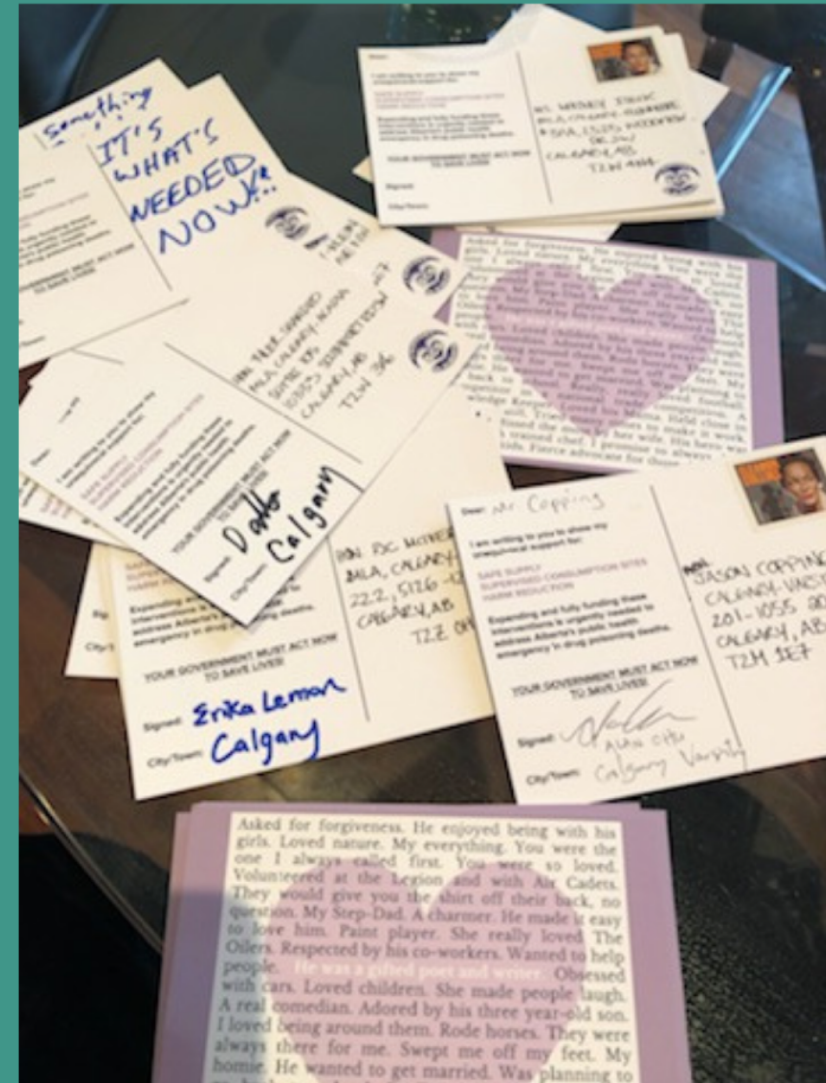




Community-Based Research Canada
Recherche partenariale du Canada

Engaging With Bereaved Parents in Substance Use Research and Policy Reform

Presented by:
Heather Morris
Petra Schulz
Rebecca Haines-Saah





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www.communityresearchcanada.ca



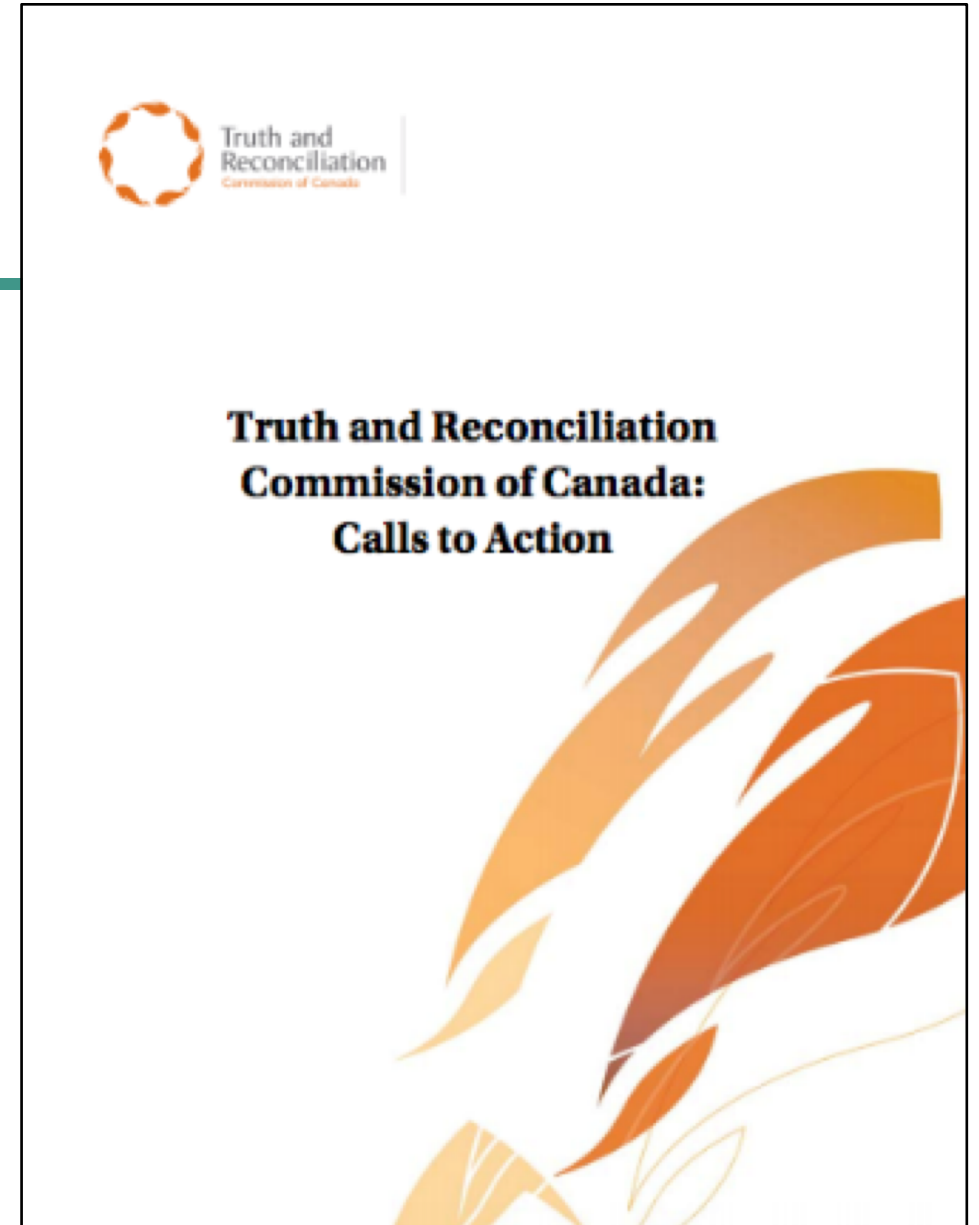
@CbrcResearch



Community Based Research Canada

Call to Action #19

We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends.



Agenda



Opening



Webinar

Presentation

Q&A period



Live Discussion

Breakout rooms

Large group
debrief



Closing

Presenters



Rebecca Haines-Saah

Associate Professor, Community
Health Sciences, University of
Calgary



Petra Schulz

Co-founder, Moms Stop the Harm



Heather Morris

RN, PhD Health Services & Policy
Research, School of Public Health,
University of Alberta

Engaging With Bereaved Parents in Substance Use Research & Policy Reform

Heather Morris, Petra Schulz,
Elaine Hyshka, Emily Jenkins,
Rebecca Haines-Saah

Community-Based Research
Canada Fall E-Learning Series:
Celebrating Community-Based
Research Excellence

October 27, 2022





Presentation Outline

1. Remembering and honouring loved ones
2. Canada's drug poisoning crisis.
3. Moms Stop the Harm
4. Engaging in Community-Based Participatory Research
5. Study Findings & Knowledge Translation



Danny Schulz 1989 – 2014

Substance use
and overdose
can affect
anyone

It affects some
more than
others



Drug Poisoning Death in Canada

21 Canadians die every day

There was a total of **30,843 apparent opioid toxicity deaths** between January 2016 and March 2022

Most in British Columbia, Alberta, and Ontario; increases observed in other regions.

Most among young- to middle-aged males

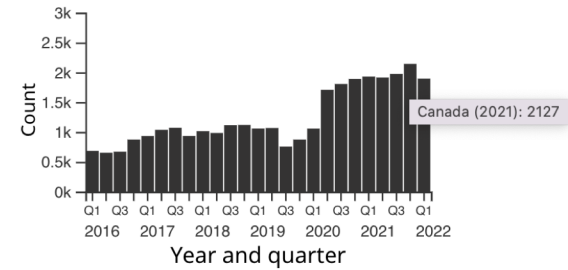
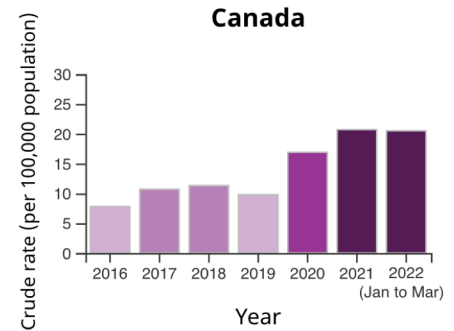
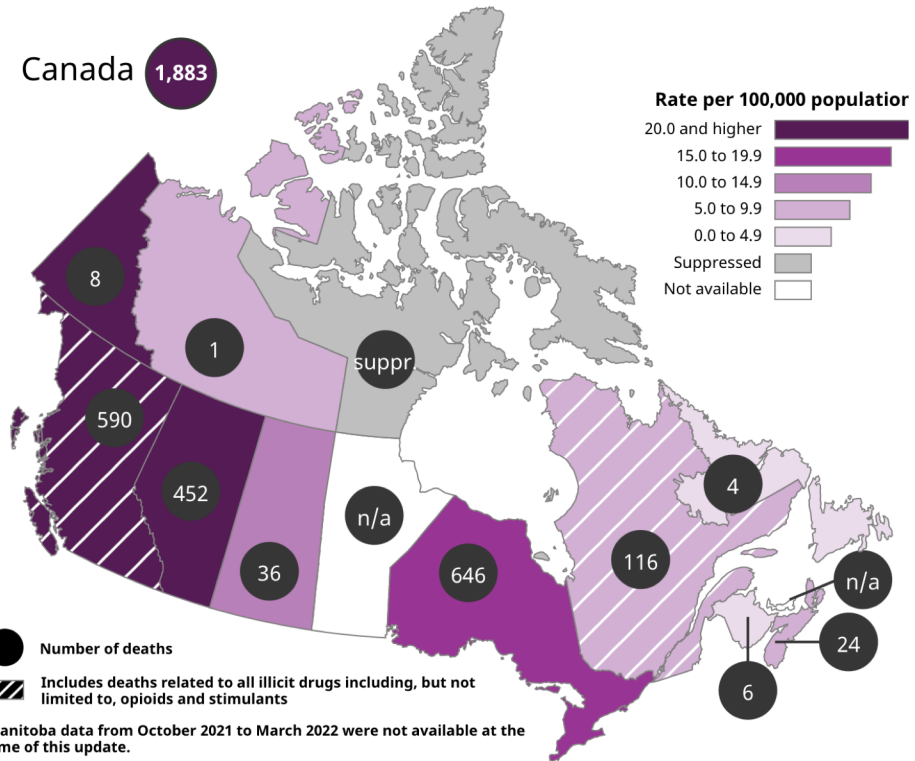
Toxicity of supply continues to be a major driver of the crisis

Total 32,319 opioid-related and 14,142 stimulant-related poisoning **hospitalizations** from January 2016 to March 2022 in Canada (excluding Quebec)

- Sept 2022 <https://health-infobase.canada.ca/substance-related-harms/opioids-stimulants/>

Number and rates (per 100,000 population) of **total**

apparent opioid toxicity deaths by province and territory in **2022 (Jan to Mar)**



[Download data](#)

Source: Government of Canada, Sept 2022



The Power of Parent Advocacy

Moms Stop the Harm (MSTH) is a network of Canadian families impacted by substance-use related harms and deaths.

3500 families Canada wide

Mission: We advocate to end substance use related stigma, harms and death.

Provide peer support and welcome new families.

<https://youtu.be/jNWjGkHCUs>





MSTH engages in Advocacy and Peer Support



Stronger Together Canada

Aims to build capacity and improve outcomes for individuals and families with peer lead support groups.

Healing Heart groups for families who have lost loved ones

Holding Hope Groups for families whose loved ones are using substances

- STCA is funded by the Health Canada Substance Use and Addictions Program

MSTH advocates for:

A safer regulated supply #safesupply

Decriminalization of PWUD

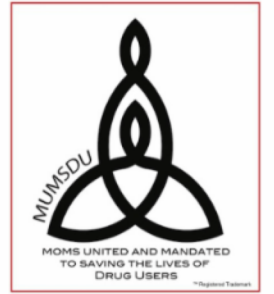
Harm reduction in all provinces

Evidence-based treatment

Upstream prevention

Meaningful inclusion of PWLLE and their families in all decisions that affect us!





Dr. Rebecca Haines-Saah



Dr. Emily Jenkins



Dr. Elaine Hyshka
Heather Morris RN MN
PhD Candidate

The Research Project:

Mother's Stories of Advocacy Following their Child's Substance Passing

Research Objectives:

1. Advance academic knowledge on parents as advocates for drug policy reform.
2. Help build parent advocates capacity to achieve evidence-based policy responses in Canada.

Data Collection:

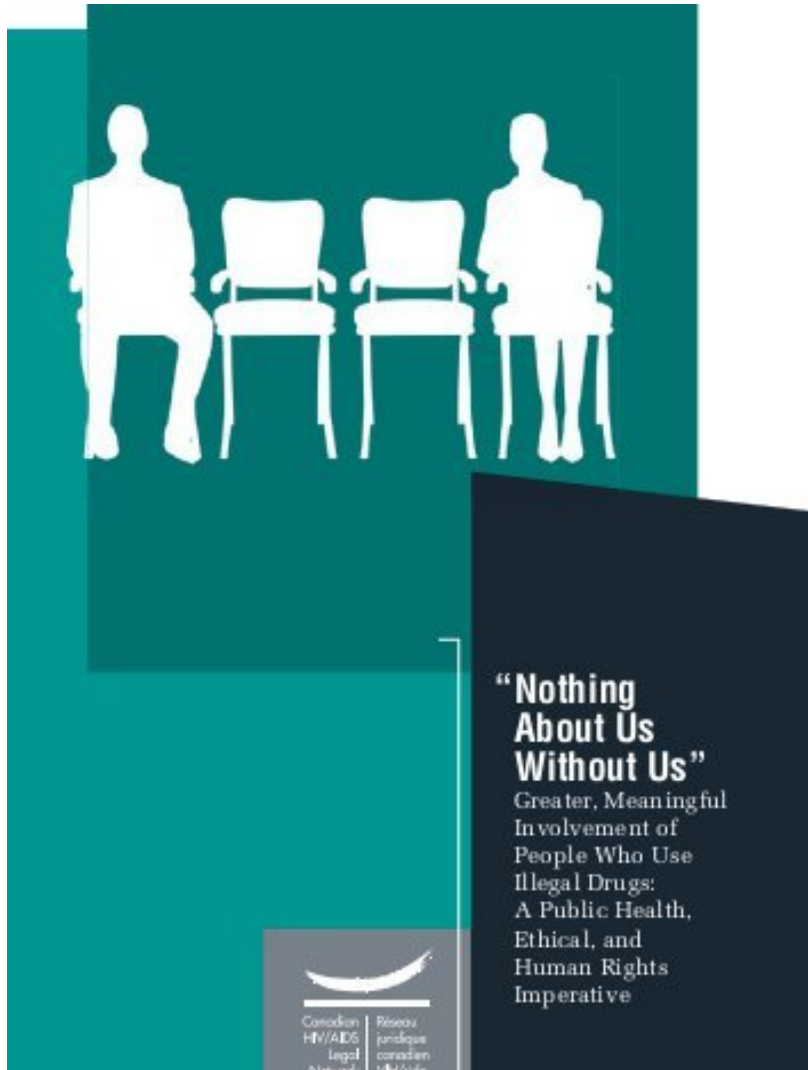
1. Qualitative interviews (n=43) between June-Nov. 2017 across Canada
2. Oral History interviews (n=3) with founders of parent advocacy groups

The Sample :

- **Age:** 75% of reported ages 45-64
- **Marital Status:** 51% married; 7% common-law; 23% separated/divorced; 9% single or widowed; 9% multiple responses
- **Children Who Passed Away:** 35 males and 10 females (2 families had 2 deaths); Children ranged in age from 17-43 when they died; most in their 20s



Ensuring
Representation so
that diverse
family voices and
family situations
are included and
respected



Providing *Compensation* in order to demonstrate that the time and contributions of parent and family volunteer advocates are valued.



Balancing *Ethical Considerations* in the research to protect the potential dual roles of parent and family advocates as “researcher-participants” on the research team.



Prioritizing joint
*Ownership and
Dissemination* to the
mutual benefit of
academic researchers,
parent and family
advocates, and research
participants



Manuscript #1: Bereaved mother's engagement in drug policy reform: A multisite qualitative analysis" (Jenkins et al., 2021). *International Journal of Drug Policy*.



Manuscript #2: It's a bit of a double-edged sword: Motivation and personal impact of bereaved mothers' advocacy for drug policy reform" (Morris et al., 2021). *Qualitative Health Research*.



Manuscript #3: “I’m not your reality show:” Perspectives of bereaved mothers’ engagement with the news media to advance drug policy reform” (Morris et al., 2021). *Social Science & Medicine – Qualitative Research in Health.*

Community Events & Forums

1. Public Forum March 2017– “A Family-Centered Approach to Substance Use in Alberta”

2. Stimulus Conference Satellite Event: “How can communities support families affected by the opioid crisis?” Oct. 4, 2018



PETRA SCHULZ
Co-Founder
MOMS STOP THE HARM

LESLIE MCBAIN
Co-Founder
MOMS STOP THE HARM
Family Engagement Lead
BC CENTRE ON SUBSTANCE USE

KATIE MAI
Stakeholder Engagement Coordinator
BC CENTRE ON SUBSTANCE USE

DR. REBECCA SAAH
Assistant Professor
UNIVERSITY OF CALGARY O'BRIEN
INSTITUTE OF PUBLIC HEALTH

DR. HAKIQUE VIRANI
Public Health & Addiction Medicine
Specialist Assistant Clinical Professor
UNIVERSITY OF ALBERTA
DEPARTMENT OF MEDICINE
Medical Director
METRO CITY MEDICAL CLINICS

Moderator: Lorna Thomas,
MOMS STOP THE HARM

**A SATELLITE
EVENT OF
STIMULUS
2018**
stimulusconference.ca

OCT 4, 7-9PM
How can communities support families affected by the opioid crisis?
A PUBLIC PANEL DISCUSSION
Shaw Conference Centre, Salon 4
9797 Jasper Ave, Edmonton
RSVP at bit.ly/Oct4Panel
Light refreshments will be provided
Support provided by the O'Brien Institute for Public Health
UNIVERSITY OF CALGARY
O'Brien Institute for Public Health



Panel discussion from left: Jennifer Woodside, Donna May, Petra Schulz, Marliss Taylor, Dr. Hakique Virani.

MOTHER'S STORIES OF ADVOCACY

Following their Child's Substance Passing
(2017 – 2019)

Project Summary and Report to Community Partners







Photo courtesy of Moms Stop the Harm

Project Summary & Report to Community Partners

<https://www.momsstoptheharm.com/research-project>

The Knowledge Translation Project:

Seeing Beyond the Numbers: What families want you to know about opioids, stigma and harm reduction

			
PHIL	KYM	DONNA	PETRA
Phil Haug lost his son, Alex. These are the words Phil would say to him today.	Kym Porter grieves for her son, Neil. Here are her thoughts for him.	Donna May talks to her daughter. This is what she wants her to hear.	Petra Schulz lost her son Danny when he was just 25. This is her letter to him.

<http://www.see-beyond.ca/>

<https://www.youtube.com/watch?v=uSy9lanywQo>

‘Seeing Beyond the Numbers’ Project: Dissemination



- **Community Events: Edmonton; Medicine Hat; Sherwood Park, Victoria, Vancouver, Red Deer; Calgary; Yellowknife; Prince Albert, Sask**
- **Health Canada (United Nations Office on Drugs and Crime, Commission on Narcotics, Vienna, March 2019)**
- **Local harm reduction agencies**
- **Harm Reduction International Conference, Portugal**
- **News media: Calgary, Vancouver, Edmonton, Toronto**

HOME VIDEOS PLAYLISTS CHANNELS DISCUSSION ABOUT

#SeeTheLives: Petra's Letter
24,430 views • 1 year ago
Visit See-Beyond.ca to learn more

0:00 / 1:33

Uploads ▶ PLAY ALL

Video Title	Views	Time
#SeeTheLives: Donna's Letter	62K views • 1 year ago	1:25
#SeeTheLives: Kym's Letter	25K views • 1 year ago	1:28
#SeeTheLives: Petra's Letter	24K views • 1 year ago	1:34
#SeeTheLives: Phil's Letter	44K views • 1 year ago	1:19
#SeeTheLives: Parent's Letters Series	573 views • 1 year ago	5:58

'Seeing Beyond the Numbers Project': Evaluation

Benefits and Challenges....

British Journal of Social Work (2008) **38**, 1610–1629

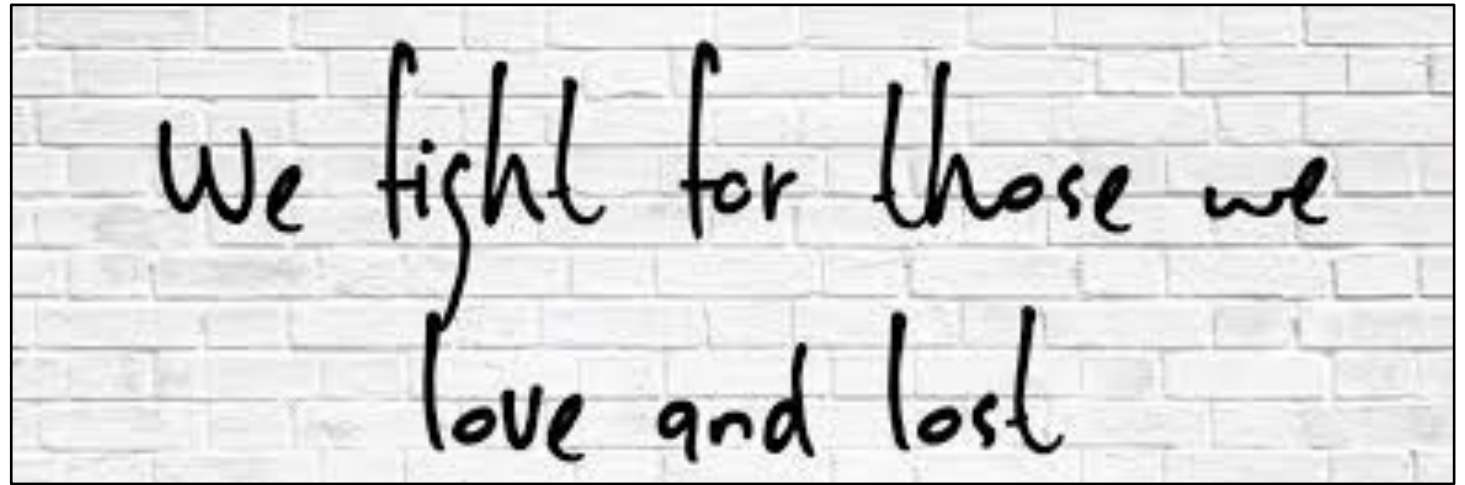
doi:10.1093/bjsw/bcm069

Advance Access publication July 31, 2007

Collaboration Between Community Advocates and Academic Researchers: Scientific Advocacy or Political Research?

Roland Stahl and Corey Shdaimah

Questions?



<https://www.youtube.com/channel/UC-jU0nERgMtq7kfGWXGgNWQ>

<http://www.see-beyond.ca/>



The Power of Partnership



Question and Answer



Stay in Touch!



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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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Thank You!

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Live Discussion

Breakout Discussion Information


1. Nominate a note-taker for each breakout group
2. Introduce yourselves within your group (your name, pronouns, role, location)
3. Discussion questions are on the google doc (link in chat) – the note-taker will record notes from your group on this shared document
4. We'll debrief as a large group following the breakout groups
5. After the event, an infographic summarizing key points of the discussion will be created and shared


Discussion Questions

1. How can we best engage people with lived experience of facing stigma and discrimination in community-based participatory research?
2. How might we best navigate challenging political contexts when working with community groups who are advocating and organizing against harmful government policies?

Large Group Debrief

Webinar Recordings



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Webinars & Discussions

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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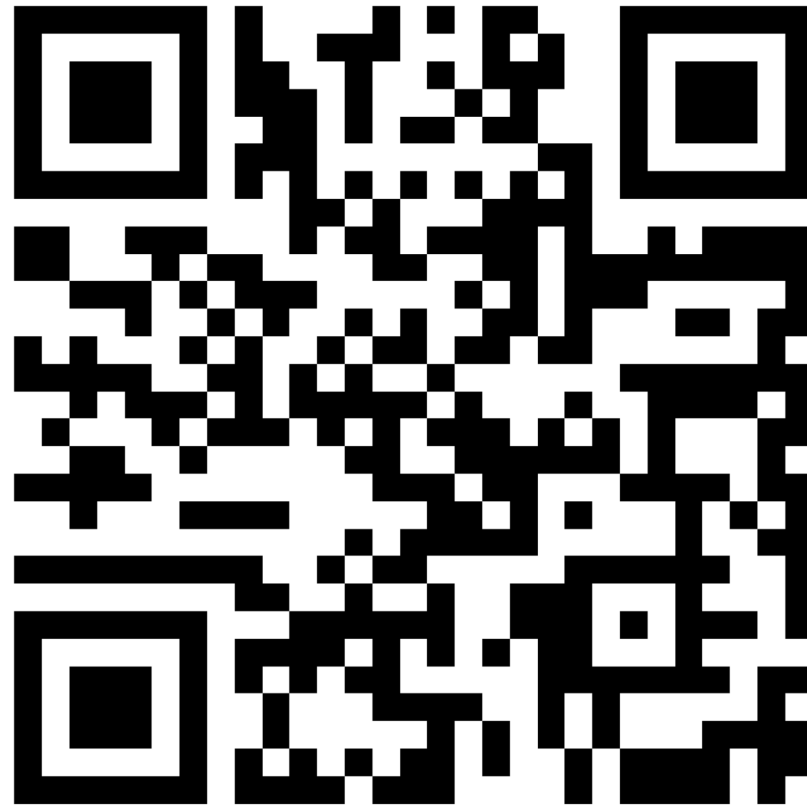
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