

DRNS Conference 2018

Democratising drugs research? Navigating the evidence and building on people's experience to make it work for everyone – handout and references

We have included some materials here that we have found helpful in this work. They are from our own experience in DRNS and wider and include resources from the UK and from Canada. If you find other useful resources please share with us!

Lessons from British Columbia: *Participant, Peer and Peep: Engaging people who have used illicit drugs in qualitative research project* (see refs below). This project has many lessons for involvement of people with lived/living experience across themes of:

- recruiting and hiring;
- fair compensation;
- role and project expectations;
- communication;
- connection and collaboration;
- mentorship;
- peer facilitated research.

The reference is below and is open access. Overall, the authors comment that participation improves the relevance, capacity and quality of research.

- Understand the process of hiring and paying peers early on: establish expectations early on
- Clear communication and flexibility in adapting process to varying learning styles, interests and skills were important: flexibility contributes to pride and satisfaction
- Working with a team remotely can be isolating and challenging
- Peers are an integral part of any community-based research project and should be paid members of the research team.

Table 2 is very helpful pasted below - from Greer, A., Amlani, A., Pauly, B., Burmeister, C., and Buxton, J. A. 2018. Participant, peer and PEEP: considerations and strategies for involving people who have used illicit substances as assistants and advisors in research. *BMC Public Health*. 18: 834.

Table 2

Lessons and strategies for engaging people who use substances or peers as active members of a research project

<p>Hiring and recruiting</p> <ul style="list-style-type: none">• Hiring over the duration of the project rather than a short, one-off commitment• Hire more than one peer within each region to promote support and representativeness• Engage with peer-based organizations wherever possible
<p>Fair compensation</p> <ul style="list-style-type: none">• Pay peers the same as others (who do not have substance use experience) in similar roles• Navigate institutional and structural barriers to compensation early on• Discuss barriers early on and develop solutions together• Be transparent and flexible with compensation
<ul style="list-style-type: none">• Lessons and strategies for engaging people who use substances Gather feedback or develop the job advertisement with peers, including the description of what the role entails• Develop a team memorandum of understanding early on; revisit this often
<p>Communication</p> <ul style="list-style-type: none">• Adapt communication to different learning styles and literacy• When possible, do training and other activities with peers in person
<p>Connection and collaboration</p> <ul style="list-style-type: none">• Meet often and consistently• Print and mail all materials if working remotely• Be flexible and committed; give space and support as participation shifts across time
<p>Mentorship</p> <ul style="list-style-type: none">• Hire a peer mentor early on who can help navigate the process and support others
<p>Peer-facilitated research</p> <ul style="list-style-type: none">• Ensure peers participate in as much decision making as possible, not just some decisions (or decisions that are convenient)• Ensure peers are involved and provide feedback on any materials that have been developed by others early on and throughout the process – beginning to end

PEER ENGAGEMENT PRINCIPLES

PEERS AS EXPERTS

Peers are the experts in the context and content of decisions that affect their lives. Through lived experience with substance use, peers have gained highly specific knowledge and insights about the realities of using substances and accessing health services. This expertise is valued by recognizing peers' interests, placing emphasis on their voices, and providing fair and equitable compensation.

EQUITY

Peers experience barriers, discrimination, and differences in relationships, compensation, and health due to the social positionality of people who use drugs in our society. This positionality can result in social, physical, and economic inequities in peer work, including power imbalances in decision making. Promoting equity requires acknowledging these factors and addressing them, and restructuring power differences in decision making.

DIVERSITY

One size does not fit all. Peers can experience different barriers to doing peer engagement and these barriers vary over time and between people. Similarly, peers are not all the same, and have a range of voices and experiences that need to be heard.

TRANSPARENCY

Transparency includes acknowledging successes and failures, or not meeting expectations. Transparency includes providing evidence and rationales for decision making, revealing hidden power dynamics, and providing honest and forthcoming explanations for processes and outcomes. Transparency is the antithesis of bureaucracy, in which peers have full knowledge of the processes that impact their lives and work.

ACCOUNTABILITY

All peer engagement practitioners must take responsibility for their decisions and actions and provide rationales for these decisions and actions in order for the team to learn from their experiences.

SHARED DECISION MAKING POWER

Decisions that affect the lives of people who use drugs should ideally involve peers in all aspects of that decision. The conditions that peers experience in our society create inequitable power relations with decision makers and other members of the public. Recognizing and addressing the differences in power that are entrenched at decision-making tables is paramount to the success and validity of the voices of peers in peer engagement work.

INCREASING CAPACITY

Capacity building is the development of concrete skills, knowledge, goals, and confidence. In peer engagement, capacity building is experienced among both peers and other professionals alike.

FROM: Page 7. British Columbia Centre for Disease Control (BCCDC). *Peer Engagement Principles and Best Practices. A guide for BC Health Authorities and other providers. Written in partnership with peers and providers.* Dec. 2017. Version 2.

Involving people who use/d drugs and family members in bid development: Tips

Produce a flyer that outlines your proposed project, the input you're looking for, what it will involve (time and effort) and what you can offer people for participating (food, hot drinks, voucher).

Liaise with your contacts in services (incl. peer groups) to ask them to discuss with clients, especially those with relevant experience. Provide the names, roles and contact details for people who will be doing the involvement work (abbreviated to public and patient involvement – PPI) so folk can ask questions before deciding to participate.

Consider what you can do to make participation:

- accessible – can you pay travel costs if people wouldn't otherwise be in the location, can you pay childcare if that enables parents to attend?
- acceptable – in the flyer and introduction at the involvement session, outline what you will be asking people to discuss. Indicate if this will involve potentially difficult or sensitive issues (removal of children, trauma, drug-related deaths).

Be clear that PPI in bid development is not participation in research – ask appropriate questions and be boundaried, don't stray into inadvertently piloting your research data collection questions. This is an opportunity for a sense-check on your proposed project: e.g. is this an important issue, the right research question, who should we engage with, how should we do this work, where/when/how should we recruit people to the project, how can we use the findings to make a difference, how can we let you know how your input shaped the project and share the results with you, (how) would you like to provide PPI input in the project?

Be clear that this input will help inform a bid, and that the project is not guaranteed to go ahead.

Don't just drop in, take what you want and then leave people cold. Share a summary of the discussion with the group. Let them know how you used their feedback, if the bid is submitted, and if the project is subsequently funded.

General

Don't assume that people with lived/living experience and family members have / lack the capacity to understand the concepts and processes you are considering. Use clear language but do not patronise people. Be aware that some people will have well-developed understandings of the issues underpinning your research question, research methods, factors affecting impact etc.

Be mindful of the potential for significant power differentials. E.g. as an academic engaging with addiction service clients in an NHS setting:

- You represent a powerful social institution (University).
- You offer resources such as cash for bus fares and supermarket vouchers that are conditional on "participation". This can be coercive for people who are living in poverty or on low incomes.

- Clients may wonder if you will discuss their participation/feedback with their GP/Psychiatrist/Addiction medic/Case manager/Nurse/Probation worker etc. This is incredibly powerful and could cause some people to feel they have to participate and/or give responses they think you want. Be very clear about the anonymity of their responses and who you will/won't share the info with. Be clear that their care will not be affected by their (non)participation.
- Whilst the subject of your project may be an abstract, social phenomenon to you – for some people in the room this could be an incredibly pressing and difficult issue. This is not to suggest you shouldn't discuss blood-borne viruses, drug-related deaths etc. – but take care not to (re)traumatise participants by being insensitive to the very real impact of these issues on people's lives.

Take care with how much you talk. Remember you're there to explain and prompt – but mainly to listen and engage.

Be aware that some participants have busy lives and things to do. Also, some may have limited attention spans due to health conditions, medication, needing a cigarette, personal preference and they may not want to sit in a room with you for a whole afternoon! Think carefully about limiting group discussions to an hour, and keep 1-to-1 conversations to 30-45 mins. Sometimes less is more! Check in with participants, ask if they're OK, want a break, want to come back to it.

References

British Columbia Centre for Disease Control (BCCDC). *Peer Engagement Principles and Best Practices. A guide for BC Health Authorities and other providers. Written in partnership with peers and providers.* Dec. 2017. Version 2. Available at:

https://www.researchgate.net/publication/322734769_Peer_engagement_principles_and_best_practices_A_guide_for_BC_health_authorities_and_other_providers_Version_2

British Columbia Centre for Disease Control (BCCDC). *Peer Payment Standards for short-term engagements. Created in collaboration with peers and providers.* February 2018. V1. Available at:

http://www.bccdc.ca/resource-gallery/Documents/Educational%20Materials/Epid/Other/peer_payment-guide_2018.pdf

Drugs Research Network Scotland. 2018. Involving people with experience of drug use and their families in the Drugs Research Network Scotland. Available here

<https://drns.ac.uk/files/2018/06/Involving-people-with-experience-of-drug-use-and-their-families-in-the-DRNS-v1.0.pdf>

Edwards, R., and Brannelly, T. 2017. Approaches to democratising qualitative research methods. *Qualitative Research*. Vol 17, 3., 271-277.

Greer, A., M. Luchenski, S. A. Amlani, A. A., Lacroix, K., Burmeister, C and Buxton, J. 2016. Peer engagement in harm reduction strategies and services: a critical case study and evaluation framework from British Columbia, Canada. *BMC Public Health*. 16. 452. Available open access

at:

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4882818/pdf/12889_2016_Article_3136.pdf

Greer, A., Amlani, A., Pauly, B., Burmeister, C., and Buxton, J. A. 2018. Participant, peer and PEEP: considerations and strategies for involving people who have used illicit substances as assistants and advisors in research. *BMC Public Health*. 18: 834. Available:

<https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-018-5765-2>

Hoddinott, P., Pollock, A., O’Cathain, A., Boyer, I., Taylor, J., MacDonald, C., Oliver, S., Donovan, J. L. 2018. How to incorporate patient and public perspectives into the design and conduct of research. *F1000Research*. Available at: <https://f1000research.com/articles/7-752/v1>

Jozanghi, E., Greer, A. M., Lampkin, H and Buxton, J. 2018. Activism and scientific research: 20 years of community action by the Vancouver area network of drug users. *Substance Abuse Treatment, Prevention and Policy*. 13: 18. Available open access at

<https://substanceabusepolicy.biomedcentral.com/articles/10.1186/s13011-018-0158-1>

Public Involvement Standards Development Partnership. Chief Scientist Office (Scotland), Health and Care Research Wales, the Public Health Agency (Northern Ireland), and the National Institutes for Health Research (England). *National Standards for Public Involvement*. Available at: <https://sites.google.com/nih.ac.uk/pi-standards/home>

There is a helpful National Standards for Public Involvement audit tool template at this link.

NIHR Involve. *Guidance on Co-producing a Research Project*. 2018. Available at:

http://www.invo.org.uk/wp-content/uploads/2018/03/Copro_Guidance_Mar18.pdf

Parkes, T. 2000. Comments on power and collaboration in a PhD research project. *Journal of Psychiatric and Mental Health Nursing*. 7, 185-187.

Pauly, B. Work on creating culturally safe primary care (using peer researchers). Unpublished but some outputs can be viewed below.

<https://www.uvic.ca/research/centres/cisur/assets/docs/spc-presentation-creating-culturally-safe-primary-care.pdf>

<https://www.uvic.ca/research/centres/cisur/projects/stigma-primary-care/index.php>

Salmon, A., Browne, A., J., Pederson, A. 2010. ‘Now we call it research’: participatory health research involving marginalised women who use drugs. *Nursing Inquiry*, 17, 4, 336-345.

Toward the Heart. How to involve people who use drugs Dec 2017. Available at:

https://openanswers.ca/wp-content/uploads/2017/11/how-to-involve-people-who-use-drugs-20140227posted_7.pdf