Harm Reduction
TA CENTER

Community-Based Participatory Research (CBPR) in Harm Reduction Settings

A Toolkit for Building Beneficial Community-Academic Research Partnerships

NASTAD

2023

Introduction

This toolkit is for harm reduction workers who are considering participating in research activities, or who already have existing community-academic research partnerships. It may also be of use to academic researchers studying issues related to harm reduction, though they are not the main audience for the toolkit.

This toolkit provides an overview of best practices for forming mutually beneficial community-academic research partnerships within harm reduction settings, to learn more about people who use drugs (PWUD) and the best ways to serve and support them to have the best possible health and wellness. The toolkit challenges traditional biomedical research methods: prioritizes the voices and lived experiences of PWUD; and confronts stigmatizing and discriminatory practices, systems, and rules by uplifting research practices that further the co-creation of knowledge between those who are traditionally seen as "researchers" and "the researched."

The toolkit also provides an easy-to-use checklist and resource list to help harm reduction workers to:

- assess whether a proposed research collaboration is likely to be mutually beneficial, and/or
- negotiate with academic research partners to agree upon the terms of a collaboration to protect the rights and needs of all participants.

An important goal of this toolkit is to ensure that academic research endeavors are beneficial and have value to harm reduction organizations and those they serve. In most communities PWUD are what is known as a "heavily researched" community,[a] and many PWUD are also part of other communities that are heavily researched, including certain racial/ethnic populations, people with stigmatized sexual orientations or gender identities, people involved in criminalized activity, religious communities, or populations of low wealth or socioeconomic status.* Ideally, this toolkit will act as an organizing agent to help harm reduction advocates collectively pursue research practices that give power and voice to their interests.

---

* It is not our intent to provide an exhaustive catalogue of nor make comparisons between forms of oppression or the historical stigma, discrimination and research abuses visited upon marginalized groups in the U.S., but only to observe that there are many reasons to scrutinize the issues of equity, power and ethics that arise when vulnerable populations are sought by academic systems for research studies.

How this Report was Developed

To develop this toolkit NASTAD contracted with Facente Consulting, a public health consulting firm that focuses on helping clients better serve people most neglected and harmed by current and historical systems – including PWUD. Facente Consulting worked closely with an expert in community-based participatory research (CBPR), Dr. Lauri Andress, to conduct a detailed literature review about best practices related to CBPR in harm reduction settings or similar, and to conduct in-depth qualitative interviews with harm reduction program staff who have experience with community-academic research partnerships in their work, and academic researchers who have experiencing conducting CBPR projects in harm reduction settings.

Centering the voice of people in the community was our goal, and this is reflected in the multiple quotations from our interviewees that appear throughout the toolkit. Invitations for interviews were extended to 19 people across a mix of harm reduction organizations in large cities and smaller states or rural settings, as well as a variety of academic settings.

We extend our deepest appreciation to the interviewees who shared their time and insights:

- **Jessie Blanchard**, 229 Safer Living Access
- **Katie Evans**, SPARC Women's Center, Johns Hopkins University
- **Mariah Grant**, The Sex Workers Project, Urban Justice Center
- **Mark Jenkins**, Connecticut Harm Reduction Alliance
- **Morgan Farrington**, Goodworks: North Alabama Harm Reduction
- **Talia Rogers**, Show Me Harm Reduction
- **Van Asher**, Keith D. Cylar Community Health Center, Housing Works

Key Terms

BIOMEDICAL MODEL OF RESEARCH: In contrast with Community-Based Participatory Research, the biomedical model of research is meant to generate evidence that is labeled as trusted, meaningful, and useful to clinicians and communities. Individuals are prioritized as research subjects to further this goal, but not seen as meaningful parts of research conceptualization, design, conduct, or dissemination of findings.[2]

COMMUNITY-ACADEMIC RESEARCH PARTNERSHIPS: Research partnerships in which researchers and community groups or stakeholders work together on a research project. Community-academic research partnerships *may* be community-based participatory research, but not always.

COMMUNITY ENGAGEMENT IN RESEARCH: The opportunity for community members, advocates and leadership of community organizations to be involved in all or some phases of a research project. Offering opportunities for community engagement in research does not necessarily make a project community-based participatory research.

Overview of CBPR

Community-based participatory research, or CBPR, is known by many other names, including Community Engaged Research (CER), Participatory Action Research (PAR), Participatory Research (PR), Integrated Knowledge Translation (IKT), Action Research (AR), and Patient and Public Involvement (PPI). Rather than being a specific research method (or set of methods), CBPR is instead a social justice-based orientation to research. Specifically, CBPR removes the distinction between the people “doing the studying” and the people who are “being studied,” because under CBPR the subjects of the study also have power to decide how the study is conceived, designed, and implemented.

Since CBPR is an orientation to research, there is a wide variety of interpretations about just what constitutes CBPR, and what it looks like in the field. However, it is generally accepted that CBPR always involves:[3]

Meaningful participation of members of the population being studied (“community members”)

Equal contributions of both community members and researchers in a joint process to develop, implement, and disseminate findings from the study

Researchers and community members learn together (sometimes known as “co-learning”)

Steps to improve infrastructure and capacity for involvement in research for members of the local community members

Increased participation agency and/or control over their lives

A balance between research and action (e.g., advocacy for shifting policy and structures)

CBPR can be an excellent approach to answering research questions related to harm reduction practice. Harm reduction is a participant-focused field, with a commitment to “meeting people where they’re at,” and insisting on “nothing about us without us.”[4] Similarly, **CBPR is an approach to research that reflects those same principles, with a goal of attending to social inequities through power-sharing and collaborative, empowering engagement between community members and academic research partners.**[5] To this end, within CBPR there is an expectation that:

1. research and community partners build and maintain relationships based on trust, credibility, respect, dignity, and transparency;
2. research and community partners co-produce knowledge and meaningfully engage community stakeholders at each phase of the research process (from defining the problem to designing the research plan, conducting the research, and analyzing and disseminating results); and
3. partners demonstrate flexibility and creativity in collaborative research activities and tailoring the approach to answering a research question that is meaningful to the community being studied.[6]

What can a CBPR project look like in a harm reduction setting?

A CBPR project could take many different forms[7] – there is no "one size fits all" approach to CBPR.

- One model involves a collaboration between an academic research institution and a community organization to try to answer a single, focused research question (or set of questions). In this time-limited community-academic research partnership, each of the partners will discuss shared goals and work together to design a study that they then implement together, analyze together, and write up together, sharing findings jointly through both academic publications and community-focused formats. **This might look like a syringe services program and a researcher partnering to understand the relationship between overdose locations and criminalization, to understand policing's impact on overdose and develop programming to respond.**
- Another model involves an ongoing collaboration between a set of academic researchers and one or more community organizations to address a general topic. This may look like the first model, but the community-academic research partnership doesn't end when the first study is completed; rather, lessons learned are discussed and then the group works together to define the next research question and repeat the cycle. In this type of CBPR arrangement, there is often a regularly occurring meeting in which partners discuss research findings that are arising, and strategize next steps. **This might look like a harm reduction program wanting to understand how to advocate for the needs of non-injectors seeking services and researchers wanting to understand shifting drug markets, routes of administration and impacts on health. They would partner on multiple studies, continuing to learn more and adjust research questions.**
- A third model involves a coalition of numerous community organizations, academic partners, and (often) government agencies to address a complex topic in data-driven ways. Instead of focusing on a specific research project, this coalition works in partnership to design and conduct ongoing research that supports the social justice goal(s) of the coalition. This type of CBPR is often part of a collective impact initiative,[8] but can also be the foundation of many other types of collaborations and coalitions. **This might look like a statewide coalition asking research questions to guide the development of services in underserved regions, learning about gaps, needs and barriers to creating new syringe access across the state.**

Although at its core CBPR is designed to meaningfully involve communities in and educate them on all phases of a research project about them,[9] many forms of research that are "community engaged" define themselves as CBPR when in fact their involvement of community members is tokenizing, or at best limited to a unequal and "supportive" role in the research. If community members are approached to encourage participation after the research questions have already been formed and the research study has largely been designed, for example, this is not truly CBPR. If community members are being used largely to recruit study participants and give suggestions for specific components of the study that the academic researcher will then decide to accept or decline, this is not empowering to the community, and is not CBPR. When "peers" are involved in the research with no attempts made to provide education or build capacity that enables them to become leaders in future community research efforts – ideally through paid employment! – then this falls short of CBPR's expectations for researchers' investment in the community members involved.[10]

How might CBPR be useful to harm reduction?

If so many research “partnerships” are disempowering or even exploitative to PWUD and workers in community-based organizations focused on harm reduction, why would advocates of harm reduction practices ever want to be involved in academic research projects? In short, despite the potential pitfalls of community-academic research partnerships, there is much to be gained from a well-run CBPR project. Recent research by Hoekstra *et al*. noted that across nearly 100 review studies looking at CBPR-style research efforts, there were many benefits to both community members and researchers.

THE MOST COMMON IMPACTS OF THESE STUDIES WERE:

- Personal benefits to community members as a result of participation in the study, or information learned from the study
- High-quality research that improves understanding of a meaningful problem
- Increased knowledge and skills related to research processes among community members
- Improved capacity of the research institution to conduct and disseminate meaningful research
- System(s) change or other actions that ultimately improve quality of life for the population under study[6]

CBPR is especially well-suited for answering research questions about complex issues relevant to the community, thereby equipping advocates with useful information to further shared goals to improve the health and wellbeing of PWUD. Some examples of research issues that could be investigated through CBPR projects[b] include:

1. How to best improve relations between harm reduction organizations and law enforcement, such that police see harm reduction workers as helping to decrease deaths, crime and arrests, not increasing problems in an area?
2. What are the reasons PWUD who are unhoused may choose to enter various types of housing, or might decline housing when it is offered? What policies and structures make permanent supportive housing more accessible and sustainable for PWUD?
3. How can community-academic research partnerships be structured so that the divide narrows between academic researchers or clinicians ("white coats") and PWUD and their advocates in the community ("black t-shirts")?

Today, many research opportunities arise through funding that comes with numerous restrictions, often ruling out the messiness and iterative process necessary for CBPR. However, concepts of "community-engaged research" are growing in popularity. Increasing the number of successful community-academic research partnerships that benefit PWUD will require many academic researchers to make substantial changes in their approach, involving community members more meaningfully in all aspects of their work – a partnership based on mutual trust and respect that is earned, not simply expected. However, it will also require a cautious leap of faith for community members who have repeatedly been disenfranchised and mistreated by institutions (including academic ones). **Research partnerships should be approached by community members with skepticism, but sometimes researchers are truly well-intentioned and are actively working to address power imbalances and subvert the status quo through their research.** Simon and colleagues highlighted their own reflections on this issue in a 2021 article in the *International Journal of Drug Policy*: "We're just so used to be oppressed [as PWUD]…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."[10]

> You know, I've gotten to include people who had no real voice before…and tell them, "Hey, this is this is an opportunity! You have full, you know, full veto here. If you don't want to do it you're not required to do it at all, but like, here's an opportunity for you to come to this thing, participate, share whatever you are comfortable sharing, and, like, you have an opportunity to speak for all of us right now and get your voice heard. And maybe actually make a little bit of a difference! That's pretty cool."
>
> – HARM REDUCTION INTERVIEWEE

---

[b] These ideas came from PWUD and harm reduction advocates who were interviewed as part of efforts to gather information to inform this toolkit.

Best Practices for Undertaking CBPR in Harm Reduction Settings

Regardless of the format used, all CBPR projects should:[9]

1. **have researchers describe their values and principles** of research in addition to their methodological approaches to answering the research question(s);
2. **value community and academic knowledge** and contributions as equally important in the design and conducting of the research, as well as during dissemination of findings (e.g., with co-authorship credit given to non-academic partners on academic papers, academic participation in community dissemination strategies led by community partners, and establishment of clear data sharing and ownership agreements from the start of the project);
3. **support community workers interested in research to build skills** that enable them to conduct research independently in the future (e.g., trainings and mentorship related to engaging with institutional review boards, or IRBs, and trainings and technical assistance related to simple methods for data analysis and reporting); and
4. **report not just on health impacts but also on evaluation of partnering practices** and the potential contribution of these practices to impacts of the study.

Beyond these core expectations, there are three themes for best practices that uplift researched communities of PWUD and help ensure that a CBPR project is being conducted with integrity: (1) setting up equitable relationships between community and academic researchers; (2) ensuring research benefits to PWUD outweigh the risks of research involvement; and (3) respecting the time and expertise of community-based harm reduction workers who engage in CBPR projects. More information on each of these themes is below.

Best practices for equitable community / academic researcher relationships

Academic researchers typically live in a world driven by the constant need to find short-term funding for research projects to support their career. This situation – often referred to as a "soft money" environment – means that the job stability and opportunity to advance in academic research careers is based almost entirely on how much grant funding they are able to bring in and how many academic articles they've succeeded in publishing. This academic system rewards the ability to convince other academics (serving as grant proposal reviewers) that they have designed optimal research methods for answering research questions that are interesting and important *to the funder*. Most funding is available for large survey-based studies with concrete procedures and little flexibility in research design once the study is begun, not for smaller studies that are designed to be responsive to community needs and allow for qualitative data collection to enhance statistics-based analysis.

It is no surprise, then, that harm reduction workers who are focused on community needs – and whose priorities may in fact be counter to the interests and priorities of academic research funders – often have experiences where academic researchers are unresponsive to their requests for partnership, or are dismissive of their needs or ideas for strategies to answer research questions, even researchers who focus on the health of PWUD and are known for "saying the right things" about harm reduction.[10] Yet with

QUICK TIPS

- ✓ As community-based harm reduction workers you should be meaningfully engaged in shaping research questions from the beginning, not just supporting researchers' goals.
- ✓ There should be collaborative discussions between academics and community partners that lead to compromises in approach so that both parties find value.
- ✓ Risks to PWUD and harm reduction organizations should be explicitly discussed throughout the project.
- ✓ Researchers should build your capacity, and that of your organization, to learn about "human subjects research" or IRB processes.

CBPR, community-based harm reduction workers should be meaningfully engaged in shaping the research questions from the beginning, as well as in determining the most appropriate ways to answer those questions. While it may not always be practical for academic researchers to support (and bankroll) the study of any question that community partners deem interesting or important, at the very least CBPR (and *all* research about PWUD) should involve collaborative discussions between academic and community partners that lead to compromises in research approach so that both funders and PWUD can find value. There should always be explicit discussions between partners about potential risks to PWUD and harm reduction organizations by becoming involved, and how those risks will be mitigated, or offset by benefits of participation.

Importantly, these types of discussions should not only happen during the initial negotiations about a research project. It is a best practice for the research team to build in periodic sessions throughout the conduct of the research to evaluate how the process is unfolding, what could work better, and whether the project continues to align with community needs and maximize benefits to those being researched while minimizing risks from continued participation. Often it isn't until partway through the study that potentially beneficial changes and/or potentially harmful consequences of the research plan are recognized.

Finally, throughout the world research on what is known as "human subjects" must be reviewed and approved by an ethics board before contact with human subjects begins. These ethics boards have many names, but are most commonly known as Institutional Review Boards, or IRBs. IRBs became a required part of human subjects research in the United States following the National Research Act of 1974,[11] after the Tuskegee Syphilis Study,[12] Milgram obedience experiment,[13] Stanford prison experiment,[14] and other research studies were determined to have placed research subjects at unacceptable risk without necessary benefit. While IRBs have the primary goal of reviewing and approving (or requiring changes to) research plans to protect human subjects from harm, today many IRBs are seen as complicated bureaucratic juggernauts, with a reputation for prioritizing traditional research practices and having low or no capacity to integrate insights and expertise of the communities from which research participants will be identified. Regardless, navigating a research project through IRB approval is a requirement for anyone wanting to do research with human beings, whether or not they are academically trained. While academic researchers are usually proficient in navigating the IRBs of their own institutions, CBPR projects provide an important opportunity for academic researchers to help build capacity among non-academic harm reduction workers to learn the IRB process. Best practices for community-academic partnerships would encourage community partners to play a role in completing (or reviewing and editing) the IRB application, allow for time for the academic partners to clearly explain the IRB process and expectations regarding timeline for approval, facilitate the process for community partners to obtain training certifications needed to be listed on the IRB application as full partners, and, ideally, also setting up a parallel *community* review board that also has authority to review and approve (or request changes to) the project before it begins.

Best practices for ensuring research benefits to PWUD outweigh the risks

As harm reduction workers well know, there are many potential risks to PWUD and people who do harm reduction work from participating in research studies. Research questions may retraumatize participants; disclosure of their identity or linkage to a research project about PWUD could lead to stigmatization, police violence, incarceration, deportation, and potential risks from abusive partners or others who would use their proximity to drugs or people who use drugs in custody disputes. Further, people who are struggling economically may be more susceptible to coercion to participate in a research study with which they are not comfortable. Harm reduction-focused community organizations that partner in community-academic partnerships run the risk of losing already scarce time and resources with little in the way of remuneration, capacity building, or operational data to show for the experience.[15]

With all research, including CBPR, it is extremely important that anyone involved in the research do everything possible to mitigate these potential risks, *and* that the potential benefits to PWUD (and ideally the specific participants involved in the research project) make those risks worthwhile. **It is *not* best practice for researchers to partner with harm reduction organizations to access PWUD as research subjects, only to solely benefit by gathering the data, publishing findings in an academic journal, and never sharing useful information back to the community organization or PWUD**. In this case, PWUD assume most of the risks and academics accrue most of the benefit. But this certainly is not how community-academic research partnerships need to (or should) look.

QUICK TIPS

- All research has potential risks for PWUD and harm reduction programs, so it is important to acknowledge and mitigate potential risks and ensure the potential benefits make those risks worthwhile.
- Researchers should be proactive in sharing their strategies for mitigating risks with partners.
- Research should include protections related to confidentiality, use trauma-informed research strategies,[16] and include flexible options for participation for PWUD.
- You and the people you work with may receive financial compensation, as well as opportunities to leverage the research project to create structural change that will improve the health of PWUD and facilitate high-profile relationships and media attention and presentations.

It is a best practice for academic researchers to be proactively forthcoming about all of the specific strategies they will put into place to protect participants from

> I do think asking about homelessness...[my] pushing back on that was surprising to some people. They were like, "Why don't you want to know people's living status?" And the way I think that they had asked the question was something like, "Have you slept outside for the last 30 days," or something like that. And so then I wanted to know, "Why do you need to know that? Because that's a pretty sensitive thing to ask somebody about," and they didn't necessarily see housing status as a sensitive topic. When it comes to more blatant traumatic things like assault, for example, people are like, "Oh, yeah, that's a sensitive topic." But sometimes when it comes to poverty-related things, people don't realize that poverty is also traumatic. And I do feel like that might be one of the biggest gaps between service providers and researchers: when people are completely siloed...they don't recognize poverty as trauma."
>
> – HARM REDUCTION INTERVIEWEE

potential risks; if academic researchers do not volunteer this information readily, community harm reductionists should treat this research project with caution and request that the academic researcher share those details before any more conversation is had about a research partnership. Specifically, the research should include stringent protections related to confidentiality, use trauma-informed research strategies,[16] and include flexible options for participation that will "meet participants where they're at" in their lives – such as being thoughtful about the interview location or using more informal interview methods (e.g., "walking and talking" instead of sitting in a formal office with an audio recorder running). Care should be taken to ensure participants are able to provide fully informed consent, and do not feel obligated to participate in order to obtain desperately needed money, or the favor of services staff.

Regardless of the steps to mitigate risks, however, a research study will not be worthwhile for PWUD or harm reduction organizations if there are not direct benefits to those participating. Planning, implementing, or providing data for a research study takes time, and even with minimal risks the time spent should be counterbalanced by tangible benefits. Benefits may include monetary compensation (see next section), but may also include opportunities to leverage the research project (and therefore the academic institution's infrastructure) to drive forward community-based interventions that will improve the health of PWUD – especially structural or systems changes that can be sustained long after the research project finishes. Benefits may also include facilitating political connections, or gaining visibility through high-profile media attention, conference presentations, or academic publications *that directly involve community partners as named collaborators.* Note that it is insufficient to expect ongoing, time-consuming engagement of community partners for months or years without periodic benefits along the way; a promise of benefits once the study is complete and results are disseminated is not an adequate way to offset participation risks with community benefit. The timing and frequency of benefits to the organization or individual participants should be discussed before the project is launched, and this should be formalized in the project timeline with written milestones that all partners can see.

> I told them I was going to put some kiosks in, and she went, "Oh, I know so-and-so the Regional Director of Parks who wanted new ones in the park. They had some years ago which had disintegrated, and they have to go through such red tape to get them in – let me put you in touch." And so I said...Look, I have them if you install them, because for me to get someone to install them is a nightmare, especially in parks, which is government land. If you install them because you have the ability, I will have someone service them and it's a win/win for everyone. And we could do this in a matter of months instead of where you've been trying to do this for years." Within three months we had 10 of them installed, one in front of my location, but nine in the parks and the areas of highest public drug injection within our community. And so it's about building ... community partnerships.
>
> – HARM REDUCTION INTERVIEWEE

Best practices for respecting the time and expertise of community-based harm reduction workers who engage in research projects

Academic researchers who exist on “soft money” still draw (often substantial) salary from their academic institutions for their role in research projects and partnerships. Yet community partners are frequently expected to participate in these same partnerships above and beyond their salaried time for direct service provision – and even if their organization supports them doing this work as part of their regular work week, their salaries are often much lower than academic partners (if they are even salaried). Finding ways to equitably compensate community workers for their time and expertise is paramount in CBPR, and is a best practice for *any* community-academic research project, whether or not it rises to the level of CBPR.

Best practices related to harm reductionist compensation include:

- having the academic institution create funding agreements with partnering community organizations that create meaningful sources of income for PWUD and harm reduction workers;
- obtaining information that demonstrates that the academic institution will be able to process agreements, contracts and payments in a timely manner so community organizations do not have to use scarce resources to support the research while waiting for payments;
- building substantial resources for the harm reduction organization into the budget, such as personnel, transportation, incentives, or equipment;
- training harm reduction workers and PWUD on new skills that can lead to future employment or income, such as paid research positions; and
- devising systems for fair compensation for low-income community members that will not jeopardize government benefits (e.g., cash payments, etc.).

QUICK TIPS

- ✓ CBPR research must equitably compensate harm reduction workers and PWUD for their time – you need to be paid!
- ✓ This should include consideration of not jeopardizing government benefits or creating burdensome systems to receive money.
- ✓ Beyond being compensated for their labor, harm reduction workers should feel respected for skills, relationships and time invested while also managing a busy drop-in center or doing outreach.
- ✓ It is easy to take on more because you care - yet having clear agreements and sticking to the scope of work will ensure there isn’t unnecessary strain on your program.

> They wanted us to talk about PrEP in every single nighttime outreach engagement. And they wanted us to document in our data tracking...how many times we talked about PrEP that night, and then they were comparing that number to the number of people that we saw. And what I had difficulty explaining is that … oftentimes people are about to take a date. So they’re like coming up to the van, they’ve got a car waiting for them, they’ve got to get back in the car. So I have like, a minute and a half with this person. And oftentimes it’s a person that I know, and then I know what some of their other needs are. And so I want to see how they’re doing in that 90 seconds, see what supplies they need...To take that last 30 seconds to instead pitch this PrEP study just feels like it kind of lacks acknowledgement of, like the number of services that we provide to people. And that it’s not just people coming up asking for supplies; there’s a relationship there and case management needs and all the other kind of stuff. And if anything, I’d really like to take that extra 30 seconds – if they don’t have other stuff to talk about – just to let them know about services going on at the Center, and less about the research study.
>
> – HARM REDUCTION INTERVIEWEE

Beyond compensation, it is a best practice for academic researchers to take additional steps to show respect to community partners for their valuable time and expert connections and insights. Even tasks that may seem “simple” (such as referring program participants to the study, putting up posters to advertise the study, having conversations with potential participants about the study, or answering questions about participation) usually take extra time, and this adds to – or detracts from – the time spent on lifesaving direct services. Professional acknowledgement and financial compensation for these efforts is a best practice. Beyond that, it is incumbent upon academic partners to guard against “scope creep” for community partners. If community organizations are already struggling to provide services with insufficient personnel, time, money, or physical space, then even small expansions of scope beyond what was originally agreed on can place real strain on the organizational system.[15] Community workers should work to set boundaries and limits when they are being asked to go above and beyond the original agreed-upon protocol.

Key Strategies for Success in Harm Reduction-Focused CBPR Relationships at Each Phase

Questions for a harm reduction organization to ask before entering a CBPR partnership

▶ **Find out where the researchers are in the process of developing the research strategy when they approach you for a potential collaboration.**

- ***Is the project funded?*** This could determine whether the community is expending energy on a long shot proposal.
- ***Have you gotten IRB approval?*** This process takes some time, and ideally will include the community as part of the IRB submission process.
- ***Has the question already been formed? And what space do we have to contribute our perspectives?*** This will ensure you have adequate space to direct the project in line with CBPR principles and values.
- ***When do you plan to start data collection, and is there still time and space for community members to help shape the direction of the research?*** This will help you plan your work and get a sense of their processes.

▶ **Assess how the researcher talks about PWUD.**

- ***What language do you use to refer to PWUD and others in your studies?*** You should observe if the researcher uses stigmatizing language. You can also ask them directly.
- ***What points of resilience do you see among PWUD? What assets do they bring to this project?*** Again, observe if they approach things from a perspective of deficit, but don’t be shy to ask directly.

▶ **Discuss budgeting and the way that community roles will be funded or otherwise compensated.**

- ***How much will be budgeted for the harm reduction agency and participants?***
- ***How will this funding be received by the harm reduction organization? What is the payment structure?*** This will help you assess if it’s feasible for your organization.

▶ **Consider requiring academic researchers to complete a written letter of request for the proposed collaboration, avoiding reliance on a pre-existing relationship.**

- Identify any potential areas of the proposed research partnership that may stigmatize, mischaracterize, or threaten the privacy or dignity of PWUD.

- **Ensure a defined, beneficial purpose and outcomes for PWUD and community partners, and determine that those benefits are likely to (far) outweigh the risks of participation.**

✔ Ask a lot of questions!

✔ Be in a state of information gathering – how are they talking about PWUD, is their goal aligned with yours and will this benefit PWUD and your program?

While negotiating the terms of CBPR partnership

- **Work together to co-define the research questions that will be studied.**
- **Identify all the members of the team and create a brief written staffing plan that lays out each person's roles and responsibilities for the project, to ensure equitable involvement and recognition.**
- **Work together to develop and define norms, rules and expectations for the project in terms of timelines and tasks.**
  - How will decisions be made across people and organizations? Do you have agreement on meetings where things will be decided and/or shared?
- **Establish a written agreement that researchers will write a community report and structure joint presentations of the study's results, with community members having an opportunity to co-write or co-present if desired, or at minimum inform the framing of the report and review/edit the document or presentation before it is shared with others.**

✔ Co-create the research questions.

✔ Set up written working agreements that outline roles and decision-making from this point through dissemination of the project.

✔ When necessary, push back on researchers to ensure PWUD are protected and centered from the start.

While designing the research project

- **Highlight for academic partners that stigmatization and criminalization of PWUD can make it difficult to capture valid samples *representative* of lived experiences.**
  - Can we share our approach to working with PWUD / our participants? It is important to us that as researchers you understand how stigmatization and criminalization of PWUD play out even when you have the best of intentions.
- **Ensure that community partners have meaningful involvement and the ability to shape the research protocols by being involved from the beginning, from IRB approval through tool development.**
  - ***Can we consider the confidentiality of PWUD in determining what instruments we use?***
  - ***Surveys can only reflect short responses based on the questions asked and may miss nuanced details and experiences. If we're utilizing surveys, can we consider supplementing them with qualitative interviewing methods?*** Work together to avoid long and invasive surveys that are onerous for both harm reduction staff and participants to complete.

- **Use a variety of activities to foster collaboration, communication, and respect amongst the team members on an ongoing basis. Strategies can include, but are not limited to:**
  - documenting a common language (e.g., key definitions and terms used)
  - ensuring that all work is appropriately compensated – if harm reduction staff are expected to administer surveys, they should be paid like any academic researcher
  - directly and respectfully addressing conflict and/or tensions if and when they arise

- **Provide opportunities to educate and train all team members on research methods or other pieces of the research study; this will build understanding and capacity for future research.**

✔ Develop deeper relationships by communicating and engaging regularly.

✔ Solidify trust by compensating people equally and developing language together rather than relying on jargon.

✔ Learn about research by being involved in the early phases of developing IRB, etc.

While conducting the research project

- **Ensure that community partners have opportunities for meaningful involvement (whether or not they ultimately decide to participate) in:**
  - recruiting participants
  - conducting interviews
  - collecting surveys
  - reviewing literature
  - ensuring quality of data collected

- **Provide practical and emotional support to community partners in recognition of the challenges and emotional labor involved with collecting data from peers in need.**
  - ***What training and support will be available to help PWUD carry out their research roles?*** PWUD should receive training in data collection, de-escalation, how to set and maintain research boundaries, etc.)

> You cannot say that you are meaningfully involving people unless you're hiring them. For one, don't tell me that you meaningfully involve people who use drugs unless you're like paying them – period. But if you also are an advocate for a group of people, but you don't take that group of people seriously when they approach you, [then] you're not an advocate, you're full of shit. You know, like, sorry, but that's the facts. That's facts. If an organization or a group or whomever won't hire people that are a part of the community that they're serving, then they're full of shit.
>
> – HARM REDUCTION INTERVIEWEE

- **Facilitate regular communication among all members of the team through structured meetings, email discussions or group texts, brief experience surveys, or other means; these communications can be in person or virtual.**

- **Evaluate the collaborative research activities on an ongoing basis and make adjustments as needed to improve the quality of research outcomes and the experience of all partners.**

- **Hold team-wide process evaluation sessions for multi-year or ongoing studies *between* efforts to renew research proposals, so improvements to the project structure can be made.**

✔ Check in regularly about all the points at which harm reduction programs can meaningfully contribute – not just collecting data from your participants!

✔ Continue to communicate as a team, take note of areas for improvement and adjust strategies as needed.

While analyzing data and disseminating findings

- **Ensure that community partners are meaningfully involved in all pieces of the finalizing process - interpreting findings, framing and writing academic articles, presenting findings and developing dissemination plans.**
  - I'd love to be a co-author and involved in the analysis. What is the best way for us to be included?

- **Make research findings available to both academic researchers *and* community partners; even data not used in a final research report or publication may still be useful to the community organization for future advocacy or funding requests.**

- **Redact any sensitive information that could be used to criminalize PWUD from the study, so the study does not inadvertently create harm.**

- **Work closely with community members to ensure that the findings are published in formats that are accessible to people at all literacy levels, do not require a paid subscription to view, and avoid unnecessary jargon.**

- **Consider non-traditional media for dissemination of results, including short toolkits, videos, content for sharing on various social media platforms, and mainstream media press releases.**

- **Academic partners should not introduce or otherwise label PWUD solely by that descriptor when they have other identities that may be relevant – sometimes including professional research or degree qualifications![10]**

✔ Make sure harm reduction workers and PWUD voices are included in the analysis, framing and meaning making parts of the project.

✔ Share data back with community – it is theirs. So make it accessible in a variety of ways, if possible, like videos, toolkits, social media, and in forms that avoid jargon.

✔ Double-check that you're protecting PWUD in information presented publicly and formally.

> 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.
>
> – SIMON, ET AL[10]

CHECKLIST WHEN CONSIDERING A PROJECT

Questions for harm reduction community providers to ask themselves when considering a possible academic-community research partnership

Any single box that remains unchecked should be considered a red flag: approach with caution.

☐ Does the researcher avoid using stigmatizing frames that portray PWUD as flawed or criminalized people who are ruined, hopeless, and/or useless?

☐ Is the research in line with community perspectives and needs?

☐ Is there enough time to complete the research, so that academic researchers can collaborate with and include harm reduction community partners in a meaningful and intentional manner?

☐ Do the academic researchers demonstrate awareness of power imbalances between academic and community partners, and are they committed to trust-building and power-sharing throughout the entire research process?

☐ Do the academic researchers seem to treat community expertise about harm reduction in the local area as equally important to the research methods expertise of academics?

☐ Are the academic researchers forthcoming with any study details when asked by community partners?

☐ Are the research processes sufficiently streamlined so that the study will not tie up community resources in administrative processes or detailed data collection procedures, leading to potential reductions in services or meaningful social support for PWUD?

☐ Did the researchers explain the Institutional Review Board (IRB) process, and is there an opportunity for community partners to be meaningfully involved in addressing ethical considerations of the study and completing the IRB application?

☐ Is there balance in the study, such that the people who are most at risk of experiencing harm also stand to benefit most?

☐ Do the academic researchers appear committed to working to mitigate risks to PWUD participants, including emotional retraumatization, potential loss of income and employment, and the policing of groups that engage in criminalized activities?

☐ Will there be concrete benefits to the harm reduction organization as a result of their participation in this project, and will benefits come throughout the study and not just at the end?

☐ Does the compensation available to the community organization (through direct funding, equipment, or other support) seem appropriate, given the role of the community partners and the importance of their expertise?

☐ Are the payment mechanisms of the academic institution timely enough that the community partners will not be expected to float any resources (equipment, personnel, etc.) to conduct the research while waiting for payment?

☐ Is compensation only available to the harm reduction organization, or will individual PWUD also be compensated adequately for their time, expertise, and insights?

☐ Is the study designed to involve a wide variety of PWUD (i.e., not just be limited to those who can adhere to restrictive times, places, or methods used by the study) and collect data that can be placed in context (e.g., pairing surveys with qualitative components like interviews with PWUD, which can better assess nuances of people's experiences)?

☐ Are there mechanisms planned for community partners to be able to provide feedback directly to academic researchers about how the study is unfolding, and vice versa?

☐ Will the researchers agree to share the study's results?

☐ Is there an opportunity for PWUD to help interpret and contextualize study findings, and shape the framing of narrative or images in any disseminated materials?

☐ Will the community see all reports of study findings before they are published?

☐ Is there a process for the community to question or disagree with the findings before they are shared outside the team?

☐ Is there an opportunity for the community to write and publish a commentary to supplement the formal publication(s) or other disseminated materials?

For more information

Articles about CBPR and community-academic research partnerships

Andress, L., Hall, T., Davis, S., Levine, J., Cripps, K., and Guinn, D. (2020) Addressing Power Dynamics in Community-Engaged Research Partnerships. *Journal of Patient-Reported Outcomes*, 4: 1-8. https://doi.org/10.1186/s41687-020-00191-z

Black, G. F., Cheah, P. Y., Chambers, M., & Nyirenda, D. (2022). Public and community engagement in health science research: Openings and obstacles for listening and responding in the majority world [Editorial]. *Frontiers in Public Health*, 10. https://doi.org/10.3389/fpubh.2022.1012678

Iton, A., Ross, R. K., & Tamber, P. S. (2022). Building Community Power To Dismantle Policy-Based Structural Inequity In Population Health. *Health Affairs*, 41(12), 1763-1771. https://doi.org/10.1377/hlthaff.2022.00540

Neufeld, S.D., Chapman, J., Crier, N. Marsh, S., McLeod, J., & Deane, L.A. (2019) Research 101: A process for developing local guidelines for ethical research in heavily researched communities. *Harm Reduction Journal*, 16, 41. https://doi.org/10.1186/s12954-019-0315-5

Wallerstein, N. (2020). Commentary on community-based participatory research and community engaged research in health for journal of participatory research methods. *Journal of Participatory Research Methods*, 1(1), 13274. https://doi.org/10.35844/001c.13274

Articles about meaningful involvement of PWUD in research

Brown, G., Crawford, S., Perry, G.E., Byrne, J., Dunne, J., Reeders, D., Corry, A., Dicka, J., Morgan, H., & Jones, S. (2019) Achieving meaningful participation of people who use drugs and their peer organizations in a strategic research partnership. *Harm Reduction Journal*, 16, 37. https://doi.org/10.1186/s12954-019-0306-6

Boilevin, L., Chapman, J., Deane, L., Doerksen, C., Fresz, G., Joe, D., Leech-Crier, N., Marsh, S., McLeod, J., Neufeld, S., Pham, S., Shaver, L., Smith, P., Steward, M., Wilson, D., Winter, P. (2019). Research 101: A manifesto for ethical research in the Downtown Eastside. 2019. https://open.library.ubc.ca/cIRcle/collections/ubccommunityandpartnerspublicati/52387/items/1.0377565

Salazar, Z.R., Vincent, L., Figgatt, M.C., Gilbert, M.K., & Dasgupta, N. (2021). Research led by people who use drugs: centering the expertise of lived experience. *Substance Abuse Treat Prevention Policy*, 16, 70. https://doi.org/10.1186/s13011-021-00406-6

Duran, B., Oetzel, J., Magarati, M., Parker, M., Zhou, C., Roubideaux, Y., Muhammad, M., Pearson, C., Belone, L., Kastelic, S.H., Wallerstein, N. (2019). Toward Health Equity: A National Study of Promising Practices in Community-Based Participatory Research. *Progress in Community Health Partnerships: Research, Education, and Action*, 13(4): 337-52. https://doi.org/10.1353/cpr.2019.0067

References

1. Neufeld SD, Chapman J, Crier N, Marsh S, McLeod J, Deane LA. Research 101: A process for developing local guidelines for ethical research in heavily researched communities. *Harm Reduction Journal*. 2019; 16(1):41.
2. Andress L. Addressing power dynamics in community-engaged research partnerships. UNC Center for Environmental Medicine, Asthma and Lung Biology (CEMALB); December 14, 2022.
3. Minkler M, Wallerstein N. Introduction to Community-Based Participatory Research: New Issues and Emphases. In: Minkler M, Wallerstein N, editors. *Community-Based Participatory Research for Health: From Process to Outcomes*. 2nd ed. San Francisco: Jossey-Bass; 2008., p. 9.
4. Charlton JI. *Nothing About Us Without Us: Disability Oppression and Empowerment.* Berkeley, CA: University of California Press; 1998.
5. Israel BA, Schulz AJ, Parker EA, Becker AB, Allen AJ, Guzman JR. Critical Issues in Developing and Following CBPR Principles. In: Minkler M, Wallerstein N, editors. *Community-Based Participatory Research for Health: From Process to Outcomes*. 2nd ed. San Francisco: Jossey-Bass; 2008., p. 50.
6. Hoekstra F, Mrklas KJ, Khan M, McKay RC, Vis-Dunbar M, Sibley KM, *et al.* A review of reviews on principles, strategies, outcomes and impacts of research partnerships approaches: a first step in synthesising the research partnership literature. *Health Research Policy and Systems.* 2020; 18(1):51.
7. Weiner J, McDonald JA. Special Issue: Three Models of Community-Based Participatory Research. *LDI Issue Brief*. 2013; 18(5). Available from: https://ldi.upenn.edu/wp-content/uploads/archive/pdf/IssueBrief18_5.pdf.
8. Kramer M, Kania J. Collective Impact. *Stanford Social Innovation Review*. 2010. Available from: https://ssir.org/articles/entry/collective_impact.
9. Wallerstein N. Commentary on community-based participatory research and community engaged research in health for journal of participatory research methods. *Journal of Participatory Research Methods*. 2020; 1(1):13274.
10. Simon C, Brothers S, Strichartz K, Coulter A, Voyles N, Herdlein A, *et al*. We are the researched, the researchers, and the discounted: The experiences of drug user activists as researchers. *The International Journal on Drug Policy*. 2021; 98:103364.
11. Rice TW. The historical, ethical, and legal background of human-subjects research. *Respiratory Care*. 2008; 53(10):1325-9.
12. Tobin MJ. Fiftieth anniversary of uncovering the Tuskegee Syphilis Study: The story and timeless lessons. *American Journal of Respiratory and Critical Care Medicine*. 2022; 205(10):1145-58.
13. Milgram S. Behavioral study of obedience. *Journal of Abnormal Psychology.* 1963; 67:371-8.
14. Zimbardo PG. *The Lucifer Effect: Understanding How Good People Turn Evil*. New York: Random House; 2008.
15. Fielding-Miller R, Kim S, Bowles J, Streuli S, Davidson P. “We’re already doing this work”: ethical research with community-based organizations. *BMC Medical Research Methodology*. 2022; 22(1):237.
16. Gum AM, Goldsworthy M, Guerra L, Salloum A, Grau M, Gottstein S, *et al*. Trauma-informed patient and public-engaged research: Development and evaluation of an online training programme. *Health Expectations*. 2023; 26(1):388-98.
17. Brown G, Crawford S, Perry GE, Byrne J, Dunne J, Reeders D, *et al*. Achieving meaningful participation of people who use drugs and their peer organizations in a strategic research partnership. *Harm Reduction Journal*. 2019; 16(1):37.
18. Lennox R, Lamarche L, O’Shea T. Peer support workers as a bridge: a qualitative study exploring the role of peer support workers in the care of people who use drugs during and after hospitalization. *Harm Reduction Journal*. 2021; 18(1):19.