multimorbidity. *BMJ* 2012;345:bmj.e5915.
- 10 Bade E, Evertsen J, Smiley S, et al. Navigating the health care system: a view from the urban medically underserved. *WMMJ* 2008;107:374–9.
- 11 Freeman HP. Cancer in the socioeconomically disadvantaged. *CA Cancer J Clin* 1989;39:266–88.
- 12 Mah JC, Penwarden JL, Pott H, et al. Social vulnerability indices: a scoping review. *BMC Public Health* 2023;23:1253.
- 13 Freeman HP, Rodriguez RL. History and principles of patient navigation. *Cancer* 2011;117:3539–42.
- 14 Freeman HP, Muth BJ, Kerner JF. Expanding access to cancer screening and clinical follow-up among the medically underserved. *Cancer Pract* 1995;3:19–30.
- 15 Freeman HP. Patient navigation: a community based strategy to reduce cancer disparities. *J Urban Health* 2006;83:139–41.
- 16 Oluwole SF, Ali AO, Adu A, et al. Impact of a cancer screening program on breast cancer stage at diagnosis in a medically underserved urban community. *J Am Coll Surg* 2003;196:180–8.
- 17 Vargas RB, Ryan GW, Jackson CA, et al. Characteristics of the original patient navigation programs to reduce disparities in the diagnosis and treatment of breast cancer. *Cancer* 2008;113:426–33.
- 18 Budde H, Williams GA, Scarpetti G, et al. What are patient navigators and how can they improve integration of care. *WHO* 2022;32. Available: [file:///Users/a14036/Downloads/Policy-brief-44-1997-8073-eng%20\(6\).pdf](file:///Users/a14036/Downloads/Policy-brief-44-1997-8073-eng%20(6).pdf)
- 19 Louart S, Bonnet E, Ridde V. Is patient navigation a solution to the problem of “leaving no one behind”? A scoping review of evidence from low-income countries. *Health Policy Plan* 2021;36:101–16.
- 20 Jiang LG, Zhang Y, Greca E, et al. Emergency department patient navigator program demonstrates reduction in emergency department return visits and increase in follow-up appointment adherence. *Am J Emerg Med* 2022;53:173–9.
- 21 Bhawra J, Toulany A, Cohen E, et al. Primary care interventions to improve transition of youth with chronic health conditions from paediatric to adult healthcare: a systematic review. *BMJ Open* 2016;6:e011871.

- 22 Chu PY, Maslow GR, von Isenburg M, *et al.* Systematic review of the impact of transition interventions for adolescents with chronic illness on transfer from pediatric to adult healthcare. *J Pediatr Nurs* 2015;30:e19–27.
- 23 Carter N, Valaitis RK, Lam A, *et al.* Navigation delivery models and roles of navigators in primary care: a scoping literature review. *BMC Health Serv Res* 2018;18:96.
- 24 McBrien KA, Ivers N, Barnieh L, *et al.* Patient navigators for people with chronic disease: a systematic review. *PLoS One* 2018;13:e0191980.
- 25 Schwaderer KA, Itano JK. Bridging the healthcare divide with patient navigation: development of a research program to address disparities. *Clin J Oncol Nurs* 2007;11:633–9.
- 26 Teitelman AM, Koblin BA, Brawner BM, *et al.* Just4Us: development of a counselor-navigator and text message intervention to promote prep uptake among cisgender women at elevated risk for HIV. *J Assoc Nurses AIDS Care* 2021;32:188–204.
- 27 Freund KM. Implementation of evidence-based patient navigation programs. *Acta Oncol* 2017;56:123–7.
- 28 C/Can. Guide on How to Implement a Nurse Navigation Programme for Cancer Patients. Switz, 2023:26. Available: <https://citycancerchallenge.org/uploads/2023/02/How-to-Implement-a-Nurse-Navigation-Programme-for-Cancer-Patients-FINAL.pdf>
- 29 Zeller J. Patient Navigation Measurement Tools: Overcoming Disparities through Patient Navigation. Rockville, Maryland, 2009. Available: <https://www.accc-cancer.org/docs/projects/pdf/patient-navigation-guide>
- 30 Doucet S, Luke A, Anthonisen G, *et al.* Implementing a Patient Navigation Program for People with Dementia. Fredericton, NB: University of New Brunswick, 2021:60. Available: https://www.unb.ca/cric/_assets/documents/implementation-resource-toolkit.pdf
- 31 Ver Hoeve ES, Simon MA, Danner SM, *et al.* Implementing patient navigation programs: considerations and lessons learned from the alliance to advance patient-centered cancer care. *Cancer* 2022;128:2806–16.
- 32 Bisson M, Aubrey-Bassler K, Chouinard M-C, *et al.* Patient engagement in health implementation research: a logic model. *Health Expect* 2023;26:1854–62.
- 33 Meskó B, deBronkart D. Patient design: the importance of including patients in designing health care. *J Med Internet Res* 2022;24:e39178.
- 34 Bate P, Robert G. Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *Qual Saf Health Care* 2006;15:307–10.
- 35 Canadian Institutes of Health Research. Strategy for Patient-Oriented Research - Patient Engagement Framework. Ottawa, ON: CIHR, 2019. Available: https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf
- 36 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8:19–32.
- 37 Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci* 2010;5:69.
- 38 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.
- 39 Skivington K, Matthews L, Simpson SA, *et al.* A new framework for developing and evaluating complex interventions: update of medical research council guidance. *BMJ* 2021;374:n2061.
- 40 Craig P, Dieppe P, Macintyre S, *et al.* Developing and evaluating complex interventions: the new medical research council guidance. *BMJ* 2008;337:a1655.
- 41 Centers for disease control and prevention. Program Operations Guidelines for STD Prevention: Program Evaluation [Internet]. n.d.:28. Available: <https://www.cdc.gov/std/program/ProgEvaluation.pdf>
- 42 Covidence: Better Systematic Review Management. Australia: Veritas Health Innovation, 2023. Available: <https://www.covidence.org/>
- 43 Jeremic V, Sénécal K, Borry P, *et al.* Participation of children in medical decision-making: challenges and potential solutions. *J Bioeth Inq* 2016;13:525–34.
- 44 Coyne I, Harder M. Children's participation in decision-making: balancing protection with shared decision-making using a situational perspective. *J Child Health Care* 2011;15:312–9.
- 45 International Association for Public Participation (IAP2). IAP2 Spectrum of Public Participation. 2018. Available: https://cdn.ymaws.com/www.iap2.org/resource/resmgr/pillars/Spectrum_8.5x11_Print.pdf
- 46 Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277–88.
- 47 Erlingsson C, Brysiewicz P. A hands-on guide to doing content analysis. *Afr J Emerg Med* 2017;7:93–9.
- 48 Alberta Strategy for Patient Oriented Research SUPPORT Unit (AbSPORU). Alberta Strategy for Patient Oriented Research SUPPORT Unit (AbSPORU, 2023. Available: <https://absporu.ca/>
- 49 Buus N, Nygaard L, Berring LL, *et al.* Arksey and O'malley's consultation exercise in scoping reviews: a critical review. *J Adv Nurs* 2022;78:2304–12.
- 50 SPOR Networks in Chronic Diseases and the PICH Network. Recommendations on Patient Engagement Compensation, 2018. Available: https://diabetesaction.ca/wp-content/uploads/2018/07/TASK-FORCE-IN-PATIENT-ENGAGEMENT-COMPENSATION-REPORT_FINAL-1.pdf