CCRAN
Colorectal Cancer Resource & Action Network
RISCC
Réseau d'informations et soutien pour le cancer colorectal
A PATIENT-FOCUSED ORGANIZATION

2025 NATIONAL EARLY AGE ONSET CANCER PAN-TUMOUR PATIENT SURVEY RESULTS: UNDERSTANDING ACCESS TO MULTIDISCIPLINARY CARE AND SUPPORT NEEDS DURING TREATMENT & SURVIVORSHIP

EXECUTIVE SUMMARY

BACKGROUND

The incidence of early age onset cancer (EAOC), a cancer which is diagnosed between the age of 18 to 49, continues to rise across multiple tumour types in Canada, creating a growing challenge for a population navigating cancer during formative stages of adulthood. Younger adults often manage complex clinical pathways while simultaneously balancing work, family responsibilities, fertility considerations, and long-term financial implications. Their care needs extend beyond standard oncology services and require coordinated access to mental health support, fertility and sexual health counselling, parenting and family support, financial and employment navigation, age-appropriate peer support, and comprehensive survivorship planning. However, the availability and structure of such multidisciplinary supports remain inconsistent across provinces and institutions.

Understanding how younger adults experience and navigate cancer care, across both traditional care pathways and specialized models of care tailored to the EAOC population, is essential for identifying the structural inconsistencies that shape access, quality, and outcomes for younger adults living with cancer across Canada. Further, there is a growing need for real-world evidence examining how existing models of care support, or fail to support, EAOC patients' medical, psychosocial, and supportive care needs.

SURVEY OBJECTIVES

In the fall of 2025, CCRAN, in collaboration with 21 patient groups, conducted a national pan-tumour online survey to understand the lived experiences of Canadians diagnosed with EAOC. The survey aimed to: **(i) assess patient-reported experiences and unmet clinical, psychosocial, and supportive care needs across treatment and survivorship; (ii) examine access to, and utilization of, hospital-affiliated EAOC and Adolescent and Young Adult (AYA) clinics and programs; and (iii) identify system-level gaps in coordination, navigation, and multidisciplinary care that impact younger adults' cancer journeys.**

The insights garnered through the survey are intended to inform national dialogue and guide improvements that advance equitable, age-appropriate, patient-centered EAOC care across Canada.

This survey focuses on hospital-affiliated EAOC and AYA clinics and programs. Community-based programs provide valuable complementary support but are outside the scope of this assessment.

METHODS

The CCRAN team developed a national pan-tumour patient survey consisting of 39 multiple-choice and open-ended questions to collect both quantitative and qualitative data. The survey explored:

(i) patient demographics and tumour characteristics; (ii) care experiences across treatment and survivorship (iii) access to, and utilization of, hospital affiliated EAOC and AYA clinics; and (iv) opportunities for system-level improvement and better integration of coordinated, multidisciplinary, and supportive services for younger adults.

The survey was hosted on SurveyMonkey from **August 19 to October 14, 2025,** and distributed through a **multi-channel, multi-stakeholder strategy** leveraging CCRAN communications, social media, and partnerships with **21 patient groups**. This collaborative approach enhanced national reach and supported participation from respondents across varied tumour types, regions, and care environments.

KEY RESULTS

RESPONDENT DEMOGRAPHICS AND TUMOUR TYPES

- **143** Canadian EAOC patients or caregivers completed the survey
- **80%** were females, **18%** males, **2%** non-binary & two-spirited
- **63%** of respondents were 40-49 years of age at diagnosis
- Respondents reported a wide range of tumour types: **Breast** and **colorectal** were the most frequently represented, with additional representation from **blood cancers**, **other gastrointestinal cancers**, **lung cancers,** and several less frequently reported tumour types (Figure 1.)
- Representation from all **10 provinces**, with the highest participation from ON **(38%)**, followed by BC **(20%)**, AB **(14%)**, QC **(8%)**, and NS **(7%)**

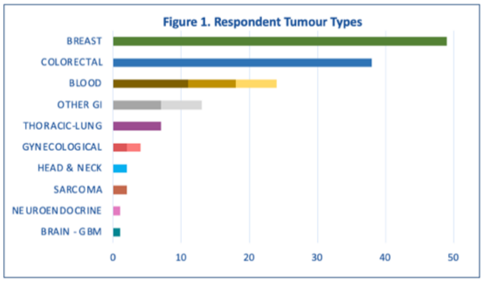
Figure 1. Respondent Tumour Types

- At the time of the survey, **49%** were employed on a full-time basis, while **37%** were not employed, and **8%** were employed part-time

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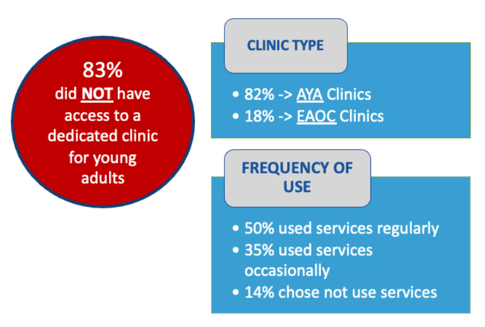
EAOC PATIENT CARE EXPERIENCES & MODELS OF CARE

Patient Care Experiences:

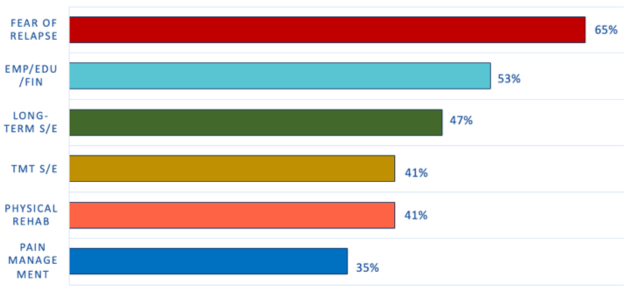
- Access to specialized EAOC/AYA models of care is critically low: **83%** of respondents reported *no access* (Figure 2.)
- Referral pathways lack standardization: only **29%** of referrals originated from oncologists; most came from other providers or non-specific routes, indicating inconsistent processes for directing younger adults to specialized care
- Awareness remains a major barrier, with approximately 65% of those without access reporting they were *unaware these clinics existed* and had *never been referred* by their healthcare team
- Among patients who accessed EAOC/AYA models of care, **mental health (76%)**, **nutrition support (59%) and fertility/sexual health (42%) were the most commonly used services**, reflecting the prominence of these needs within the younger adult population

Figure 2. Access to Specialized Young Adult Cancer Clinics



- Despite access to specialized clinics, patients identified substantial gaps, particularly fear-of-relapse support **(65%)**, socioeconomic support **(53%)**, and services related to long-term symptom management, physical rehabilitation, and pain management (Figure 3.)

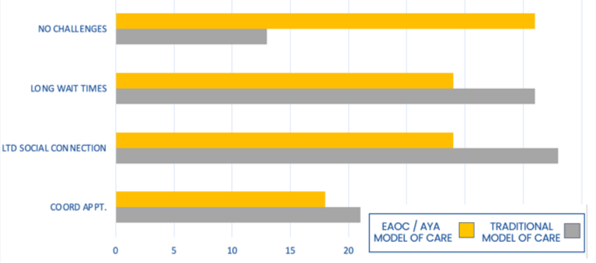
Figure 3. Gaps within Specialized Clinics



AYA/EAOC Models of Care vs Traditional Care:

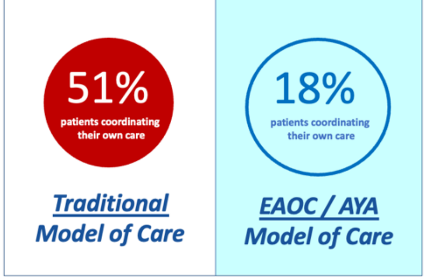
- **Unmet needs were substantially higher in traditional care, with mental health (53%), nutrition (46%), and fertility/sexual health (31%)** reported as the top gaps. By comparison, AYA/EAOC clinic users accessed these same supports far more often **(76%, 59%, 42% respectively)**, demonstrating stronger alignment with patient needs

Figure 4. Challenges while Receiving Care



- Specialized clinic users accessed key supports more often, while traditional care showed minimal availability, reflected in higher reported long wait times **(36%)** and limited social connections **(38%)** (Figure 4.)
- Only **13%** of patients receiving traditional care reported that they experienced no challenges while receiving care, compared with **36%** in AYA/EAOC clinics; this speaks to how specialized models may more effectively *detect, triage, and mitigate* care-related issues that otherwise remain unaddressed in standard of care pathways (Figure 4.)

Figure 5. Care Coordination



- Care coordination burden was markedly higher in traditional care, where **51%** of patients managed their own care compared with **18%** in AYA/EAOC clinics, highlighting that specialized models structurally reorganize care so that **patients are not required to function as their own care managers** (Figure 5.)
- Survey findings show that **86%** of patients without access to an AYA/EAOC clinic believed ***dedicated models* could have *improved their care*** highlighting a substantial unmet need in current care pathways

Patients Without Access to AYA/EAOC Models of Care Speak Out on Missing Supports:

> "It should be mandatory for a **nurse navigator** to call everyone diagnosed - not just hand a card when you have no idea what's coming."

> "I wanted access to a **family therapist** so my children and husband would have someone they know when they may need **grief counselling."**

> "I wish the **doctors would communicate with each other**… I found myself acting as the intermediary, which shouldn't be expected of me."

> "A **centralized digital hub for young adults** is desperately needed—no one tells you what exists, and you only **find supports by accident**. We need someone who **knows the system**, someone who can guide us, answer questions, and connect us to the right supports."

> "I often felt **my care was something being done *to* me, not <u>*with*</u> me."**

> "I really would have liked to have **met others my age**… I felt very **alone** and **isolated."**

> "No one talked to me about **sexual health** or how radiation would affect **intimacy** — we had to piece it together ourselves."

CONCLUSIONS AND CALLS TO ACTION

Findings from this national pan-tumour EAOC patient survey highlight substantial gaps in the delivery of age-appropriate cancer care across Canada. Younger adults frequently encounter fragmented care pathways, inconsistent access to supportive services, and variability in coordination across providers. In contrast, respondents with access to dedicated AYA/EAOC clinics reported markedly improved care experiences, reflecting the effectiveness of coordinated, multidisciplinary models. The strong perceived value of these clinics illustrates a clear system-level gap: most younger adults with cancer do not have access to a model of care known to substantially strengthen patients' overall care experience. Addressing these structural inconsistencies is essential to advancing equitable, comprehensive, multidisciplinary cancer care that meets the distinct needs of younger adults. The following are calls to action resulting from the outcomes of the survey findings:

i. **<u>Expand access to AYA/EAOC models</u>** of care across Canada
ii. Implement dedicated **care coordinators** at diagnosis to strengthen navigation
iii. Integrate **supportive care into standard pathways** with clear referral routes
iv. Enhance visibility and access to AYA/EAOC **resources through centralized entry points** and online hubs

CCRAN extends its sincere appreciation to the patient groups whose collaboration enabled the broad dissemination of the 2025 National EAOC Pan-Tumour Patient Survey, and to the patients and caregivers who generously contributed their time. Their commitment and dedication were instrumental in bringing this report to fruition.

Prostate Cancer Foundation Canada prostatecanada.ca
Canadian Cancer Survivor Network / Réseau canadien des survivants du cancer
GIST Sarcoma Life Raft Group Canada / Groupe Sauvetage GIST Sarcome Canada – *Ensuring that no one has to face GIST alone*
IPANE Immunocompromised People Are Not Expendable
Cholangio-Hepatocellular Carcinoma Canada / Carcinome Cholangio-Hépatocellulaire Canada
CBCN RCCS Canadian Breast Cancer Network / Réseau canadien du cancer du sein
InspireHealth Supportive Cancer Care
Lung Cancer Canada / Cancer Pulmonaire Canada – Awareness. Support. Education. / Sensibiliser. Soutenir. Éduquer.
yacc Young Adult Cancer Canada
braintumour foundation of Canada
AYA CAN Canadian Cancer Advocacy
Childhood Cancer Canada
Craig's Cause Pancreatic Cancer Society
Myélome Canada / Myeloma Canada
CORD Canadian Organization for Rare Disorders
Leukemia & Lymphoma Society of Canada / Société de leucémie & lymphome du Canada
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