

AT A GLANCE

Collaborating with Community Experts in Evaluation and Research on Substance Use

Background

There is increasing recognition of the importance of the principle of “Nothing About Us, Without Us”¹ and the equitable² engagement of community expertise in research and evaluation.¹ One strategy has been using community-based participatory research - an approach where community members and community-based organizations are involved in all aspects of the research and evaluation process. Community-based participatory research has direct benefits to the community members involved (e.g., skill-building, valued expertise, employment, empowerment) as well as producing relevant results to inform programs and policies.² However, there are key considerations that need to be taken into account when using such an approach; for example, there is a need to provide accessible payment options for engagement and to provide training opportunities for community partners (i.e., people with living and lived expertise of drug use) to build capacity for engagement in a range of roles.

The information in this document is based on key resources and discussions with experts, a Google search, and note-taking at a lunch and learn discussion. We reached out to researchers with expertise in community-based participatory research for relevant resources. We also searched Google at the end of November 2021 for grey literature on research training programs for people who use drugs and scanned the reference list of relevant documents. Next, we engaged our partners at the Ontario Network of People who use Drugs (ONPUD) to incorporate their expertise, experiences, and learnings. This led to a collaboration with ONPUD to hold a lunch and learn conversation with a panel of community experts who shared their experiences in partnering with organizations or groups responding to opioid/overdose harms.

The objectives of the lunch and learn were to:

- Centre the experiences of people with living and lived expertise of drug use in conversations on collaborations to conduct evaluation and research;
- Provide space for people with living and lived expertise of drugs use to exchange ideas and learn; and

1 “Nothing About Us, Without Us” is a concept that recognizes that people who use drugs have the right to be involved and informed about decision-making that affects their health and well-being.

2 Engagement should not only be meaningful but also equitable. We use the term ‘equitable engagement’ to reflect equitable practices such as fair pay, addressing power imbalances, and providing appropriate supports for engagement.

- Share information about best practices working with people with living and lived expertise and supports with local partners.

The discussion-based event involved three panel speakers who shared their reflections, expertise, experiences, and examples from practice. Meeting attendees included the project team, people with living and lived expertise of drug use, drug strategy coordinators, and local partners.

In this document, we summarize the key themes from the documents we found and the lunch and learn discussion. An initial draft of the document was also sent to the panel speakers and ONPUD to check for accuracy and language. Sharing a summary of the discussion and expertise of people with living and lived expertise can help support best practices in the collaborations of organizations responding to opioid/overdose harms.

Lessons on Collaboration from Community Experts

The panel speakers shared a number of key lessons on collaboration from their diverse experiences in research and evaluation. Below is a summary of the lessons.

- **Be flexible and adaptable:** It is not necessarily helpful to create specific roles at the start of a project. Flexibility with roles helps to loosen expectations with the community you are working with and use people's talents to the best effect. This can allow time to better understand and recognize the capacities of people and support their strengths and talents. It also allows room to better meet the needs of people, for people to take a break, or take a step back from the work.
- **Provide accessible payment options for research participants and research associates/positions:** There are issues with paying participants with gift cards (e.g., perceived as condescending). A more accessible method is paying participants through e-transfer or cash. Another example is to partner with drug user organizations to pay participants in cash and then get reimbursed (assuming that they have funds). As for research positions, it is important to work with people and determine payment policies and how they want to be paid. Leverage the expertise and knowledge of community experts to mitigate issues related to social assistance income and others.
- **Provide fair and equitable pay wages:** Research positions for community experts should have rates of pay that are equitable to other positions. Plan budgets and wages for involvement in the entire project rather than hours of work for certain tasks and deliverables (e.g., data collection). The differences in the pay across projects sets expectations and inequities. Under capitalism, it is recognized that community members are often left to accept whatever they can get.
- **Encourage in-person work for team-building:** While most work has been virtual during the COVID-19 pandemic, any opportunity to work safely in-person is encouraged (e.g., bringing the team together for in-person data analysis). In-person opportunities are helpful in allowing informal conversations to happen during breaks and building camaraderie among the team

- **Understand and practice allyship with African, Caribbean, and Black (ACB) and Indigenous communities:** While their histories are distinct, ACB and Indigenous communities have parallel experiences of the impact of colonization, systemic racism, and oppression. In working with ACB and Indigenous communities, it is important to define the word ally and allyship. Allyship means being an advocate and speaking out when you see something that is oppressive. Being an ally does not mean being impartial or selective when to be an ally or not. When talking about allyship, it is also important to reflect on and define privilege. There are innate privileges with being white including having greater access to power and resources. While privilege can be harmful, it can also be a powerful tool that can be used to assist with opening access to resources and other areas. There are a number of ways that people can use their privilege such as:
 - Inviting people to the table and actively listening
 - Getting funding or support funding for ACB and Indigenous-led organizations
 - Understanding the representation and proportion of ACB and Indigenous people within organizations, projects, and communities that you are serving
 - Hiring at least two people from the ACB and Indigenous community for the evaluation project and process (start to finish)
 - Having open conversations and questioning and challenging your own privilege

It is also important to recognize the diversity within groups. The diverse voices of ACB and Indigenous communities must be integrated into the evaluation of services and programs that touch on cultural and historical backgrounds or the effects of racism. Failure to do so will result in data that is biased and not truly reflective of the realities of people. Cultural awareness and cultural humility must be put into practice.³

- **Address power dynamics within research and evaluation projects:** Community experts are typically engaged in projects in ways that are tokenistic⁴ and often do not involve decision-making power. Their roles are often the lowest paid and at the bottom of the project hierarchy, which perpetuates stigma. Community experts' roles are often precarious in nature, with no access to benefits. Some ways to address the power dynamics in projects include:
 - Providing proper employment and hiring practices including leadership roles within project and payment as consultants
 - Building in flexibility and adaptability in the funding process
 - Starting collaboration at the beginning of a project and throughout every process rather than as an afterthought (e.g., adding the names of community experts to the work) or for only one component (e.g., data collection but not analysis)
 - Providing choice and autonomy to be able to work and contribute

³ 'Cultural humility' describes one's "willingness and openness to demonstrate respect and a lack of superiority when interacting with those whose cultural identities, values, and worldviews differ from theirs."

⁴ Tokenistic practices include those that rely on one to two people who use drugs, rely on the same people, have minimal efforts of inclusiveness, and devalue expertise.

- **Share knowledge back to the community in ways that are accessible:** It is important to share the final product back to community members who contributed to the work. Community members and experts should be provided with the opportunity to review the final reports to understand what information will go out and when it will be shared. Final products should be accessible and easy for the community to understand. This includes being clear, using pictures, and less academic language.
- **Value and respect the expertise and knowledge of community experts:** The expertise and advice of community experts have often been ignored in research and solutions that impact their lives. Community experts have experiential knowledge of drug use, connections, and bring an important voice to the table that may not be heard. Engagement and inclusion cannot occur unless there is great respect for what community experts are saying. Their engagement should not be tokenistic or reliant on one person.
- **Create a safe space for community experts to share ideas and bring forward challenges.**

Research and Evaluation Training Opportunities

The panel of community expert speakers also spoke of the need to provide opportunities for training in research and evaluation and space for community members to ask questions. They noted that community members may have different backgrounds, training, and experiences with research. Given this, it was important to start with discussing the basics of the research or evaluation process and build capacity. A range of topics were also described including becoming familiar with research ethics (e.g., Tri-Council Policy Statement: Ethical Conducts for Research Involving Humans) and data collection (e.g., principles of ownership, control, access, and possession of data collection with Indigenous communities).

We also reviewed documents that included important considerations for the design, delivery, content, and audience for training opportunities with people with living and lived expertise of drug use.^{5,6}

Table 1. Considerations for training on research and evaluation

Design and delivery	Content and materials	Audience
<ul style="list-style-type: none"> • Ask community experts about their accessibility needs to inform the design and delivery of the training, including duration and time commitments • Design training sessions based on the job description and expectations, e.g., the roles of community experts, administering surveys, interviewing skills, facilitation skills, data analysis, and knowledge translation • Offer sessions in a low-barrier setting • Offer food before and during sessions • Provide mentorship opportunities for community experts once they are engaged 	<ul style="list-style-type: none"> • Clearly outline expectations around attendance, group norms • Provide content and materials on community-based participatory research, the research and evaluation process including research design, data collection, analysis, and knowledge translation • Cover a range of relevant skills for data collection including ethics, privacy, confidentiality, informed consent, interviewing skills, verbal and non-verbal communication, diversity of participants, administering quantitative surveys • Ensure that content and materials are accessible to community experts with varying levels of literacy and diverse backgrounds (including distribution of materials on paper and through email) 	<ul style="list-style-type: none"> • Bring together a mix of people to share practices and learn from one another • Spend extra time building connection between people

Training Examples from Practice

We identified two examples of training resources from practice in British Columbia and Ontario. We recognize that there are likely many more relevant examples that may not be publically available. Our search in Google focussed on research training for people who use drugs, which may not have identified more broad and relevant training resources on the support of people with living/lived expertise in programs. However, these examples provide some helpful details related to the format of trainings, the audience, and topics as a starting point.

Table 2. Examples of training in practice

“Research 101” workshops in the Downtown Eastside of Vancouver⁵	A community-based participatory research (CBPR) partnership in Ottawa⁶
Six weekly 2.5-hour workshops with 13 people from drug user organizations to discuss ethical community-based research.	A week of training for community experts and medical students on a range of topics specific to the study. Topics included: CBPR, HIV and harm reduction, the role of community expert in interviews, research ethics, interviewing skills, confidentiality, privacy, informed consent, communication, diversity, and administration of surveys.

Other Relevant Resources on Collaboration and Training

The panel speakers and attendees shared resources related to the payment of community experts. We also found some relevant resources on research training through our grey literature search and consultation with experts. These include:

- **The British Columbia Centre for Disease Control Peer Payment Standards for Short-Term Engagements:** Standards for short-term engagement and payment of people with living and lived expertise of drug use, including attending meetings as experts.⁷
- **Ontario Harm Reduction Network Program Participant Payment Guidelines:** Payment guidelines for in-person training/workshop facilitation, online events, meetings, and other tasks.⁸
- **CIRTification:** A research ethics training program designed for community partners that covers content related to research with human subjects, recruitment, informed consent, and managing data.⁹
- **Community-based research modules:** Seven free modules offered by Trent University that introduce the principles and practices of community-based participatory research.¹⁰

Conclusion

Collaborating with community experts is critical to responding to opioid/overdose harms. This document reflects the lessons and experiences of community experts discussed at a meeting about collaborating on research and evaluation of community initiatives. We also summarize key considerations and examples of training opportunities from relevant resources to build skills and knowledge for collaboration. Together, these experiences and considerations can be used to inform best practices for organizations to collaborate with community experts on research and evaluation of initiatives addressing opioid/overdose harms.

References

1. Jurgen R. "Nothing about us without us". Greater, meaningful involvement of people who use illegal drugs: a public health, ethical, and human rights imperative [Internet]. Toronto, ON: Canadian HIV/AIDS Legal Network, 2008 [cited 2022 Mar 01]. Available from: <https://opensocietyfoundations.org/uploads/b99c406f-5e45-4474-9343-365e548daade/nothing-about-us-without-us-report-20080501.pdf>
2. Souleymanov R, Kuzmanović D, Marshall Z, Scheim AI, Mikiki M, Worthington C, et al. The ethics of community-based research with people who use drugs: results of a scoping review. *BMC Med Ethics*. 2016;17(1):1-13. Available from: <https://doi.org/10.1186/s12910-016-0108-2>
3. Jones CT, Branco SF. Cultural considerations in addiction treatment: the application of cultural humility. Virginia, USA: National Association for Addiction Professionals; 2021 [cited 2022 March 29]. Available from: https://naadac.org/assets/2416/aa&r_winter2021_cultural_considerations_in_addiction_treatment.pdf
4. Austin T, Boyd J. Having a voice and saving lives: a qualitative survey on employment impacts of people with lived experience of drug use working in harm reduction. *Harm Reduc J*. 2021;18(1):1-12. Available from: <https://doi.org/10.1186/s12954-020-00453-5>
5. Neufeld SD, Chapman J, Crier N, Marsh S, McLeod J, Deane LA. Research 101: a process for developing local guidelines for ethical research in heavily researched communities. *Harm Reduc J*. 2019;16(1):1-11. Available from: <https://doi.org/10.1186/s12954-019-0315-5>
6. Lazarus L, Shaw A, LeBlanc S, Martin A, Marshall Z, Weersink K, et al. Establishing a community-based participatory research partnership among people who use drugs in Ottawa: the PROUD cohort study. *Harm Reduc J*. 2014;11(1):1-8. Available from: <https://doi.org/10.1186/1477-7517-11-26>
7. Becu A, Allan L. Peer payment standards for short-term engagement [Internet]. Vancouver, BC: BC Centre for Disease Control; 2017 [cited 2022 Mar 01]. Available from: https://bccdc.ca/resource-gallery/Documents/Educational%20Materials/Epid/Other/peer_payment-guide_2018.pdf
8. Ontario Harm Reduction Network. OHRN program participant payment guidelines [Internet]. Toronto, ON: Ontario Harm Reduction Network; 2020 [cited 2022 Mar 01]. Available from: <https://acrobat.adobe.com/link/track?uri=urn:aaid:scds:US:ee67fa94-2f10-3aa1-9068-7cc6f915e764#pageNum=1>
9. Anderson EE. CIRTification: Training in human research protections for community-engaged research partners. *Progress in community health partnerships: research, education, and action*. 2015;9(2):283. Available from: <https://doi.org/10.1353/cpr.2015.0044>
10. Trent University. Community-based research modules [Internet]. Trent, ON: Trent University; 2022 [cited 2022 Mar 01]. Available from: <https://doi.org/trentu.ca/community-based-research/cbr-modules/community-based-research-module>

Citation

Ontario Agency for Health Protection and Promotion (Public Health Ontario). Collaborating with community experts in evaluation and research on substance use. Toronto, ON: Queen's Printer for Ontario; 2022.

Disclaimer

This document was developed by Public Health Ontario (PHO). PHO provides scientific and technical advice to Ontario's government, public health organizations and health care providers. PHO's work is guided by the current best available evidence at the time of publication. The application and use of this document is the responsibility of the user. PHO assumes no liability resulting from any such application or use. This document may be reproduced without permission for non-commercial purposes only and provided that appropriate credit is given to PHO. No changes and/or modifications may be made to this document without express written permission from PHO.

Community Opioid/Overdose Capacity Building

Started in 2019, COMmunity Opioid/Overdose CAPacity Building (COM-CAP) is a four-year project funded by Health Canada's Substance Use and Addiction Program. The goal of COM-CAP is to support community-led responses to opioid/overdose-related harms in communities across Ontario. The supports focus on strengthening the knowledge, skills, and capacity of the key stakeholders involved.

- The Ontario College of Art & Design University (OCAD U) - Health Design Studio
- University of Toronto - Strategy Design and Evaluation Initiative
- Black Coalition for AIDS Prevention
- Chatham-Kent Public Health
- NorWest Community Health Centres
- Drug Strategy Network of Ontario
- The Ontario Network of People who Use Drugs

PHO collaborates with external partners in developing COM-CAP products. Production of this document has been made possible through funding from Health Canada. These materials and/or the views expressed herein do not necessarily reflect the views of Health Canada.

For more information contact substanceuse@oahpp.ca.