

# The YACC Recover Study: A community-led study on quality of life in young adults diagnosed with cancer



JUNE 13 12-1PM EASTERN TIME

# RECOVER

A STUDY ON LIFE AND CANCER FOR THE LONG ROAD

Presented by:

Pam Crotty  
Dani Taylor  
Carolyn Van  
Alyssa Dickey  
Geoff Eaton



WINTER 2024 E-LEARNING SERIES:  
YOUNG PEOPLE IN COMMUNITY-BASED RESEARCH





Community-Based Research Canada  
Recherche partenariale du Canada

[www.communityresearchcanada.ca](http://www.communityresearchcanada.ca)



@CbrcResearch

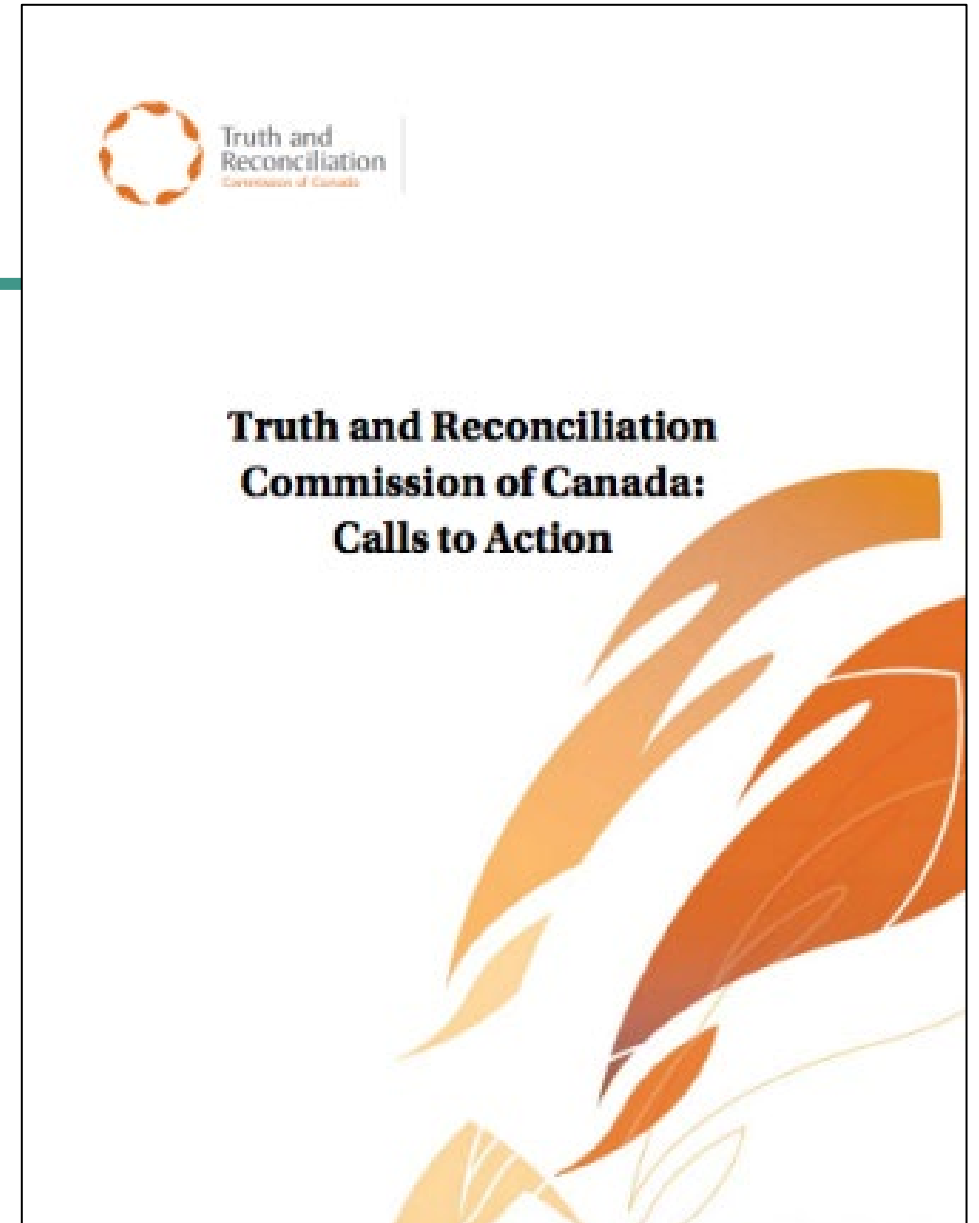


Community Based Research Canada



## Call to Action #22

“We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients.



# Agenda

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**Opening**



**Presentation**



**Q&A**



**Closing**

# Presenters

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**Pam Crotty** (she/her), Senior Research Manager, Young Adult Cancer Canada

**Dani Taylor** (she/her), Manager of Programs and Partnerships, Young Adult Cancer Canada

**Carolyn Van**, Recover Study Leadership Team Member, Young Adult Cancer Canada

**Alyssa Dickey** (she/her), Insight Team Member, Young Adult Cancer Canada

**Geoff Eaton**, Founder & Executive Director, Young Adult Cancer Canada



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RECOVER

A STUDY ON LIFE AND CANCER FOR THE LONG ROAD

yacc

young adult cancer canada



# Agenda

Please use the chat ask questions throughout!  
We will host a Q&A after the slides are done.

- **Introductions** (Full Team)
- **Introduction to Young Adult Cancer Canada** (Geoff)
- **Introduction to the Insight Team** (Alyssa)
- **The Recover Study: Origins & Updates** (Dani & Pam)
- **The Leadership Team: Development & Overview** (Carolyn)

# Today's Presentation Team



**Alyssa** she/her  
Insight Team Member



**Carolyn** she/her  
RECOVER Leadership  
Team Member



**Dani** she/her  
Manager of Programs



**Geoff** he/him  
Executive Director &  
Founder



**Pam** she/her  
Senior Research  
Manager

Have lived experience of a  
cancer diagnosis before the  
age of 40!





Life is different

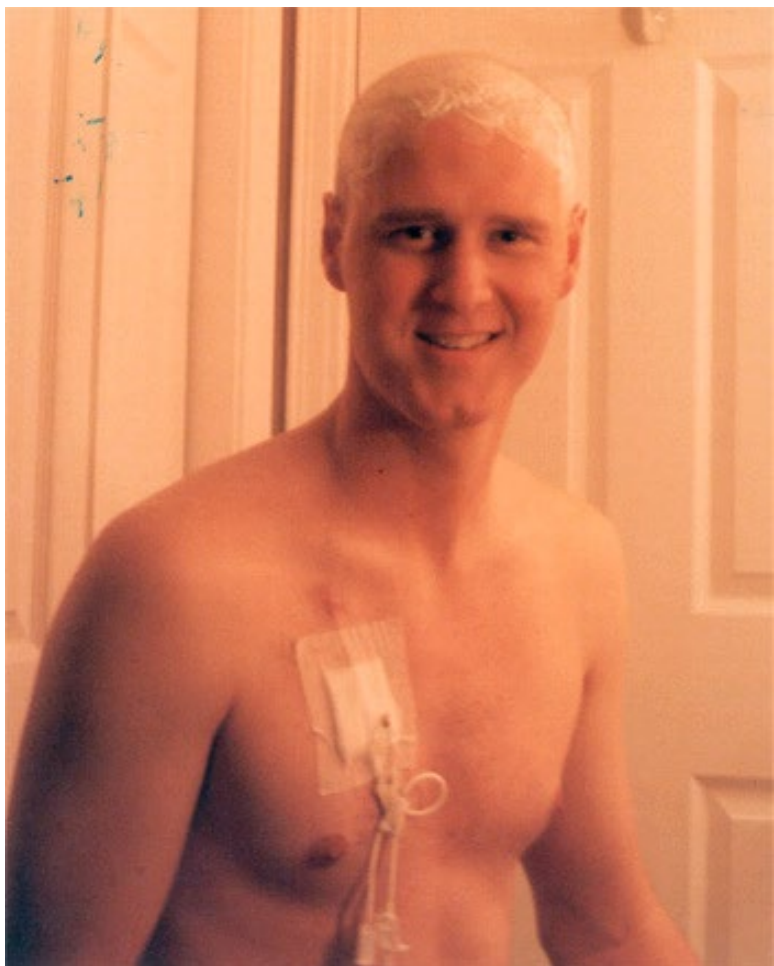


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YOUNG ADULT  
CANCER CANADA



# Cancer is different



**“When you’re just starting your life, cancer forces you to face the end of your life and that impacts the rest of your life.”** – Steve Webster, YACCer

## **Cancer impacts your whole life:**

- Physically
- Mentally
- Socially
- Financially



## Why YACC?

**Cancer is different for  
young adults.**

And...

**It takes longer to recover from  
cancer than to be treated for it.**

# PRIME

YOUNG ADULT CANCER

## A STUDY TO INCITE CHANGE

Gave us important findings on:

- QUALITY OF LIFE
- PSYCHOLOGICAL DISTRESS
- FEAR OF RECURRENCE
- SLEEP
- BODY IMAGE DISTRESS
- FERTILITY
- COST
- THE POWER OF CONNECTION

More at <https://youngadultcancer.ca/yac-prime-study/>



### ORIGINAL #YACPRIME TEAM



Geoff Eaton  
Young Adult Cancer Canada



Karine Chalifour  
Young Adult Cancer Canada

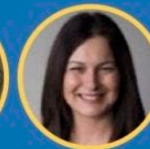


Sheila Garland  
Memorial University

### #YACPRIME EXPANSION TEAM



Jackie Bander  
University of Toronto



Norma D'Agostino  
University of Toronto



Catherine Sabiston  
University of Toronto



Fiona Schulte  
University of Calgary



Lauren Daniel  
Rutgers University



Eric Zhou  
Harvard University

### #YACPRIME FELLOWS AND STUDENTS



Breanna Lane  
Memorial University



Kaitlyn Mahon  
Memorial University



Scott Adams  
University of Toronto



Anika Petrella  
University of Toronto



Madison Vanl  
University of Toronto



Ashley Mah  
University of Toronto



Joshua Tulk  
Memorial University



Sharon Hou  
University of Calgary



Amanda Wurz  
University of Calgary



Riley Cotter  
Memorial University



Marissa Maheu  
Memorial University





It takes longer to recover from cancer than to be treated for it. At Young Adult Cancer Canada (YACC), **recovery is about more than remission**, it is about living a life worth loving, hopefully for the long road.

### **Alyssa - March 1, 2018**

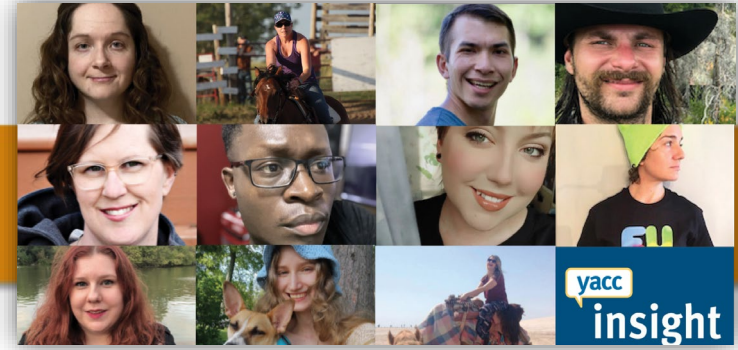
1 month after stem cell transplant #2. No hair, pale tired, a look many may associate with cancer.







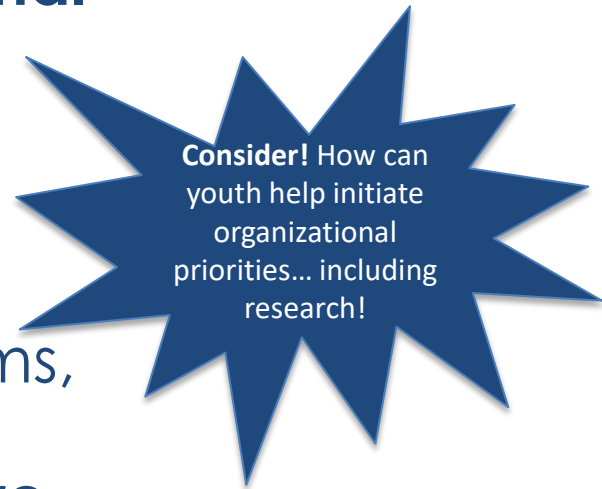
# YACC Insight



<p><b>Thanh</b> Insight <a href="#">View Thanh's profile</a></p>	<p><b>Noelle</b> Insight <a href="#">View Noelle's profile</a></p>	<p><b>Sierra</b> Insight <a href="#">View Sierra's profile</a></p>
<p><b>Misshka</b> Insight <a href="#">View Misshka's profile</a></p>	<p><b>Michael Rumsby</b> Insight <a href="#">View Michael Rumsby's profile</a></p>	<p><b>Lucy Khudair</b> Insight <a href="#">View Lucy Khudair's profile</a></p>
<p><b>Jamie L.</b> Insight <a href="#">View Jamie L.'s profile</a></p>	<p><b>Emily Gallant</b> Insight <a href="#">View Emily Gallant's profile</a></p>	<p><b>Emily</b> Insight <a href="#">View Emily's profile</a></p>
<p><b>Joey</b> Insight <a href="#">View Joey's profile</a></p>	<p><b>Meagan</b> Insight <a href="#">View Meagan's profile</a></p>	<p><b>Nick</b> Insight <a href="#">View Nick's profile</a></p>

YACC's Insight team was developed to provide **personal experiences, expertise, and support** for developing and delivering YACC initiatives.

This includes support programs, fundraising, research, and communications, **all to ensure YACC uses a wide range of knowledge in decision-making.**





# Insight Meeting – Sept. 14, 2022

## Discussion – “Recovery”

- Is this word a good fit to describe what happens next?
- Different perspectives and synonyms were explored
- Insight endorsed the word Recovery to the Committee



## RECOVERY – Recover

There is no end point. The timeline may be different for all going through it, but experiences during this period can be shared

# If Prime captured a moment, Recover captures a lifetime

What important issues raised in the PRIME study do Insight feel need to be explored more in Recover?

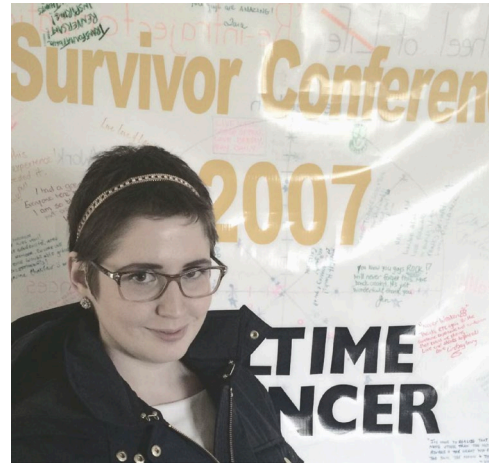
- Quality of Life
- Fear of Recurrence
- Body Image
- Fertility
- Cost (!)

**Cancer Impacts every area of one's life: mentally, socially, financially and physically.**



# Discovery – Research That Works For Us

- Project stalls over different opinions with Academic Researchers, specifically over population priorities
- Lots of questions about how to move forward!
- Re-discovery of community-based research and how it can shape YACC's future in research



# **YACC Recover:** Prospective Recovery of Quality of Life in Young Adults Diagnosed with Cancer

## *Research Goal:*

This community-led, mixed-methods, longitudinal study seeks to engage YA 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 quality of life for young adults and support their recovery.





# Research Objectives

## Primary:

To understand the quality of life (QoL) in young adults (YA) with cancer over a 5-year period.

## Secondary:

To explore several variables (e.g., sociodemographic, diagnostic, treatment, psychological and social well-being, relationships, finances etc.) to determine their effect on quality of life.

To understand the effect of YACC programs on QoL and to identify opportunities for improvement.



# Research Objectives (continued)

## Secondary:

To develop integrated knowledge translation materials to inform program delivery, advocate for change and improve the experience and QoL outcomes amongst YA with cancer.

To build capacity of YACC and YA with cancer to engage in and facilitate community-based research.





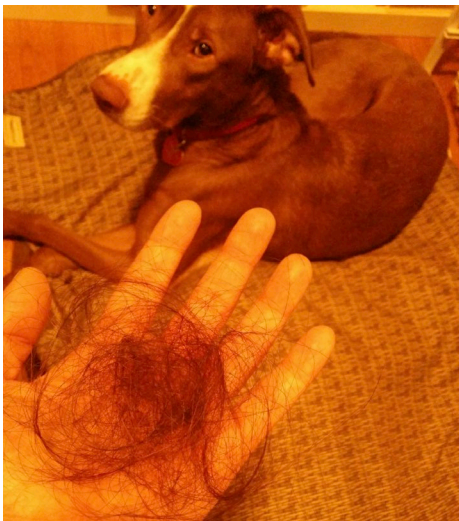
# Study Procedures

- **Online Survey:**
  - Baseline and yearly for 5 years
- **Optional:**
  - Interviews, focus groups and creative methods
  - Linking survey responses to YACC administrative databases
  - Individualized programming outreach
  - Linking survey responses to cancer registry data
    - *Future research studies*



# The Recover Study Leadership Team

2014: Diagnosed with Non-Hodgkins Lymphoma




Chemotherapy, radiation, transplants, psychosocial therapy, life changes.

Along the way, I observed and experienced some **gaps in our healthcare systems and communities.**



# The Recover Study Leadership Team

**September 2023:**  A national call out for volunteer team members who could offer guidance and direction to YACC on the Recover Study.

- Over **40** applicants
- Across **Canada**
- **Interviews** were conducted, and **seven** were selected to be part of the team.



# The Recover Study Leadership Team

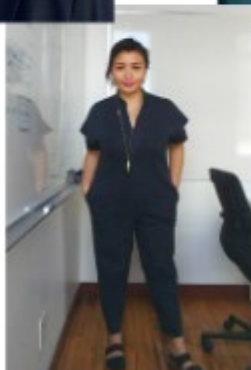
## The Result:

7 individuals who "get it" having had first-hand experience with Young Adult Cancer equipped with a ***diverse range of professional areas of expertise***, currently guiding the YACC research team with the implementation of procedures, engagement and knowledge mobilization.





# Meet our Recover Study Leadership Team



**Ainsley, Carolyn, Karl-Erik, Meghan, Michelle, Michaela, and Sarah**

Learn more about us at <https://youngadultcancer.ca/team-type/recover-leadership-team/>

# The Recover Study Leadership Team

## Outcomes, Wins & Takeaways to Date 🎉

- An influx of interest to lead
- 7 dedicated volunteer professionals representing a range of diverse skill set, cultural backgrounds, stages of young adult cancer impact
- Published behind-the-scenes summaries from Leadership Team members
- In-progress study updates on the latest
- Increased confidence in community-facing communications and efforts



# The Recover Study Leadership Team

What we are looking forward to 🌟

- More in-progress study updates to the greater community
- Community rallying and engagement hosted by Leadership Team members
- Leveraging other mediums and formats to engage and communicate
- Opportunities to collaborate alongside individuals and groups external to YACC



FINANCIAL POST

## Student Loan Debt is a Major Barrier to Homeownership for Young Ontarians

SUCCESS · GEN Z

Many Gen Zers have a full-time job and a side hustle, partly because they're wary of getting burned by their employers: 'They've seen it happen to their parents, to millennials'

BY PAOLO CONFINO  
September 27, 2023 at 3:52 PM GMT-2:30



### A Generational Struggle: Gen Z and Millennials on Mental Health

Quebec / News / National / Local News

## Young Quebecers are the least optimistic about the climate crisis: survey

*Eco-anxiety in young people can express itself in various forms, psychologist says.*

HEALTH

## Cancer cases soared 79% globally among young adults over past 3 decades: study



By Katie Dangerfield · Global News

Posted September 5, 2023 5:30 pm · Updated September 6, 2023 9:25 am

## Social media particularly damaging to mental health of Gen Zers, says study

Compared with other generations, members of Gen Z spend more time passively consuming social media

ATLANTIC | News

## Majority of Millennials, Gen Z don't see homeownership as a possibility

BUSINESS

## The unluckiest generation in U.S. history

Millennials have faced the worst economic odds, and many will never recover



Analysis by Andrew Van Dam  
Staff writer · Follow

June 5, 2020 at 1:08 p.m. EDT

CANADA | News

## Half of millennials and Gen Z living paycheck-to-paycheck in Canada while stressing about climate crisis: survey

## Today's young adults are far less likely than young adults in the early 1990s to be married or to have kids

BREAKING

## Millennial And Gen Z Women Face Greater Health Risks Than Prior Generations, Report Finds

## Political discord an ongoing challenge in workplaces — especially for Gen Z



# Outreach and Next Steps

## Qualitative Research

- Interviews, focus groups, creative methods
- Community feedback on meaningful topics

## Opportunities for

- Health Care Professionals
- Individuals diagnosed with cancer between 18 to 40 years old

## We can provide!

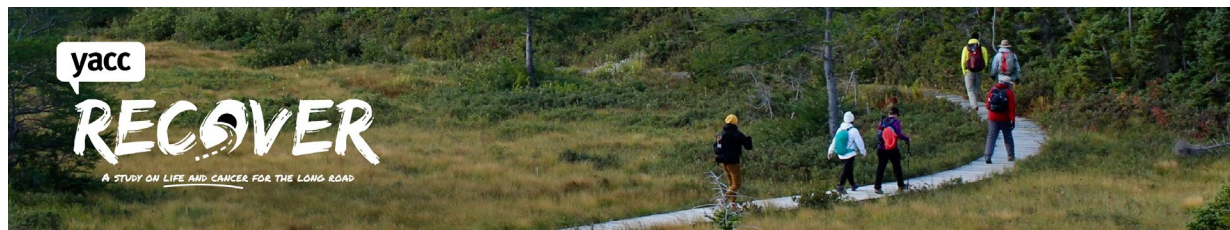
- Interactive panel discussions on Recovery
- Information sessions and webinars on the Recover Study
- Digital and print posters available to circulate to your network

## Get in touch

[pam@youngadultcancer.ca](mailto:pam@youngadultcancer.ca) or [research@youngadultcancer.ca](mailto:research@youngadultcancer.ca)



# Thank you. We're happy to answer your questions!



It takes longer to recover from cancer than to be treated for it. At Young Adult Cancer Canada (YACC), recovery is about more than remission, it is about living a life worth loving, hopefully for the long road.

Recover is a community-led study where we work together to set the priorities and better understand life and cancer for young adults and how it affects your quality of life over time.

We hope to enrol 2000 people from all across Canada.

*Gardez l'oeil ouvert car notre étude sera bientôt disponible en français.*

### Who can take part?

Young adults living in Canada who are over the age of 18 and were diagnosed with any type of cancer before the age of 40.

### How do I take part?

You will complete an online survey once a year for up to 5 years. Each survey will take approximately 30-45 minutes to complete.

### Why should I take part?

The information you provide will be used to increase awareness and develop programs to address the issues that young adults with cancer feel are most important.

You will be paid \$20 for each year you complete the survey.

### How do I sign up?

For more information or to participate, please fill out the sign up form on [recoverstudy.ca](https://recoverstudy.ca).



This project has been reviewed and approved by the Community Research Ethics Board. If you feel you have not been treated according to the descriptions in our information, or your rights as a participant in research have been violated during the course of this project, you may contact the Chair, Community Research Ethics Board, at: Community Research Ethics Office (Canada) Corp. c/o Centre for Community Based Research, 140 Westmount Road North, Waterloo ON N2L 3G6  
Email: [creoadmin@communityresearchethics.com](mailto:creoadmin@communityresearchethics.com)







# Question and Answer

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# Webinar Recordings



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CBR Canada hosts webinars and live online discussions to bridge capacities and promote research excellence. Below are webinar recordings and event summaries, organized from the most recent to earlier. Upcoming webinars and discussions are posted on the [Events page](#).

[2022](#) | [2021](#) | [2020](#) | [2019](#) | [2018](#) | [Earlier](#)



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## e-Newsletters

The CBR Canada e-Newsletter is released every Fall, Winter and Spring, providing updates on the latest news, resources, and opportunities in Canadian-led community-based research.

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SYSTEMS

## Responding to Crises:

What is the value of community-based research?

**Sept 2024-Jun 2025**

An E-learning series brought to you by



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# Thank You!

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