



Recovery Science and Harm Reduction Reading Group: October 2021 Summary

Article Summary

This article is a commentary from activists in Urban Survivors Union, the United States national drug users union, focusing on the interactions between academic researchers and community members. The authors described multiple challenges that exist in these interactions, including power imbalances and structural issues. The authors also detailed their own experiences with community-based participatory research and how it often does not engage the community in the ways that it should. Community driven research is then described as research questions that are posed in collaboration between academic researchers and people in the community, not posed by academic researchers alone.

The authors conclude their commentary with multiple recommendations for moving toward community driven research instead of community-based participatory research. Some of the prioritized recommendations include: 1) research including community-initiated research questions, 2) directly impacted persons having priority hiring in low threshold positions, 3) research projects providing immediate benefit(s) to the community, 4) institutional review boards both protecting and empowering subject populations, and 5) community review boards providing ethical decision-making regarding research activities.

Key meeting themes



Benefits of including people with lived experience in research design and planning.



Reframing participants as consultants.



Challenges trusting researchers.



The importance of academic knowledge and lived experience.



Commentary

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

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ABSTRACT

In this commentary, activists from Urban Survivors Union, the United States national drug users union, discuss our experiences conducting research on methadone clinic adoption of relaxed SAMHSA guidelines during the COVID-19 epidemic. In particular, we focus on our interactions with academic researchers as a grassroots organization of criminalized people designing our own research. We describe the challenges we navigated to retain decision making powers over the research question, data analysis and interpretation, and dissemination. We find that our collaborations with academic researchers are often complicated by power imbalances and structural issues. In our experience as directly impacted people, even community based participatory research (CBPR) often sidelines us. Our eventual research approach demonstrates how our process transcends CBPR by becoming community driven research (CDR). We suggest several changes to the research process in order to propagate this model.

Commentary

Activists in movements by and for people who use drugs are considered content experts and asked to participate in research in a variety of ways. However, we feel that **negative stereotypes distort the way academic researchers interact with us**. They are often accustomed to viewing us as a subject population for their research rather than as collaborators or as researchers in our own right. Although our lives are shaped by subjects of interest to many researchers including stigma, infection risk, incarceration, and overdose, we struggle to share our experiential knowledge on these topics with academics in a way that benefits us. Though many of us work hard to go to college, establish nonprofits, and participate in local and national organizing groups, our status as people who use drugs and people with drug dependencies overshadows every other identity we may hold.

In this article, we share our challenges as people who use drugs doing research that aids our communities, including our experiences researching methadone patient treatment during the COVID-19 pandemic. We focus on issues that arise in our collaborations with academics such as **developing leadership capacity and retaining decision-making power over the research questions, data analysis, interpretation, and dissemination**.

ination. We discuss adopting Community Directed Research (CDR) to address these issues.

Urban Survivors Union methadone advocacy during the COVID-19 pandemic

Urban Survivors Union (USU) is the national union representing people who use drugs throughout the United States. Over the last five years, USU has developed a sustainable national union of over 30 **chapters and affiliate groups**. Many of us actively inject drugs or smoke stimulants or have experience doing so. Our membership also includes many current and former sex workers. Our heterogeneous group represents a range of people who use drugs in terms of gender, race, disability, and social, economic, and educational capital. However, we are united by our in-group consensus on many policy issues such as opioid agonist treatment reform and opposition to drug-induced homicide laws. We are committed to including members experiencing housing insecurity, mental health issues, or chaotic drug use in our low-threshold activism. We are the experts—we know what is happening on our streets and to our dope.

As people who use drugs and people who inject drugs, we are already at high-risk of HIV, Hepatitis C, overdose, and other health

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DISCUSSION SUMMARY

The following themes came from the discussion:



Benefits of including people with lived experience in research design and planning

Group attendees discussed the benefits of including people with lived experience in the research process. It was emphasized that those with lived experience understand how members of the community are impacted by the issues being researched.



Reframing participants as consultants

It was noted in discussion that community members should be reframed as consultants in research studies as opposed to participants. Group attendees asserted that lived experience expertise is valuable to addressing research concerns and framing research questions.



Challenges trusting researchers

The group discussed their concerns that the community will not fully trust researchers until the power imbalance between community members and researchers is acknowledged and corrected.



The importance of academic knowledge and lived experience

Attendees of the group noted that academic knowledge is often valued more than the knowledge people gain from their own lived experiences. Lived experiences provide valuable insights that academic knowledge does not always offer.



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