# Practical considerations for engaging youth with lived and/or living experience of substance use as youth

advisors and co-researchers

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### Introduction

Youth have traditionally been excluded from research and, when included, have often been limited to being sources of data (1). Although youth participatory action research (YPAR) has been gaining popularity over the last decade (2-4), few studies report on how best to apply these methods effectively with youth. To address this gap, we describe how we engaged youth as advisors and research assistants in a qualitative research study and our key learnings for engaging youth with lived and/or living experience of substance use.

### **Methods in Phase 1**

### Youth Engagement & Evaluation

We applied YPAR methods and formed a Project Youth Advisory Committee called Youth4Youth (Y4Y) to inform all phases of the project. It is comprised of youth (n=14) with lived/living experience of substance use from across BC. From Y4Y we hired:

- Youth Research Assistants (YRAs) to facilitate interviews and support the thematic analysis and knowledge translation of the research findings.
- Youth Peer Evaluators (YPEs) to co-develop the evaluation plan and conduct evaluation activities.
- Curriculum Working Group Members to co-create youth-informed substance use training for peer support workers and other service providers.

Mid- and end-point surveys were distributed to evaluate and improve our engagement methods. Evaluation surveys were co-designed by the YPEs and an evaluation specialist using Likert scales and open-ended questions. Study participants who took part in a focus group or interview were also asked to complete a follow-up survey about their experience.

## Results

The positive impact of engaging youth with lived experience was reflected by study participant responses to the quality and relevance of the interview questions and positive experiences with the youth facilitators. Youth partners described developing new skills in research, group facilitation, leadership, communication and professionalism. Lessons learned also led to organizational changes to foster more equitable relationships with youth and practical considerations for engaging youth with lived experience, as outlined below:

### **Equitable hiring** process

- Diverse recruitment methods
- Representation from diverse voices and experiences, unless studying a specific population
- Multiple hiring points based on phases of work
- Pay youth adequately for their time and expertise
- Offer youth the same compensation, unless a leadership position is offered
- Transparency about the compensation process (e.g., paperwork, processing time, tax info)
- Transparency about existing structural barriers to compensation

#### • Create a community agreement Safe spaces

- Ask youth how they would like to be engaged
- Ensure youths' confidentiality and privacy
- Check-in with youth before talking about certain topics
- Have sufficient project staff trained in youth engagement methods
- Meet youth where they are at and engage them in a way that
- reflects their interest, capacity and skills
- Acknowledge other commitments and personal factors youth may be dealing with
- Allow advisory members to take breaks from the opportunity if needed

**Flexibility** 

Proper

compensation

### The Experience Project

Our work is part of a larger project to create youth-informed substance use training for peer support workers and other service providers working within an integrated youth service (IYS) model (4). This project engages youth during each of its phases:

### PHASE 1: Knowledge Gathering

Curriculum **Development** 

PHASE 3: **Implementation** & Evaluation

Semi-structured interviews with youth and peer support workers

Develop substance use training

PHASE 2:

Pilot and evaluate trainings

## **Step in the research process**

#### **Partnership development**

**YPAR** methods

Developed a project youth advisory committee (Y4Y)

### Research design

Bi-weekly Y4Y meetings to inform the research

### **Data collection**

Trained YRAs facilitated focus groups and interviews

#### **Data analysis**

Meetings between the research coordinator and YRAs to discuss the data, review and refine the themes, and select the most impactful quotes

### **Dissemination of findings**

Shared findings back to the Y4Y and curriculum working group

YRA involvement in knowledge mobilization planning, drafting academic journal publications, conference presentations, etc.

### **Action plan**

Curriculum working group made up of Y4Y members and peer support workers to co-develop peer support substance use training

Future activities still to be determined

"I am incredibly appreciative of the flexibility with this role for the project because it allowed me to jump right back in when I was ready without pressure of persecution/consequence or exclusion from future meetings. Because of this flexibility, I am able to attend meetings knowing that I am able to bring my best self forward and provide better quality contributions to meetings...It has been empowering being able to jump in when I can and know I am doing good work during those times." - Y4Y member

#### Communication, transparency, accountability

- - Clear roles and responsibilities
  - Point person for each engagement opportunity
  - Break up project into phases of work

  - Multiple forms of communications
  - Discuss youths' interests and capacity

#### Transparency about: • Shifts in timelines

- How feedback is
- implemented
- Role and decision-making power

• Ask youth what they are hoping to gain from the experience

- Empower youth to develop their strengths
- Offer youth relevant professional development opportunities
- Offer youth additional opportunities during slower project phases if possible

"I really appreciated creating a community agreement that the group followed and used regularly throughout meetings to provide a safer space for everyone involved." - Y4Y member

### Conclusion

Even though shared decision-making across all phases of research is considered the gold standard for YPAR (5), these methods require sufficient resources, capacity among the project team and youth partners, and flexible project timelines to execute competently and effectively. Assessing capacity for engagement is imperative to avoid potentially harmful practices and embrace the fluid nature of the engagement process.

1. Cuevas-Para, P. (2021). Deconstructing the role of adult facilitators in research led by young people. Journal of Youth Development, 16(2-3), 175-196. 2. Valdez, E.S., et al. (2020) Youth participatory action research for youth substance use prevention: A systematic review. Substance Use & Misuse, 55(2), 314-328. 3. Branquinho, C., et al. (2020). Community-based youth participatory research studies with a focus on youth and well-being: A systematic review. Journal of Community

4. Raanaas, R.K., et al. (2020). A scoping review of participatory action research to promote mental health and resilience in youth and adolescents. Adolescent Research Review, 5(2), 137-152.

5. Ozer, E.J. (2017). Youth-led participatory action research: Overview and potential for enhancing adolescent development. Child Development Perspectives, 11(3), 173-177.

"Using your lived experience for

triggering and emotionally

exhaustive....so compensation

helps not only pay people for the

time they have taken out of their

message that their contributions

day, but it also helps affirm the

are valuable." - Y4Y member

this kind of work can sometimes be

We acknowledge with respect and gratitude that the project team works on the ancestral, traditional and unceded lands of the Coast Salish Peoples, including the territories of the xwməθkwəýəm (Musqueam), Skwxwú7mesh (Squamish), and selímlwmitulh (Tsleil-waututh) Natons, and that the Substance Use and Addiction Program (SUAP) has taken place on many strong Indigenous Nations which we now call British Columbia. Production of this poster has been made possible through a financial contribution from Health Canada as part of the Substance Use and Addiction Program, a partnership between the Foundry and the Youth Wellness Hubs Ontario (YWHO). The views expressed herein do not necessarily represent the views of Foundry, YWHO or its

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Youth capacity

building