Shaking the Tree of Science:
COBRE's Principles for Community Empowering Research

Five Principles of Community Empowering Research

1. Research should be shaped by communities and researchers
2. Research should be community building and benefit communities
3. Research should center marginalized voices
4. Results should be brought back to communities and shared accessibly
5. Community labor should be fairly compensated

Five Questions for Researchers

1. Is our approach trauma informed?
2. Have we considered hidden labor that we are asking community members to perform?
3. Are we being tokenistic?
4. Are we making ourselves accountable to the communities that we study?
5. Have we done our homework?

Introduction

The "War on Drugs," structural racism, and stigma have shaped every facet of the overdose epidemic. They also define the landscape where relationships between university or hospital-based researchers and frontline communities—especially people who use drugs and people in recovery from addiction—take shape. This stigma manifests throughout the health care system; it can also make itself felt in academic research practices.

Inspired by disability justice advocacy, HIV/AIDS activists, and the global movement of Indigenous peoples to redefine their relationship with researchers, people who use drugs and recovery advocates have started to challenge exploitative practices in how they are researched and depicted. Documents like "Nothing About Us Without Us," Vancouver's "Research 101" manifesto, and the Urban Survivor League's "We are the Researched, the Researchers, and the Discounted" challenge the use of uncompensated labor and knowledge, traumatizing research practices, and narratives that collectively pathologize stigmatized groups by depicting them as "deficient" or "broken." Increasingly, people who use drugs and people in recovery have refused to accept how, through hierarchies of academic power and prestige, they have been excluded from shaping knowledge production about their own lives.

There is a larger context to these conversations. The problem of the relationship between researchers, especially biomedical researchers, and communities has never been more urgent or fraught. In the past decade, rightwing populists across the globe have sought to undermine the institutions and credibility of science, mobilizing "medical mistrust" for political ends. The villanization of experts, especially in medicine and public health, has become a widespread and cynical strategy. At the same time, the deep suspicion of the medical establishment among marginalized communities, reflecting both generations of mistreatment and current structural discrimination, has undermined the public health responses to the overdose epidemic and the COVID 19 pandemic. Repairing the long-term damage of both these fissures and rebuilding trust may require decades of work as well as institutional and cultural change. But this work can also begin locally. In our everyday research practices, we can develop new forms of knowledge production based on humility, greater transparency regarding the process of research, and ongoing collaboration between community members/organizations and researchers. Community empowering research is an opportunity for community-based science education.

Galvanized by our current moment, a group of academic researchers and people with lived experience of addiction (including individuals who are in both groups at once) came together under the sponsorship of the COBRE on Opioids and Overdoses to reflect on the research culture around substance use in Rhode Island. This document is the result. It is premised on the understanding that lived experience can no longer be framed solely as bias; it is also expertise that will be critical to addressing challenges faced by the sciences and social sciences, for example the widely recognized crises in replication and external validity. Furthermore, research will have little impact in many communities if the results cannot be implemented. Stigma, distrust, and marginalization—sometimes perpetuated by researchers themselves—all prevent the implementation of effective interventions, which are desperately needed. A key goal of this initiative is to empower the community to inform academic experts so that results can be disseminated, applied, and improve the health of those communities that need it the most.

Below we advance five principles of community-empowering research and present five questions that community members posed to the COBRE. These principles were developed through an 18-month process that included public workshops, contributions from dozens of community activists and leaders, feedback from local recovery advocacy and harm reduction organizations, and extensive input from the COBRE's Community Advisory Board. They incorporate critiques and concerns about research practices that we have heard dozens, sometimes hundreds, of times. They also seek to codify some of what is innovative and vital in our current efforts. Not every COBRE project will implement these principles perfectly, at once, or in the same way. By their nature principles are flexible and sometimes require balancing both against each other and the constraints of time and resources. Community empowering research is an ideal. By adopting these principles, we have pledged to take concrete steps toward better realizing this ideal in our collective scientific work.

The Concept of this Document

This document explains five principles of Community-Empowering Research and restates five questions posed by community members to the COBRE. We motivate these principles and questions by presenting the feedback of community members and organizations in their own words. When feasible and appropriate, these principles can guide the development of projects from inception. The five questions provide an opportunity for reflection at different stages: design, recruitment, data collection, and dissemination of results. For COBRE researchers already working closely with community partners, we offer these principles as a bridge to connect their ongoing work with a larger discussion about community empowerment and substance use research in Rhode Island. The intention is to reflect on our practices collectively, as scientists committed to working together with specific communities over the long-term, not solely as individual investigators.

Through this collaboration, we hope to challenge not only the hierarchy, but also the overly simplistic distinction, between "researchers" and "the community" from three directions simultaneously. First, we hope to create more space to recognize the richness of the lived experience that many scientists bring to substance use research, even when—for personal or professional reasons—they do not openly discuss their background. Many of our colleagues—many of us—have experiences of addiction and recovery, mental health struggles, homelessness, incarceration, sex work, disability, and trauma and we need to be more contentious about the presence of these histories, even when they are not voiced or visible to all. Second, we seek to support and train community members from outside of traditional education pathways so that they can become consultants, research assistants, project coordinators, and independent researchers either in the academy or the community. We need to open the doors to people who have been excluded from the scientific community, especially those from communities rendered marginal by institutional racism and other forms of structural violence. These translators—and, given the scarcity of multilingual research spaces, they are sometimes literally translators—move back-and-forth between the research world and multiple communities. They are essential. Third, we need to strengthen resources and capacity within community partners to support these collaborations. Otherwise, encouraging researchers to work more closely with the community considerably increases financial, administrative, and emotional demands on grassroots organizations buffeted by the combined impacts of COVID 19 and the overdose pandemic, deepening already extractive dynamics.

There is no single method or model for this type of work: every community is different, there is tremendous diversity within communities, and every research project entails a distinct set of methodological, logistical, and institutional demands. We are challenging researchers to think beyond the impacts of individual studies and to consider how their way of working may contribute to larger social and institutional dynamics. The full benefits of collaborations between academic researchers and community members or organizations are cumulative and will become manifest across multiple projects, collaborations, organizations, spaces, and years of dialogue. We invite you to join us in building a new, more inclusive kind of research community.

Five Principles with Community Explanations

Research should be shaped by both communities and academics

What we heard from the community:
We believe that research is strongest when it is informed by the rich and diverse views of people with lived experiences of substance use, addiction, and recovery. Researcher/community collaboration is not only a matter of equity and social justice, it also produces better research. We understand things about our communities that you likely don't. We know questions to ask that are not in any books or journals. Our people will talk to us about struggles, joys, and concerns that they rarely share with strangers. As outsiders, you are often only scratching the surface of our complex lives.

The type of research that funders or academic journals prioritize does not always fit with the needs of our advocacy and activism. **Don't assume your credentials give you more knowledge than us. Don't assume that you have skills we don't. Don't assume you know the best questions to ask.** Slow down. Get to know us. Listen. Spend time finding out what our organizations and communities need.

Everything needs to be more transparent. Your research and advocacy agenda needs to be clear and open to feedback. You should be upfront about who is funding you. You should develop plain language summaries of your research protocols, consent forms, and IRB applications. You should do your best to make these summaries available in the languages of the communities that you are researching. You should be as forthcoming with us about what ethical concerns you foresee and how you plan to address them as you are with your institutions. Please walk community partners patiently through the entire research process. Please trust that, if you take the time and use accessible language, we can understand your research either as collaborators or study participants.

Research should be community building and benefit communities

What we heard from the community:
We value engaging on many levels: one-off discussions, project consultations, serving as members or organizers of community advisory boards; and acting as research assistants, co-investigators, and co-authors. We value projects that employ people with lived experience in a variety of roles and at more than one stage (conceptualization, research, and interpretation).

We are open to conversations about what projects are viable and will best serve our acute needs and long-term goals. We know that researchers are often scrambling to meet funding deadlines. **But coming to us with a fully worked-out project at the last minute is the least useful way to work together.** We want you to take some time to get to know our communities and think creatively with us about how your research can be empowering.

We think researchers have a responsibility to invest back into the communities that they study. Research projects can help build the capacity of organizations. They can hire research assistants or consultants from the community. They can help support difficult to fund areas of work. They can help community members develop new skills and open future employment opportunities. They can give organizations from marginalized communities greater visibility and credibility. We want you to consider the long-term impacts and benefits of your research within the communities that you study.

Research should center marginalized voices

What we heard from the community:
Stigma, racism, and other forms of power reinforce the idea that the only expert knowledge is academic knowledge. When we engage with state institutions, media, or universities, we are regularly told that the only valuable opinion is credentialed opinion and the only meaningful data are statistical. Our communities are seen as spaces of damage and suffering. Rarely are they celebrated as sites of resilience, insight, love, and creation.

We are frequently invited to be the “voice of lived experience” as window dressing. **We say our piece and then nothing changes. There are never tangible results.**

As a researcher, you can help make room for us to challenge the ways that we have been silenced, especially in academic spaces. We want to be more than anonymous informants. We want to be recognized as co-producers of knowledge. You can invite us to present with you at conferences. You can credit us as coauthors.

It takes time to learn about the various groups and individuals working within a specific area, but this effort is critical. **Hand picking individuals as community voices can be tokenistic. Relying on one or two organizations as the “voice” of the community can confuse those directly affected with the non-profits or activist groups that claim to represent them.** This practice can also reinforce racial inequalities, as community organizations are more likely to be led by white, first-language English individuals and whose experiences differ in significant ways from Black, Indigenous, and People of Color. The perspective of people in active addiction is often different from people in recovery or from more functional drug users. Both voices—organizations and diverse individuals with lived experience—are necessary for an honest conversation.

Your research sometimes silos us and falsely places our issues into neat little boxes. Much of what people blame on drugs or addiction can’t be understood without looking at housing insecurity, criminalization of sex work and drug use/selling, racism, a fragmented mental health treatment system, intergenerational and community trauma…. Consider how your research is being attentive to these intersections.

For many of us, entering elite, largely cisgender and heteronormative, white academic spaces is exhausting, if not painful. This is doubly true for those of us who don’t use English as our first language—and those of us who don’t communicate in English are rarely invited at at all. Are you willing to organize events in our spaces? Are you willing to change the formats of your events to accommodate ways that we may be comfortable speaking and engaging? Are you willing to invite participants who communicate in other languages (including like non-spoken languages such as American Sign Language) and provide translators?

Results should be brought back to the community and shared accessibly

What we heard from the community:
Researchers come into our communities, solicit our time and effort, and then rarely return. It is the exceptional researcher that comes back. We want you to present results to us, ask for help with interpretation, and talk to community members about next steps. **We want you to talk with us about making your research results known outside of academic journals and in contexts that are more directly meaningful to us.** We want to see that you will sometimes show up for us when you have nothing personally or professionally to gain. We want to know that you see us as more than objects.

Community Labor Should be fairly compensated

What we heard from the community:
Lived experience is expertise. Emotional labor requires energy and time. When we are talking with you about your grant idea, recruiting participants, serving on study/community advisory boards, speaking to classes or university events, organizing community-based events, and recruiting participants for your studies, we are doing skilled work that deserves compensation and recognition. We understand that up-front work is sometimes required to develop projects to the point that they are fundable. But whenever possible, **we expect to have our time compensated as people with expertise.** We get that you can't guarantee that grant funding will come through in advance. But if we are donating our time to your project, class, grant application, recruiting study participants, etc. in what ways are you supporting us as individuals and organizations in return? Are you compensating us at a rate that genuinely reflects our expertise? Are you paying us in the way that is most useful to us (cash when possible)?

5 Questions from the Community to Substance Use Researchers

Is our approach trauma informed?

What we heard from the community:
Have you really considered they ways that research can contribute to the individual and collective trauma faced by marginalized communities at all stages—design, recruitment, payment, interviewing, and our representation? Have you made sure that your research staff is adequately trained in trauma informed approaches to conducting research? Have you taken enough time to explain the overall aims of the research project to participants in plain language so that we understand the motivation of your questions? Have you given participants a way to follow up if they are interested in the results?

Are you prepared to offer us resources and support beyond a "business as usual" reference to a phone number or website? Are you leaving space for our emotional response in interviews? Are you taking time to debrief participants at the end of interviews and giving them an opportunity to give feedback on your process? **Have you considered whether the questions that you are asking us, which are often intimate and deeply personal, are truly necessary?** Have you taken the time to explain to us why they are necessary? Are you paying us at the start of the interview or are you using the implicit threat of non-payment as leverage?

Have we considered the unpaid labor that we are asking community members to perform?

What we heard from the community:

Are you asking for feedback on research design? Are you asking for introductions to individuals, organizations, or communities? Are you asking for help in study recruitment? Are you asking for assistance in promoting your study on social media? Are you new to the fields of substance use, addiction, or recovery and relying on us to help orient you? Are you putting us in a position to unpack the different ways your research might be harmful or traumatizing? Are you asking us to travel to your spaces, neighborhoods, or institutions for meetings? **Each of these is work.** We may be willing to help you in some or all of these cases if our time is compensated and our inclusion is not tokenistic, but only after consultation. Our time and labor should not be presumed.

Are we being tokenistic?

What we heard from the community:
Our definition of tokenism is representation without power. Are you including community members or organizations in a tokenistic or empowering fashion? Are you including people who are the most directly affected or settling on community members or organizations who are the most visible and easy to work with (which often means white and/or English speaking)? Are you including both community organizations, who represent our history and collective experience, and diverse individuals who are currently experiencing what you are researching—whether it is addiction, substance use, insecure housing, racism, or criminalization? Are speaking for us or amplifying our voices?

Are we making ourselves accountable to the communities that we study?

What we heard from the community:
In what ways are you making yourself accountable to the community organizations and members impacted by your research, before, during, and after the conclusion of your project? Are you using community advisories boards or public (non-academic) forums at more than one stage of your project? Are you providing collaborators, research subjects, or the broader community space to provide feedback and engagement while you are performing research? Are you hiring research assistants or consultants from the communities that you are studying? **Are you engaging with more than one organization or community space, or are you using a single collaborator as a stand in for us as a group?**

Have we done our homework?

What we heard from the community:
Disability justice activists, Indigenous scholars, HIV/AIDS advocates, African American Civil Rights leaders, recovery community organizers, drug user unions, sex workers, and other activist groups have been warning about power differences and the damage that researchers can cause in our communities for decades. (See reading list below.) They have also been imagining more democratic, participatory forms of research. Have you taken time to read their writings? **Are you listening to intellectual voices and research frameworks from outside the university?**

Some Steps toward Implementation

The COBRE Community Engagement Core (CERC) commits to collaborating with investigators throughout the research process to put these principles into practice. Other resources to support investigators will include the community ethics consult (see below), the development of a trauma informed research training, and the COBRE's Community Advisory Board.

As initial steps toward implementing these principles, the COBRE CERC proposes three actions over the next year:

1) **The COBRE CERC will offer support, training, and advice to Principal Investigators, community organizations, and community members working with research teams in developing and implementing these principles.** We will provide training for investigators, research assistants, and community members in particular skills needed to support this type of work, for example compiling manuals and benchmarks for engagement tailored to particular projects. The CERC is particularly interested in developing a program of ongoing mentorship that would support investigators in integrating community members into research teams as project consultants or research assistants so that community members could gain the skills to conduct their own research at a future point.

2) The COBRE CERC will facilitate the creation of a **community ethics consult composed of two researchers with experience in community-based research and two community members from the group being researched.** This idea was directly inspired by Vancouver's Research 101 manifesto. The community ethics consult will give researchers an opportunity to present their recruitment, data collection, analysis, and dissemination process and receive feedback on potential community impacts, as well as opportunities for collaboration, that might not be readily apparent to individuals without lived experience. The consult will also, when helpful, give additional feedback about ways in which projects can integrate community engagement strategies. If useful, researchers can also request a meeting of the consult at a later stage in the process. Both researcher and community membership will rotate regularly; with more experienced board members mentoring newer participants.

3) The COBRE will develop and implemen**t standards of trauma-informed research** for future projects. A major point of feedback from the Community Advisory Board was that research conducted with people who use drugs is sometimes unnecessarily invasive, depersonalizing, and traumatizing. In recent years, trauma-informed care has emerged as diverse set of frameworks that allow non-clinical professionals to work with clients in a way that minimizes re-triggering their early experiences of trauma. Developing a trauma-informed research framework and training will be a major outcome of implementing these principles.

Readings to Begin this Conversation

There is a large academic literature on models of community-based research, participatory action research, and co-production in the context of medical research. Instead of beginning with what academics write about community engagement, we suggest researchers read some important pieces, both recent and historical, by voices from outside the university that can serve as an introduction to these discussions. We also wish to gratefully acknowledge the influence of these writers, activists, and organizations on the process of writing this document.

"Research 101: a Manifesto for Ethical Research in the Downtown Eastside"
https://www.homelesshub.ca/resource/research-101-manifesto-ethical-research-downtown-eastside

Urban Survivors Union, "We are the researched, the researchers, and the discounted: The experiences of drug user activists as researchers"
https://www.clinicalkey.com/#!/content/playContent/1-s2.0-S0955395921002693?returnurl=null&referrer=null

Eve Tuck, "Suspending Damage: A Letter to Communities"
https://pages.ucsd.edu/~rfrank/class_web/ES-114A/Week%204/TuckHEdR79-3.pdf

Dr. Martin Luther King, jr. "The Role of the Behavioural Scientist in the Civil Rights Movement"
https://www.apa.org/monitor/features/king-challenge

James I. Charelton, *Nothing about Us Without Us: Disability Oppression and Empowerment*
https://vidaindependente.org/wp-content/uploads/2018/07/Nothing-About-Us-Without-Us-Disability-Oppression-and-Empowerment-ilovepdf-compressed.pdf

Iowa Harm Reduction Coalition, "A Note to Researchers"
https://www.iowaharmreductioncoalition.org/contact/

"Nothing About Us Without Us—Greater, Meaningful Involvement of People Who Use Illegal Drugs: A Public Health, Ethical, and Human Rights Imperative"
https://www.opensocietyfoundations.org/publications/nothing-about-us-without-us

"Towards Reconciliation: 10 Calls to Action to Natural Scientists Working in Canada"
https://www.facetsjournal.com/doi/10.1139/facets-2020-0005

The Maiam nayri Wingara Aboriginal and Torres Strait Islander Data Sovereignty Collective
https://www.maiamnayriwingara.org/news-and-updates

South African San Institute, "San Code of Research Ethics"
http://trust-project.eu/wp-content/uploads/2017/03/San-Code-of-RESEARCH-Ethics-Booklet-final.pdf

Acknowledgements

The idea for these principles emerged from a conversation about Vancouver's "Research 101 Manifesto" between Michelle McKenzie, Jon Soske, and Colleen Daley Ndoye near the end of 2019. Our greatest appreciation goes to all the individuals and organizations involved in creating "Research 101" and the other activists whose work we cite above. Colleen first suggested that we create a Rhode Island version of the Vancouver manifesto. We circulated "Research 101" to two dozen community-based advocates and activists and received feedback from Ian Knowles, Rich Holcomb, A.J. Yolken, Diego Arene-Morely, Karen Davis, Roxxanne Newman, and Cathy Schultz, among others. Ariella Aisha Azoulay also provided valuable input at this point. In order to inform the process going forward, Jon and Michelle organized a three-part series of public events on community empowered research in August 2020. Our thinking was shaped by the valuable contributions of Dennis Bailer, Alexandra Collins, Elizabeth Samuels, Sarah Ziegenhorn, Vivian R. Chavez, Jule Chapman, Samona Marshand, and Scott Neufield.

Based on these conversations, Jon and Michelle developed the five principles and presented them to the COBRE's Community Advisory Board—the five questions first emerged out of that discussion. We are particularly grateful to the feedback of Meko Lincoln, Ashley Perry, Tyrone McKinney, and the many others present. Jon then drafted the first version of this document, which was then workshopped by Colleen Daley Ndoye, Megan C. Smith, Sarah Edwards, Cathy Schultz, Michelle McKenzie, and Cherie Cruz. Jon then drafted a new version, which was circulated for comment to a group of early career researchers, including Elizabeth Samuels, Rahul Vanjani, Jessical Jaiswal, Alexandra Collins, Arryn Guy, Jennifer Carroll, Megan C. Smith, Kate Elizabeth Creasey, and Scott Neufield. In late 2021, Jon and Michelle presented the resulting framework to a full meeting of the COBRE on Opioids and Overdoses and the annual symposium of the Rural Drug Addiction Research Center. Brendan Jacka and Brandon Del Pozo contributed important feedback at these events. Dahianna Lopez's searching comments led us to reconsider how the document addressed the lived experiences of researchers that are often invisible within academic spaces. Soon afterwards, the COBRE's Community advisory Board held a follow-up discussion about people's experiences as participants in research studies. Kirsten Langdon's research team read and commented on the document at this stage as well. At each stage in the process, the COBRE Community Engaged Research Core (Curt Beckwith, Laurie Bazerman, Haley McKee, Jon Soske, Michelle McKenzie, and Sarah Martino) reviewed the document. Brandon Marshall's support and example was crucial to the entire process. Traci Green and Tim Flanagan provided incisive edits to the final draft. Shivani Nishar, Alexandra Collins, and Fulya Pinar also read the final draft with critical eyes. The online version was designed by Abdullah Shipar and Michelle DeOrsey.

We thank Tyrone McKinney for challenging us to "shake the trees" for the community and inspiring the document's title.

The sections that report community feedback were distilled early in this process. They were circulated for comment and revision several times among community members and partners until both the authors and our collaborators were satisfied that they accurately captured the input that we received regarding community priorities and current research practices in Rhode Island.

Version: Friday, April 22, 2022