

The Unconference:

A Community-Led Conversation about Substance Use, Harm Reduction, and Recovery Research in Rhode Island

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Disclaimer: the perspectives offered in this report do not necessarily reflect those of the Unconference attendees or community members more broadly

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Acknowledgments

“My main takeaway from the Unconference was the overwhelming role that institutions and systems play in taking all aspects of research out of the hands of the community and individual researchers. Many of the problems we hear about—reimbursement for community members, lack of investment in community organizations that enable this research to happen, lack of community members’ agency in choosing the research topics that ultimately affect them—these decisions are often made at the *institutional* level. Researchers and community members are just cogs in a big machine that brings in research money for the sake of power and prestige. The Unconference laid bare how this research is carried out on the backs of those who are consistently violated and used.”

—Colleen Daley Ndoye, Executive Director, Project Weber-RENEW

The “Unconference” was the culmination of years of work on the part of advocates to bring together people who use drugs (PWUD), recovery advocates, community organizations, researchers, and academic administrators in an ongoing dialogue to chart a path forward for the community’s rightful co-ownership of the research agenda. We extend our appreciation to Colleen Daley Ndoye, Michelle McKenzie, Jon Soske, and all the individuals and organizations for beginning this local movement in late 2019, which is documented in “Shaking the Tree of Science: Principles for Community Empowering Research.” Inspired by works such as “Research 101: A Manifesto for Ethical Research in the Downtown Eastside,”¹ “Shaking the Tree of Science” was circulated to over two dozen community-based advocates and activists. In particular, we would like to thank Diego Arene-Morely, Ariella Aisha Azoulay, Karen Davis, Rich Holcomb, Ian Knowles, Selene Means, Roxxanne Newman, Cathy Schultz, and A.J. Yolken for their feedback. Jon Soske and Michelle McKenzie subsequently organized a three-part series of public events on conducting research with PWUD, Rhode Island’s harm reduction organizations, advocates, and people in recovery in August 2020. The valuable contributions of Dennis Bailer, Jules Chapman, Vivian Chavez, Alexandra Collins, Samona Marshand, Scott Neufield, Elizabeth Samuels, and Sarah Ziegenhorn informed these events. Jon Soske led the development of the “Five Principles of Community-Empowering Research” and subsequent documents, presentations, and events

¹Boilevin, L., Chapman, J., Deane, L., Doerksen, C., Fresz, G., Joe, D., Leech-Crier, N., et al. (2019, March 15). Research 101 : A Manifesto for Ethical Research in the Downtown Eastside. UBC Community and Partner Publications. O, . Retrieved August 29, 2024, from <https://open.library.ubc.ca/collections/ubccommunityandpartnerspublicati/52387/items/1.0377565>

that laid the foundation for the Unconference. This work could not have been accomplished without, Alexandra Collins, Kate Elizabeth Creasey, Cherie Cruz, Colleen Daley Ndoye, Sarah Edwards, Meko Lincoln, Claire Macon, Edne Tai, Anusha Alles, Brandon Marshall, Sarah Martino, Machiste Rankin, Haley McKee, Tyrone McKinney, Andre Willis, Scott Neufield, Ashley Perry, Cathy Schultz, Megan Smith, and Rahul Vanjani. The support of Project Weber/Renew, Ocean State Advocacy, DARE, Advance Rhode Island Clinical and Translational Research (RI-CTR), the Centers of Biomedical Research Excellence (COBRE) on Opioids and Overdose, the Center for Complexity at the Rhode Island School of Design (RISD), and the People, Place & Health Collective at Brown University (PPHC) were critical to the entire process.

Executive Summary

Problem & Opportunity

The stigmatization of people who use drugs (PWUD) and people in recovery is manifest in every aspect of the overdose crisis, including the very research that purports to “help” these groups in the name of science. PWUDs, Rhode Island’s harm reduction organizations, advocates, and people in recovery, particularly those who identify as Black, Indigenous, and other People of Color (BIPOC) within these groups, have endured decades of harm by research institutions. Discriminatory and stigmatizing depictions of PWUD, failure to compensate PWUD/people in recovery for their labor and knowledge that contributes to the research, and engagement in traumatizing or re-traumatizing research practices have often resulted in communities’ generalized mistrust in researchers’ motivations, regardless of whether the research is carried out in good faith. Ultimately, the cumulative effect of these harms has further marginalized those who have historically been excluded from research and the scientific community. An opportunity therefore exists to redress harms committed against PWUD/people in recovery and to hold researchers accountable to these communities. By looking to PWUD/people in recovery to help prioritize and shape the institutional response, the research community can take meaningful steps toward systemic improvement. Doing so stands to improve the quality of substance use research, improve the likelihood that marginalized communities participate in and benefit from the research, and enhance public trust in science.

Purpose of this Report

The primary goals of this report are to (1) document the co-design by PWUD, recovery advocates, harm reductionists, and researchers of an “Unconference” held at the Providence Public Library on March 7, 2024; (2) synthesize findings from the event; and (3) provide a roadmap in the collective efforts to end the stigma and harmful practices prevalent in substance use research.

Origins: Guiding Principles of Community Empowered Research

Beginning in late 2019, Project Weber/RENEW and RICARES, supported by the COBRE on Opioids and Overdose, led a process involving community organizations and researchers

across the state to articulate principles to guide collaborations between researchers and the community. The principles, which emerged in response to practices that community members and organizations identified as common in substance use research, including in research conducted by participating organizations, state that: 1) research should be shaped by both 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 the community and shared accessibly; and 5) community labor should be fairly compensated. Finally, the principles serves as a starting point for repairing and reimagining the way researchers and community members can work together toward improvements in cultural and institutional practices.

A Call to Action: The Development of an “Unconference”

The “Unconference” was the culmination of years of work on the part of advocates to bring together PWUD and recovery advocates, community organizations, researchers, and academic administrators in an ongoing dialogue to chart a path forward for the community’s rightful co-ownership of the research agenda. Attendees included approximately 50 community members, 30 researchers, and 10 individuals who are researchers with lived experience and close community ties. Across this cohort of attendees was a representation of local community organizations and research institutions. Unlike a traditional conference, the Unconference allowed community members to submit session proposals in advance and vote on which ones they wanted to attend on the day of the event; however, attendance was open. At the end of the day, Unconference attendees voted on their top three priorities for the coming year. This flexible format allowed the event to center voices with lived and living experience; build stronger relationships between PWUDs, their allies, and researchers; commit to tackling problems together; set an agenda for institutional change; and work towards concrete results. A sign-up sheet was circulated so that community participants who wanted to join subcommittees after the Unconference would be contacted regarding next steps.

Unconference Key Findings & Top Priorities:

At the end of the Unconference, attendees voted on their top three priorities for researcher engagement over the next year. The priorities were to:

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- 1) Establish clear mechanisms of accountability of both individual researchers and research institutions to the organizations and communities that make their research possible.
 - 2) Ensure active involvement of community partners in choosing research study topics and determining future directions of research.
 - 3) Involve community members and organizations in training substance use researchers to be ethical (i.e. Involve community members and organizations in training substance use researchers how to be more sensitive to the lived experiences of community partners and participants).

Next Steps:

A standing planning committee consisted of members of the Unconference sponsoring organizations: the Center for Complexity at Rhode Island School of Design, Advance Rhode Island Clinical and Translational Research (RI-CTR), the People, Place & Health Collective at Brown University (PPHC), the Brown School of Public Health, the Center for Alcohol and Addiction Studies at Brown University (CAAS), and the COBRE on Opioids and Overdose. The main charge of the planning committee was to further explore topics that emerged during the Unconference by facilitating internal coordination, monitor progress, and address barriers to participation so as not to put the onus on community members or community organizations. Additionally, three subcommittees were charged with focusing on the following:

- 1) Community-Led Accountability for Researchers
- 2) Institutional Accountability, including training and ethics and payments, incentives, and hiring
- 3) Research Generation and Dissemination

Subcommittee leaders will be responsible for convening regular meetings, ensuring community representation on their respective subcommittees, establishing and adhering to timelines, identifying required resources, and reporting progress back to the planning committee.

Conclusion

The Unconference facilitated honest, productive dialogue that will require extensive commitment and follow-up on the part of the research community. Importantly, participants recognized the need to follow through on promises, namely to produce concrete results that are aligned with the three aforementioned priorities. Next steps will include follow-up with community members who wish to stay involved and informing Rhode Island's harm reduction organizations of Unconference findings.

More information can be found on the event website at <https://community-led.us/>.

Acronyms

Advance RI-CTR - Advance Rhode Island Clinical and Translational Research

CAAS - Center for Alcohol and Addiction Studies at Brown University

CAB - Community Advisory Board

COBRE - Centers of Biomedical Research Excellence

DARE - Direct Action for Rights and Equality

IRB - Institutional Review Board

PPHC - People, Place & Health Collective at Brown University

PWUD - People Who Use Drugs

RISD (Center for Complexity at) - Rhode Island School of Design

SDoH - Social Determinants of Health

SSP - Syringe Service Provider

Laying the Groundwork

Guiding Principles of Community-Empowered Research

The Unconference was the culmination of decades of discontent among some of Rhode Island's most marginalized communities: people who use drugs, recovery advocates, people who are unstably housed, people who are justice-involved or formerly incarcerated, and sex workers. Many community members viewed Brown's research activities as an extension of the University's larger political and economic impact in Providence, which had its roots in the slave trade. These communities called for change in how institutions and researchers interact with these communities and in their spaces. While the predominant researcher response to the notion of "community-engaged research" has been surface-level enthusiasm, these communities continued to feel exploited and mistreated by researchers and research institutions. With no established mechanism for cultural or systemic change, advocates saw little opportunity for progress.

In response to this growing frustration, the Center for Complexity at the Rhode Island School of Design (RISD), the People, Place & Health Collective (PPHC) at the Brown University School of Public Health, Project Weber/RENEW, COBRE on Opioids and Overdose, and RICARES, worked together (and with extensive additional community input) to develop guiding principles that aim to redefine the community-researcher relationship. A document entitled, "Shaking the Tree of Science: Principles of Community-Empowering Research" grew out of these community-generated conversations. These principles state that:

1. Research should be shaped by both 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 the community and shared accessibly
5. Community labor should be fairly compensated

It is important to note that these were not abstract demands but emerged in response to practices that community members and organizations identified as common in Rhode

Island substance use research, including in research conducted by some participating organizations.

These guiding principles laid the foundation for a forum that aimed to challenge the top-down, hierarchical structure of a typical conference. The Unconference aimed to achieve a more neutral space to discuss what researchers are doing wrong, how they can do better, and to achieve concrete results. Specific goals of the Unconference were to:

- Center voices with lived experience.
- Build stronger relationships between community members and researchers.
- Tackle problems together.
- Set out an agenda for institutional change.
- Work towards concrete results.

Unconference Concept, Design & Planning

The Unconference planning and design phases were an iterative, reflexive process led by Jon Soske, Dara Beno, Charlene Sequira, and Tim Maly of the Center for Complexity at RISD, in collaboration with harm reduction organizations, especially Project Weber/RENEW and Ocean State Advocacy, and its allies and advocates. The Unconference, its website, and all related materials were designed with the intent that they would remain neutral spaces that centered community voices and facilitated equitable collaboration. To this end, branding of the materials by academic institutions was therefore not permitted. Organizations' logos appear on one page of the Unconference website, but all participating organizations were required to acknowledge that they were not owners of the website and did not control or set the conference agenda. At every stage of the conceptualization, design, and planning of the Unconference, the Center for Complexity at RISD made revisions based on solicited feedback from people with deep knowledge of the community.

Communication Platform

The Center for Complexity at RISD developed a website, <https://community-led.us/>, to serve as a point of reference for the Unconference and as an archive of event communication and materials. While the website was not intended to be the primary source of communication to local harm reduction organizations, it was designed to be accessible to

anyone. The look and feel of the site were intentionally non-academic. The platform was simple to navigate and incorporated visual elements borrowed from local harm reduction culture and color palettes from Harlem Renaissance art.

Community Outreach

Extensive community outreach was required to ensure wide representation from the community. Organizers started with a mapping technique developed at the Center for Complexity at RISD in which they identified: 1) all relevant community organizations, 2) individuals who are not part of organizations but who are key actors in shaping conversations in the local harm reduction space, and 3) who might be missing from the two above groups. The last step was important because it served as a way to avoid gatekeeping and include only the “familiar faces” from Rhode Island’s harm reduction organizations, which is a particular challenge in a small state and has produced frustrations among sections of the community. Further, it helped to avoid the “echo-chamber” phenomenon by including those who may have divergent perspectives. Meetings were subsequently held with each stakeholder to identify how they wanted to contribute to the Unconference and how to document their proposal for a session topic. Ultimately, approximately 30 researchers were invited and 50 community members attended, with some attendees spanning both categories. There was no limit of community member attendance. About one-third of attendees (both categories included) were intentionally selected because of their experience with facilitation in challenging contexts. While attendance was capped for researchers at 30, the event was free and open to all community members. A group of observers from Massachusetts-based Harm Reduction and Recovery organizations also attended.

Topic Proposals & Selection

Prior to the Unconference, and on the morning of the Unconference, organizers solicited topic proposals from community members and interested researchers. Session proposals were submitted through the Unconference website, via email, phone, and at a workshop that was run with the COBRE Center on Opioids and Overdose’s Community Advisory Board (CAB) and the Direct Action for Rights and Equality (DARE). When organizers received proposals in writing, they were posted as-is (with light editing for typos) to the website. Proposals were printed in advance of the event, and attendees were invited to submit

additional proposals on the day of the event. On the morning of the Unconference, every participant received three stickers to select sessions they wanted to attend. Participants put their stickers on their top three choices. Once all the votes were cast, the eight topics with the most votes were selected. A three-way tie for the last two slots was broken by merging two thematically linked proposals into a single session.

Physical Space

The Providence Public Library was selected as the venue for the Unconference because it provided a safe, welcoming, and neutral space to hold the event. Flower arrangements and other visual elements (e.g., posters) were present throughout the physical space to show respect and help people to feel comfortable. For example, organizers hung posters with printed statements borrowed from harm reduction culture and other voices from the community on the wall that read:

- The smartest person in the room is the community as a whole.
- Welcome to the conversation! This isn't a conference.
- Listening is essential labor.
- Everyone here today wants change.
- We are figuring out some things as we go. That's OK!

"I don't speak researcher" note cards were distributed to attendees as a way for someone to signal that jargon or complex language was preventing them from understanding something. The cards served as a playful micro-intervention built into the physical space that could help to bridge communication gaps. Photographs and videos were not permitted to respect the privacy of attendees.

Other Logistics

Extensive planning and forethought went into ensuring the safety, comfort, and respect of attendees. Two pre-meetings—one for researchers (via Zoom) and one for community members—were held prior to the event. Led by experienced facilitators with expertise in community-engaged research, these meetings served as an orientation to the Unconference and an opportunity to ask questions. Attendees were also invited to submit session proposals at the meetings.

Several additional Unconference invitees were integral to ensuring that the event ran as smoothly as possible. These included session notetakers; outreach workers who facilitated the attendance of several of their clients; people who were experienced facilitators in the community; "social integrators" to offer assistance to attendees who may find it challenging to be in this setting; and physicians who have experience working in substance use were present to respond in the event of an emergency.

Flexibility in the agenda was critically important. Sessions were intentionally kept at about 45 minutes to ensure accessibility, although most sessions went at least slightly over. Four sessions ran concurrently in the morning, and four ran concurrently in the afternoon. The number of attendees was not capped, nor was the ratio of researchers to community members fixed per session. Participants were free to leave or enter a session at any time to accommodate those who may need to take a break, use drugs, or get up and walk around. One-third of the event was break time, which helped to encourage impromptu or informal conversations and community networking.

Lunch was served, and snacks and beverages were provided throughout the day, which was particularly important for making sure those experiencing homelessness or who were food insecure were able to remain at the event as long as they desired.

A sign-up sheet for community members (who were not researchers) allowed organizers to track who would receive cash stipends for their attendance. A sign up sheet was also available for those who wanted to provide their contact information to stay involved after the Unconference ended.

Selected Sessions & Content

1. How can we make research more relevant to the community?

How do we ensure that the community is involved in shaping the research that affects them?

Community members have long been voicing their needs and identifying priorities for advancing the health and wellbeing of communities, but still feel that research is not relevant to them. There were two major issues identified during the session: 1) A misalignment exists between researchers' priorities and the communities' actual needs; and 2) the current landscape does not facilitate conducting true community-engaged research and supporting the community in meaningful ways. Efforts to address these problems are often viewed as perfunctory and tokenistic, resulting in a general lack of trust in researchers and their motivations.

Challenges identified:

- Often heavily influenced by funders, current substance use and overdose prevention research in the state tends to focus on problems that the community is already aware of rather than investigating concrete solutions.
- Many researchers do not consider those who have lived or living experience as true colleagues and dismiss their ideas and potential solutions because they challenge the status quo.
- Researchers are not prepared to work with community members in a trauma-informed way and ask study participants highly personal and unnecessary questions.
- Once the research is complete, researchers rarely communicate study results to the community.
- The bulk of research money is being taken by the research institution itself, and researchers are perceived as "gatekeeping" research funding.
- Staff who work for community organizations are constantly struggling to allocate limited resources to be able to provide services.
- Currently, there is a lack of support for community organizations at *all levels* and during *all stages* of the research.

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- Effective programs and interventions are often not sustained after the project and funding ends, which is extractive and harmful.
 - Community members need better access to green spaces, such as bike paths, parks, and beaches.
 - Researchers are currently not held accountable for conveying the results of the research to community partners using plain language.

Opportunities identified:

- Informal forums, such as community centers and events that offer food and childcare, are places where researchers and community members could convene to discuss the alignment of research and community needs.
- Direct service providers have an understanding of the importance of reciprocity, respect, and boundaries when working with the people they serve. Increased meaningful involvement of direct service providers in the research could help to build trust between researchers and community members.
- Researchers can continue their work with community organizations by helping them use and display data effectively when applying for their own grants.
- Researchers can leverage their privilege to advocate for the creative use of grant funding to support community organizations and the people they serve, but they need to ensure that senior leadership from research institutions is at the table during these discussions.
- Research funding could be used to support community centers and other brick-and-mortar organizations, including syringe services programs (SSPs), that meet people's basic needs, such as access to food and transportation.
- "Research report cards" could be used to hold researchers accountable. Researchers who do not conduct research ethically would not be permitted to re-enter certain community spaces for research purposes.
- Researchers should assume more responsibility for the full range of work that is imposed on community organizations that are asked to partner in research. This includes doing some of the "grunt work" that is required in research, which would alleviate some of the burden on organizations that are already operating at capacity, and high-level work, such as advocating for policy change at the state and local levels, alongside community partners.

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- Create a formal pathway for the community to identify priorities and align those with researchers who are interested in listening to foster more regular and effective communication channels throughout all stages of the research. This could be in the form of a Community IRB or a Community Advisory Board (CAB).
 - Draw up an agreement outlining researcher responsibilities vis-à-vis the community organization outlining how the research institution would commit to the community partner's mission; how the staff will receive training to become meaningfully involved in the research; and how the research institution will demonstrate support and sustainability of its involvement after the project ends.
 - Create a mechanism that allows researchers to feel comfortable sharing information and taking risks on behalf of the community, helping to advance community-led goals, and leveraging institutional resources.

2. Making it easier for community members to get paid

Overcoming institutional barriers to paying community members engaged in research.

Academics are increasingly recognizing that people with specific expertise, knowledge, personal experiences, and histories can help inform strategies that aim to address specific social, medical, or public health issues. However, community members with lived/living experience or expertise and who participate in academic events and research studies, such as speaking in classes, organizing and participating in events, supervising students, and consulting on projects, are not always adequately reimbursed for their services or paid in ways that are not accessible or beneficial to them. If academic institutions truly want to include the voices of the most marginalized, they need to recognize that engaging in research is work, and make paying community members easier and quicker.

Challenges identified:

- Research institutions require community members to register as "vendors" through complicated processes. Further, payment can take months after services have been provided. People who are not legally authorized to work in the US, do not have a bank account, or do not have a fixed address are completely excluded from this payment mechanism. This is a systemic problem that requires advocacy on the part of researchers.
- Honoraria, Amazon gift cards, and ClinCards are some alternatives but can incur extra charges, are time-consuming from an administrative perspective, and not always beneficial to people without internet access or a fixed address.
- Institutions do not allow the use of Venmo or Paypal due to difficulties in tracking payments.
- Maintaining the privacy of research participants can be challenging if personal identifiers are required for tracking payments.
- Cash disbursements are almost always preferred by research participants, but research institutions impose multiple administrative barriers to this practice.
- Perceptions of who is and is not "deserving" of cash compensation (i.e., PWUD cannot be trusted to use cash "responsibly"), reinforce oppressive and discriminatory practices.

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- Payment of research participants in any form (cash or gift cards) can have tax implications that can be financially burdensome to them.

Opportunities identified:

- Researchers can use monthly meetings and brown bag lunches to brainstorm tips and workarounds for paying study participants.
- Researchers can collectively advocate for making this process simpler and more convenient for both researchers and study participants.
- Convene a committee to conduct a “landscape analysis” to document payment modalities and amounts for previous and current studies and CABs that collaborate with PWUD, Rhode Island’s harm reduction organizations, advocates, and people in recovery.
- Develop flexible policy with community input that allows research to best meet participants’ needs and preferences that also recognizes the need for transparency and mitigation of other risks, such as coercion, that are consistent with research ethics.

3. Internal accountability for substance use researchers

How do we collectively ensure that researchers are behaving ethically with the community?

Substance use, harm reduction, and recovery researchers in RI are spread across multiple institutions, and there is little coordination of the research or accountability of researchers. Researchers often enter the field with little knowledge of work that has already been done with the community and the community's long history working with researchers. Duplication of efforts creates undue demands on community organizations and repeated mistakes by researchers, which is particularly the case with out-of-state "helicopter" researchers. Community organizers are angry enough with the overall situation that the idea of a "blacklist" of some researchers has been raised. Some members of the community have called on academic institutions to make reparations for these injustices.

Challenges identified:

- Research spaces are predominantly white and cisgender, and consequently do not always feel like welcoming spaces for all community members.
- A lack of accountability exists in academia that bleeds into researchers' interactions with community members. Making real change will require changing the values and culture of academic institutions. Researchers who want to make change are battling a historical paradigm in which community is not valued. Academics need to engage in active listening instead of projecting their own ideas onto the community.
- An oversaturation of researchers in certain community organizations is contributing to staff feeling overwhelmed and overburdened by research responsibilities.
- The work of trying to hold researchers accountable falls to the community, and the researchers and research organizations involved in the most problematic practices simply ignore these efforts.
- Research funding does not adequately reflect the needs of community members.
- The consent process is supposed to protect research participants but often appears to protect researchers and institutions.
- Institutions—not community organizations—need to assume the responsibility of training researchers to interact ethically with community members.

Opportunities identified:

- Community voices need to be included in the research process from the very start rather than as an afterthought or to “check a box.”
- Researchers can support community organizations and frontline workers in the data collection that they are already doing by coordinating data sharing among organizations.
- An “organization of substance use researchers” could be created in RI for internal coordination among researchers and to ensure accountability.

4. After the research

How can research participants play a central role in the research and shaping the policies that affect them?

After the research is published, it should be used to advance the field through policy, advocacy, or practice. Researchers typically respond to a call for proposals and then retroactively make a decision about how to use the data. The tenet of the harm reduction and recovery communities in RI has been “Nothing About Us Without Us,” but their role has historically been tokenized to “comment” on existing policy rather than to help advance new policies and strategies.

Challenges identified:

- Communication between researchers and the community has historically been “top down,” rather than “bottom up,” which has led to the infantilization of community members.
- Study consent forms specify the risks and benefits to the participant but not explain the content or scope of the academic papers that may be written based on findings.
- Researchers do not “connect the dots” for participants about the broader impact of their participation.
- Community may be more concerned about immediate needs than the study aims. Researchers need to recognize that many people have felt used by research in the past and have to establish trust first before engaging communities in research.
- Researchers have not always abided by the ethics of storytelling (i.e., people’s narratives), which often include sensitive information, and are altered to serve the purposes of the research.
- Policymakers’ involvement in research is always retroactive and not well-integrated into the research from the start.
- Researchers are not communicating community needs to funders.

Opportunities identified:

- Study design needs to be informed by the community. Conversations about relevant topics with community members need to happen from the inception of the research.
- A collaborative team consisting of community members with lived experience, liaison roles (i.e. peer recovery specialists, researchers, and policymakers) would help to align everyone's priorities from the beginning of the research process.
- Transparency is key: researchers need to explain who is funding the research, who they represent, and why certain questions are being asked.
- Within marginalized communities, there are likely established, trusted individuals who can offer perspective and advice on how to prioritize community needs, garner support for studies and convey research results.
- There may be opportunities to use data that results from data collection that are not directly related to the study aims, but highly relevant to the most pressing issues for communities participating in the research.
- Community members *want* to be trained and included in the research at key moments when their input will be valuable.
- Require cultural humility training for all researchers who work with vulnerable populations.
- A PWUD/peer recovery advocacy board could be modeled after the existing social work advocacy board.

5. "Is that necessary?"

Balancing the collection of study specific data with respecting the dignity of study participants.

Researchers often ask study participants invasive and/or traumatizing questions as part of their study protocol, with little or no justification or explanation. Further, the participant consent process is supposed to be the basis for ethical research. But most consent forms are wordy legalese that few participants can understand, and they almost never do a good job of clearly explaining the purpose or rationale for the study. "Informed consent" has become an empty ritual. Once we delve into these factors, how do we address them in a meaningful way that can benefit participants, as well as gather necessary data?

Challenges identified:

- A sense of cooperation between researchers and the community in the data collection process is lacking, resulting in some survey questions that are vague, useless, unnecessarily invasive, triggering, or traumatizing.
- Study participants often feel that researchers do not understand the burden of some interview questions and feel like they are being treated like "lab rats."
- Researchers often have to weigh the potential risks and benefits of collecting information that they deem important and asking research participants personal or highly sensitive questions.

Opportunities identified:

- Researcher awareness and acknowledgment of contextual considerations, such as collective histories of trauma, local practices and norms, or previous negative interactions with researchers.
- Include individuals that researchers are seeking to better understand in the research process as consultants and not just "study subjects."
- Research and utilize existing guidelines for developing interview questions for vulnerable study participants.
- Think through what data truly needs to be collected to answer the research question(s), and not just what might be "interesting" to collect in case it is needed down the road.
- Train research assistants on why certain questions are being asked.

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- Pilot questionnaires with focus groups consisting of the target study population to refine and validate questionnaires.
 - Ask study participants if they are “okay” during the data collection process and ensure that study compensated mental health supports, resources, and follow-up “check-ins” for those who need it are in place.

6. Who is excluded from harm reduction research?

Sex work and intersectionality in substance use research

Sex workers are integral to harm reduction as a community-based practice. Sex workers have always existed at the forefront in community spaces as connectors and strong advocates for harm reduction in communities of people who use drugs and HIV/AIDS and queer/trans activism. As harm reduction becomes increasingly accepted as a public health measure, sex workers are increasingly excluded from the conversation. Much of the funding allotted to studying sex work minimizes the nuance and complex idea of sex work to disease transmission. How do we create space for a deep and ongoing conversation between sex work activism, sex work research, and substance use researchers? How do we build conversations that reflect the complexity of people's multiple identities when research grants are asking us to put people into neat categories?

Challenges identified:

- People often conflate sex work and sexual exploitation, and these are not one in the same.
- Researchers frequently fail to recognize the multiple identities of sex workers, only focusing on a single (negative) aspect of sex work, such as HIV or trafficking.
- People fail to recognize the nuances or "grey areas" of sex work and either see sex workers as being victimized and exploited or not.
- Misconceptions about sex workers and associated stigma prevail in research, particularly as a result of viewing sex workers as a single demographic.
- Sex workers are not being paid appropriately for their time to participate in research, especially if interview questions are invasive and traumatizing.
- Sex workers are concealing their identities in recovery programs because of shame and stigma.
- Policy on sex work is flawed. Sex workers can be asked to testify in court, but there is no protection for them. They can only be identified as former sex workers and not current sex workers.
- It is difficult to leave sex work because it is the highest-paying work most people in the industry will ever make.

Opportunities identified:

- Sex workers need a community of support.
- Consider other aspects of sex work outside of intercourse and recognize that sex workers are often expert communicators and can get people to open up. There are positive aspects of sex work, such as earning an income, improved self-esteem, and power.
- Interview and survey questions should include the positive aspects of sex work and not only focus on the negative aspects of the profession.
- A broader definition of sex work is needed, including various types of activities and virtual work.
- Researchers require meaningful training on trauma-informed practices when working with this population.
- Researchers need to carve out space to include sex workers in harm reduction research.

7. Employing peers as skilled research team members

Valuing people with lived experience in all stages of the research process.

In most cases, people with lived experience are merely research subjects. Though they may occasionally be compensated for their time, they are rarely invited to take part in the actual research process. As a result of stigmatization, people with lived experience are viewed as having nothing to offer other than their trauma experiences and struggles. They are not considered valuable or skilled enough to be engaged or employed at any other level of the research process unless they happen to be peers *and* have had the privilege of attaining master's degrees and PhDs—a relatively rare combination. In order to ensure research is culturally responsive, reaching the people most impacted, engaging in ethical ways of gathering information through using population-appropriate storytelling methods, and truly centering the people the researchers purport to care about, people with lived and especially living experience should be employed as consultants directly involved with the entire scope of the project with real and tangible power and never as tokens. This includes people who use drugs, from whom we may have the most to learn if we learn how to truly listen to and respect them.

Challenges identified:

- There is a huge wage discrepancy between researchers and paid community members in research.
- The spectrum of community involvement in research ranges from true ownership to tokenism. It is a formality with no “teeth.” For example, community members who attend IRB meetings are still often left out of the planning process. Likewise, it is often unclear where feedback in community advisory boards goes and how it is or is not utilized.
- Researchers and community members have different incentives. Researchers are incentivized by publications and funding, while community members’ priorities are saving lives and improving livelihoods and the social determinants of health.
- Researchers do not always realize the impact that research studies have on people’s lives.
- Compensating individuals does little to improve the community.
- The community lacks faith in the current systems imposed by research institutions.

Opportunities identified:

- Community liaison roles can be integrated into research projects. For example, a peer can be paid to help study participants understand researchers' motivations and the purpose of the study.
- Challenge the co-opting of harm reduction by recognizing that harm reduction was borne of community members sharing information with each other and not researchers telling community members how to protect themselves.
- Researchers can best support the community by supporting organizations that are already doing the work on the ground. They should strive to integrate into the community rather than trying to get more community members into *their* spaces.
- Community members can come together and collectively refuse to participate in research studies, CABs, and IRBs.
- In addition to participant compensation, researchers can offer communal resources, such as a community garden or harm reduction supplies (e.g., naloxone).
- Researchers need to "show up" literally and figuratively by volunteering at the community organizations they are partnering with to gain perspective on what is truly needed as well as people's strengths.
- Recognize that ending poverty and homelessness are number one priorities for the community and researchers should work towards helping to meet that goal.

8. Harm reduction in the 4th wave of the opioid epidemic: What needs to change?

Rethinking our collective response to a rapidly shifting epidemic.

Current harm reduction tactics were largely developed during the second and third waves of the “opioid” epidemic. As we enter the fourth wave of the overdose crisis, what do we need to be doing differently? How do we redefine the community? How has the community redefined itself? How do we conduct research in a way that reaches this community more effectively, rather than doing what the researcher is most comfortable with? Furthermore, what should be the focus of harm reduction during the fourth wave, reversing overdoses, or preventing them?

Challenges identified:

- Getting harm reduction supplies to the people who need them at low cost is a top priority.
- Identify a more comprehensive way to teach community members how to administer intramuscular naloxone as opposed to intranasal naloxone.
- Closing the gap between research priorities and on-the-ground public health solutions that work.
- Changing the messaging about naloxone so that we reach people who do not see themselves at risk for overdose.
- Countering the stigma against opioid use that prevents people from carrying naloxone.
- Identifying the number of prescriptions for naloxone filled when prescribing opioids.
- Students have voiced that they are experiencing emotional pain and are turning to opioids for help.
- Parents are huge obstacles in distributing naloxone in schools.
- There are limited drug checking/testing options for people who use stimulants that may be contaminated.
- Fentanyl test strip messaging is currently not reaching all populations.

Opportunities identified:

- Focus on distributors: Develop mechanisms for those distributing/selling unregulated opioids into the community to simultaneously distribute naloxone.
- Identify ways to distribute naloxone to youth and also involve schools, promoting activities and spaces for youth to feel empowered to share their experiences.
- Increase distribution of naloxone through community centers.
- Normalizing fentanyl test strip use to reduce stigma around addiction and opioid use.
- Distribution of fentanyl test strips in bars and restaurants has the potential to reach more people.

Outcomes & Key Takeaways

During the final session of the Unconference, facilitators invited nominations for the community's top three priorities to address over the next 12 months. A team of notetakers documented on whiteboards what attendees felt were the most important issues that emerged from the sessions. Facilitators clustered the issues thematically and then asked attendees if there were any corrections or changes. Once it was agreed that the right balance of clustering and differentiation was achieved among the groups, attendees voted on their top priority. Those with the top three highest number of votes were then selected.

1) Create a coalition

Action summary: Clear mechanisms of accountability of both individual researchers and research organizations to the organizations and communities that make their research possible. (31 votes)

The community wants mechanisms to hold researchers accountable, particularly in light of examples of behaviors by researchers that were identified as concerning. Exhausted by having to repeatedly hold researchers accountable for their actions, community members called for a collective voice—including that of researchers—to push back against systemic harms and to have a way of gathering and formalizing feedback so as to not duplicate efforts or repeat mistakes. For example, creating a “researcher report card” that would track researcher infractions against the community, a “community IRB” similar to an institutional IRB, designated community representatives who would consult on specific studies, or a public “restricted researcher” list were examples of accountability measures for consideration. Part and parcel to holding researchers accountable is instituting policy on fair and equitable remuneration of research participants, which will require addressing the structural, administrative, legal and policy barriers to remuneration that community members face. Such barriers include university rules that require individuals to register as suppliers, which assumes that people have fixed addresses, bank accounts, and are permitted to work legally in the US. Paying people with gift cards not only assumes that this modality is the equivalent of cash, but is also patronizing in that it dictates how and where people choose to spend their money.

2) Let the community decide

Action summary: Active involvement of community partners in choosing research study topics and determining future directions of research. (7 votes)

The community demanded earlier involvement in the decision-making process in terms of research priorities, and a mechanism to voice these priorities is needed. Sub-populations often already have a good sense of what they want to know about their communities, for example, how they can access better care or how they can use data for advocacy purposes. Creating forums to directly communicate questions and community-led ideas to researchers emerged as a potential promising practice that has been successful in other settings; however, this mechanism would require a sustainable structure and firm commitment on behalf of all parties. In summary, cultural change is needed to embed community input into all aspects of research: from the creation of the research agenda, to sharing results, to sustaining interventions after the research ends. This need is particularly acute given the rapidly evolving nature of the overdose crisis.

3) Teach researchers to be ethical

Action summary: Involve community members and organizations in training substance use researchers how to be more sensitive to the lived experiences of community partners and participants. (7 votes)

There was consensus that there is a lack of respect for persons with lived and living experience in research. There is a lack of clarity conveyed to the community on the goals of the research and no justification for asking certain groups invasive questions, often resulting in traumatization or retraumatization. A cultural shift is needed to value what certain groups bring to the table, such as sex workers, including their strengths and not only their deficits. Researchers require specific ethics training on how to work with populations who use drugs. The community therefore called for training of substance use researchers on interaction standards and practices. Training should center research participants as people first and foremost, include skills in active listening, and incorporate a variety of evidenced-based, trauma-informed, and ethnographic methods that go beyond

simply what the IRB or ethics committee requires. Additionally, the majority of the information that is collected from research participants is not published, which increases the risk of tokenism and the discounting of community voices and feedback. The community called for researcher training to include the ethics of storytelling and producing research that reflects the complexity of people's multiple identities. Community members themselves voiced the need to be involved in these trainings, and that they should be standardized and accessible to researchers.

Looking Ahead

The organizers of the Unconference gleaned several lessons from planning and holding the event to inform future Unconferences:

- Having petty cash on site to pay community members to facilitate on-time payment to participants
- Ask people to include their phone numbers on sign-up sheets for future involvement (in subcommittees, for e.g.) facilitates participation for those who do not use email
- Increased staffing at the door will help attendees to get situated faster and also enable payment of participants *before* the event
- Smaller groups allow for more focused, intimate conversation
- A standardized method for note-taking (preferably electronic) for notetakers
- Designated event follow-on team to plan the next Unconference

Following the Unconference, researchers at Brown University established the Community Centered Substance Use Research Fund to manage the funding for events that came out of the Unconference. The Fund is stewarded by The Committee for Community Centered Research, which meets regularly to steward the Unconference, the working groups, and outcomes. Updates and information about the next unconference and outcomes and follow up from the last unconference can be found at <https://community-led.us/>.

Organizers

Many individuals and organizations have contributed to making this event happen, including Project Weber/RENEW, Direct Action for Rights and Equality (DARE), Advance Rhode Island Clinical and Translational Research (RI-CTR), the People, Place & Health Collective (PPHC) at Brown University, the Center for Complexity at RISD, the COBRE on Opioids and Overdose, and Ocean State Advocacy.

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