

## Original Article

# Paediatric patient navigation models of care in Canada: An environmental scan

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#### **Abstract**

**Objectives:** (1) To provide other organizations with useful information when implementing paediatric navigation programs and (2) to inform the implementation of a navigation care centre in New Brunswick for children with complex health conditions.

**Methods:** This environmental scan consisted of a literature review of published and grey literature for paediatric patient navigation programs across Canada. Additional programs were found following discussions with program coordinators and navigators. Interviews were conducted with key staff from each program and included questions related to patient condition; target population and location; method delivery; navigator background; and navigator roles. Data analysis included analysis of interviews and identification of common themes across the different programs.

**Results:** We interviewed staff from 19 paediatric navigation programs across Canada. Programs varied across a number of different themes, including: condition and disease type, program location (e.g., hospital or clinic), navigator background (e.g., registered nurse or peer/lay navigator) and method of delivery (e.g., phone or face-to-face). Overall, navigator roles are similar across all programs, including advocacy, education, support and assistance in accessing resources from both within and outside the health care system.

**Discussion:** This scan offers a road map of Canadian paediatric navigation programs. Knowledge learned from this scan will inform stakeholders who are either involved in the delivery of paediatric patient navigation programs or planning to implement such a program. Specifically, our scan informed the development of a navigation centre for children with complex health conditions in New Brunswick.

**Keywords:** Adolescent; Child; Infant; Paediatrics; Patient navigation; Youth.

Approximately 13% to 18% of North American children and youth have a complex health condition that will impact their health and limit their daily activities (1,2). Children with complex health conditions (CCHC) are those with one or more chronic physical, emotional, behavioural or developmental condition(s) that require health and other services from multiple care providers in multiple locations (3). CCHC not only consume the majority of health care dollars, but they are vulnerable to experiencing a number of challenges and barriers to accessing care (4). Due to concerns regarding quality and fragmentation of care, stakeholders are exploring innovative ways to improve the quality and coordination of care for children and their families/caregivers, such as

the use of patient navigation (PN) programs (5). Unfortunately, there is currently little in the published literature about PN programs in Canada, particularly in a paediatric context. This lack of information is challenging for stakeholders who plan to develop patient-centred navigation models of care for CCHC. The purpose of this paper is to present results from an environmental scan of paediatric PN models in Canada.

#### **BACKGROUND**

PN is a relatively new concept. Developed in 1990, PN programs were initially created to eliminate barriers to care for poor

African American women with cancer from time of diagnosis to resolution (6). Since its first inception, PN has expanded and is now applied across the entire health care continuum. In the USA, PN programs have demonstrated improved outcomes for children and adults with chronic conditions, including increases in early intervention referral completion for poor, urban children (7), increased engagement with mental health services for mothers with depression (8) and improvement in care for patients with sickle cell disease (9). In Canada, numerous clinics and hospitals already incorporate PN into the services they provide. For example, Ontario has established numerous Community Health Centres that employ community health workers to help patients and families navigate the system (10). PN is often implemented to 1) improve patient care coordination, patient education and patient access to community resources and 2) provide emotional support and further develop community supports (11–13). For the most part, the literature on PN programs focuses on conditions (14), resulting in a lack of publications summarizing programs for specific populations, such as children and youth.

An agreed-upon comprehensive definition for PN is also missing in the literature. Definitions vary depending on the specific navigator (e.g., nurse, social worker, lay person), the clinical context (e.g., cancer, AIDS), the organizational setting of the navigator (primary care or acute care, not-for-profit organization) or the target population (insured versus uninsured underserved; marginalized versus ethnically or culturally diverse populations) (14).

## **PURPOSE**

PN has the potential to improve care coordination in a complex system (14); however, our preliminary review of the published and grey literature confirmed that there is sparse literature about PN programs in Canada, particularly within a paediatric context. The aim of this environmental scan was to address this gap in the literature by describing Canadian paediatric PN models in terms of their target populations and setting, navigator background and navigator roles. For the purposes of this environmental scan, PN is broadly defined as a process of collaboration between a professional (e.g., nurse, social worker) or lay person (e.g., peer) with a patient and his or her family and/or caregivers to provide navigational support, including education, emotional support and logistical guidance, as they attempt to navigate through a complicated maze of services, treatments, clinical interventions and/or programs (15).

#### **METHODS**

An environmental scan was used to generate a map of paediatric PN models of care in Canada. Originating in the business context, environmental scans are useful tools to develop insight

into the utilization of health services (16,17). Environmental scans allow for the assessment of trends, status, policy initiatives and strategies within a specific area (18) and have the advantage of identifying and avoiding potential problems and implementing useful solutions (19).

#### Search methods

This environmental scan consisted of a systematic Google search to identify paediatric PN programs across Canada. Search terms included: patient navigation, patient navigator, nurse navigator, care coordinator, family care coordinator, children, youth, paediatric and/or Aboriginal. To filter out programs from other countries, the search terms Canada, Canadian program or a reference to specific Canadian provinces were used. Once an initial list was generated, e-mails were sent to approximately 48 contacts from the programs identified in the scan. Phone interviews were then conducted with program coordinators and navigators from the paediatric PN programs. These stakeholders referred us to other relevant paediatric navigation programs in Canada. In total, we received responses and spoke with representatives from 23 programs. At this point, we were not finding models that differed significantly from the ones already documented and therefore stopped collecting data on models. After compiling the data into a table, we e-mailed each contact again sharing the table and inviting them to fill in any gaps and assess the data for accuracy.

#### Inclusion criteria

Only programs with at least one individual who is tasked with helping children aged 0-19 (with any condition) and/or their families, and/or their care provider(s) navigate the health care system and/or other related resources and services (e.g., transportation, education, social services) were included in the environmental scan. The intention was not to be completely exhaustive given the differing terminology used for PN programs in Canada, but rather to pull together a comprehensive list from across the country representing different types and models of programs.

## Data abstraction and synthesis

We extracted data using an abstraction form and included details related to condition; target population and location; method delivery; navigator background; and navigator roles. We validated the findings with each program contact prior to publication.

## **RESULTS**

Results from the scan indicated that a variety of paediatric navigation programs exist across Canada. Specifically, we found 23 navigation programs with representation across Canada, except for Saskatchewan, Prince Edward Island, Northwest Territories, Nunavut and Yukon (see Table 1 for a summary of programs). Please note that programs will be referred to in the results by their assigned letter from Table 1. The paediatric navigation

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Program title	Condition	Setting and target population	Delivery method	Background and position type Role	e Role
Alberta (AB) A. Diabetes Mellitus Transition Program	Type 1 and Type 2 diabetes	Calgary, AB (and surrounding area) Navigator works out of paediatric diabetes clinic Community based Youth 16–25 years old	Face-to-face Some social media (Twitter, Facebook)	Lay navigator (not a health professional)	Support Education Access services and resources
British Columbia (BC) B. The Sooke Navigator Project	) Mental health and addictions	Sooke, BC Navigator works out of Family Resource Society Community based Two groups: 13–19 years old and 19–25 years old	Face-to-face Some text messaging	Youth worker with a bachelor degree in the social services or equivalent	Support Access services and resources Advocacy Counselling Referrals made when case is too complex
C. Parents in Residence (PiR) and Youth in Residence (YiR) Programs	Mental health and addictions	The province of BC PiR often work from home YiR work out of The Kelty Mental Health Resource Centre at BC Children's Hospital Community based Youth up to 25 years old	Phone Some face-to-face	Peer navigators (parents or youth with lived experience)	Support Access resources and services Advocacy and mentorship
D. Indigenous Patient Liaison at BC Women's Hospital and Health Centre	All conditions	BC, Yukon, Whitehorse and parts of the Prairies Patient Liaisons work from Women's Hospital and Health Centre in Vancouver, BC Hospital based All Indigenous patients Children up to 17 years old	Face-to-face Some follow up over phone, e-mail, text	Social work (not mandatory but both liaisons have BSW)	Support Education Access resources and services
E. Complex Care Service at BC Women's Hospital and Health Centre	All conditions although must be determined to be complex	BC, Yukon, Whitehorse and parts of Prairies Team works from BC Women's Hospital and Health Centre in Vancouver, BC	Some face-to face (initial meeting) Phone, e-mail, text	Social work and registered nurse	Support Education Access services and resources

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Program title	Condition	Setting and target population	Delivery method	Background and position type Role	e Role
	(either from a health or psychosocial perspective)	Hospital to community Children and youth up to 17 years old			
Manitoba (MB) F. The Maestro Project	Type 1 and Type 2 diabetes	Winnipeg, MB Manitoba as well as North Western Ontario and Eastern Saskatchewan Community based Youth 14–16 up to 25 years old	Phone, e-mail, or social media Some face-to-face	Bachelor degree (BA, BSc, BSW) with 5 years work experience	Support Education Advocacy
New Brunswick (NB)					
G. Pediatric Oncology Patient Navigator	Oncology	Province of NB  Hospital to community All children up to 18 years old with a cancer Some face-to-face diagnosis (diagnosis made in Quebec or Nova Scotia) and their families, as well as members of health care team	Phone and e-mail Some face-to-face	Registered nurse	Support Access services and resources Care coordination
H. Rehabilitation Counsellors with Ability	Mobility disability	Province of NB Rehabilitation Counsellors either work out of office or their own home Community based Anyone (young children to seniors) with a mobility disability	Face-to-face (location varies) Some social media, e-mail, Skype	BA in psychology or social work	Support Access services and resources
Newfoundland and Labrador (NL) I. Aboriginal Patient All conditio Navigator Program	abrador (NL) All conditions	Health Sciences Centre General Hospital in Saint John's, NL Hospital based All Aboriginal patients (children and adults) who are brought to the hospital for the duration of their hospital stay	Face-to face Some phone and e-mail when necessary	Lay patient navigator	Support Access services and resources

Program title	Condition	Setting and target population	Delivery method	Background and position type Role	e Role
Nova Scotia (NS) J. Non-Insured Health Benefits Navigator Program	All conditions	Navigator is located in NS Atlantic Canada as well as a few Mi'kmaq communities in Quebec Community based All First Nations and Inuit persons (children and adults) living on or off reserve as well as health care professionals	Phone Some face-to-face	Bachelor degree	Support Access services and resources Education
K. Family Care Coordinator (FCC)	Oncology	Located in IWK Health Centre in Halifax, NS All of maritime provinces (NB, Prince Edward Island [PE] and NS) Hospital to community Children and youth 0–16 with a diagnosis of oncology and hematology and brain tumors will see patients up to 19 years old diagnosed with childhood cancer	Face-to-face when in hospital E-mail, phone	Registered nurse	Support Coordinate care Education
L. Diabetes Care Program of Nova Scotia	Type 1 diabetes	Located in Halifax but covers all of NS Community based Primarily work with professionals who work with youth between 13 and 18 years old with Type 1 diabetes	Phone, e-mail	Social worker	Education
Ontario (ON) M. Care Navigator	Mental health	Located in the Hospital for Sick Children in Toronto, ON Hospital based Children and adolescents 4–18 years old referred to psychiatry outpatients program	Face-to-face	Registered nurse, child and youth worker and social worker (3 positions)	Coordinate care Access services and resources Support

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Program title	Condition	Setting and target population	Delivery method	Background and position type Role	Role
N. Family Navigation Project	Mental health	Community program housed at Sunnybrook Hospital, ON Serves Greater Toronto Area Community based Families of youth with mental health or	Phone, e-mail	Masters in a related field (social work or psychology) and 2 years clinical experience Peer navigators (parents with lived experience)	Support Access services and resources Access programs
O. The 'Navigator' Program with the Children's Hospital in Eastern Hospital (CHEO)	N A	Ottawa, ON but targets Champlain Local Health Integration Network area Navigators work from Pinecrest Community Health Centre and CHEO Complex Care Centre Community based Parents of medically fragile children	Face-to-face (various locations)	Community development training, social worker Peer navigators (parents with lived experience)	Support Access services and resources Education
P. Champlain Complex Care Program with the Children's Hospital in Eastern Hospital (CHEO)	Medically complex conditions	Ottawa, ON but targets Champlain Local Health Integration Network area Hospital to community Medically fragile children	Face-to-face, phone, Registered n e-mail	Registered n	Coordinate care
Q. The Pediatric Oncology Group of Ontario (POGO) Interlink Community Nursing Program	Oncology	Province of ON Located in a hospital (based on region) but will meet patients, families and caregivers in community Hospital to community Children up to 18 years old with a cancer diagnosis	Face-to-face, e-mail, Registered nurse phone	Registered nurse	Support Education Access services and resources Advocacy
R. Transition Navigator for Sickle Cell and Thalassemia Programs	Sickle cell and thalassemia	Based in Hospital for Sick Children, Toronto, ON, works with children/youth from sickle cell and thalassemia clinic Community based	Face-to-face, e-mail, phone	Masters-educated health care provider Registration with a college/ regulatory body	Support Access services and resources Education Coordinate care

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Program title	Condition	Setting and target population	Delivery method	Background and position type Role	: Role
S. Family Advisor with Pediatric Family Resource Centre at the Children's Hospital, London Health Sciences Centre	Any child/youth who is in hospital	Works with youth at children's hospital up to 18 years old then follow up for 1 year (19 years old) at an adult hospital Based in the Children's Hospital in London, ON, works with any family that contacts or is referred to the centre Hospital to community	Face-to-face, some phone follow-up	Parent with lived experience (paid position)	Support Access services and resources Education
T. Service Navigator with Children's Treatment Network	Children with multiple complex needs—but will help anyone who calls	Simcoe and York Region Community based Children and youth (newborn to 18 years old or while still enrolled in school)	Phone, e-mail	(Backgrounds vary) Access services a Occupational Education therapist, registered nurse, Coordinate care social worker, resource teacher, communication disorder assistant	Access services and resources Education Coordinate care
U. Northern and Native Health	All conditions	Montreal Children's Hospital, Montreal, QC Work with clinical team Hospital to community Aboriginal children (newborn to 18 years old) and their families/caregivers who come to hospital for appointments or as inpatients	Face-to-face	Registered nurse	Access services and resources Coordinate care

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Program title	Condition	Setting and target population	Delivery method	Delivery method Background and position type Role	e Role
V. Complex Care Services	Medically complex	Montreal Children's Hospital, Montreal, QC	Face-to-face initially, Registered nurse then phone	Registered nurse	Support
		Serves children and families from Montreal and surrounding area			Access services and resources Education
		Hospital to community Medically complex children up to			
W. Health Care	All conditions	18 years old Wendake, QC	Phone, e-mail, fax	Bachelor degree in Health	Support
Liaison Agent		Community based Program covers all First Nations and		or Social Sciences or equivalent education and	Access services and resources Education
		Inuit persons living on or off reserve in Quebec Region		work experience	

programs differed across several features, namely: condition; target population and setting of program; method of delivery; navigator background; and navigator role, which will each be discussed separately.

#### **Condition**

Paediatric PN programs in Canada have been established to assist children and youth with a variety of conditions and their families/caregivers, with the majority being in the area of mental health and addictions (B, C, M, N). There are also several well-established care models for diabetes transition (A, D, J), medically complex conditions (E, O, P, V) and oncology (G, K, Q), with 3 out of 19 for each. The programs for children with medically complex conditions targeted CCHC who are fragile and require high-intensity care. These children may be technology dependent, have multiple care needs and are vulnerable to sudden changes in health (1,3). Four of the programs included did not target a specific condition. Rather, they were established to either serve First Nations and Inuit peoples (D, I, J, U, W) or any child with a complex condition (S, T). Navigation for Aboriginal people is available to all First Nations and Inuit patients who required assistance while either hospitalized or accessing health coverage. The two remaining programs targeted patients with sickle cell and thalassemia (R) and families with children and youth with a mobility disability (H).

## Target population and setting

Programs also varied based on the target population, including the age of child or the stakeholder group (e.g., children, parents, health professionals), as well as the setting in which the program is delivered. In terms of the target population, Canadian programs targeting children with a mobility disability (H), paediatric oncology (G, K, Q), complex conditions (E, P, V), children in hospital (S), children with complex needs (T) and First Nations and Inuit populations (D, I, J, U, W) assisted children and youth 0 to 18/19 years of age and their parents/caregivers. The remaining paediatric navigation programs targeted teens. Transition-focused programs (A, F, L, R) (e.g., diabetes and sickle cell and thalassemia) typically started navigation around age 12 and continued until patients were in their early 20s. Most mental health and addictions navigation programs (B, C, M, N) served adolescents, although there was flexibility regarding ages for this population. The one exception was the Care Navigator program (M) at the Hospital for Sick Children in Toronto. This program targeted children and youth aged 0 to 18 with mental health and addictions, as the program is constrained by rules governing the children's hospital (they only served children up to age 18). One unique program targeted the caregivers of CCHC (O), arguing that when parents/caregivers are stressed, children have poorer health outcomes.

In terms of setting, four programs worked exclusively with patients while they were either inpatients or outpatients of a hospital-based department (D, I, M, U). Of these, three Aboriginal navigation programs were established to assist First Nations and Inuit patients who had to travel for hospitalization (D, I, U), while the third included a mental health and addictions outpatient program (M) that worked with patients receiving treatment through the hospital. Seven programs assisted with the hospital-to-community transition following patients and families/caregivers after discharge. These programs included navigation for medically complex children (E, P, V), children admitted to a local children's hospital (S) and paediatric oncology (G, K, Q). Once discharged, these programs assisted patients and families/caregivers within their communities. Most navigation programs (12 of 23) worked with patients and families/caregivers primarily within a community setting to access community-based resources, including programs targeting mental health issues (B, C, N), transition from paediatric to adult care (A, F, L, R), Aboriginal communities (J, W), mobility disabilities (F), parents of medically complex children (O) and a program for any child or youth with multiple, complex needs (T).

Although still in the early stage of program development, two programs targeted health professionals, specifically a diabetes transition program (L) and a Native and northern health program (U). In these instances, programs had minimal contact with patients and families, rather, navigators worked with health care professionals to assist in the provision of patient-centred care.

## Delivery method

Program delivery method also varied, including face-to-face, phone, e-mail and social media format—with most programs relying on a combination of delivery methods. Several programs emphasized a face-to-face delivery format, including all inpatient programs (D, I, M, U) and many of the community-based programs (A, B, H, O, R). Most programs that assisted patients transition from hospital to community, such as complex care programs (E, P, V) and paediatric oncology programs (G, K, Q), used faceto-face interaction when patients were in hospital and then shifted to phone and e-mail once patients returned home. Remaining programs relied on e-mail, phone and some social media for contact with patients and families/caregivers (C, F, J, L, N, T, W). Social media was most common with one transition program for youth who were more inclined to text or use Facebook Messenger (F). Programs that covered large geographical areas were forced to rely on different methods of contact (phone, e-mail or other virtual methods), such as two transition programs (F, L), three paediatric oncology programs (G, K, Q) and two First Nations and Inuit programs (J, W). One exception was a mental health and addictions program in Toronto (N). Although this program targets individuals living in the Greater Toronto Area, it relies on phone and e-mail as communication tools.

## Navigator background

Programs varied based on the background of the navigator, including registered nurses (RN), social workers, counsellors, community health workers or peer navigators. Six programs targeting paediatric oncology (G, K, Q) or medically complex children (E, P, V) employed RNs as navigators or care coordinators with clinical experience. A program for children and youth with mental health and addiction issues (M), as well as a program for Aboriginal children (U), also relied on a RN for one of their navigator positions. Programs targeting children and youth with mental health and addiction issues (B, M, N), transition programs (L), families with a child or youth with a mobility disability (H), children with multiple, complex conditions (T) and parents with medically complex children (E, O) often employed professionals, such as social workers and mental health counsellors. Several programs required a university degree as the only credential (F, J, L, R, W), whereas others also required experience working in the health care field in addition to a degree. The few remaining programs employed peer navigators or individuals with lived experience (A, C, N, O, S). This was most typical with programs targeting youth with mental health and addiction issues. In two programs (N, O), both peer navigators and professionals worked collaboratively to assist families.

## Navigator roles

Overall, navigator roles were similar across all programs, including education, support and assistance in accessing resources from both within and outside the health care system. Care coordination was mentioned in a few programs (G, K, M, P, R, S, T, U). While all programs assisted in care coordination with children/youth, caregivers/families and the health care system, only six specifically worked within the context of an interprofessional and at times an intersectoral team. Although some programs placed an emphasis on advocacy work and even empowerment, most did not.

## **DISCUSSION**

The goal of this environmental scan was to describe paediatric PN programs in Canada. Data were collected on a number of program criteria, namely: condition; target population and setting; method of delivery; and navigator background and roles.

This scan has informed the implementation of a navigation centre in New Brunswick for CCHC. Our scan also provides other organizations with useful information when developing and/or implementing similar PN programs.

Although the role of PN has lacked clarity (14,15), results from this scan demonstrate that paediatric navigation programs in Canada share a common philosophy and goals which are adapted to target population and condition types. Shared goals included support, education and improved access to resources and services. Programs adapt how these goals are

reached by altering method of delivery or background of the navigator. For example, a diabetes transition navigator in Winnipeg relied heavily on social media as the primary method of delivery due to the geographic location of most of the target population. Programs that require more advanced clinical knowledge and skills hired RN, while most programs that assisted families of children and youth with mental health issues and/or addiction relied on counsellors or parents with lived experience. This reflects an emphasis on the support you can only receive from someone who 'has been here'.

## STRENGTHS AND LIMITATIONS

The main strength of this scan is a report of Canadian paediatric navigation programs that reflect the uniqueness of each program and of different regions of the country. Stakeholders who are either involved in the delivery of paediatric PN programs or planning to implement such a program can use this scan to help inform their planning. Nevertheless, despite our initial efforts to include all existing programs, this scan remains limited in its scope. Specifically, the final list of paediatric navigation programs is not comprehensive, primarily because of inconsistent language used in the program name or navigator position. For example, although many programs emulate a navigation model, few actually call themselves or refer to their programs as 'navigation programs'. There is also confusion between clinics or hospitals that employ a 'patient navigator' versus stand alone navigation 'programs'. Again, these variations pose a challenge for research as well as reporting.

## **CONCLUSION**

PN has the potential to improve care coordination in a health care system that is fragmented and complex. Despite the variation in condition type, target population, patient navigator background and delivery format, most programs share the same explicit or implicit mission of alleviating fragmentation within the health care system. This scan will assist other organizations, health care professionals and stakeholders in findings ways to improve care coordination by providing them with a description of the Canadian navigation programs that target children, families and the care team.

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