International Journal of Drug Policy xxx (xxxx) xxx

Contents lists available at ScienceDirect

International Journal of Drug Policy

journal homepage: www.elsevier.com/locate/drugpo

Commentary

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

Caty Simon[a,b,*], Sarah Brothers[a,c], Knina Strichartz[a,d], Abby Coulter[a,e], Nick Voyles[a], Anna Herdlein[a], Louise Vincent[a,d]

[a] Methadone Advocacy Working Group, Urban Survivors Union, 1116 Grove Street, Greensboro, NC 27403, United States
[b] Whose Corner is it Anyway, Holyoke, MA 01040, United States
[c] Department of Sociology, Yale University, New Haven, CT 06511, United States
[d] North Carolina Survivors Union, 1116 Grove Street, Greensboro, NC 27403, United States
[e] Medication Assisted Treatment Support & Awareness, 68 Harrison Street, Morgantown, WV 26501, United States

ARTICLE INFO

*Keywords:*
People who use drugs
Community engagement
COVID-19
Methadone
Community based participatory research (CBPR)
Community driven research (CDR)

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. 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 heterogenous 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

---

[*] Corresponding author at: Urban Survivors Union, 1116 Grove Street, Greensboro, NC 27403, United States.
*E-mail address:* caty@urbansurvivorsunion.org (C. Simon).

https://doi.org/10.1016/j.drugpo.2021.103364

Please cite this article as: C. Simon, S. Brothers, K. Strichartz et al., We are the researched, the researchers, and the discounted: The experiences of drug user activists as researchers, International Journal of Drug Policy, https://doi.org/10.1016/j.drugpo.2021.103364

risks as immunocompromised people. COVID-19 and its accompanying social distancing requirements have only increased our community's risk (Alexander, Stoller, Haffajee, & Saloner, 2020; Mallet, Dubertret, & Le Strat, 2020; Slaunwhite et al., 2020), and those most vulnerable among us–such as Black union members with co-morbidities or houseless in-person sex workers whose markets have been decimated–have been the most impacted (van Dorn, Cooney, & Sabin, 2020; Yancy, 2020).

During the COVID-19 crisis, the overdose crisis is ongoing and worsening (Friedman, Beletsky, & Schriger, 2020; Mallet et al., 2020; Slavova, Rock, Bush, Quesinberry, & Walsh, 2020). Organizing by people who use drugs is suffering as our leaders fall in their prime. The overdose crisis has affected all of us who use illicit drugs in a profound way. We have watched as our friends, family members, and lovers die all around us. As we move into yet another year of rising overdose rates, our community is managing multiple challenges.

Decades of data show that methadone treatment drastically reduces fatal overdose rates for people with opioid use disorder (Degenhardt et al., 2009; Sordo et al., 2017). However, there are high barriers to treatment in the United States because of draconian state and federal regulations as well as individual clinic rules (Jaffe & O'Keeffe, 2003). Methadone can only be dispensed through clinics disconnected from the rest of the healthcare system. There are rigorous federal standards for take-home dose privileges, daily monitored in-person dosing is the norm, and at least eight toxicology screens a year are required (Federal Opioid Treatment Standards, 2021). States add extra requirements, including stricter admission standards, additional toxicology screens, and mandatory counselling sessions. Finally, individual methadone clinics often implement further restrictions in all the areas detailed above, as well as to take-home dosing eligibility criteria and take-home dose storage.

Our membership has called for methadone reform for years now. We have organized, agitated, participated in clinic grievance processes, and taken classes to learn the ins and outs of methadone advocacy. With COVID-19 came new problems. How could people be expected to risk infection by dosing daily in crowded clinics? How were clinics going to maintain social distancing? USU jumped into action. After all, we were experiencing these risks firsthand.

Relaxed federal guidelines for opioid agonist treatment (OAT) during the pandemic offered USU members an opportunity to advocate for our rights. In March 2020, the Substance Abuse and Mental Health Services Administration (SAMHSA) suggested that methadone clinics provide 28 days of take-home bottles for patients stabilized on their doses and 14 days of take-home bottles for patients less stabilized (SAMHSA, 2020). But ultimately, the decision to implement these changes still lay with each methadone program. We were aware, through our experiences as methadone patients and activists, that although some clinics were giving increased take-home doses, many clinics did not adopt the relaxed guidelines, exposing us to infection as we crowded into waiting rooms for daily doses. Although some clinics suspended toxicology screening, many did not suspend or reduce these screenings, despite the increased infection risk of in-person testing. Some clinics even required people to use public bathrooms to give urine samples for toxicology screening.

Thus, the choice offered to many methadone patients has been between risking death from COVID-19 by dosing in crowded facilities or risking death from overdose by discontinuing treatment (Alter & Yeager, 2020). As the pandemic exacerbated an already existing overdose crisis, we were trapped between these two lethal outcomes.

Still, this situation gave us a platform to further challenge OAT regulations. USU wrote an open letter to stakeholders, organized around the SAMSHA guidelines allowing for reduced in-person clinic attendance requirements (Urban Survivors Union, 2020). We were motivated by our knowledge that many clinics were ignoring this opportunity to increase take-home doses and protect patients. We recommended further OAT policy reform during COVID-19 and collected 140 organizational signatories including Families for Sensible Drug Policy, the Drug Policy Alliance, and Voices for Recovery, as well as 131 prominent individual signatories. Obama-era drug czar Michael Boticelli signed on as the executive director of the Grayken Center. Our efforts were covered in over 15 national media outlets, such as *Time Magazine* and *Rolling Stone*.

However, media coverage for our recommendation letter initially gave credit to our collaborators in a more reformist organization, though our members did the majority of the work. One publication published a corrected piece and subsequent coverage accurately identified us as the letter's authors, but the damage had been done.

We continued our work by launching public education campaigns. We presented on OAT reform for the California Department of Public Health, and 250 viewers registered to watch our first national webinar for methadone patients, "It Takes a Pandemic to Get a Take-home."

## Research challenges during COVID-19

In addition to these advocacy efforts, we wanted to discover whether our experiences at methadone clinics during COVID-19 were shared by patients throughout the country. We reached out to researchers. We hoped to interest them in conducting a study on methadone treatment inspired by our preliminary experience-based findings on the lack of take-home doses, our crowded unsafe clinics, and the costs, travel times, and exposure to COVID-19 that put us at risk. We offered access to participants and our services for free. We had already done the groundwork as unpaid volunteers.

Many researchers did not respond to our inquiries at all, or only did so after long delays. When we finally scheduled meetings, they appeared uninterested in what we had to say or our research questions. The researchers we appealed to were some of the people who were supposed to be helping. In public, they said all the right things about the autonomy of people who use drugs and the value of lived experience, but not when we turned to them to get work done that could help save our lives.

The few researchers who seemed interested in working with us told us we needed to go through their institutions' internal review board (IRB) for ethical approval. They assured us they would get approval quickly once they received a grant to conduct the research. But it soon became apparent that what they sought approval for would no longer be *our* study or address *our* research questions, and there would be a long delay while they sought funding. These researchers did not seem to want what we envisioned: a true collaboration where their infrastructure worked in hand with our unique insight.

Moreover, we felt some researchers were shaping their research agendas solely to fit funding agencies' priorities. For instance, though we approached them about methadone patient experiences during COVID-19, one group of researchers proposed a project that had nothing to do with methadone at all, nor did they express any interest in combining research questions. They did not seem interested in conducting research on the issues that were putting us at risk. Instead, they persistently pursued us for access to the union's populations and resources for their research project even after we said it did not fit our current priorities.

One of our members told us that she had had many similar experiences—some of the people most dangerous to her journey, mental health, and work are people who attempt to align with her through advocacy. Her organization faced incidents many times over the years where universities, students, and media reached out to request that members "'help them" with articles or take part in a study but offered her organization no help in return. Because of her experiences, she and her USU affiliated organization are protective of their members and have yet to allow outside researchers or journalists to conduct projects. Many of our affiliate groups and chapters have adopted similar policies because of repeated negative experiences with academics and journalists.

As our discussions with researchers continued, we understood that even if we could find researchers who were interested in our research questions, if we utilized their academic institutions to submit a proposal to an IRB, we would lose access to the data. Thus, our organizers would not be able to gain research skills by contributing to the data analysis and we would not have any say in data interpretation or the dissemination of findings. A study that would not be possible without our participation would belong entirely to outsider researchers and we might not get credit for our ideas or they might be misinterpreted. Our research interests might not be addressed in the final product. While IRBs are a necessary part of the research process in order to protect research subjects, we found that the process of finding an academic partner to secure ethical approval created barriers to our research involvement. The process as we experienced it reinforced the academic/activist hierarchy. In addition, the process seemed to not be conducive to rapid research and dissemination. We worried that if we partnered with academic researchers, our communities might never receive any benefit from our work during the pandemic—in our experience, researchers can take years to disseminate findings.

Weeks went by. We felt it was imperative to gather data on how clinics were failing to protect methadone patients from COVID-19 transmission. We hoped more clinics could be urged to reduce in-person requirements in time to save patients from infection. However, we were unsuccessful in securing an academic research partnership and we did not have the funds or the knowledge to pursue IRB approval without an academic affiliation. In addition, we could not find clear guidance on how to do the research ourselves, or much literature on peer-led organizations for people who use drugs conducting and disseminating their own research.

At first, we envisioned our project as a community building exercise. If we could not get researchers interested in what we were experiencing, at least we could show our members that they were not alone and that people throughout the country were having the same experiences. We wanted to see whether our personal experiences as methadone patients—a huge improvement in quality of life for those whose clinics took advantage of the new guidelines, but also peril for patients whose clinics retained pre-COVID-19 in-person dosing requirements—matched the experiences of others.

We conducted a survey of our members and affiliates to understand changes to methadone treatment during COVID-19. We developed the survey measures together in our methadone advocacy group, basing survey questions directly on our own experiences in the clinics during COVID-19. A member who is an academic researcher phrased many of the questions, then another member rephrased them into the plain language usually spoken among clinic patients, so any methadone patient would find the survey accessible.

We knew that people who use drugs and methadone patients have limited resources and therefore limited and valuable time. In consideration of the fact that we could not afford to pay our respondents, we designed a survey approximately seven-minutes in length which we hoped would not be too time-consuming for most participants. The exceptional thing about our research was that it was done by the people who are usually the subject population for research like this, so we intimately understood the perspective of respondents. Our survey was simply a formalized way of doing what we always do in USU: listen to and learn from the experiences of other people who use drugs.

We were able to quickly reach out to our community through social media and we received 450 responses to our anonymous survey in just a few weeks. We initially planned to release the findings only to our members. However, the response was so robust we decided to see if we could distribute it to a larger audience. Many grassroots organizations have used white papers to broadly publicize their research, for example, within the sex workers rights movement (Blunt & Wolf, 2020; Fullwood, Iman, Hassan, Hassan, & Paz, 2009; Ray & Caterine, 2014). However, we did not feel we had the extensive social media network and infrastructure to do so. After we completed data collection, we learned that we could potentially publish our findings in an academic journal by allowing researchers to conduct secondary data analysis. One of our academic researcher members obtained ethical approval to review the anonymous data so that we could move towards publishing it in a peer reviewed journal. In the future, we plan to contract with independent review boards so we can obtain ethical approval for our research and lead our own research projects.

Broadly, our survey data describes how many clinics implemented the relaxed guidelines for their patients. Our data supports our anecdotal observations that many clinics nationwide did not take full advantage of revised federal guidelines, and increased take-home privileges were quickly rescinded by many programs throughout the country. This is a national problem, well beyond what we experienced ourselves in the first months of COVID-19. One of our methadone advocacy team members commented, “Methadone clinic practices during COVID-19 are a good example of how taken advantage of we all are. There is blatant guidance saying you can allow drug users to protect their health and it is being blatantly ignored.”

Another author elaborated, “We’re not imagining things or just behaving this way because we’re angry. It is what everybody’s experiencing. Clinics often tell us that every grievance is individual and it’s caused by our inability to go along and get along and not by any greater injustice, not because these regulations create a profound lack of access and in the case of COVID-19, profound, lethal danger.”

Participating in a research project led by people with lived experience gave our members a chance to speak out without fear or hesitation. It reminded every single member that their voices matter and their stories and experiences have value.

## Broader research challenges we encounter as people who use drugs

When we move through professionalized circles we feel we are not able to maintain our multiplicity of identities. We are labeled solely as people who use drugs and not in terms of our careers and our fields of expertise. For example, one of our leadership team members has given invited talks at multiple conferences and received co-author credit on several research papers. “They always forget to list my MPH,” she points out.

We believe there is a way for peer researchers to work with academic researchers who use drugs and those who don’t in truly community-led studies. We would not have been able to do this research the way we wanted to without the help of academic researcher members. Ideally, we envision a collaborative ecosystem of research efforts led by impacted communities, in which all parties benefit and help each other achieve substantive change. We aspire to be full participants in the research process by shaping the research design and ensuring that the research questions address the problems that we face.

Our experiences conducting research must be considered in the broader context. Marginalized and criminalized people such as people who use and sell drugs and people who trade sex, the populations USU is composed of, have historically been exploited by researchers (Mcneill, 2014; Tuck (2009); Boilevin et al., 2019). Conversely, ethical review boards often treat subjects who use drugs as passive entities to be “protected” rather than equals and co-researchers (Boilevin et al., 2019; Boser, 2007). Most research still places us in a subsidiary role that defines us entirely as research subjects.

Many criminalized populations have no access to the final research product because it is hidden behind paywalls. Many of us have no idea where studies are likely to be published in the first place, and have no contact with researchers beyond the initial interview or survey. How would we even know how our labor as subjects and our ideas might be used, or how we might be misquoted?

Some academic researchers lack the cultural competency to know which research questions to ask, what research might be useful for our community (Lebovitch & Ferris, 2015), or how to understand the information they receive. Many times we have read qualitative research papers and felt that the authors misinterpreted the quotes they include from people who use drugs. There are researchers who are sensitive to and knowledgeable about the issues we face, particularly those with lived experience or those who have been educated by communities of people who use drugs, but this lack of cultural competency among some researchers is another reason why research design and data interpretation would be improved by true collaboration with people who use drugs. However, we realize that cultural competency is difficult to attain. We ourselves lack cultural competency in various areas because we have each experienced different levels of privilege and come from vastly different backgrounds.

There is excellent community based participatory research (CBPR) being conducted with vulnerable and marginalized communities, including people who use drugs (Brown et al., 2019; Israel et al., 2010; Survived & Punished, 2019). However, although CBPR aims to integrate communities into the research process and educate community members (Wallerstein et al., 2020), we find that some research defined as CBPR places us in supportive roles at best. Too often, we are asked to participate when the research questions have already been formulated and many of the nuanced issues which would be facilitated by our expertise have been decided, leaving little room for authentic partnership. For instance, academic researchers have offered some of our leaders a token co-author credit or a small sum and expected in return the leader would help them recruit participants for their research, but otherwise did not want any input into their study from our community.

When we do participate as peer researchers, many institutional researchers do not teach us the skills we need to move out of tokenized positions and develop the leadership capacity to initiate research projects, write our own grants, or simply acquire paid positions on other research projects. In some CBPR studies, criminalized people spend hours training to become peer researchers and more hours filling these roles. All this experience is usually non-transferable. Academic researchers receive career benefits when they contribute to studies, but peer researchers often do not qualify for further research-related entry-level job opportunities.

The power differential is clear: even within CBPR models which emphasize leadership capacity development, community-developed research questions, and peer participation in data analysis, interpretation, and dissemination, 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.

For instance, some of the literature on CBPR with people who use drugs defines the category of researchers as one that excludes people who use drugs. A scoping review on ethics and CBPR with people who use drugs states that “the research team for this project is made up of people who have experience conducting CBPR with people who use drugs, researchers with experience and expertise in research ethics, and people who use drugs,” as if people were incapable of belonging to multiple categories at once (Souleymanov et al., 2016).

## A model for community driven research

We call for a shift from CBPR to Community Driven Research (CDR) (Montoya & Kent, 2011) in which the research supports our research questions, which are formulated in *consultation with* institutional researchers, rather than *by* institutional researchers. Academic researchers should act proactively to mediate the power imbalance between them and the directly impacted people who make up our organizations. CDR should include community-initiated research questions, leadership capacity development, and joint data ownership so that community members can access the anonymized data and have decision making powers over the speed and medium of dissemination of findings relevant to the community. We aim to drive research, with decision making powers and full inclusion and exposure to the research process, including inclusion in research ethics training and data interpretation and dissemination. We propose more research with criminalized and marginalized groups should be pursued in this way. Such community driven research would necessitate changes in how academic researchers approach our field.

All grant proposals for studies on vulnerable populations should justify if and how they will benefit the community. If the specific research will not provide direct or immediate benefit, researchers can provide training, networking opportunities, or low-threshold employment—or find other ways to benefit the community. Review boards and researchers themselves should ensure that the studies do not exhaust grassroots community resources that could be better utilized elsewhere, for instance on campaigns that provide more immediate benefits (Jello, 2015; McCracken, 2019). Proposals should include compensation for subjects and peer researchers through cash payments of a living wage for their time and labor. Underpaying not only devalues subjects, it also skews data towards the economically most vulnerable. The practice of giving gift cards should end. In addition, poor peer researchers should receive cash payments that do not threaten their government benefits and which do not value them less highly because of their limited allotments (Boyd, 2008).

Researchers should tell community research participants where papers are published and give them free access to them. We also encourage researchers to publish in accessible language in organizational blogs and mainstream media outlets and to speak in media that reaches the general public.

Research protocols should ensure directly impacted community members are meaningfully involved in study leadership and all stages of research from each study’s conception, before ethical approval is secured, research questions are finalized, and implementation is decided (Lebovich & Farris, 2015). Grassroots organizations should be full research partners with powerful academic entities rather than merely playing a subsidiary role. Low-barrier accreditation and training should be given to criminalized people as research assistants, interviewers, and other integral roles.

Institutional review boards’ purpose should include empowering subject populations to drive research as well as protecting subject populations from researchers. Furthermore, community review boards should have joint ethical approval making power with institutional review boards and adequate funding for community member board positions (Small, Maher, & Kerr, 2014, Australian Injecting and Illicit Drug Users League, 2010). Review board criteria for study approval should include training in CDR for researchers proposing to work with vulnerable subjects such as people who use drugs— training designed in collaboration with these communities and taught by members of these communities.

## Conclusion

We did ultimately have positive experiences in our interactions with researchers. For instance, we are establishing a relationship with an academic group who aspire to do a multi-year study on OAT regulation. After we sent them a guide to ethical research with our community written by one of our chapters (North Carolina Survivors Union, 2020), they assured us they understood that they were working with us in the context of a history of academic researchers mistreating, extracting information from, and ignoring people who use drugs. The same chapter, North Carolina Survivors Union (NCSU), received funding and collaborative support from researchers at the University of North Carolina to conduct an in-person survey on take-home dosing in area clinics. People with lived experience were involved in the design of the study, questionnaire development, data collection, and interpretation of data, and NCSU staff conducted on-site recruitment and survey administration (Figgatt, Salazar, Day, Vincent, & Dasgupta, 2021). These experiences give us hope for collaborations with researchers with institutional power in which we are treated as equals.

However, our interactions with researchers who have institutional power continue to be complicated because even our interactions with researchers who are operating in good faith are tainted by structural factors. We are at a disadvantage as outsiders in research. We don’t know the professional norms and standards; we don’t know what is legitimate to ask for and what is not.

We have a broad membership made up of people with varying degrees of education and expertise, eager to take on new skill sets. However, we are often condemned as being difficult to work with and overly emotional. We feel that some researchers would rather not have people who use drugs in positions of power, because then they must accommodate our quirks, timelines, and opinions. We are too invested in the work, which makes balance and boundaries hard to establish, but we know that this also makes us devoted to the cause in a way outsider researchers can never be. We are always at risk of struggle and trouble, but we are also very capable of doing good work— and we are the only ones with the knowledge base to do the *best* work when it comes to studying our own communities.

We also acknowledge that our own mindsets can threaten research partnerships. One member of our methadone advocacy team commented on how easy it was for us to turn to conspiracy theory, even when interacting with well-intentioned researchers actively working to bridge the power imbalance between us: "We're just so used to being oppressed [as people who use drugs]…it was easy for my mind to go there for five seconds and demonize them." We are committed to working on our own systemic trauma so that we do not miss opportunities to collaborate with and learn from academic researchers willing to contribute to our communities.

Our work is driven by our real anger that immunocompromised people must appear daily in crowded clinics as COVID-19 continues to sweep the nation. As harm reductionists, we know that the directly impacted understand the needs of their own communities— OAT patients are essential to achieving real OAT reform through relevant OAT research. The COVID-19 pandemic demonstrates that in desperate and uncertain times CDR is even more important. In times like these, people on the ground need to be able to do rapid research on the problems they already face.

We feel we must act urgently because lives are at stake. Every moment of inaction leads to more deaths from overdose and drug war-related harms. While these have been ongoing struggles throughout the harm reduction movement, COVID-19 has created unexpected opportunities for our activism while exponentially increasing our vulnerability. Research validates our anecdotal experiences of vulnerability and transforms them into empirical evidence of the lethal dangers we face. Thus, we cannot leave the power to do that research entirely in the hands of outsiders to our community whose motives and values are not ours. For the same reason, we believe we must act quickly and decisively to retain allies among academic researchers who are committed to CDR. Improving the inclusivity of research practices would benefit not only people who use drugs. The quality of the research itself would then be grounded in lived realities and thus more applicable and relevant.

## Summary of our recommendations for community driven research

We are pursuing Community *Driven* Research (CDR), moving beyond CBPR. The list below summarizes our suggestions, but it is by no means exhaustive:

*Research should include community-initiated research questions, joint data ownership, and leadership capacity development.

* Grassroots organizations should be full partners on academic research in their communities.

* Academic researchers who work with vulnerable subjects should be trained in CDR.

* Research grant proposals should include adequate cash payment to directly impacted participants.

* Directly impacted people should have priority hiring in low-threshold positions.

*Low-barrier accreditation and training should be given to directly impacted people.

* Published findings should be freely accessible to community research participants.

* Research projects should provide immediate benefit to the community.

* Institutional review boards should empower as well as protect subject populations.

*Community review boards should be given ethical approval decision making power

## Funding sources

This work was funded in part by a Rapid Response Grant from Urgent Action Fund.

## Ethics approval statement

Ethical approval for the conduct of this study was obtained from the Institutional Review Board at Yale University.

## Declarations of Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

## Acknowledgements

The authors thank the USU methadone advocacy team, Elizabeth Day, Zach Salazar, and everyone who volunteered their time on this project. We are grateful for help and support from Medication Assisted Treatment Support & Awareness and North Carolina Survivors Union. We thank the Urgent Action Fund for funding this last phase of the project. And we thank all the grassroots organizations who have created community driven research before us, and especially, all the participants in our study.

## References

Alexander, G. C., Stoller, K. B., Haffajee, R. L., & Saloner, B. (2020). An epidemic in the midst of a pandemic: Opioid use disorder and COVID-19. *Annals of Internal Medicine, 173*, 57–58.

Alter, A., & Yeager, C. (2020). In *COVID-19 impact on US national overdose crisis. Report prepared by the university of Baltimore center for drug policy and enforcement: 6* (pp. 1–16). Baltimore, Maryland: University of Baltimore Press. Australian Injecting and Illicit Drug Users League. Australian Injecting and Illicit Drug Users League Research and Policy Update2010.

Blunt, D., & Wolf, A. (2020). Erased: The impact of FOSTA-SESTA and the removal of Backpage on sex workers. *Anti-Trafficking Review*, (14), 117–121. 10.14197/atr.201220148.

Boilevin, L., Chapman, J., Deane, L., Doerksen, C., Fresz, G., Joe, D. et al. (2019). Research 101: A manifesto for ethical research in the downtown eastside [O]. March. doi:http://dx.doi.org/10.1 4288/1.0377565

Boser, S. (2007). Power, ethics, and the IRB: Dissonance over human participant review of participatory research. *Qualitative Inquiry, 13*(8), 1060–1074.

Boyd, S. C. (2008). Community-based research in the Downtown Eastside of Vancouver. *Resources for feminist research, 33*(1/2), 19.Boyd, S. C. (2008). Community-based research in the Downtown Eastside of Vancouver. *Resources for Feminist Research, 33*(1/2), 19.

Brown, G., Crawford, S., Perry, G. E., Byrne, J., Dunne, J., Reeders, D., et al. (2019). Achieving meaningful participation of people who use drugs and their peer organizations in a strategic research partnership. *Harm Reduction Journal, 16*(1), 1–10.

Degenhardt, L., Randall, D., Hall, W., Law, M., Butler, T., & Burns, L. (2009). Mortality among clients of a state-wide opioid pharmacotherapy program over 20 years: Risk factors and lives saved. *Drug and Alcohol Dependence, 105*(1–2), 9–15.

Figgatt, M. C., Salazar, Z., Day, E., Vincent, L., & Dasgupta, N. (2021). Take-home dosing experiences among persons receiving methadone maintenance treatment during COVID-19. *Journal of Substance Abuse Treatment,* (123), 0740–5472.

Friedman, J., Beletsky, L., & Schriger, D. L. (2020). Overdose-related cardiac arrests observed by emergency medical services during the US COVID-19 epidemic. *JAMA Psychiatry, 78*(5), 562–564.

Fullwood, C., Iman, J., Hassan, D., Hassan, S., & Paz, N. (2009). Girls do what they have to do to survive: Illuminating methods used by girls in the sex trade and street economy to fight back and heal. *Chicago: Young Women's Empowerment Project.* https://ywepchicago.files.wordpress.com/2011/06/girls-do-what-they-have-to-do-to-survive-a-study-of-resilience-andresistance.pdf.

Israel, B. A., Coombe, C. M., Cheezum, R. R., Schulz, A. J., McGranaghan, R. J., Lichtenstein, R., et al. (2010). Community-based participatory research: A capacity-building approach for policy advocacy aimed at eliminating health disparities. *American Journal of Public Health, 100*(11), 2094–2102.

Jaffe, J. H., & O'Keeffe, C. (2003). From morphine clinics to buprenorphine: Regulating opioid agonist treatment of addiction in the United States. *Drug and Alcohol Dependence, 70*(2), S3–S11.

Jello, L. (2015). Why you shouldn't study sex workers. *Tits and Sass*, 16.

Lebovitch, A., & Ferris, S. (2015). *Out of the frying pan, into the fire: Sex workers in the courts and in research*. The Whore and the Feminist accessed 19 September 2020 http://www.whoreandfeminist.ca/presentation/out-of-the-frying-pan-into-the-fire-sex-workers-in-the-courts-and-in-research/.

Mallet, J., Dubertret, C., & Le Strat, Y. (2020). Addictions in the COVID-19 era: Current evidence, future perspectives a comprehensive review. *Progress in Neuro-Psychopharmacology and Biological Psychiatry*, Article 110070.

McCracken, J. (2019). *Learning with women in jail: Creating community-based participatory research*. New York: Springer Nature.

Mcneill, M. (2014). *Lies, damned lies, and sex work statistics* March 24. The Washington Post accessed 22 February 2021 https://www.washingtonpost.com/news/the-watch/wp/2014/03/27/lies-damned-lies-and-sex-work-statistics/.

Montoya, M. J., & Kent, E. E. (2011). Dialogical action: Moving from community-based to community-driven participatory research. *Qualitative Health Research, 21*(7), 1000–1011.

North Carolina Survivors Union (2020). NCSU ethical research outline V2, accessed 20 September 2020 https://docs.google.com/document/d/1hda_MbF62ycxvM72qngHJLg2zNBg1qvTrvM3TeE51Ik/edit?ts=5f57e67a

Ray, A. &, & Caterine, C. (2014). *Criminal, victim, or worker? The effects of New York's human trafficking intervention courts on adults charged with prostitution-related offenses*. New York: Red Umbrella Project.

Slaunwhite, A. K., Gan, W. Q., Xavier, C., Zhao, B., Buxton, J. A., & Desai, R. (2020). Overdose and risk factors for severe acute respiratory syndrome. *Drug and Alcohol Dependence*, Article 108047.

Slavova, S., Rock, P., Bush, H. M., Quesinberry, D., & Walsh, S. L. (2020). Signal of increased opioid overdose during COVID-19 from emergency medical services data. *Drug and Alcohol Dependence, 214*, Article 108176.

Small, W., Maher, L., & Kerr, T. (2014). Institutional ethical review and ethnographic research involving injection drug users: A case study. *Social Science & Medicine, 104*, 157–162.

Sordo, L., Barrio, G., Bravo, M. J., Indave, B. I., Degenhardt, L., Wiessing, L., et al. (2017). Mortality risk during and after opioid substitution treatment: Systematic review and meta-analysis of cohort studies. *BMJ (Clinical research ed.)*, 357.

Souleymanov, R., Kuzmanović, D., Marshall, Z., Scheim, A. I., Mikiki, M., Worthington, C., et al. (2016). The ethics of community-based research with people who use drugs: Results of a scoping review. *BMC Medical Ethics, 17*(1), 25.

Substance Abuse and Mental Health Services Administration. (2020). *Opioid Treatment Program (OTP) Guidance*. Rockville, MD: Substance Abuse and Mental Health Services Administration https://www.samhsa.gov/sites/default/files/otp-guidance-20200316.pdf.

Survived And Punished. (2019). Research across the walls: A guide to participatory research projects & partnerships to free criminalized survivors https://survivedandpunished.org/wp-content/uploads/2019/02/SP_ResearchAcrossWalls_FINAL-compressedfordigital.pdf.

Tuck, E. (2009). Suspending damage: A letter to communities. *Harvard Educational Review, 79*(3), 409–427. 10.17763/haer.79.3.n0016675661t3n15 .

Urban Survivors Union. (2020). *MAT treatment recommendations*. Accessed 27 September 2020 http://ncurbansurvivorunion.org/2020/04/09/mat-treatment-recommendations/.

van Dorn, A., Cooney, R. E., & Sabin, M. L. (2020). COVID-19 exacerbating inequalities in the US. *Lancet (London, England), 395*(10232), 1243.

Wallerstein, N., Oetzel, J. G., Sanchez-Youngman, S., Boursaw, B., Dickson, E., Kastelic, S., et al. (2020). Engage for equity: A long-term study of community-based participatory research and community-engaged research practices and outcomes. *Health Education & Behavior, 47*(3), 380–390.

Yancy, C. W. (2020). COVID-19 and African Americans. *JAMA, 323*(19), 1891.