Ensuring the Inclusion of People with Lived and Living Experience in Health Departments' Overdose Surveillance and Prevention Efforts: AN OVERVIEW



NATIONAL COUNCIL for Mental Wellbeing

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Glossary of abbreviations

ABBREVIATION	MEANING
СВО	Community Based Organization
CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare and Medicaid Services
PSS	Peer Support Services
PWID	People Who Inject Drugs
PWLLE	People With Lived and Living Experience
PWUD	People Who Use Drugs
SAMHSA	Substance Abuse and Mental Health Services Administration
SUD	Substance Use Disorder
SSP	Syringe Services Program



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Background

The overdose epidemic continues to be one of the nation's most challenging public health crises, and overdose is a leading cause of injury-related death (Centers for Disease Control and Prevention & National Center for Injury Prevention and Control, 2023). As such, there is an increasing need for more comprehensive data collection methods and evidence-based prevention strategies. The complex and ever-evolving epidemiology of the drug overdose crisis has prompted local and state health departments to increase their efforts to better serve communities impacted by drug use and overdose. To address these challenges, many health departments are seeking ways to improve their engagement of people with lived and/or living experience (PWLLE) with substance use in the planning, implementation and evaluation of overdose prevention work.

PWLLE provide a crucial perspective on overdose surveillance and prevention efforts and can lead the identification of key strategies and focus areas for programming. They have expertise stemming from personal experience, including knowledge of community conditions, needs, barriers and resources. Information and perspectives provided by PWLLE are critical to effective program design, implementation and delivery. Their insights are vital to creating programs that meet local community needs, and their expertise is an invaluable resource for addressing public health crises (Javed et al., 2020).

Health departments have utilized varying methods for engaging PWLLE, including formal channels such as community advisory boards, community-based participatory research efforts and hiring health department staff with lived experience, as well as informal channels to solicit advice and feedback. Health departments are well-positioned to meaningfully engage PWLLE in overdose surveillance and prevention efforts because of their influence on the design, scope and operationalization of overdose prevention initiatives, as well as their duty to foster strong relationships with diverse community partners.

The National Council for Mental Wellbeing (National Council), with support from the Centers for Disease Control and Prevention (CDC), conducted an environmental scan and a series of key informant interviews to identify ways in which health departments can meaningfully involve PWLLE in overdose surveillance and prevention. These information-gathering activities identified a range of recommendations and strategies, which are summarized in this package of actionable resources and tools for health department staff.



Methods

To inform these tools, National Council project staff conducted a mixed methods review, including key informant interviews, a literature review and an environmental scan. Manuscripts were reviewed if their content applied to ensuring the inclusion of PWLLE in the context of health departments' overdose surveillance and prevention efforts. Due to the limited availability of peer-reviewed literature related to this subject in the U.S., international research was included, as well. Web-based content was also gathered, including webinars, educational videos, implementation guides and reports.

Between January 2023 and March 2024, project staff conducted key informant interviews with 26 employees of 17 health departments, public health agencies, universities and harm reduction organizations that engage in overdose surveillance and prevention efforts. Represented organizations and departments are located in 15 states: Alabama, Arizona, Colorado, Georgia, Illinois, Kansas, Kentucky, Michigan, Minnesota, Nevada, New Mexico, New York, North Carolina, Washington and Wisconsin. To facilitate the interviews, staff developed a semi-structured interview guide. Interviews took place using Zoom videoconferencing software and were approximately one hour in duration. Interviews were recorded and transcribed with the consent of the participants. A \$75 electronic gift card was provided to each key informant who completed the interview.

Defining people with lived and living experience

The Substance Abuse and Mental Health Services Administration (SAMHSA) defines people with lived and living experience (PWLLE) as individuals who self-identify as having experienced mental health and/or substance use conditions and their family members (Coderre & Delphin-Rittmon, 2023). For the purposes of this project, we define PWLLE as anyone who has experienced drug use, identifies as a person who uses drugs (PWUD), experienced a drug overdose, has come in contact with overdose response interventions or has received or is receiving substance use disorder (SUD) treatment. In defining PWLLE, we incorporate a harm reduction principle of "meeting people where they are," by which we mean that we include both people with lived experience and living experience, representing people who are actively using drugs in addition to those who are no longer using drugs (National Harm Reduction Coalition, 2020a).

Historical involvement of PWLLE in public health programming

Involving people directly affected by the circumstances that public health programming intends to address is a well-documented practice. Communities have innately understood that the people with the expertise most valuable and relevant to developing effective services are those who have experienced or are currently experiencing a need for those services. Historically, social and health justice movements have been led by the people who have been impacted the most (National Harm Reduction Coalition, 2020b; Voyles et al., 2020).

For example, in the late 1960s, in a community-led response to meet the needs of Black communities, the Black Panther Party (an African American social and political reform group/revolutionary party) began operating a free breakfast program for children, along with numerous other community programs (e.g., health clinics, ambulance services and free clothing programs) integral to community health and aimed at reducing harm (Hilliard, 2008; Lateef & Androff, 2017). In the 1970s, the Black Panther Party and the Young Lords (a street gang that became a human and civil rights organization) developed acupuncture programs in the South Bronx as a treatment option for PWUD, later described as "health care for the people by the people," given that it was a community-led response to a public health crisis (Meng, 2021; Voyles et al., 2020).

At the same time, the women's health movement emerged from feminist and reproductive health activism, including the Boston Women's Health Book Collective, which shared women-authored texts on women's health; Jane, the abortion referral group; feminist health clinics for reproductive and gynecological care; the Committee to End Sterilization Abuse; the Native American Women's Health Education Resource Center; and numerous other movements that centered women in women's health care (Clio Visualizing History, 2023; National Harm Reduction Coalition, 2020b).

In response to the growing HIV/AIDS crisis in the 1980s, activists, grassroots organizations and communities — including the LGBTQ+ and sex worker communities and people who inject drugs (PWID) — all advocated for or directly provided health services for the people by providing access to HIV testing, condoms, sterile syringes and medications to minimize harm to their communities and other marginalized groups (National Harm Reduction Coalition, 2020b).

Each of these social justice and public health movements, as well as many others, exemplify what it looks like to have impacted communities lead or inform effective public health programming. Across history, health care for the people by the people is a demonstrably well-practiced and effective public health approach for reducing harm in marginalized communities. Health departments must recognize and leverage the leadership and expertise of marginalized communities and create partnerships with them to ensure successful public health outcomes.

Historical involvement of PWLLE in substance use services

PWLLE are often involved in substance use services as peers who deliver peer-to-peer mentoring, education and nonclinical services focused on supporting people's individualized substance use recovery (Ashford et al., 2021; Reif et al., 2014; SAMHSA, 2017). There are many different types of terms for PWLLE in peer support services (PSS), including peer support staff, peer support worker, recovery coach, recovery specialist, peer practitioner, peer specialist, certified peer specialist, peer advocate and peer mentor (Mace et al., 2022).



Establishing Peer Support Services for Overdose Response

In the early 2000s, employing PSS became an increasingly common strategy for addressing the dual SUD and mental health crises (New York State Office of Alcoholism and Substance Abuse Services, 2018). PSS are included in a wide range of clinical and community-based settings, including emergency departments, outpatient clinics, inpatient hospital services and syringe services programs (Mace et al., 2022).

As the peer programs and initiatives increase, so do the opportunities to involve PWLLE in health departments' broader decision-making processes, beyond only peer-based roles. PWLLE must be prioritized as critical partners and leaders in health departments' efforts to reduce, prevent and monitor opioid overdoses across the country. Their leadership is vital to the creation, implementation and measurement of successful overdose prevention programs and policies, and health departments may need to make changes to leverage PWLLE's expertise. This series of tools will explore opportunities for PWLLE partnership and leadership.

Defining harm reduction

Harm reduction aims to reduce the negative consequences associated with using drugs by putting the lived and living experience of PWUD at the center of community-led strategies, practices and interventions (National Harm Reduction Coalition, 2020; SAMHSA, 2023). Harm reduction is a decades-long movement for social justice built by and for PWUD, and it can and should be adapted to reflect both individual and community needs (National Harm Reduction Coalition, 2020a). As such, there is no single way to implement or define harm reduction (National Harm Reduction Coalition, 2020a), though SAMHSA (2023) has offered the following key principles, which contend that harm reduction:

- 1. Is guided, in all aspects, by PWLLE of drug use.
- 2. Embraces people's inherent value and treats them positively, with dignity and respect.
- **3.** Is deeply committed to engaging and building communities, particularly those that have been impacted by systemic harm.
- 4. Promotes, in all aspects of its work, equity, social justice and rights by incorporating and acknowledging power differentials based on race, gender, sexual orientation, class and language, among others.
- 5. Offers the lowest barriers to accessing noncoercive services and support.
- 6. Focuses on individually determined definitions of positive change in one's quality of life.

Why health departments benefit when PWLLE's expertise is included

Increasingly, federal agencies such as the CDC, SAMHSA, the Centers for Medicare & Medicaid Services (CMS) and the Office of the Assistance Secretary for Planning and Evaluation (ASPE) are recognizing that PWLLE are fundamental to improving and enhancing substance use and mental health services (CDC, 2023a, 2023b; Coderre & Delphin-Rittmon, 2023). As such, they are beginning to implement inclusion policies, guides and frameworks for how to meaningfully include PWLLE in the development, implementation, monitoring and evaluation of the services and supports intended for them and their communities, in addition to any policy development and implementation that may result from these efforts (Coderre & Delphin-Rittmon, 2023). Health departments are recognizing that they can and should do the same, and as this series of tools shows, many health departments are using such implementation methods to meaningfully include PWLLE expertise.

By using harm reduction and recovery-oriented frameworks, including **recovery capital**, health departments that include PWLLE "facilitate recovery-oriented culture change and can help to reduce stigma and discrimination associated with substance use" (Faces & Voices of Recovery, 2019; Mace et al., 2022). This requires viewing substance use as a continuum, which allows for incremental changes and risk reduction as positive change. Employing PWLLE demonstrates a health department's commitment to improving the lives, health and rights of PWUD and makes clear that it values PWLLE and the important knowledge, skills, experience and expertise they have to share (Balian & White, 2010). It is important to note that

health departments likely already employ PWLLE, whether or not those employees are open about their experiences or job postings explicitly sought their expertise. By being explicit about the importance of lived and living experience, hiring PWLLE and ensuring that their voices are included in various aspects of overdose prevention and response efforts, health departments can increase the impact of their efforts.

Recovery capital

A set of internal and external resources and assets that a person has available to them to find, initiate and maintain recovery from SUD.

- SUD (Faces & Voice of Recovery, 2019)

PWLLE have a unique understanding of PWUD that can help inform programming, policy and data collection and analysis (Skelton-Wilson et al., 2021). For example, PWLLE can provide insight into the evolving context of social issues impacting PWUD and the common challenges, behaviors, patterns and experiences of PWUD, allowing health departments to effectively support practice changes, improve services and programs, highlight urgent priorities and address them (Skelton-Wilson et al., 2021). Ultimately, PWLLE bridge the gap between health departments and the communities they serve (Fulfilling Lives South East Partnership, 2022). Furthermore, including PWLLE at all levels of health departments' efforts to address the overdose epidemic ensures the implementation of true evidence-based solutions and strategies and is necessary to reducing inequities impacting PWUD (Canadian Centre on Substance Use and Addiction, 2021). By tapping into the full extent of PWLLE's experience and expertise, everyone — including PWLLE, health departments and the communities they serve — will benefit. Lived experience is as essential to this work as the academic experience of someone with a public health degree or other education or training.

Recovery orientation

"People with, affected by or at risk for mental health and substance use conditions receive care, thrive and achieve wellbeing."

- SAMHSA (Mace et al., 2022)

Language do's and don'ts

State and local health departments can set an example by using person-first and non-stigmatizing language, which can reduce negative bias and ongoing stigma, allowing for a nonjudgmental environment, rapport-building and more positive interactions (National Council for Mental Wellbeing, 2021). Not only does person-first language reduce stigma and shame, but it also allows for shared vocabulary, which ensures all parties are on the same page and creates space for trust to be built (Mace et al., 2021). Stigmatizing language is described as words or phrases that have a negative association and assign judgment, resulting in feelings of shame. Some examples include calling someone an "addict" or a "junkie," which implies fault or places blame on the person using substances. Person-first language, on the other hand, removes stigma and reframes the context to emphasize a person first and their experience or diagnosis second (Shatterproof, 2021). Examples of person-first language include "a person with a substance use disorder" or "a person who uses drugs," acknowledging that they are a person who has this experience rather than defining them as their condition or experiences (CDC, 2022). It is important to note many PWLLE have their own language preferences, which may not align with the person-first model outlined previously. Asking PWLLE about their preferred terminology is a good practice (National Council for Mental Wellbeing, 2021).

Instead of this	Say this
Drug habit	Substance use
Substance abuse	Substance use disorder, substance use challenge
Addict, junkie, abuser, user, alcoholic, drunk, druggie	Person with a substance (alcohol, opioids, stimulants, etc.) use disorder or challenge
Former addict, clean, reformed addict	Person in recovery, person in long-term recovery
Relapse	Return to use, recurrence
Dirty/clean drug screen	Positive/negative drug screen

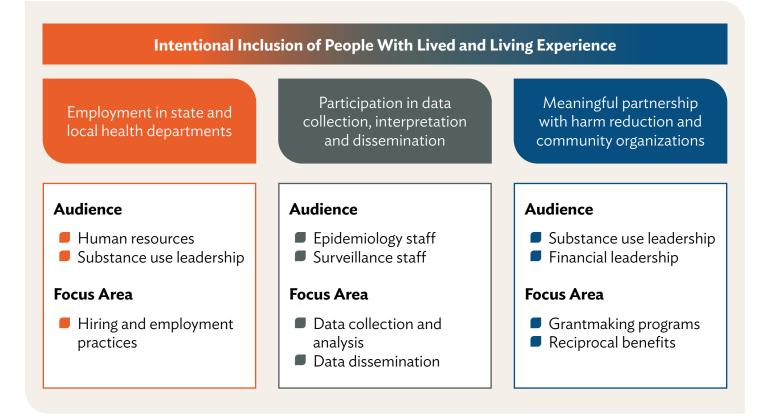


Framework for health departments to engage PWLLE

Based on interviews with key informants and a literature review, the project team identified three main methods for ensuring the inclusion of PWLLE in health departments' overdose surveillance and prevention efforts, which are outlined throughout the following series of tools and resources. They include hiring PWLLE directly within health departments, specifically on overdose surveillance, epidemiology and prevention teams, and partnering with community-based and harm reduction organizations. These methods for engaging PWLLE are influenced by several domains identified and summarized in Figure 1. Each domain has a corresponding focus area and audience, with key elements and considerations for health department staff looking to ensure meaningful inclusion of PWLLE in overdose surveillance and prevention programs.

It is important to consider key focus areas and relevant audiences when utilizing various methods for elevating the voices of PWLLE. Strategies for hiring PWLLE within health departments should be rooted in mindful hiring practices implemented by human resources professionals and substance use leadership staff. PWLLE participation in overdose surveillance and epidemiology efforts requires thoughtful methods for data collection, analysis and dissemination, carried out by staff and leadership on surveillance and epidemiology teams. To be successfully, partnerships with community-based groups, harm reduction organizations and PWLLE must be mutually beneficial, reflect harm reduction principles and be supported by all substance use staff.

Figure 1. Domains that influence inclusion of PWLLE in health departments' overdose prevention and surveillance efforts



Intentionally including PWLLE: A series of tools and resources

The following package of tools for use by state and local health department staff describes methods for intentionally including PWLLE in their overdose prevention and surveillance work, along with related recommendations, strategies and resources.

Elements of the tools		
Ś	Resource	Calls out resources, tools, methods, and more that support further learning and understanding of key topics through the series of tools.
-9-9-	Quote	Quotes from interviews with staff and employees from health departments, harm reduction organizations, and community-based organizations that informed these tools.
8	Example from the field	Field examples further detailing key themes and recommendations outlined in the tools.

Hiring people with lived and living experience within local and state health departments

This tool identifies key elements for health departments to consider when hiring PWLLE, from identification and description of job roles and responsibilities to recruitment and interviewing. The tool discusses the specific challenges to hiring PWLLE within government agencies — including human resources policies on educational requirements and criminal background checks — and reviews examples of innovative pathways health departments have created to hire PWLLE as full-time health department staff and as contractors or consultants for specific initiatives. The target audiences for this tool are human resources departments and leadership within substance use-related departments. <u>View Resource.</u>

Engaging people with lived and living experience in overdose data collection, interpretation and dissemination

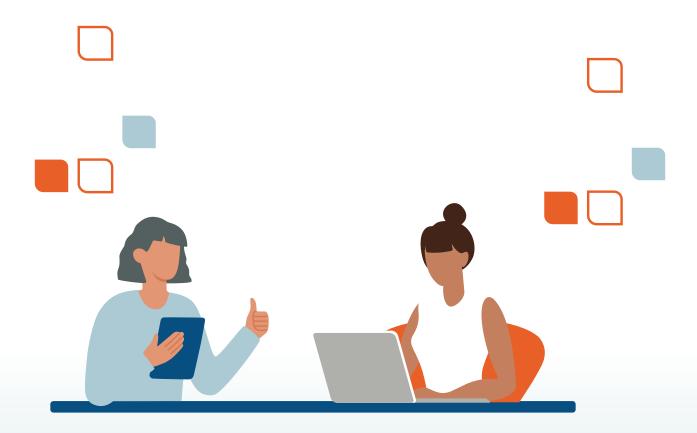
While health departments are becoming more familiar with PWLLE inclusion in their prevention and response activities, they still have a long way to go in data collection, interpretation and dissemination efforts. This tool highlights examples of successful PWLLE engagement in data collection, interpretation and dissemination, gathered through key informant interviews — including overdose fatality review committees, drug checking, patient surveys and overdose reversal reporting — as well as novel approaches to community-based participatory research, such as patient journey mapping and PWUD/researcher collectives. It also includes key considerations for gathering and disseminating data. The target audience for this tool includes the staff of epidemiology and surveillance departments. <u>View Resource.</u>

Meaningfully partnering with harm reduction organizations and other community-based organizations that serve people who use drugs

This tool highlights another valuable method for health departments to ensure the inclusion of PWLLE: establishing grantmaking programs and developing meaningful partnerships with community-based organizations (CBOs) that are led for and by PWLLE, including harm reduction organizations. As gathered from key informant interviews, the tool provides examples, strategies and key considerations for developing partnerships with CBOs, including the strategic roles of governments and CBOs, granting funds and request-for-proposals language. The target audience for this tool includes all staff within substance use-related departments. <u>View Resource.</u>

Annotated resource list

The annotated resource list provides a summary of each resource highlighted within the package of tools. **View Resource.**



Appendix A. List of key informants

STATE	KEY INFORMANT
Alabama	Kathy House, MS State Opioid Coordinator Division of Mental Health and Substance Use Services Alabama Department of Mental Health
	Danielle Simpson, MPA Overdose Prevention Program Administrator Mobile County Health Department
Arizona	Earl Harris, MA, BS, ADC-II Substance Use Program Supervisor Maricopa County Department of Public Health
Colorado	Andrés Guerrero, MPH Overdose Prevention Unit Manager Colorado Department of Public Health and Environment
Georgia	Dita Broz, PhD, MPH Epidemiologist Centers for Disease Control and Prevention
Illinois	Maya Doe-Simkins, MPH Co-Director Remedy Alliance / For The People
Kansas	Seth Dewey Health Educator, Kansas Certified Peer Mentor Reno County Health Department
Kentucky	John Moses Team Leader Harm Reduction Services Lexington-Fayette County Health Department
Michigan	Alicia Goodman Public Health Coordinator Michigan Department of Health and Human Services
	Rita Seith, MPH Opioids and Emerging Drugs Unit Manager Michigan Department of Health and Human Services

STATE	KEY INFORMANT
Minnesota	Julie Bauch, MS, RN, PHN Opioid Response Coordinator Hennepin County Public Health
	Pearl Evans Prevention Program Administrator Minnesota Department of Health
Nevada	Iris Key Grants and Project Analyst Office of Health Investigations and Epidemiology Division of Public and Behavioral Health Nevada Department of Health and Human Services
	Elyse Monroy Public Health Diversity Advisor, Opioid Program Lead Nevada Public Health Training Center University of Nevada, Reno
New Mexico	Kathryn Lowerre, PhD, MPH Section Head, Overdose Prevention Epidemiology and Response Division New Mexico Department of Health
New York	Yarelix Estrada, MSPH Drug Checking Manager Bureau of Alcohol and Drug Use Prevention, Care and Treatment NYC Department of Health and Mental Hygiene
	Angela Jeffers, MA Senior Director, Harm Reduction Initiatives Bureau of Alcohol and Drug Use Prevention, Care and Treatment NYC Department of Health and Mental Hygiene
	MD Nass, MSW Director of Care Innovation and Quality Improvement Bureau of Alcohol and Drug Use Prevention, Care and Treatment NYC Department of Health and Mental Hygiene
	Ellenie Tuazon, MPH Senior Epidemiologist and Director of Surveillance Bureau of Alcohol and Drug Use Prevention, Care and Treatment NYC Department of Health and Mental Hygiene

STATE	KEY INFORMANT
North Carolina	Zach Salazar, MPH, CHES Former Director of Operations North Carolina Survivors Union
	Louise Vincent, MPH Founder and Executive Director North Carolina Survivors Union
Washington	Jenna van Draanen, PhD, MPH Assistant Professor University of Washington School of Public Health and School of Nursing
	Brad Finegood, MA, LMHC Strategic Advisor Public Health – Seattle & King County
	Julia Hood, PhD, MPH Epidemiologist Prevention Division Public Health – Seattle & King County
	Thea Oliphant-Wells, MSW Harm Reduction and Fentanyl Testing Program Manager Public Health – Seattle & King County
Wisconsin	Jake Niesen Public Health Program Coordinator Public Health Madison & Dane County



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