McMaster University

Family Medicine

David Braley Primary Care Research Collaborative

Involving People with Lived Experiences in Research

Watch a recording of the session here

Claire Bodkin
Jammy Pierre

October 18th, 2022

@McMasterFamMed

Michael G. DeGroote SCHOOL OF MEDICINE

Working with the Experts

Research collaboration with people with lived and living experience

October 18, 2022

Members of Keeping Six and HAMSMaRT

Claire Bodkin, Assistant Clinical Professor (Adjunct) & HAMSMaRT member, Principal Investigator Nowhere to Go

Jammy Pierre, Keeping Six member, Peer Investigator Nowhere to Go

Learning Objectives

1. Describe the rationale for engaging people with lived and living experience in research
2. Identify recommended practices for collaborating on research with people with lived and living experience
3. Plan for engaging people with lived and living experience in their own research

Lots of ways to think about engagement!

Power focused

Priority setting

Study focused

Report focused

Partnership

Greenhalgh et al 2019

McMaster University
REDEFINING THE STORY OF INCARCERATION AND OPIOID USE
Share your experience of incarceration and street drug use to help guide research
We want to hear from you!
Contact Amanda: butlea17@mcmaster.ca

NOWHERE TO GO

mcmaster.ca

Figure adapted from Steven Reis, University of Pittsburgh and Harold Pincus, Columbia University; in Canada's Strategy for Patient-Oriented Research, CIHR, 2011.

NALOXONE
MOUTH TO MOUTH RESUSCITATION DEVICE
QUICKSAVER
Clear airways of any obstructions
BY SKILLED PERSONS IN MOUTH TO MOUTH RESUSCITATION
Tilt patient's head backward.
Insert "Quicksaver" mouth piece between patient's teeth
Pinch patient's nostrils. Breathe into patient's mouth through the valve and control if the chest rises.
Let patient exhale. Repeat immediately 3 times, then every 4 seconds until patient gets to normal conditions.
5 STEPS TO RESPOND TO AN OPIOID OVERDOSE
STEP 1 SHOUT & SHAKE
STEP 2 CALL 9-1-1
STEP 3 GIVE NALOXONE:
STEP 4 PERFORM RESCUE BREATHING AND/OR CHEST COMPRESSIONS.
STEP 5 IS IT WORKING?
RECOVERY POSITION
SIGNS OF OPIOID OVERDOSE
PEEL HERE
3mL
25G x 1" (0.50mm x 25mm)
REF 10391
VanishPoint® syringe
STERILE EO
Medium - Moyen
TAMPON ALCOOLISÉ ISOPROPYLIQUE ANTISEPTIQUE
LORIS
ANTISEPTIC ISOPROPYL ALCOHOL PAD
Manufactured by:/Fabriqué par:
LERNAPHARM

Nothing About Us Without Us!

PEEP

Professionals for Ethical Engagement of Peers

Guidelines for Partnering with People with Lived and Living Experience of Substance Use and Their Families and Friends

Canadian Centre on Substance Use and Addiction

Evidence. Engagement. Impact.

Make a plan

- Start early
- Start somewhere
- Involve multiple people bringing multiple perspectives
- Consider partnering with a peer-run organisation
- Plan = Resources

Relationships

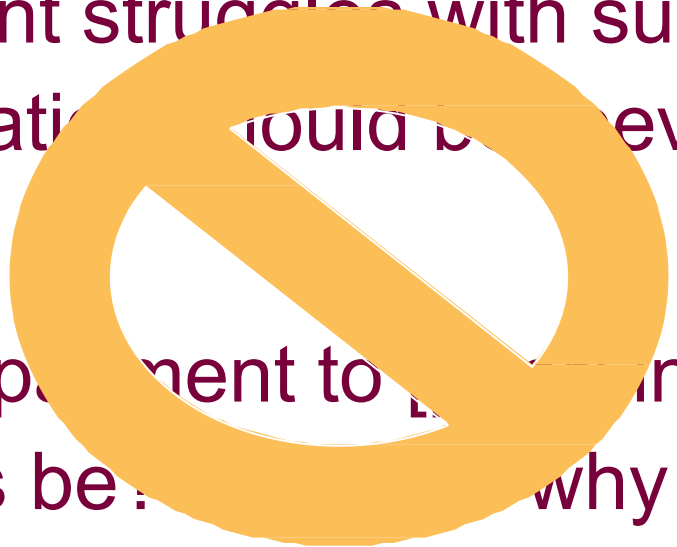
The heart of family medicine …

… and working with people with lived/living experience

What does it look like to have good relationships?

Payment

“If the participant struggles with substance use, cash compensation should be re-evaluated.”



“Please clarify payment to [illegible] investigator(s)? Who would this be? [illegible] why this is provided?”

Payment

PWLE should be paid “A living wage that is equitable to other forms of expertise/qualifications” - CAPUD

Be transparent, provide options, pay cash when possible (not everyone has a bank account).

Consider implications of income on ODSP or OW payments.

McMaster's Rules

Tracked via Mosaic

Must be electronic payment (direct deposit or EFT)

Payees must provide their full name, home address, and SIN

- once a SIN is in the McMaster payment system, it is in a secure area and not visible or accessible to users.

>$500 in a calendar year, a T4A will be issued

<$500 in a calendar year, no T4A will be issued

Supporting participation

Communication - not just email! Text, facebook, in person, & more

Cultural & emotional safety

Equipment

Transportation

Child care

Food

Location of meetings/work

Access to harm reduction supplies/consideration of substance use

& lots more …

Skill building

Formal - e.g. courses, certifications, presenting at conferences

Informal - e.g. in service/as needed training on software, methods, writing

We are the researched, the researchers, and the discounted: The experiences of drug user activists as researchers

“The power differential is clear …

most research is still framed as something that academic researchers embark on and then invite impacted people to participate in, rather than as partnerships between community organizations of impacted people and academic researchers.”

Simon C, Brothers S, Strichartz K, Coulter A, Voyles N, Herdlein A, and Vincent L 2021.

Simon et al suggest:

Research should include community-initiated research questions, joint data ownership, & leadership capacity development.
Directly impacted people should have priority hiring in low-threshold positions.
Published findings should be freely accessible to community.
IRB should empower as well as protect subject populations.
Community review boards should be given ethical approval decision making power.

Breakout Rooms

In your group, choose a project someone has been working on where there was no/minimal engagement of people with lived or living experience.

Imagine you are doing that project all over again - what resources specific to the patient population could help you make an engagement plan? Who do you already know who could help you to engage PWLE? What would some of the most important considerations be when engaging that community? How do you think the project would change if PWLE were (more) involved?

Questions?

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Resource List

EXTRA SLIDES

ONPUD Participation Standards

Fair Compensation

Each consultant from ONPUD will be fairly and equitably compensated for their time at a base rate of $30 per hour by cash or e-transfer.

Participation

Coming to the table we bring a wealth of knowledge and expertise. We ask that our participation be valued, not to be tone policed, and not to be tokenized. We also ask that we are not invited last minute as it

Safety Considerations

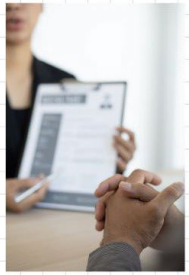
Ensuring this is a safe space for us to be transparent and offer the best of ourselves, we can not be made to feel surveilled, group norms be established and upheld, and language isn't stigmatizing, or there is space for us to address it.

Accessibility Considerations

We ask that meetings don't fall on the beginning or end of the month. If transportation is identified as a barrier that we get assistance with it, someone to check in before and after the meeting to debrief, and that meetings are held preferably mid day.

Topics

We ask that we are not invited to a drug user/harm reduction hostile environment without full disclosure to allow us to consent to this. We wish to be respected as People who use Drugs and then as ONPUD members.



Centre of Excellence on Partnership with Patients and the Public

PUBLIC AND PATIENT ENGAGEMENT COLLABORATIVE

McMaster University