Recommendations for Community Driven Drug Policy Research



In Spring 2022, Drug Policy Alliance, Urban Survivors Union, and the Network of Drug Researchers with Lived Experience co-hosted a four-part virtual series **"Beyond participatorybased research: Innovations in community driven drug policy research."** The sessions were designed to encourage drug researchers to think critically about their relationships with people who use drugs and people impacted by the drug war. They were intended to provide drug researchers with tools to conduct community driven research (CDR) and authentically co-lead research with impacted people through every phase of the research process. CDR not only makes research better by strengthening research questions, methods, analyses, and dissemination; it can also serve as an organizing tool, helping to galvanize people to change policies and practices.

CDR's success necessitates creating a space where people do not feel bound to the traditional binary of the "researcher" and "researched" (<u>Simon et al. 2021</u>). **The** following recommendations aim to support you in creating an environment where all people are empowered; feel belonging in the research process; and can explore and own their positionalities, identities, and lived experiences:

Understand that community driven research requires time and care.

- Researchers in all fields should consider community driven research, recognizing that this approach may take more time and energy than other approaches. However, researchers should strive to make their work as authentically community engaged as possible. Community driven research is a spectrum, and work can be more or less community driven.
- Be upfront and transparent and don't make promises or commitments to community that you can't keep.
- Community researchers directly impacted organizers, activists, and people with living experience – should be involved in the entire research process from conceptualization to research to analysis to dissemination.

Build relationships with community organizers and organizations prior to engaging in research.

• Trust and relationships are the foundation of CDR and building them cannot be rushed.

- Maintain community relationships to stay current with what is going on in peoples' lives and to understand immediate and long-term needs.
- Show up repeatedly for and on time with community members, in both research and non-research related settings, and stand up for them when they're under attack.
- Challenge unethical research in conferences and in writing. CDR is not just about working with your community; it requires advocating for community even when they're not around.

Compensate community researchers for their time and expertise.

- Work with your institution's accountants to compensate your research participants in the way they want to be compensated (e.g. check, wiring, PayPal).
- Ensure that all members of the research team are offered the opportunity to receive credit for their contributions.

Focus on research that benefits the community.

- Ensure that research addresses community needs, brings community members together, advances their political and material goals, or builds connections so that it ultimately contributes to community organizing.
- Pursue community-initiated research questions.
- Complicate your traditional role as a researcher by fully engaging with community members as equals with complementary forms of expertise throughout the research project.

Challenge the notion that the best research is distanced and "objective" and be open to different research methodologies.

- Facilitate an environment where academics and community members are equal and acknowledge the different types of knowledge and expertise they bring. Value experiential data as evidence.
- Consider using oral histories or autoethnographies, which can allow people to tell their stories authentically and

own them, rather than have their experiences used as anonymized data.

- Use innovative and inclusive interview methods, such as extended guided conversation.
- Consider using community surveys including community-administered surveys with substantial community input into phrasing, questions, length, and delivery – as they can be a powerful tool for garnering deep insight and influencing policy.

Make your research procedures accessible for all people to participate.

- Give people adequate time to review documents.
- Be mindful of ableist defaults (e.g. font size, viewing documents on phones, eyesight and literacy considerations).
- Teach norms and hidden curricula (such as meeting times, turnaround times, concrete information on timelines and expectations, methods of collaboration) about each other's work.
- When necessary, translate academic language for those involved in your research. Specialized, academic jargon may create barriers between you and community members.
- Work in alternatives, like Google Docs, to include people with different levels of access to technology and the internet, who may not have their own computers.
- Use various methods to review documents to engage people with different skill sets and collaborative styles.
 Some people may be more comfortable listening and speaking, while others may be more comfortable reading and writing.
- Take care to have flexible meeting times.
- Provide community researchers with the skills to contribute to the research process.

 Do not assume that everyone can be open about their identities and experiences and consult with community members to ensure that they are properly anonymized, while still receiving appropriate credit for their work.
However, also be sure to check in with all team members and do not simply assume they want their contributions to be anonymous.

Work with community organizations to leverage research as credibility and power. Structure your research findings so that they have the greatest possible impact for community collaborators.

- Pre-register your study on a public scientific service (like OSF.io) so everyone is clear before data collection starts on what is being asked and how it will be analyzed.
- Consider releasing data and research results prior to peer-reviewed publication so that they can have more immediate impact.
- Consider the various audiences. Create different versions of the same material using different language and formatting for different audiences. Mediums can include, but aren't limited to:
 - Peer-reviewed articles, which can prove expertise and attract allies by being published in citable academic journals. Prioritize making the articles open access.
 - White papers and pre-prints, which can help disseminate research findings more quickly than peer-reviewed articles.
 - Infographics
 - One pagers, handouts, mini-comics
 - Videos
 - Webinars
 - Podcasts
- Consider disseminating research findings at events and town hall gatherings.

These recommendations arose from panelist discussions throughout the four-part series. Panelists included:

- Shaquita Borden, Front Porch Research Strategy/Women with a Vision
- Sarah Brothers, Pennsylvania State University
- Abby Coulter, North Carolina Survivors Union and Urban Survivors Union
- Nabarun Dasgupta, University of North Carolina
- Shawna Ferris, University of Manitoba
- Mary Figgatt, University of North Carolina at Chapel Hill
- Morgan Godvin, Health in Justice Action Lab
- Brittany Graham, Vancouver Area Network of Drug Users
- Helena Hansen, University of California, Los Angeles
- Naomi Lauren, Whose Corner is it Anyway
- Amy Lebovitch, Sex Professionals of Canada and Sex Workers of Winnipeg Action Coalition

- Laura McTighe, Florida State University and Front Porch Research Strategy/Women with a Vision
- Garth Mullins, Vancouver Area Network of Drug Users and Crackdown Podcast
- Danielle Ompad, New York University School of Global Public Health and Center for Drug Use and HIV HCV Research
- Caty Simon, Whose Corner Is It Anyway and Urban Survivors Union
- Louise Vincent, North Carolina Survivors Union and Urban Survivors Union
- Nick Voyles, Indiana Recovery Alliance and Urban Survivors Union
- Ingrid Walker, Network of Drug Researchers with Lived Experience
- Ariel Wolf, Hacking//Hustling

Resources for Community Driven Drug Policy Research



Articles and resources examining the principles of community driven research

- "Ethical Research Manifesto." North Carolina Survivors Union. Accessed November 1, 2022. <u>https://docs.google.com/</u> <u>document/d/1UFm5EYCCgr5Shv9TjOCobobF4Jwl12i8uN98TV8Fr34/edit</u>.
- Ferris, Shawna, Amy Lebovitch, and Danielle Allard. "Sex Work Research, Ethics Review Processes, and Institutional Challenges for 'Sensitive' Collaborative Research." *International Journal of Qualitative Methods*, 20 (2021), 1-12, <u>https://journals.sagepub.com/doi/10.1177/16094069211033437</u>.
- Jello, Lime. "Why You Shouldn't Study Sex Workers." *Tits and Sass*. April 16, 2015. <u>https://titsandsass.com/why-you-shouldnt-study-sex-work/</u>.
- Jozaghi, Ehsan, Alissa M. Greer, Hugh Lampkin, and Jane A. Buxton. "Activism and Scientific Research: 20 Years of Community Action by the Vancouver Area Network of Drug Users." Substance Abuse Treatment, Prevention and Policy 13, no. 18 (2018), <u>https://substanceabusepolicy.biomedcentral.com/articles/10.1186/s13011-018-0158-1</u>.
- McTighe, Laura. "Front Porch Strategy: Sacred Space and Demonic Grounds." Front Porch Research Strategy. July 31, 2016. <u>https://frontporchresearch.org/2016/08/01/front-porch-strategy-sacred-space-and-demonic-grounds/</u>.
- Montoya, Michael J., and Erin E. Kent. "Dialogical Action: Moving from Community-Based to Community-Driven Participatory Research." *Qualitative Health Research* 21, no. 7 (2011): 1000-1011, <u>https://doi.org/10.1177/1049732311403500</u>.
- Rhodes, Tim, and Kari Lancaster. "Evidence-Making Interventions in Health: A Conceptual Framing." *Social Science & Medicine* 238 (2019): 112488, <u>https://pubmed.ncbi.nlm.nih.gov/31422173/</u>.
- Simon, Caty, Sarah Brothers, Knina Strichartz, Abby Coulter, Nick Voyles, Anna Herdlein, and Louise Vincent. "We Are the Researched, the Researchers, and the Discounted: The Experiences of Drug User Activists as Researchers." *The International Journal of Drug Policy* 98 (2021): 103364, <u>https://pubmed.ncbi.nlm.nih.gov/34294521/</u>.
- Tuck, Eve. "Suspending Damage: A Letter to Communities." Harvard Educational Review 79, no. 3 (2009): 409-427, <u>https://meridian.allenpress.com/her/article-abstract/79/3/409/31956/Suspending-Damage-A-Letter-to-Communities?red</u> <u>irectedFrom=fulltext</u>.
- Vancouver Area Network of Drug Users. "Research." Accessed November 1, 2022. <u>https://vandureplace.wordpress.com/</u> research/.
- Vancouver Area Network of Drug Users. "VANDU Manifesto." Accessed November 1, 2022. <u>https://vandureplace.</u> wordpress.com/research/vandu-manifesto/.
- van der Meulen, Emily. "Action Research with Sex Workers: Dismantling Barriers and Building Bridges." Action Research 9, no. 4 (2011): 370–384, <u>http://journals.sagepub.com/doi/pdf/10.1177/1476750311409767</u>.

Community driven research study examples

- Blunt, Danielle, and Ariel Wolf. "Erased: The Impact of FOSTA-SESTA & the Removal of Back Page." Hacking//Hustling. 2020. <u>https://hackinghustling.org/erased-the-impact-of-fosta-sesta-2020</u>.
- Dasgupta, Nabarun. "'He Is the Object of Information': The Intersection of Big Data and the Opioid Crisis." American Journal of Public Health, 108, no. 9 (2018): 1122–1123, <u>https://doi.org/10.2105/AJPH.2018.304601</u>.

- Ferris, Shawna, Amy Lebovitch, Micheline Hughes, and Danielle Allard. Sex Work Activist Histories Project. Accessed November 1, 2022. <u>https://swahpca.wordpress.com</u>.
- Figgatt, Mary C., Zach R. Salazar, Elizabeth Day, Louise Vincent, and Nabarun Dasgupta. "Take-Home Dosing Experiences among Persons Receiving Methadone Maintenance Treatment during COVID-19." *Journal of Substance Abuse Treatment*, 123 (2021): 108276, <u>https://www.journalofsubstanceabusetreatment.com/article/S0740-5472(21)00002-7/fulltext</u>.
- Figgatt, Mary C., Zach R. Salazar, Louise Vincent, Diannee Carden-Glenn, Kelly Link, Lauren Kestner, Tyler Yates, Asher Schranz, Elizabeth Joniak-Grant, and Nabarun Dasgupta. "Treatment Experiences for Skin and Soft Tissue Infections among Participants of Syringe Service Programs in North Carolina." *Harm Reduction Journal* 18, no. 80 (2021), <u>https:// harmreductionjournal.biomedcentral.com/articles/10.1186/s12954-021-00528-x</u>.
- Iman, Jazeera, Catlin Fullwood, Naima Paz, W. Daphne, and Shira Hassan. "Girls Do What They Have to Do to Survive: Illuminating Methods Used by Girls in the Sex Trade and Street Economy to Fight Back and Heal." Young Women's Empowerment Project. 2009. <u>https://ywepchicago.files.wordpress.com/2011/06/girls-do-what-they-have-to-do-tosurvive-a-study-of-resilience-and-resistance.pdf</u>.
- McTighe, Laura, and Deon Haywood. "Front Porch Revolution: Resilience Space, Demonic Grounds, and the Horizons of a Black Feminist Otherwise." *Signs: Journal of Women in Culture and Society* 44, no. 1 (2018): 25–52, <u>https://www.journals.uchicago.edu/doi/full/10.1086/698276#d2289936e1</u>.
- McTighe, Laura, Catherine Haywood, Deon Haywood, Danita Muse, and Iris Gottlieb. "Keep the South Dirty and Our Needles Clean." Southern Cultures 27, no. 3 (2021): 120–129, <u>https://www.southerncultures.org/article/keep-the-south-dirty-and-our-needles-clean/</u>.
- Neufeld, Scott D., Jule Chapman, Nicolas Crier, Samona Marsh, Jim McLeod, and Lindsay A. Deane. "Research 101: A Process for Developing Local Guidelines for Ethical Research in Heavily Researched Communities." *Harm Reduction Journal* 16, no. 41 (2019), <u>https://harmreductionjournal.biomedcentral.com/articles/10.1186/s12954-019-0315-5</u>.
- Simon, Caty, Louise Vincent, Abby Coulter, Zach Salazar, Nick Voyles, Lindsay Roberts, David Frank, and Sarah Brothers. "The Methadone Manifesto: Treatment Experiences and Policy Recommendations From Methadone Patient Activists." American Journal of Public Health 112 (2022): S117–S122, <u>https://ajph.aphapublications.org/doi/full/10.2105/</u> <u>AJPH.2021.306665</u>.
- Simon, Caty, Sarah Brothers, Knina Strichartz, Abby Coulter, Nick Voyles, Anna Herdlein, and Louise Vincent. "We Are the Researched, the Researchers, and the Discounted: The Experiences of Drug User Activists as Researchers." *International Journal of Drug Policy* 98 (2021): 103364, <u>https://pubmed.ncbi.nlm.nih.gov/34294521/</u>.
- "We Deserve Better: A Report on Policing in New Orleans By and For Queer and Trans Youth of Color." BreakOUT!. 2014. https://www.youthbreakout.org/resources.