

# Understanding the Current Landscape of Survivorship Care for Childhood, Adolescent, and Young Adult Survivors of Childhood Cancers and Developing a Canadian Survivorship Care and Advocacy Network

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## Introduction

- **Rising survivorship:** Advances in pediatric oncology have resulted in a growing population of childhood cancer survivors across Canada.
- **High burden of late effects:** Most survivors develop chronic health conditions by midlife, highlighting the need for long-term, multidisciplinary care.
- **Variable survivorship care:** Survivorship care models and follow-up protocols vary across jurisdictions, leading to inconsistencies and inequities in care delivery.
- **Access barriers:** Geographic disparities, workforce shortages, and inconsistent funding limit access to survivorship services, particularly for survivors in rural and remote communities.
- **Need for equitable survivorship care models:** Scalable, coordinated, and equitable survivorship care models are urgently needed to address the long-term needs of childhood cancer survivors nationwide.

## Objectives

1. Assess survivorship care practices for childhood cancer survivors in Canada to identify gaps, unmet needs, and desired supports from diverse stakeholder perspectives.
2. Establish a pan-Canadian network of healthcare providers, childhood cancer survivors, and families, **the Canadian Survivorship Care and Advocacy Network for Children, Adolescents, and Young Adults with Cancer (CAN SCAN)**, to deliver consistent, person-centred survivorship care and advance research nationwide.

## Timeline

1. **Project Start Date:** January 2025
2. **Anticipated Project Completion Date:** March 2026

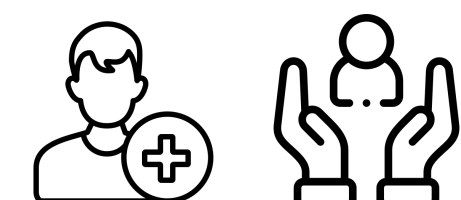
## Methods

This study is employing a mixed-methods approach, integrating both quantitative and qualitative methods to understand the current landscape of survivorship care in Canada, focusing on two cohorts:

### A. Healthcare providers



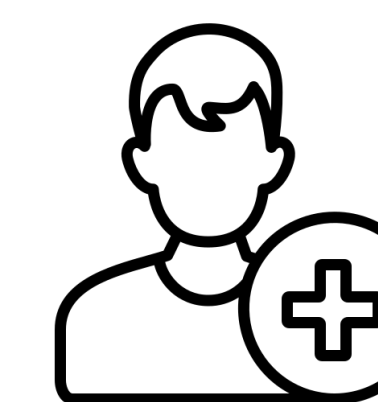
### B. Survivors and caregivers



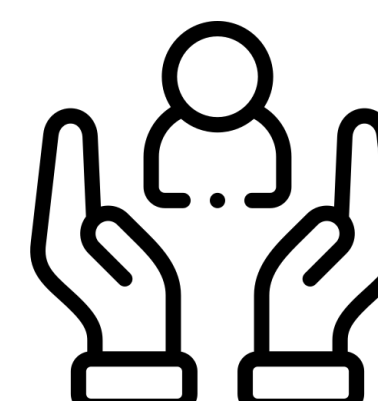
## Study Participants



**Healthcare Providers:** Physicians, nurse practitioners, nurses, psychologists, social workers and other healthcare providers involved in survivorship care delivery at 16 pediatric or adult oncology centers in Canada.



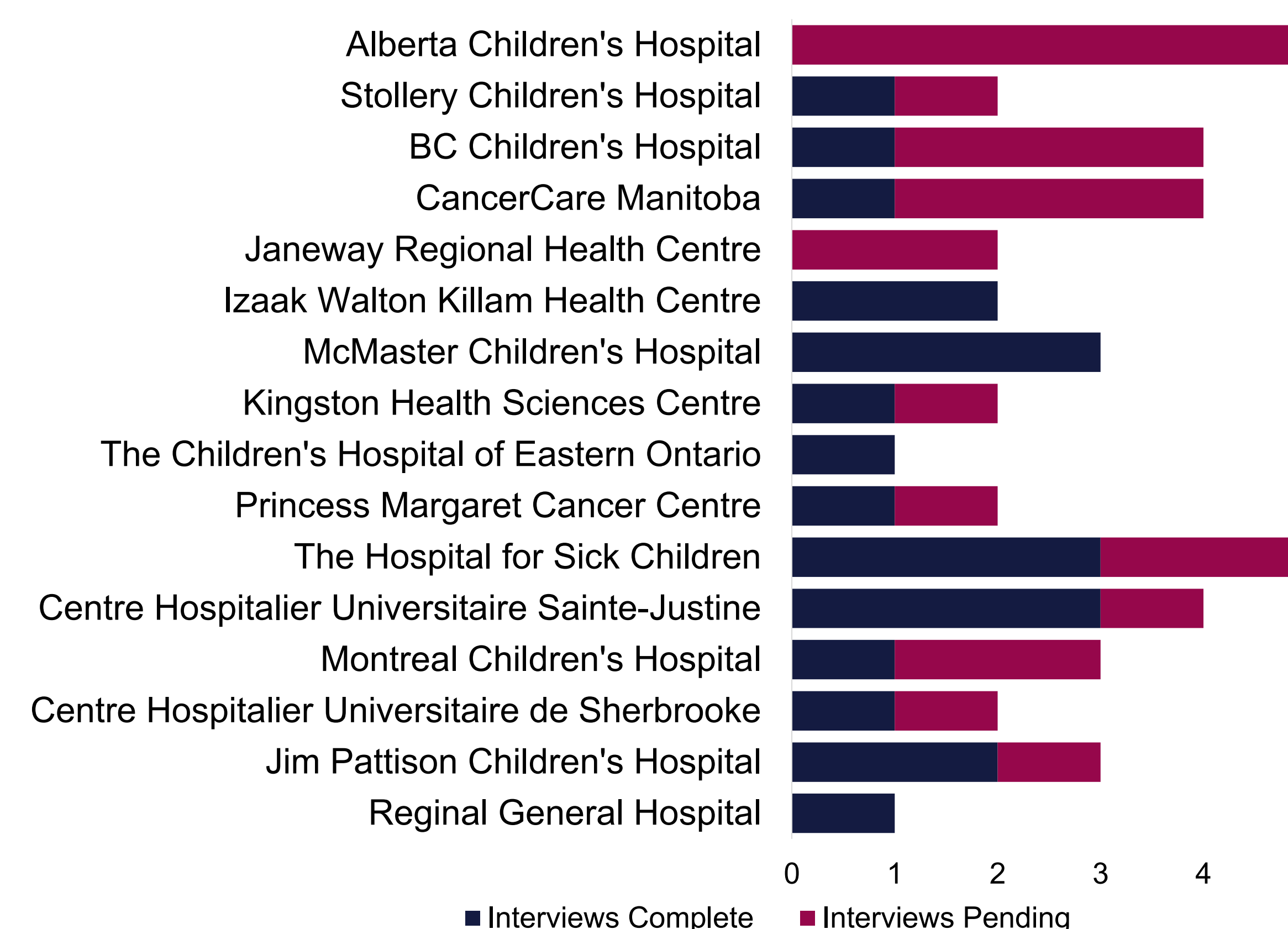
**Survivors:** Individuals diagnosed with cancer before age 21, now age 18 or older, having completed treatment 5 or more years ago, residing in Canada, capable of participating in phone or video calls in English or French.



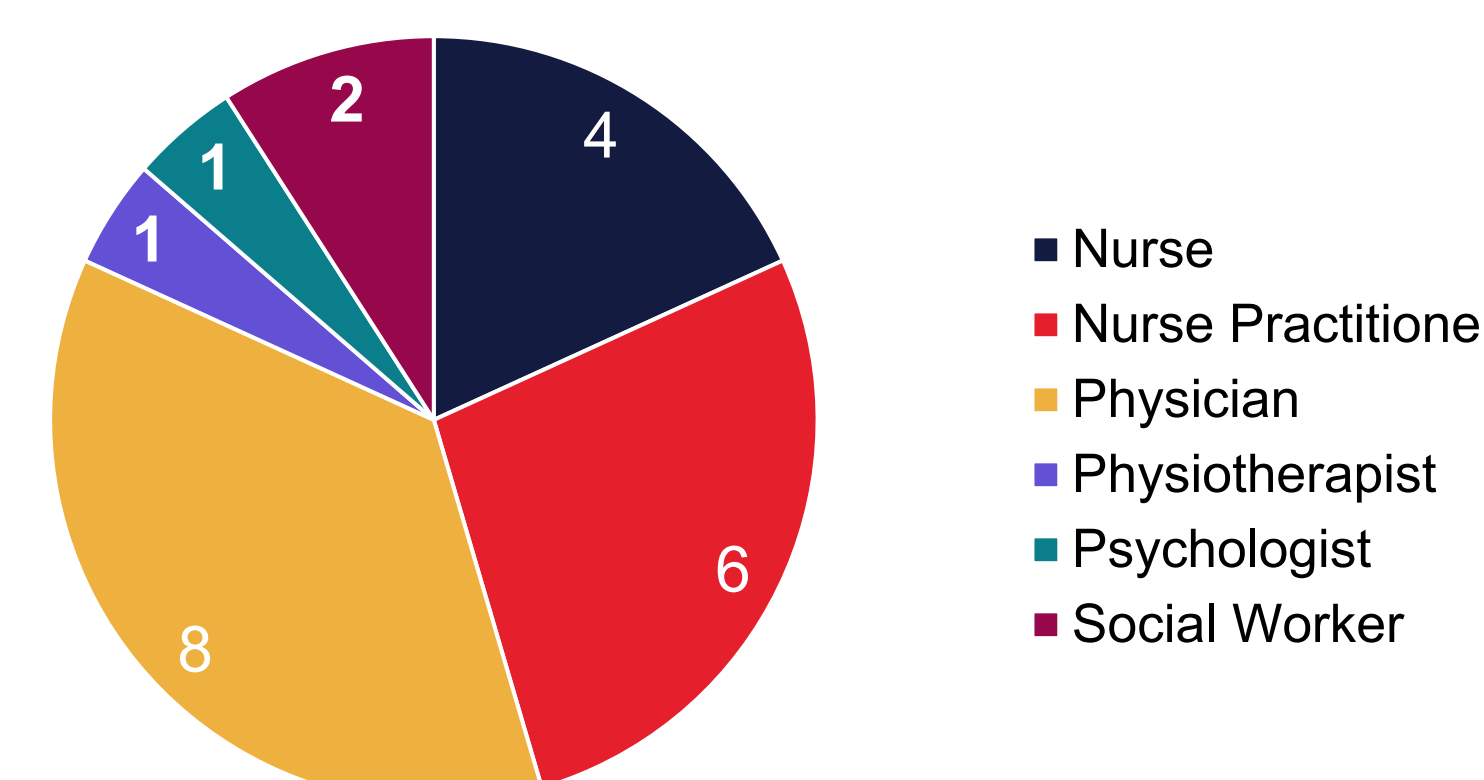
**Caregivers:** Primary caregivers of children diagnosed with cancer before age 21, their child having completed treatment 5 or more years ago, residing in Canada, and able to participate in phone or video calls in English or French.

## Preliminary Results – Healthcare Provider Cohort

- Cross-sectional survey and interview of survivorship clinic leads (n = 7)
- Interview of healthcare providers in diverse roles (n = 15)



Distribution of interviewed healthcare providers by role (n = 22)



## Preliminary Results – Survivor and Caregiver Cohorts

Survivor (A) and caregiver (B) focus group participation by province.

### A. Survivors

First focus group – 5 participants

Manitoba	1
New Brunswick	1
Ontario	3

Second focus group

Recruitment in progress

### B. Caregivers

First focus group- 6 participants

Alberta	2
British Columbia	1
Manitoba	1
Ontario	1
Quebec	1

Second focus group

Recruitment in progress

## Outcomes

Analysis ONGOING

Planned Outcomes:

- Examining childhood cancer survivorship care across Canada to delineate strengths, gaps, barriers, and regional disparities, informed by healthcare provider, survivor, and caregiver perspectives.
- Building a pan-Canadian survivorship coalition, CAN SCAN, to prioritize and advocate for high-quality survivorship care, standardize best practices, and catalyze coordinated research and funding opportunities.

## Next Steps

1. Complete healthcare provider surveys and interviews
2. Recruit survivors and caregivers for Group 2
3. Conduct Group 2 survivor and caregiver focus groups
4. Analyze quantitative and qualitative data
5. Engage healthcare providers, survivors, and caregivers in CAN SCAN based on expressed interest

We are recruiting participants for second focus group.

If you are a survivor of childhood cancer or caregiver to a survivor of childhood cancer and are interested in participating in this study, please contact:

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