

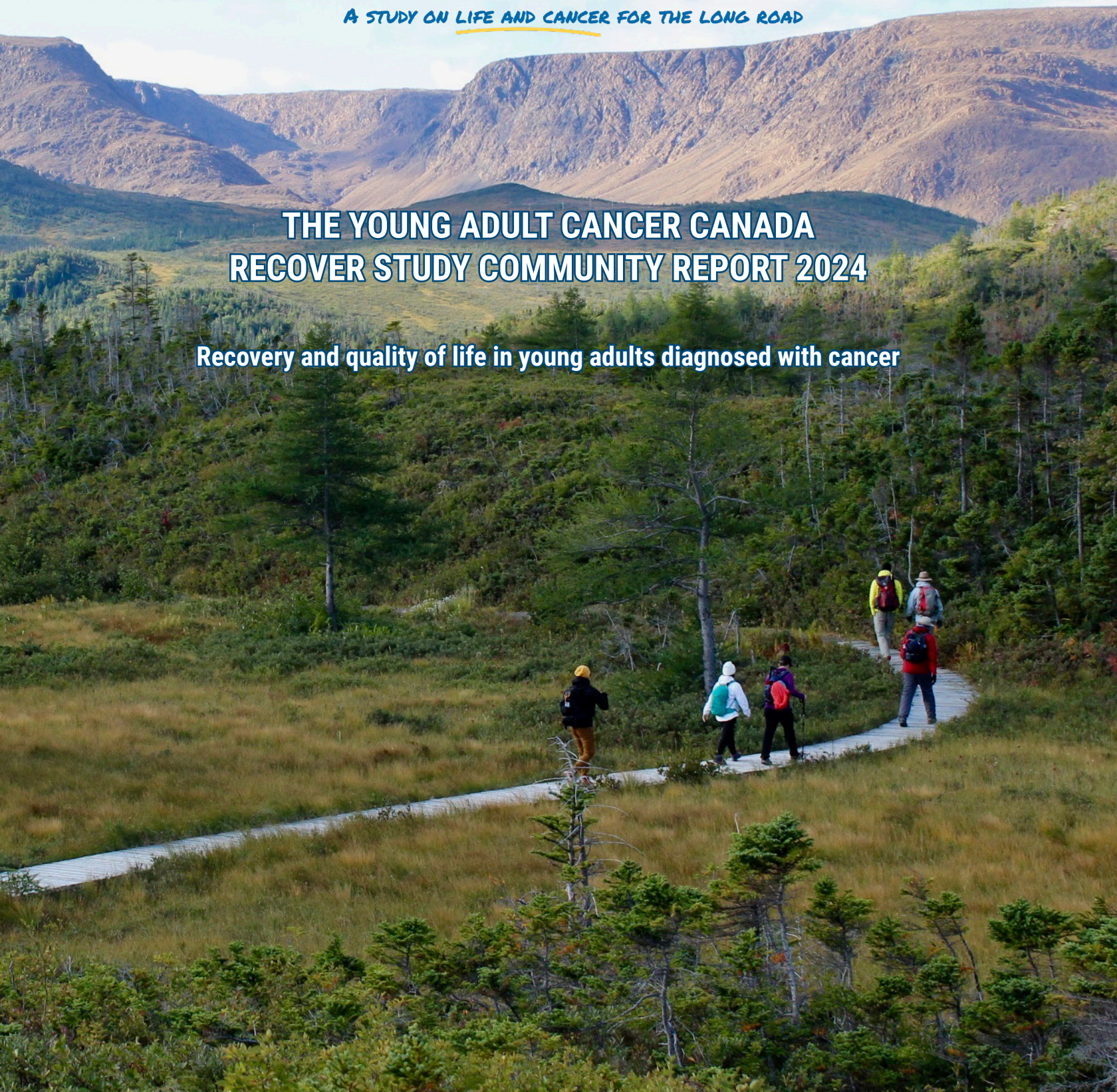


# RECOVER

A STUDY ON LIFE AND CANCER FOR THE LONG ROAD

## THE YOUNG ADULT CANCER CANADA RECOVER STUDY COMMUNITY REPORT 2024

Recovery and quality of life in young adults diagnosed with cancer





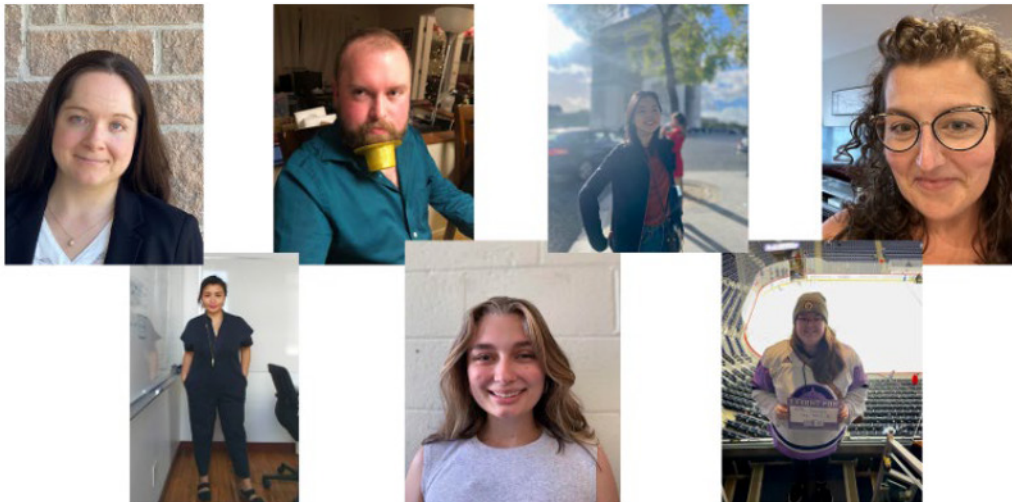
## Welcome to the first ever community report for the YACC Recover Study!

Young Adult Cancer Canada (YACC) intends to produce a report on a yearly basis to provide an overview of study activities and updates.

Young Adults (YAs) aged 18-39 are a forgotten group in the cancer research space. This study is a **first of its kind** examining quality of life (QoL) in this stage of life during a cancer diagnosis over a five-year period. Building on the [YAC PRIME Study](#), we aim to engage young adults with lived/living experience with cancer to understand the holistic quality of life (e.g. physical, mental, social, and financial) over time and identify recommendations to improve the QoL for young adults and support their recovery.

The [Recover Study](#) is a **community-led study**, which means:

- YACC owns the data!
- YAs with lived/living experience with cancer are more than just participants in the study! Through the [leadership team](#) (pictured below), they also inform the study design, support recruitment, identify data priorities, and will support knowledge translation.
- The research is also guided by an advisory committee composed of YACC staff and academic researchers.
- This study will inform YACC programming so the community will directly benefit and as data becomes available.
- YACC will share study details directly with the community!



### WHY

Findings from the Recover Study will be used to help inform and guide YACC program design and delivery decisions as part of YACC's ongoing advocacy work for evidence-based care for AYAs.

### DID YOU KNOW?

- Compared to older adults, AYAs have significantly higher levels of depression and anxiety after cancer treatment.<sup>1</sup>
- In Canada, the overall incidence rate of cancer in AYAs has increased since 1992.<sup>2</sup>

1. Understanding the Symptoms and Concerns of Adolescents and Young Adults with Cancer in Alberta: A Comparative Cohort Study Using Patient-Reported Outcomes. Claire Link, Siwei Qi, Sarah Thompson, Andrea Delure, Sarah McKillop, and Linda Watson. *Journal of Adolescent and Young Adult Oncology* 2023 12:2, 199-206

2. Canadian Partnership Against Cancer. Adolescents and Young Adults with Cancer, A Reference Report. 2017.

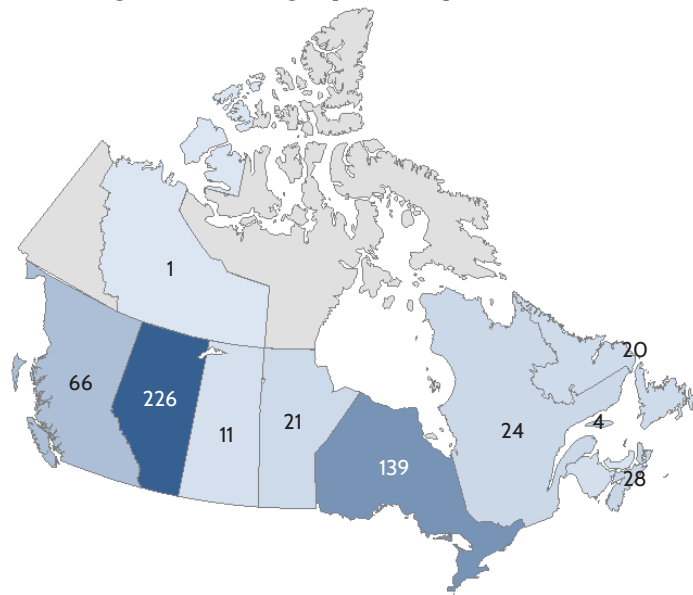
## WHO

Our hope is to better understand the young adult cancer experience through community-based research methods to develop evidence-based programming that will improve the experience and QoL outcomes of YAs with cancer.

### “Cancer doesn’t end with treatment”

During the period from September 2023 to October 2024, we have enrolled 553 people. There is a broad Canadian representation which includes most provinces and territories with representation from various demographic identities (Figure 1). However, there is more work to do to reach out to underrepresented populations to ensure we include a broad perspective on quality of life in young adults living with cancer in Canada. We need your help! Check out the Recover website to determine eligibility and to learn more! We aim to enroll 2000 YAs across Canada by early 2025 with representation from various cultural, ethnic, gender, sexual, educational and financial backgrounds.

**Figure 1. Geographic Representation**



## WHAT

Questions we hope to explore include but are not limited to:

- “How might cancer impact my ability to form and maintain relationships over time?”
- “What might contribute to and be impacted by the fears I have of the cancer coming back?”
- “How might my quality of life evolve two years vs. five years vs. 10+ years after my diagnosis?”
- “How might the age of when I was diagnosed impact the severity of my mental well-being?”
- “How might my experience as an YA with the lived experience of trauma tied to my demographic background impact my mental health after a cancer diagnosis?”
- “Will my unique needs and experiences be recognized? I am often not represented and don’t feel a sense of belonging in the cancer care community.”
- “How does being diagnosed before the age of 39 years impact my financial health and career goals and ambitions?”

“Young adults who have received a cancer diagnosis are the experts on their experiences. The nuances of our experiences are pivotal to designing research that will effectively capture the unmet needs and experiences of this community...It’s more common to do a short-term study about outcomes for young adult cancer survivors. I am curious as to how the results of such studies would be different if the studies were to follow young adults many years out of diagnosis and/or treatment. That’s what the Recover Study is going to do!”

-YACcer, diagnosed with brain cancer  
at 29 years old

If you have any ideas on questions that you would like answered that affect QoL of YAs, or any questions about the study, please contact [research@youngadultcancer.ca](mailto:research@youngadultcancer.ca).

## Get involved in the YACC Recover Study and change the future for YAs affected by cancer!

YACC wants to ensure there is real-time information about this study that could be available to the community.

### WHAT DOES PARTICIPATION INVOLVE?

- **Participating in surveys**  
To gain a better understanding on QoL, we ask YAs about distress and identity, fear of cancer recurrence, psychological distress, resilience, social support, and the financial impacts of cancer.
- **Engaging in other qualitative methods**  
We will hold interviews, focus groups and creative methods sessions to better understand the topics we explore in the survey.
- **Community engagement**  
We want to engage YAs diagnosed with cancer in the research methods and request feedback on the development of materials to publicly share study information as it becomes available.

“When I was first diagnosed with cancer, I was 35. I thought that I would fight through treatment and then I'd be finished. I didn't know that cancer didn't end when the treatments stopped. When I did finish treatment and got clear scans I couldn't understand why I didn't feel finished with the cancer and why I felt like I couldn't just move on. It wasn't until I was able to connect with my peers and hear that they were experiencing the same feelings that I realized that survivorship might be different for young adults. We need studies like this to ensure that the voices of young adults who have experienced cancer shape the narrative of survivorship for young adults.”

-Sarah, diagnosed with Hodgkin's Lymphoma  
at 35 years old

“It is challenging to find resources for individuals who have been impacted by cancer as a young adult, let alone for those like myself who are 10+ years out from their diagnosis. There seems to be a knowledge gap on the long term impacts. The further away I became from my diagnosis, the more resources became irrelevant. It was a common occurrence for me to participate in programs/services only to discover that they were no longer inclusive to where I was along my recovery stage. Unfortunately, individuals like myself are faced with trying to recover, navigate and thrive through life after cancer on their own at a time when support might be needed most. My hope is that the Recover Study is just the start and inspires more efforts to better serve those like myself”

-Carolyn, diagnosed with Non-Hodgkin's Lymphoma  
at 28 years old

**LEARN MORE AT RECOVERSTUDY.CA!**

