

BEYOND THE BINDER: TOOLS FOR THE JOURNEY, NOT THE SHELF – INNOVATIVE AND INTEGRATIVE FAMILY-CENTRED NAVIGATION RESOURCES

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DEFINITION OF PEDIATRIC CANCER NAVIGATION

Pediatric patient navigation is a coordinated function that facilitates access, advocacy and continuity across health, education and social systems for patients and their families. For the purpose of this study, rather than being tied to a single role or individual, patient navigation represents a proactive, system-integrated process that ensures children and families receive timely, equitable, accessible and individualized support throughout the continuum of care – from diagnosis through treatment, survivorship or end-of-life. Patient navigation bridges formal healthcare services with informal community-based supports, addressing the holistic and evolving needs of pediatric cancer patients and their families. It encompasses the identification and elimination of barriers, the coordination across settings and transitions, and the navigation of resources that span biological, psychological, social, emotional, cultural, spiritual, financial and gender-diverse domains. Patient navigation in the pediatric cancer community fosters trust, communication and family empowerment. It is rooted in the Bioecological Model¹ and Family Systems Theory². Both theories underscore the importance of considering that the environment that encompasses the child is interrelated and directly impacts outcomes, making it vital to consider the family and its relations as one system. Patient navigation should also be informed by trauma-informed, culturally inclusivity and inclusion principles to ensure that every interaction supports the patients and their families' voices, values, beliefs and right to informed decision-making.

BACKGROUND

Approximately 1,500 children and adolescents are diagnosed with cancer in Canada each year. Pediatric oncology care is complex, multidisciplinary, and frequently fragmented across healthcare, education, and social systems.³⁻⁶ Families report persistent challenges navigating services during diagnosis, treatment, survivorship, and palliative care.^{7,8} Patient navigation has emerged as a strategy to improve care coordination, access, and continuity, though a national assessment of existing patient navigation programs and resources for pediatric oncology has not been done yet in Canada.⁹⁻¹³

This project aims to:

- Conduct an **environmental scan** of existing patient navigation programs and resources for children with cancer and their families in Canada;
- Lead a **national needs assessment** to identify unmet navigation needs among patients, families, and healthcare teams & community-based organizations;
- Leveraging ACCESS' network, Community organizations, PWLE Community and social media platforms, we intend for the cross-sectional survey to be conducted Spring 2026 and will involve the administration of a self-administered online questionnaire using the REDCap™ electronic data capture system;
- Assemble the existing patient navigation resources into a centralized repository for use by the pediatric cancer community in Canada; and
- Use the information gleaned from the environmental scan and needs assessment to guide the development, implementation and dissemination of national patient navigation resources that support families, healthcare workers and community-based organization improve access, coordination, and integration of care.

OBJECTIVES & STUDY DESIGN

RATIONALE

Hi, I am Stephanie Reid, and this is my family (*well the cartoon version*).

This project grew from years of conversations with children, youth, parents, and caregivers across diverse and intersecting lived experiences. A consistent message emerged: navigating healthcare systems from diagnosis, through treatment, and into survivorship or bereavement is overwhelming, fragmented, and often isolating. Families described unclear pathways, repeated storytelling, gaps between hospital and community care, and inequities that compound stress during already traumatic moments. We recognize the limits of any single survey tool; no instrument can fully capture the depth, nuance, and diversity of experiences within the childhood cancer community; however, alongside an amazing research and working group team, this work is a step in an ongoing commitment to family-centered pediatric oncology care.

PARTICIPANTS

Adults aged ≥18 years including:

- Pediatric oncology healthcare professionals
- Childhood, adolescent, and young adult cancer survivors
- Parents or family members of pediatric cancer patients or survivors

RECRUITMENT

ACCESS Network & Partner Organizations
 Community Organizations
 Social Media Dissemination
 Patient Partners

INPUT & OUTCOME

Beyond the Binder: Tools for the Journey, Not the Shelf – Innovative and Integrative Family-Centered Navigation Resources will provide an evidence-based foundation to guide the development, implementation and dissemination of patient navigation solutions across Canada's pediatric cancer community to help reduce the burden on families, strengthen service integration and ensure that every child diagnosed with cancer has access to and receives the optimal care and support they need.

METHODOLOGY

This is a prospective, multi-phase, mixed-method study with a multidisciplinary team of investigators intended to describe the current landscape for pediatric oncology patient navigation resources across Canada in addition to highlighting opportunities to enhance patient navigation care delivery. Importantly, all phases of this project aim to seek input from persons with lived experience, health care professionals, and community organizations.

- Quantitative Methods: Survey development was led by a small group and reviewed with the broader working group for refinement. Distribution of the survey is planned through the ACCESS network, pediatric oncology community, and community organizations for broad engagement.
- Qualitative Methods: Investigators developed an interview guide to conduct semi-structured interviews with Key Informants.

Phase I - Environmental Scan of Existing Patient Navigation Programs and Resources for the Pediatric Oncology Community

- Phase IB – Review of Published and Grey Literature
- Phase IC – Interviews with Key Informants

Phase II - Assessment of the Patient Navigation Needs of the Pediatric Oncology Community in Canada (see table)

Phase III - Development of National Patient Navigation Resources

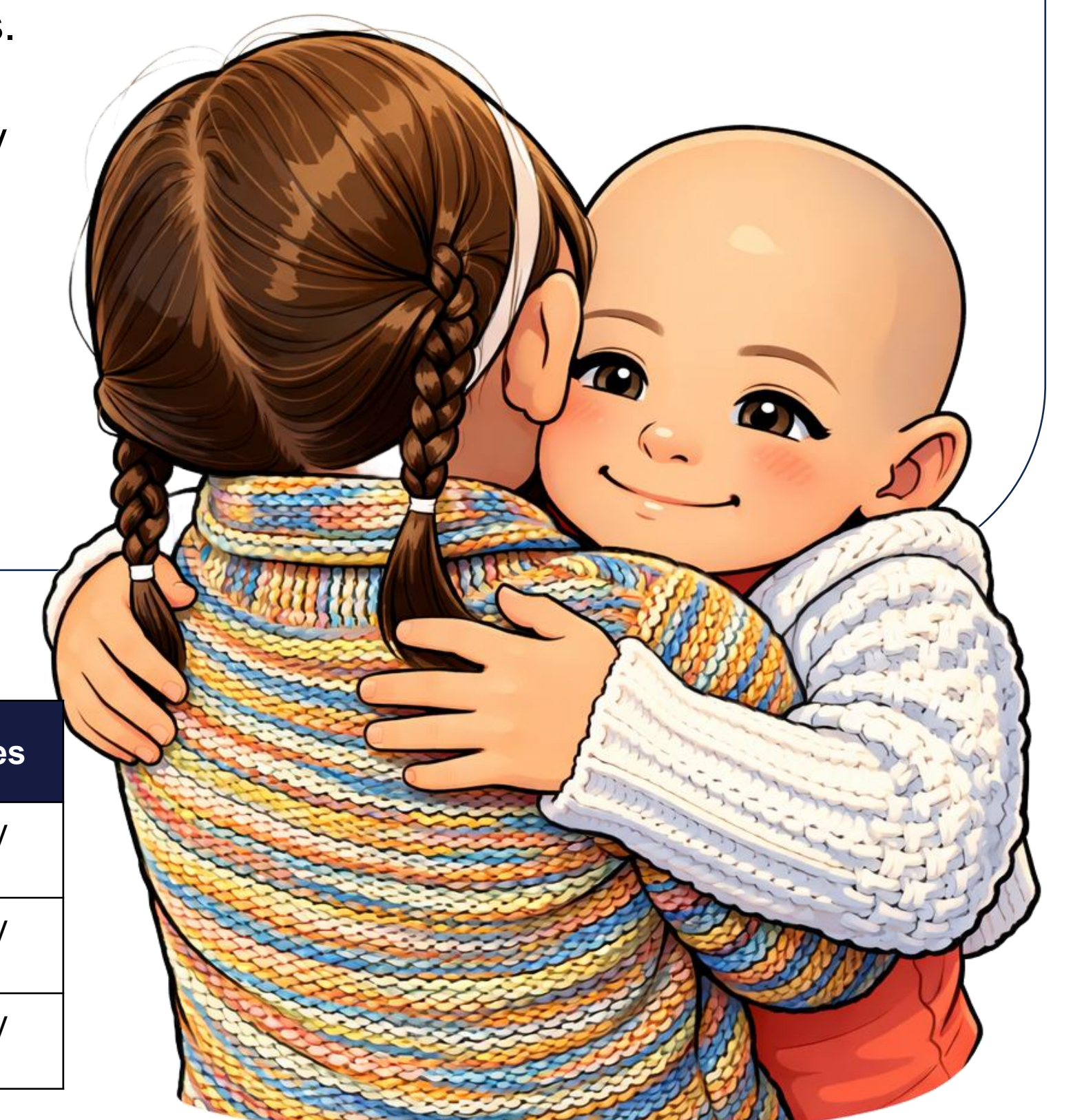
REFERENCES

1. Bronfenbrenner U. Ecological models of human development. In: International Encyclopedia of Education. 2nd ed. Vol 3. Oxford, UK: Elsevier; 1994:1643-1647.
2. Bowen M. *Family Therapy in Clinical Practice*. New York, NY: Jason Aronson; 1978; 3. Giammona AJ, Malek DM. The psychological effect of childhood cancer on families. *Pediatr Clin North Am*. 2002;49(5):1063-1081. x. doi:10.1016/S0031-3955(02)00036-6; 4. Chan RJ, Milch VE, Crawford-Williams F, et al. Patient navigation across the cancer care continuum: An overview of systematic reviews and emerging literature. *CA Cancer J Clin*. 2023;73(6):565-589. doi:10.3322/caac.21788; 5. Pannier ST, Warner EL, Fowler B, Fair D, Salmon SK, Kirchoff AC. Age-Specific Patient Navigation Preferences Among Adolescents and Young Adults with Cancer. *J Cancer Educ*. 2019;34(2):242-251. doi:10.1007/s13187-017-1294-4; 6. Keegan THM, Tao L, DeRouen MC, et al. Medical care in adolescents and young adult cancer survivors: what are the biggest access-related barriers? *J Cancer Surviv Res Pract*. 2014;8(2):282-292. doi:10.1007/s11764-013-0332-4; 7. A Mixed-Methods Quick Strike Research Protocol to Learn About Children With Complex Health Conditions and Their Families - Shelley Doucet, Daniel A. Nagel, Rima Azar, William J. Montelpare, Pat Charlton, Nicky Hyndman, Alison Luke, Roger Stoddard, 2017. Accessed November 8, 2024. <https://journals.sagepub.com/doi/10.1177/1609406917731426>; 8. Luke A, Doucet S, Azar R. Paediatric patient navigation models of care in Canada: An environmental scan. *Paediatr Child Health*. 2018;23(3):e46-e55. doi:10.1093/pch/pxx176; 9. Case MAB. Oncology nurse navigator. *Clin J Oncol Nurs*. 2011;15(1):33-40. doi:10.1188/11.CJON.33-40; 10. Pedersen A, Hack TF. Pilots of oncology health care: a concept analysis of the patient navigator role. *Oncol Nurs Forum*. 2010;37(1):55-60. doi:10.1188/10.ONF.55-60; 11. Parker VA, Lemak CH. Navigating patient navigation: crossing health services research and clinical boundaries. *Adv Health Care Manag*. 2011;11:149-183. doi:10.1108/s1474-8231(2011)0000011010; 12. Cook S, Fillion L, Fitch M, et al. Core areas of practice and associated competencies for nurses working as professional cancer navigators. *Can Oncol Nurs J Rev Can Nurs Oncol*. 2013;23(1):44-62. doi:10.5737/1181912x231445; 13. Guevara JP, Rothman B, Brooks E, Gerdes M, McMillon-Jones F, Yun K. Patient navigation to facilitate early intervention referral completion among poor urban children. *Fam Syst Health J Collab Fam Healthc*. 2016;34(3):281-286. doi:10.1037/fsh0000207

OpenAI. (2026). ChatGPT (GPT-5.2) [AI image generation]. <https://chat.openai.com/>



Participant Group	Survey Components	Domains Assessed
Patients & Families	Demographic and Socioeconomic Information Barriers to Resources and Care	Access to Information Access to Optimal Care Emotional, Psychological Cultural & Spiritual Barriers Legal, Financial & Social Barriers
Trainees, Learners & Healthcare Providers	Demographic and Socioeconomic Information Barriers to Resources and Care	Access to Information Access to Optimal Care Emotional, Psychological Cultural & Spiritual Barriers Legal, Financial & Social Barriers
Community-Based Organizations	Community Organization Demographics Supported	Patient Navigation and Care Coordination Psychosocial & Practical Supports



PHASE II	Written Data Sources	Verbal Data Sources
Professional Perspective	Survey and Systematic Review	Interviews with Key Informants
Patient & Family Perspective	Survey and Systematic Review	Interviews with Key Informants
Community based Organizations	Survey and Systematic Review	Interviews with Key Informants