

COMMUNITY ENGAGED RESEARCH WITH  
PEOPLE WHO USE DRUGS

CONNECTION, IMPLEMENTATION, AND  
DISSEMINATION

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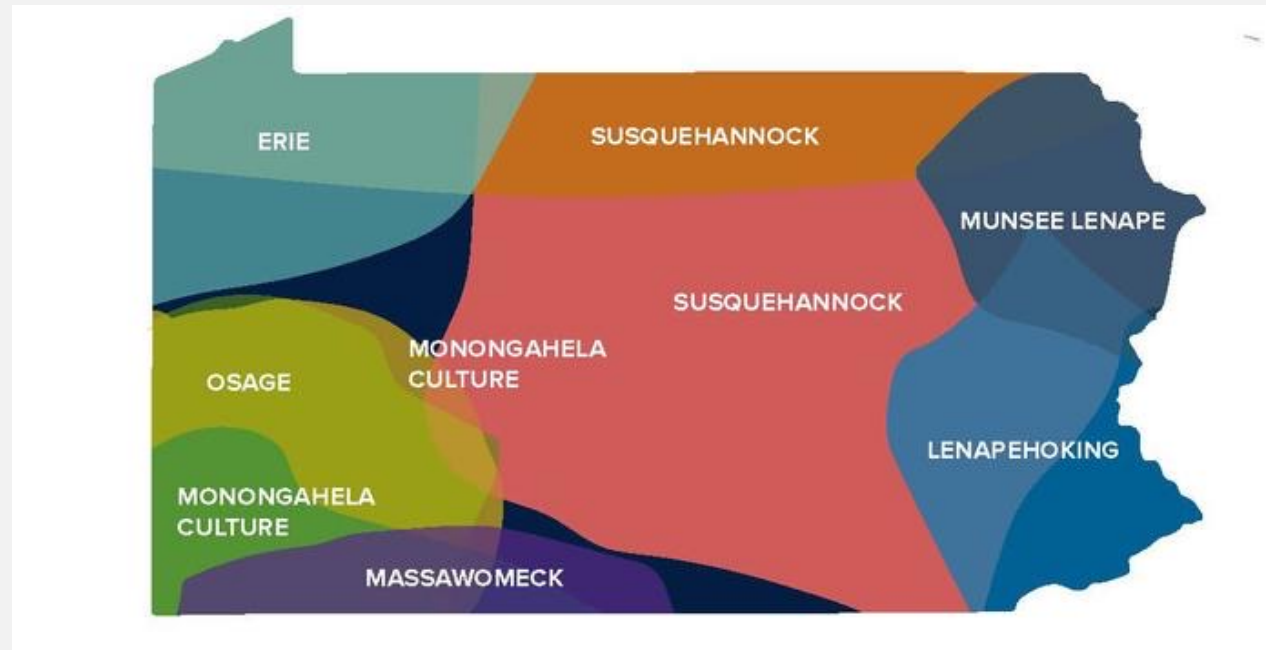
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# ACKNOWLEDGEMENT OF LAND

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# OUTLINE

1. The Case for Community Engaged Research

2. Community Driven Research (CDR)

3. Suggestions for Engagement:

- Connection
- Implementation
- Dissemination

I. THE CASE FOR  
COMMUNITY  
ENGAGED RESEARCH  
(CER)

**Community Engaged Research (CER):**

Involves directly impacted people in the research process

Advances knowledge and is ethically appropriate

Vulnerable groups: significant distrust of researchers

Christopher et al. 2008 Israel, et al. 2012; Wallerstein et al. 2020; Carrera et al. 2019; Jones 2018; Mikesell, et al. 2013; Montoya and Kent 2011

I. THE CASE FOR  
COMMUNITY  
ENGAGED RESEARCH  
(CER)

## Community Engaged Research (CER):

Important for addressing rising fatal overdose risk and emerging drug-related harms

### Longstanding CER tradition in drug use research

Brown et al. 2019; Chang et al. 2021; Figgatt et al. 2021; Elkhalfa et al. 2020; Hayashi et al. 2012; Jozaghi et al. 2018; Meyerson et al. 2019, Nieweglowski et al. 2018



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2.  
COMMUNITY  
DRIVEN  
RESEARCH  
(CDR)

Community-initiated research questions

Capacity development

Full engagement throughout the research process

Transparency

Foregrounds community perspectives

Low-threshold methods

“Methods that promote skill building and are inclusive of people with disabilities, varying substance use, and limited financial and technological resources”

Brothers et al. 2023; Simon et al. 2022; Simon et al. 2021; Brothers, Simon, Vincent *under review*

*Draws on:* Fullwood et al. 2009; Coombes et al. 2022; McTighe and Haywood 2018; Simonds and Christopher 2013 Albert 2021; Downey and Zuiderent-Jerak 2017; Fricker 2007



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2.  
COMMUNITY  
DRIVEN  
RESEARCH  
(CDR)

***Moves away from***

- Directly impacted people as passive

Carrera and Key 2021

- “Damage Centered Research”

Tuck 2009

***Our approach***

- Situated, embodied, partial, emotional

Haraway 1988; Benjamin 2016





3.  
ENGAGEMENT  
SUGGESTIONS:  
  
CONNECTION  
STRATEGIES

- **Contribution**
  - Collaborate on projects outside the research focus
  - Contribute skills to people's needs outside research focus
  - Provide advice and support for other projects
- **Transparency**
  - Clear objectives
  - Accessible language
  - Grant timelines
- **Positionality**
  - Flexibility in meeting times and structure
- **Compensation**
  - All meetings
  - In money or in trade
  - Avoid gift cards (Festinger et al. 2005, Ritter et al. 2003)



3.  
ENGAGEMENT  
SUGGESTIONS:  
IMPLEMENTATION  
STRATEGIES

## **Community centered research questions**

- Work from people's needs and concerns
- Develop questions collaboratively
- Develop questions from collaborators' current advocacy projects

## **Promote full transparency**

- Share documents whenever possible
- Share information on funding, timeline
- Explain terminology

## **Collaborations with organizations**

- Built on collaborator's existing practices
- Focus on group work
- Skill sharing



3.  
ENGAGEMENT  
SUGGESTIONS:  
IMPLEMENTATION  
STRATEGIES

## Low threshold inclusive methods

- Employ co-working practices
- Read data and drafts out loud
- Inclusion in:
  - Survey and interview guide design
  - Pilot interviews and surveys (ask for criticism!)
  - Data analysis
  - Manuscript review, writing, and editing
- Care centered work
  - Allow space for emotional discussions
- Ethics training: CIRTification programs (Anderson 2015)



3.  
ENGAGEMENT  
SUGGESTIONS:  
IMPLEMENTATION  
STRATEGIES

## Skill-building

- Training in basic research practices and methods
- Data analysis training and one-on-one support
- Trainings on assessing peer-reviewed publications
- Synchronous co-writing as teaching opportunity
- Help write and rehearse talks
- Emphasize transferrable skills



3.  
ENGAGEMENT  
SUGGESTIONS:  
DISSEMINATION  
STRATEGIES

## Dissemination

- Prioritize rapid open access dissemination
- Accessible language and in community's familiar venues
- Dissemination in multiple mediums:
  - White papers, webinars, press, plain language summaries, story sharing, and documentary shorts
- Support project ties to advocacy work



# CONCLUSIONS AND RECOMMENDATIONS

- Can be time intensive for academic researchers and community researchers
- Involves skill building, low threshold work, and collaborations on outside projects
- Facilitates flow of information from subject to researcher and researcher to directly impacted community members
- Funding for exploratory projects, deeper engagement, collaborator training, community organization infrastructure

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# REFERENCES

Albert, Alexandra. 2021. "Citizen Social Science in Practice: The Case of the Empty Houses Project." *Humanities and Social Science Communications* 8(70).

Anderson, Emily E. "CIRTification: Training in human research protections for community-engaged research partners." *Progress in community health partnerships: research, education, and action* 9, no. 2 (2015): 283.

Ashford, Robert D., Austin M. Brown, Georgeanne Dorney, Nancy McConnell, Justin Kunzleman, Jessica McDaniel, and Brenda Curtis. "Reducing harm and promoting recovery through community-based mutual aid: Characterizing those who engage in a hybrid peer recovery community organization." *Addictive behaviors* 98 (2019): 106037.

Brothers, Sarah, Adam Palayew, Katy Simon, Abby Coulter, Knina Strichartz, Nick Voyles, Louise Vincent. 2023. "Patient Experiences of Methadone Treatment Changes During the First Wave of COVID-19: A National Community Driven Survey." *Harm Reduction Journal* 20:31.

Brothers, Sarah, Katy Simon, Louise Vincent. "Community Driven Research with People who Use Drugs: A Virtual Project During Multiple Epidemics." *Under Review*.

Brown, Graham, Sione Crawford, Gari-Emma Perry, Jude Byrne, James Dunne, Daniel Reeder, Angela Corry, Jane Dicka, Hunter Morgan, and Sam Jones. 2019. "Achieving Meaningful Participation of People Who Use Drugs and Their Peer Organizations in a Strategic Research Partnership." *Harm Reduction Journal* 16(1):1-10.

Carrera, Jennifer S., Kent Key, Sarah Bailey, Joseph A. Hamm, Courtney A. Cuthbertson, E. Yvonne Lewis, Susan J. Woolford, E. Hill DeLoney, Ella Greene-Moton, Kaneesha Wallace, DeWaun E. Robinson, Ismael Byers, Patricia Piechowski, Luther Evans, Athena McKay, Don Vereen, Arlene Sparks, and Karen Calhoun. 2019. "Community Science as a Pathway for Resilience in Response to a Public Health Crisis in Flint, Michigan." *Social Sciences* 8(3):94.

Carrera, Jennifer S., and Kent Key. 2021. "Troubling Heroes: Reframing the Environmental Justice Contributions of the Flint Water Crisis." *Wiley Interdisciplinary Reviews: Water* 8(4):e1524.



# REFERENCES

- Chang, Judy, Shaun Shelly, Machteld Busz, Claudia Stoicescu, Arif Rachman Iryawan, Dinara Madybaeva, Yuri de Boer, and Andy Guise. "Peer driven or driven peers? A rapid review of peer involvement of people who use drugs in HIV and harm reduction services in low-and middle-income countries." *Harm Reduction Journal* 18, no. 1 (2021): 1-13.
- Christopher, Suzanne, Vanessa Watts, Alma Knows His Gun McCormick, and Sara Young. "Building and maintaining trust in a community-based participatory research partnership." *American Journal of Public Health* 98, no. 8 (2008): 1398-1406.
- Coombes, Emily, Ariel Wolf, Danielle Blunt, and Kassandra Sparks. 2022. "Disabled Sex Workers' Fight for Digital Rights, Platform Accessibility, and Design Justice." *Disability Studies Quarterly* 42(2).
- Downey, Gary L., and Teun Zuiderent-Jerak. 2016. "Making and Doing: Engagement and Reflexive Learning in STS." *Handbook of Science and Technology Studies*: edited by Ulrike Felt, Rayvon Fouché, Clark A Miller, and Laurel Smith-Doerr, 4th ed., 223–51. Cambridge, MA: The MIT Press.
- Elkhalifa, Sulaf, Ehsan Jozaghi, Samona Marsh, Erica Thomson, Delilah Gregg, Jane Buxton, and Ann Jolly. 2020. "Social Network Support and Harm Reduction Activities in a Peer Researcher-led Pilot Study, British Columbia, Canada." *Harm Reduction Journal* 17:1-11.
- Festinger DS, Marlowe DB, Croft JR, Dugosh KL, Mastro NK, Lee PA, Dematteo DS, Patapis NS. 2005. "Do Research Payments Precipitate Drug Use or Coerce Participation? Drug and Alcohol Dependence. 78(3):275-81.
- Figgatt, Mary C., Zach Salazar, Elizabeth Day, Louise Vincent, and Nabarun Dasgupta. 2021. "Take-Home Dosing Experiences Among Persons Receiving Methadone Maintenance Treatment During COVID-19." *Journal of Substance Abuse Treatment* 123:108276.
- Fricker, Miranda. *Epistemic Injustice: Power and the Ethics of Knowing*. 2007. England: Oxford University Press.
- Fullwood, C., Iman, J., Hassan, D., Hassan, S., & Paz, N. (2009). *Girls do what they have to do to survive: Illuminating methods used by girls in the sex trade and street economy to fight back and heal*. Chicago: Young Women's Empowerment Project

# REFERENCES

Haraway, Donna. 1988. "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective." *Feminist Studies* 14(3):575-599.

Hayashi, Kanna, Nadia Fairbairn, Paisan Suwannawong, Karyn Kaplan, Evan Wood, and Thomas Kerr. 2012. "Collective Empowerment While Creating Knowledge: A Description of a Community-Based Participatory Research Project With Drug Users in Bangkok, Thailand." *Substance Use & Misuse* 47(5):502-510.

Israel, Barbara A., Eugenia Eng, Amy J. Schulz, and Edith A. Parker. 2012. *Methods for Community-Based Participatory Research for Health*. Hoboken, NJ: John Wiley & Sons.

Jones, Loretta. 2018. "Commentary: 25 Years of Community Partnered Participatory Research." *Ethnicity & Disease* 28(Suppl 2):291.

Jozaghi, Ehsan, Alissa M. Greer, Hugh Lampkin, and Jane A. Buxton. 2018. "Activism and Scientific Research: 20 Years of Community Action by the Vancouver Area Network of Drug Users." *Substance Abuse Treatment, Prevention, and Policy* 13(1):1-9.

McTighe, Laura, and Deon Haywood. 2018. "Front Porch Revolution: Resilience Space, Demonic Grounds, and the Horizons of a Black Feminist Otherwise." *Signs: Journal of Women in Culture and Society* 44(1):25-52.

Meyerson, Beth E., Danielle M. Russell, Michaela Kichler, Tyson Atkin, Graeme Fox, and Haley B. Coles. "I don't even want to go to the doctor when I get sick now: healthcare experiences and discrimination reported by people who use drugs, Arizona 2019." *International Journal of Drug Policy* 93 (2021): 103112.

Mikesell, Lisa, Elizabeth Bromley, and Dmitry Khodyakov. "Ethical community-engaged research: A literature review." *American journal of public health* 103, no. 12 (2013): e7-e14.

Montoya, Michael J., and Erin E. Kent. 2011. "Dialogical Action: Moving From Community-Based to Community-Driven Participatory Research." *Qualitative Health Research* 21(7):1000-1011.

# REFERENCES

- Nieweglowski, Katherine, Patrick W. Corrigan, Tri Tyas, Anastasia Tooley, Rachel Dubke, Juana Lara, Lorenzo Washington, Janis Sayer, Lindsay Sheehan, and Addiction Stigma Research Team. 2018. "Exploring the Public Stigma of Substance Use Disorder Through Community-Based Participatory Research." *Addiction Research & Theory* 26(4):323-329.
- Ritter, Alison J., Craig Fry and Amy Swan. 2003. "The Ethics of Reimbursing Injecting Drug Users for Public Health Research Interviews. What Price are We Prepared to Pay?" *International Journal of Drug Policy* 14(1)1-3.
- Simon, Caty, Louise Vincent, Abby Coulter, Zach Salazar, Nick Voyles, Lindsay Roberts, David Frank, Sarah Brothers. 2022. "The Methadone Manifesto: Research and Policy Recommendations from Methadone Patient Activists." *AJPH* 112(S2) S117–S122.
- Simon, Caty, Sarah Brothers, Knina Strichartz, Abby Coulter, Nick Voyles, Anna Herdlein, Louise Vincent. 2021. "We are the Researched, the Researchers, and the Discounted: The Experiences of Drug User Activists as Researchers." *International Journal of Drug Policy* 103364.
- Simonds, Vanessa W., and Suzanne Christopher. "Adapting Western research methods to indigenous ways of knowing." *American journal of public health* 103, no. 12 (2013): 2185-2192.
- Tuck, Eve. 2009. "Suspending Damage: A Letter to Communities." *Harvard Educational Review* 79(3):409-428.
- Wallerstein, Nina, John G. Oetzel, Shannon Sanchez-Youngman, Blake Boursaw, Elizabeth Dickson, Sarah Kastelic, Paul Koegel, Julie E. Lucero, Maya Magarati, Kasim Ortiz, Myra Parker, Juan Peña, Alan Richmond, and Bonnie Duran. 2020. "Engage for Equity: A Long-Term Study of Community-Based Participatory Research and Community-Engaged Research Practices and Outcomes." *Health Education & Behavior* 47(3):380-390.