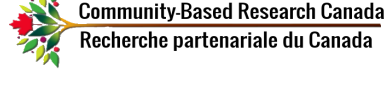


Engaging with Bereaved Parents in Substance Use Research and Policy Reform



On October 27th, CBRCanada members participated in a webinar and live discussion of participatory research influenced by the network of families in Canada impacted by substance use-related harm and death. In their presentation Heather Morris, Petra Shultz and Rebecka Haines-Saah first honoured loved ones lost to drug use, overdose and poisoning. Secondly, they shared their study findings from engaging in Community-based participatory research on Canada's drug poisoning crisis, particularly the influence of parent advocacy in shaping evidence-based drug policy reform to end substance use-related stigma, harms and death. After the webinar, presenters facilitated live discussions on two questions addressed below.



Drug poisoning-related deaths and hospitalization in Canada

January 2016 to March 2022

21
Daily deaths

30,843
Apparent opioid toxicity deaths

32,319
Opioid poisoning-related hospitalization

30,843
Stimulant poisoning-related hospitalization

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

ADDRESSING THE DRUG POISONING CRISIS THROUGH SCIENTIFIC ADVOCACY

How can we best engage people with lived experience of facing stigma and discrimination in community-based participatory research?



How might we best navigate challenging political contexts when working with community groups who are advocating and organizing against harmful government policies?

Advocacy

Advocacy is going beyond performative allyship.

Advocacy starts with **knowledge** influenced by lived experience expertise and professional expertise.

Knowledge

Knowledge from **experts** capture and highlight systemic problems and needs unique to each community to avoid policies made by government officials that do not address or improve the drug poisoning crisis.

Knowledge mobilization by experts eliminate stigma and provide appropriate training and educational resources that provoke healthy changes on a societal level. as **individual lived and living experience become collective voices for change.**

Lived and Living Experience Experts

Lived and living experience experts can use their stories to influence works of **professional experts** as "researcher-participant" and community advocates.

Professional Experts

Professional experts are scientific advocates such as healthcare professionals working in/with research institutions.

Professional experts use individual voices of those with lived and living experiences in research and/or partner in advocacy with them to find themes that lead to community driven solutions that can direct grassroots advocacy movements and government policies.

Work as a professional expert...

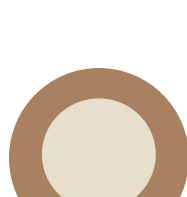
is not more important than lived experience expertise. Professional expertise involves **amplifying the voices** of those with lived experience expertise to make impactful change. It should reward the vulnerability of these individuals, their families and communities. It should make the role of "researcher-participant" worth it!

It begins with **building trust.**

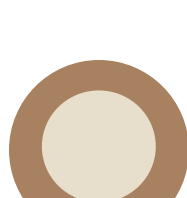
Trust is built through:

- Building relationships via participating in the life of the community.
- being transparent with participants as scientific advocate about research goals, and what information will be private or public.
- Trust is maintained** when researchers show compassion and care for the wellness of participants. This can mean having a biased sample of participants who are emotionally ready to revisit the past.

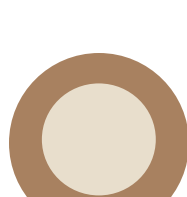
Considerations for working with "Researcher-Participants"



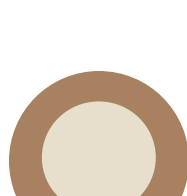
Ensure representation so that diverse family voices and family situations are included and respected.



Provide compensation in order to demonstrate that the time and contributions of parents and family volunteer advocates are values.



Balance ethical considerations in the research to protect the potential dual roles of parent and family advocates as "researcher-participant" on the research team.



Prioritize joint ownership and dissemination to the mutual benefit of academic researchers, parent and family advocates, and research participants.

Want to learn more and take action?

THE KNOWLEDGE TRANSLATION PROJECT

Seeing [Beyond the Numbers: What families want you to know about opioids, stigma and harm reduction](#)



MOMS STOP THE HARM

CANADIAN OPIOD RELATED HOSPITALIZATION AND DEATH STATISTICS

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

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