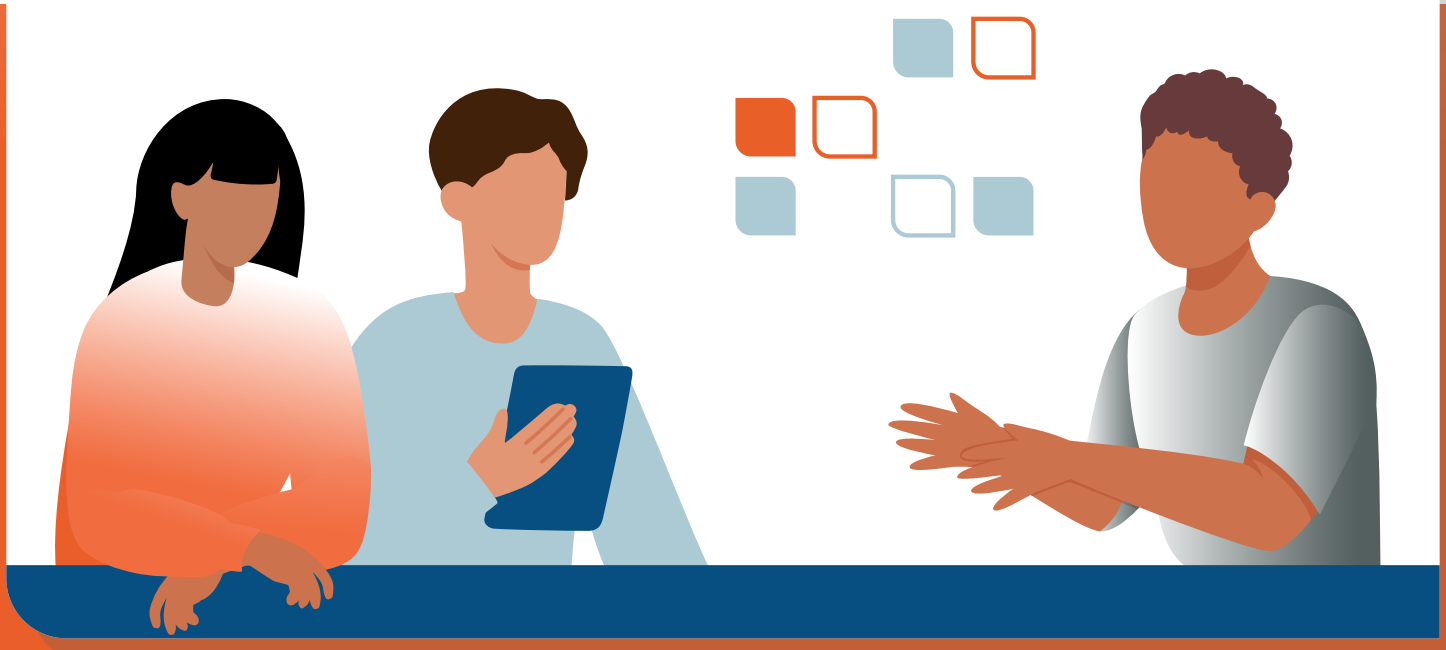
ENGAGING PEOPLE WITH LIVED AND LIVING EXPERIENCE

in Overdose Data Collection, Interpretation and Dissemination



NATIONAL COUNCIL *for* Mental Wellbeing

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Glossary of abbreviations

ABBREVIATION	MEANING
CDC	Centers for Disease Control and Prevention
PWLLE	People with Lived and Living Experience
ESOOS	Enhanced State Opioid Overdose Surveillance
OD2A	Overdose Data to Action
PWUD	People Who Use Drugs
OFR	Overdose Fatality Review
SUD	Substance Use Disorder
COSSUP	Comprehensive Opioid, Stimulant and Substance Use Program
BADUPCT	Bureau of Alcohol and Drug Use Prevention, Care and Treatment
NYC DOHMH	New York City Department of Health and Mental Hygiene
PWID	People Who Inject Drugs
SSP	Syringe Service Program
NHBS	National HIV Behavioral Surveillance
READU	Research With Expert Advisors on Drug Use
CBPR	Community-based Participatory Research
CAB	Community Advisory Board
CAC	Community Advisory Committee
PROUD	Participatory Research in Ottawa: Understanding Drugs
FAQ	Frequently Asked Questions
HIDTA	High Intensity Drug Trafficking Areas
LEAD	Law Enforcement Assisted Diversion Programs
EMS	Emergency Medical Services
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer or Questioning and more
GLITC	Great Lakes Intertribal Council

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Overview and methodology

The National Council for Mental Wellbeing, 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 people with lived and living experience (PWLLE) in overdose surveillance and prevention. These information-gathering activities identified a range of recommendations and strategies, which are summarized in this and other tools as a package of actionable suggestions and resources for health department staff.

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.

Intentionally including PWLLE: A series of tools and resources

1. **Ensuring the Inclusion of People with Lived and Living Experience in Health Departments' Overdose Surveillance and Prevention Efforts: An Overview**
2. **Hiring People with Lived and Living Experience within Local and State Health Departments**
3. **Engaging People with Lived and Living Experience in Overdose Data Collection, Interpretation and Dissemination**
4. **Meaningfully Partnering with Harm Reduction Organizations and Other Community-based Organizations that Serve People Who Use Drugs**
5. **Annotated Resource List**

Background

Overdose-related data collection is a crucial part of local and state health departments' overdose prevention and response efforts. Health departments conduct surveillance involving the monitoring of overdose-related data from various sources, such as emergency department visits, encounters with emergency medical services, mortality records and hospital discharges. Health departments may also conduct specific research or evaluation projects to understand the dynamics of drug overdoses in particular communities or settings as well as the efficacy of intervention activities. The data gathered in these processes may include details on overdose risk factors, toxicology and demographics, and it is used to inform public health responses aimed at preventing and responding to overdoses (Hoots, 2021).

There are numerous benefits to including PWLLE in collecting and interpreting data obtained via overdose surveillance, program evaluation, or other means. PWLLE can:

- Serve as vital connectors between the community of people who use drugs (PWUD) and the health department.
- Assist in the establishment of bidirectional trust between the community and health department.
- Contribute their unique perspectives to interpret complex data findings and provide important context.
- Help shape the right research questions to ask and from whom, where and how to get the data.

As a result of PWLLE's intimate knowledge of their communities, health departments can create overdose prevention and response initiatives based not only on data but also on the community's priorities and needs, ultimately enhancing the effectiveness of programs. Furthermore, providing PWLLE with an opportunity to influence programs that directly impact their community is a crucial step toward increasing diversity of representation in decision-making processes related to overdose prevention and response programs and policies.

Hiring PWLLE epidemiologists

Perhaps one of the most effective methods of involving PWLLE in health department overdose surveillance efforts is directly hiring PWLLE staff as epidemiologists. As experts and leaders in the field of overdose prevention, and as members of the communities most impacted by the overdose crisis, PWLLE have the knowledge and expertise needed to research current drug trends, monitor trend changes and anomalies, contextualize data and directly inform health department surveillance programs, helping to identify necessary overdose response and prevention efforts. Hiring PWLLE as epidemiologists within health departments requires significant intentionality in the outreach, recruitment, interview and employment management processes. Another tool in this series, **Hiring People With Lived Experience Within Local and State Health Departments**, identifies these key considerations, discusses challenges and barriers to hiring PWLLE and reviews innovative examples of health departments that have hired PWLLE successfully.

Innovative areas of PWLLE involvement in overdose data collection, interpretation and dissemination

Many offices or bureaus focused on overdose prevention are already employing the expertise of PWLLE in critical ways. This section describes some of the ways PWLLE are involved in these data collection, interpretation and dissemination activities and highlights health departments that are doing this well.

Overdose fatality review

An overdose fatality review (OFR) is a local or regional body that convenes to review overdose cases, with the goal of creating actionable recommendations and identifying key gaps and patterns of need across systems to inform future prevention and response efforts (Ray et al., 2022). OFRs review various types of data related to overdose cases, such as a decedent's history of drug use, substance use treatment and care, involvement with the criminal justice system, adverse childhood experiences, etc. (Heinen & O'Brien, 2020). These reviews are often more qualitative in their interpretation in order to help understand the scope of an individual's experience, however, aggregate data about all cases in a jurisdiction are sometimes reviewed as well. Based on models of fetal and infant mortality reviews and hospital mortality review committees, these groups regularly convene members across agencies and specialties, usually including medical examiners/coroners, law enforcement and other criminal justice professionals, health care and social service providers and emergency service workers. OFRs were designed and created by the field for the field. Preliminary studies suggest that OFRs can break down care silos, improve coordination between public health and public safety, and aid in strategic planning of overdose prevention efforts (Haas et al., 2019). Unlike other fatality reviews, OFRs often include next-of-kin interviews, which provide greater context regarding a person's life and give the opportunity to extend services to those affected by the death of a loved one.

Staff from Public Health – Seattle & King County, King County's health department attend medical examiner meetings twice a month. PWLLE review overdose fatality data and can provide experiential insight into some of the contextual factors of the overdose death. This, in turn, informs other members of the health department about current trends in the community.

> ***"We review our most recent overdoses, any trends. We look at pictures of overdose scenes to try and give them more insight into what they're seeing. And so there is this give and take, like, 'Why would there be this at this scene? How does that make sense?' Having our folks who use drugs look and say, 'Oh, hey, this looks like they thought it was cocaine because these are really long lines that they put out. You wouldn't do a long line like that if it were fentanyl.' So, having some of that time and space to talk through specific overdose situations with people who've done some drugs that cause overdose [is really helpful]."***
>
> *— Thea Oliphant-Wells, Harm Reduction and Fentanyl Testing Program Manager, Public Health – Seattle & King County*

One health department staff member involved in overdose fatality reviews noted that sometimes PWLLE, particularly those in smaller, more tightly knit communities, may feel uncomfortable disclosing their status in larger statewide meetings, often with law enforcement present.

> ***"It was very interesting to me as the evaluator, when I was doing a wrap-up survey with [members of the OFR team] — and this was also something the facilitators heard — was that we should include more people with lived experience, [but] they were in the [virtual] room the whole time. They just didn't always feel comfortable declaring themselves as such."***
>
> *— Kathryn Lowerre, Section Head, Overdose Prevention, New Mexico Department of Health*

Including PWLLE on OFR teams is critical. PWLLE provide firsthand knowledge of the challenges and barriers faced by people struggling with substance use disorders (SUDs), as well as the various factors that may contribute to overdose fatalities. Their inclusion ensures that the review process is truly comprehensive and considers the complexity of factors involved (Dewey & Lynch, 2023).

Overdose fatality review

This **resource library** provides further technical assistance resources on starting your own OFR committee.

PWLLE also can humanize the data. Overdose fatality data may seem abstract and detached from the real-life experiences of those affected. The involvement of PWLLE reminds the team of the human toll of these tragedies. Their presence helps ensure that the team remains focused on the people affected and the need for evidence-based interventions and prevention strategies.

When done well, including PWLLE in OFR team meetings also brings a sense of empowerment and inclusion. It recognizes their expertise and acknowledges their essential role in shaping policies and interventions related to SUDs.

Health departments must take care, however, to ensure that PWLLE are prepared for the OFR team meetings to include content that can be emotional and sometimes even traumatic. Health departments can take several steps to help prepare and support PWLLE before, during and after the OFR process (Dewey & Lynch, 2023).

1. **Informed consent**: Prior to participating, PWLLE should be provided with in-depth information about the purpose, format and potential emotional impact of the meeting. They should have a clear understanding of what will be discussed and the potential triggers that may arise. This is especially important in smaller communities, where it will be harder to find people who do not have associations with the cases being discussed.
2. **Emotional support**: It is crucial to arrange for emotional support services before, during and after the meeting. This may include access to counselors, therapists or support groups experienced in dealing with trauma and addiction.
3. **Safe environment**: Creating a safe and supportive environment is essential. This involves ensuring that privacy and confidentiality are maintained, and that people feel comfortable expressing their thoughts and emotions. It may be helpful to establish guidelines for respectful and empathetic communication during the meeting.
4. **Debriefing sessions**: Following the meeting, it is important to offer debriefing sessions for participants. This allows them to process their thoughts and emotions and receive support if needed. Debriefing also can provide an opportunity for participants to offer feedback and suggestions for improving future meetings.
5. **Ongoing support**: Providing participants with ongoing support and resources is crucial. This can include access to further education, training or support networks related to substance use and mental health.

Example from the field

The Minnesota Department of Health, as part of its response to tremendous statewide racial and ethnic disparities in overdose death, developed several community-specific OFR teams. They designated state funds to seed OFR team development and facilitation within communities disproportionately impacted by overdose. The first of its kind, working with the Somali immigrant community in the Twin Cities, launched in 2020. It is hosted by a Somali treatment and recovery center and facilitated by Somali stakeholders from the field, and it reviews cases of Somali overdose deaths. A short description of this OFR team can be found on the **Comprehensive Opioid, Stimulant and Substance Use Program (COSSUP) website**.

A similar culturally specific OFR team has been launched within the Minnesota Native American communities, and plans are underway to build an African American-specific OFR team, as well. To support these efforts, the Minnesota Department of Health developed its own **OFR Implementation Guide** specific to needs in the state, based on the COSSUP resource described above. OFR teams specifically housed within and facilitated by people from these communities have helped cut through stigma and expertly navigate the nuances of community culture.

Example from the field

The local health department in southern Wisconsin's Dane County, Public Health Madison & Dane County, has an OFR team that centers lived experience. Among the roughly 40 OFR team members who meet every other month, approximately half are PWLLE. Meetings are co-led by two county employees, one of whom is public about their experience with drug use. Careful attention is paid to who is in the room, with an explicit effort to include both those in recovery and those actively using drugs.

"Depending on who's in the room, it's going to make a difference in the recommendations [and] what kind of focus there is. For example, if you don't have people with lived and living experience, both of them, you're going to have very siloed recommendations. For example, if you only have people in recovery, our recommendations are going to have a very siloed recovery side and zero harm reduction side. The harm reduction side is going to be distilled down to just giving out Narcan, and that's just not — that's insulting in itself," said a Madison & Dane County Public Health Program Coordinator.

In addition, the OFR team's recommendations are systematically reviewed by a local alliance of PWLLE, before dissemination. The alliance is tasked with thinking through how recommendations are worded, how they will be carried out and what kinds of unintended consequences they may cause. "When we send out the recommendations … just because people want to be involved in this, they may not know all the pieces that would make a recommendation successful. People who are directly impacted, … they're going to be better at it. People who never did drugs trying to figure out what would be best for the lives of drug users? That doesn't make sense to me," said the Public Health Program Coordinator. While these reviews are unpaid currently, the county is looking into funding possibilities so that the local alliance can get paid for this critical labor.

Another way that Public Health Madison & Dane County centers lived experience can be seen in the county's **annual report on drug overdose deaths**. Noticeably different from typically dry, data-heavy epidemiological reports of this kind, it begins with descriptions of the decedents using the words of their family and friends, and it includes them throughout. One, for example, reads, "He had dreams. And he was loved by so many people. I just want people to know, this was a loved one."

Drug checking

Increasingly, health departments can use funding to support the infrastructure for point-of-care drug checking programs. Drug checking programs can be both overdose prevention tools and harm reduction strategies. Through these programs, PWUD can have a sample of their substance tested to learn what it contains and make a more informed decision about whether and how to use the drug. Aggregated data from these procedures can help harm reduction organizations and partners understand trends about what drugs are in use in a community. In some areas, health departments have partnered with PWUD and harm reduction organizations to learn how to structure and implement drug checking programs, or they have

directly funded harm reduction and community programs to conduct drug checking. PWLLE bring instrumental knowledge and skills, and their experiential expertise is paramount to the creation and implementation of effective drug checking services. PWLLE also can quickly establish trust with participants of drug checking programs, an important quality for an intervention that generally takes less than 20 minutes to complete.

As mentioned frequently throughout this collection of tools, collaborating with harm reduction and community organizations is an effective method that many health departments use for meaningful engagement with PWLLE. Partnering with community organizations is particularly beneficial for health departments implementing drug checking programs, because it prioritizes centering PWLLE throughout the planning, implementation, evaluation and communication stages of the drug checking process (Wu et al., 2023). It encourages the gathering of more comprehensive data, as PWLLE bring real-time, community-informed, experiential expertise that can provide valuable insight into drug data and trends, including those on new drugs in the local supply (Wu et al., 2023).

Additionally, the proximity of harm reduction organizations to their communities is essential to drug checking program effectiveness. When possible, drug checking services should be housed at harm reduction organizations. Harm reduction organizations and community-based groups have existing relationships with PWUD. These trusted relationships inform organizational priorities and keep community needs at the forefront of services. By partnering with and housing drug checking services in harm reduction organizations, the needs of PWUD can be prioritized most effectively, and services can remain as low barrier as possible (Wu et al., 2023).

Enhancing harm reduction services in health departments: fentanyl test strips and other drug checking equipment

This **resource** from the National Council provides information on how health departments can implement or enhance harm reduction services to increase access to fentanyl test strips and drug checking services.

Creating safer spaces with harm reduction in drug checking settings

This **manual**, developed by the Drug Resource and Education Project, provides information, examples and practical guidance on how to create safer spaces for people who use drugs in drug checking settings.

Drug checking implementation guide: lessons learned from a british columbia drug checking project

This **guide**, developed by the British Columbia Centre on Substance Use, provides an overview and lessons learned from a drug checking project in British Columbia.

"For us as the health department to stand this up, it would not be successful. As government, we're often not connected enough to the community of people using drugs outside of individual relationships and stuff like that. So, to have connections in the community of harm reduction agencies that serve folks already, that may be people with lived and living experience with drug use, is really important to have the community along and to have that community voice at that table from the beginning to the end, this can't really be a top-down thing and be successful at all."

— Brad Finegood, Strategic Advisor, Public Health – Seattle & King County

Example from the field

Establishing trust and developing rapport with people using drug checking services is of utmost importance to effective programs. One method that health departments are using to help foster this trusting rapport is prioritizing PWLLE as drug checking technicians. The Bureau of Alcohol and Drug Use Prevention, Care and Treatment (BADUPCT) of the NYC Department of Health and Mental Hygiene (NYC DOHMH) employs multiple PWLLE as drug checking technicians on its team of drug checking program staff.

Yarelix Estrada, Drug Checking Manager at the BADUPCT, describes the importance of having drug checking staff with lived experience: "I'll say for myself, I'm a drug user. I'm someone who identifies as a drug user and I'm really open about that. And I think that being a drug checking technician, being in that role and being someone who uses drugs, it opens an entire world with the participant because they know that you know what you're talking about, because they know that you've been there at some point or at least understand what it means to get high. … Moving forward, I would like to prioritize people who use drugs in those positions to be technicians because I feel that there's also this curiosity that comes from being someone who uses drugs to learn more about drugs, because it's immediately relevant in your life, as opposed to having academics that have never used drugs."

Estrada's experiences underscore the value of participants being able to engage with drug checking technicians who have lived or living experience with drugs. This shared experience between staff and participants helps to foster rapport much more quickly, and perhaps more meaningfully, than can be done in such a brief intervention between participants and a drug checking technician without lived or living experience. The ability to quickly develop a trusting relationship greatly increases the accessibility and effectiveness of drug checking programs.

Another way some health departments that provide drug checking services involve PWLLE is through qualitative work. Despite drug checking services often occurring as brief interactions, health departments have found many ways to engage thoughtfully with participants and PWLLE during these short periods. Examples of qualitative activities health departments are using in drug checking programs include:

- Collecting feedback during conversations between drug checking technicians and program participants.
- Hosting monthly meetings with drug checking technicians and other program staff.
- Engaging with participants through emails and other informal communications, using electronic feedback collectors like SurveyMonkey to gather information, comments and feedback.
- Facilitating qualitative interviews.

Drug checking for the people

This **webpage**, developed by Remedy Alliance / For The People, contains resources, tools and templates for starting drug checking services, including a sample job description.

Collecting qualitative information is perhaps one of the most easily implemented methods for actively engaging with PWLLE through drug checking programs, and it is a method that many health departments are using successfully.

Innovative qualitative approaches

For many, the concepts of surveillance and community responsiveness are at odds. Good surveillance requires consistency: the same questions asked the same way over time. Community responsiveness, on the other hand, requires flexibility and rapid adaptability.

National HIV behavioral surveillance resources

These tools from the CDC include manuals for qualitative research, primary data collection, assessment activities, methodologies and bibliographies in collaboration with PWLLE and people who inject drugs (PWID).

While health departments routinely use forms of surveillance that are relatively unmalleable and unable to adapt quickly to changing contexts, there are some examples of field surveillance that are, in fact, quite adaptable. The **2015 outbreak of 135 HIV cases among PWUD** in Scott County, Indiana — a county which typically has fewer than five new HIV infections annually — led to a classic example of "shoe-leather epidemiology," where epidemiologists from the Indiana State Department of Health, with support from the CDC, interviewed patients and their social contacts about syringe sharing and sexual risk factors (Conrad et al., 2015). A key factor in the success of many of these innovative surveillance mechanisms is the meaningful involvement of PWLLE.

"It became very clear that what we needed to do was talk to people. And in this community, there was no SSP at the time or other services for people who use drugs where we could connect with people. There were major issues with trust and stigma related to drug use and HIV, and with fear of arrest. So, to engage with the community, we ended up just walking the streets. We knew that the local physician was trusted in the community and so we walked with him through neighborhoods known for drug use. We approached people on the street to say, 'Hey, we're here. We're trying to help. We'd like to know more about what's going on in the community and what's needed. Will you talk to us?' And it took some time to get there, to build trust. But once we talked to one person, somebody down the street saw us and came by and started listening and then sharing, and then it just grew."

— *Dita Broz, Epidemiologist, Division of HIV Prevention, National Center for HIV, Viral Hepatitis, STD and TB Prevention, Centers for Disease Control and Prevention*

It is worth noting that integrating PWLLE into quantitative dimensions of data collection and interpretation also holds potential benefits.

Example from the field

National HIV Behavioral Surveillance (NHBS) is a 20-year-old ongoing project run by the CDC, in collaboration with local health departments, to identify patterns in behavioral risk factors for HIV, HIV testing behaviors, receipt of prevention services and use of prevention strategies. PWID comprise one of three priority populations, and the **project focuses on this community** every three years. It takes place in approximately 20 locations that are identified by HIV prevalence, primarily large metropolitan areas.

The formative assessment process employed by NHBS offers some excellent examples of qualitative fieldwork in collaboration with PWUD. This process gathers initial qualitative data about the priority population, engages local PWUD in the process and helps inform the quantitative data collection process that follows.

Each locality develops its plan differently, in accordance with the needs and characteristics of the local population, but all plans include ways to identify important gaps in knowledge and methodology, which often include key informant interviews, focus groups, observations and brief intercept surveys. Each formative assessment includes "qualitative interviews with people who inject or use drugs, focus groups and other qualitative methods to ensure that we describe to the community what we do, what the project goals are, and get their input so that our operations are successful and that we provide the data that they need or want in the community," according to an epidemiologist.

Key to garnering community support is paying people for their time and expertise when they are interviewed as part of the formative assessment. "An important component is that we compensate participants for their time in completing the interviews. Part of it is to get the information we need to inform the project, but part of it is also garnering community support and just being out there and having that kind of face-to-face, being in the community, being known. We're here. We care. We want your input," said an epidemiologist.

Local health departments can employ PWLLE to carry out the NHBS research. According to an epidemiologist, "Some health departments are able to partner [with PWLLE]. If they're not able to directly hire people with lived experience, they are able to partner or contract with teams who can. And that's another way to gain input, is to actually hire staff with lived experience. And that can be challenging sometimes, particularly if people have a criminal record. But many have been able to do that. And so that is extremely helpful, because then you have somebody who's part of the project, who understands, and they're working directly with the community."

Key considerations

Across the different activities and models of overdose data collection and interpretation, health departments should consider several key aspects to intentionally and thoughtfully engage PWLLE. These key considerations are divided into two sections, which reflect the stages of the data life cycle at which these considerations most commonly arise: (1) when gathering data and (2) when disseminating data.

When gathering data

Data collection is an essential activity of any state or local health department and as such, it could benefit greatly from the inclusion and input of PWLLE. The following considerations gathered from key informants include recommendations and methods for building and sustaining improved community relationships and leveraging the expertise of PWLLE throughout the data collection process.

Real partnership with communities and people providing data

Trust has not been easily established between government agencies and PWUD. Often, there is a history, and current reality, of health departments enacting stigma against, or otherwise harming, PWUD. Health department representatives should not expect to repair relationships quickly or by simply "showing up" without laying the groundwork. The most productive relationships between PWUD and programs that serve them are not short term. They build over time and are stable, long lasting and reliable.

"Our syringe service points, the individuals that are just doing outreach on their own, ... that would be, I think, for us what was successful. Going to people and places where people in recovery, people in drug use, are and have trust, and then showing up and working ourselves to build trust is a big thing. You can't just drop in and be like, 'Give us your data. Send these forms,' and then leave. So, we worked really hard to build — I have worked really hard to build trust with people and community."

— Elyse Monroy, Public Health Diversity Advisor, Opioid Program Lead, Nevada Overdose Data to Action

Example from the field

An innovative partnership between three institutions — Public Health – Seattle & King County, the University of Washington and VOCAL-Washington, a grassroots organization of people affected by substance use — has resulted in the formation of Research With Expert Advisors on Drug Use (READU). This group, which blends a peer research assistantship model and a community advisory board model, works collaboratively on overdose response research. It is made up of a combination of community members with lived experience and formally trained researchers, all of whom are referred to as co-researchers. All co-researchers participate in developing study designs, data collection, analysis and dissemination. "For some of the scientific decision-making and grant writing, the labor is not necessarily equally distributed, but we try to do shared decision-making and make the decision-making process equitable," said Dr. Jenna van Draanen, assistant professor at the University of Washington and READU lead.

A recent research project investigated how King County's first responders could better meet the needs of people experiencing overdose. Together, the co-researchers performed a scientific literature review and then conducted feasibility and acceptability testing of a few models locally, which included interviewing first responders and PWUD.

The team is now working together to create a dissemination plan. They've presented recommendations to Public Health – Seattle & King County (the administrators of emergency medical services in the county) and are now exploring additional ways of sharing their learnings. "We've gotten a lot of cool ideas about nonacademic dissemination from our team," said van Draanen.

Health departments also need to invest time to overcome the bureaucratic hurdles that impede building trust with PWUD. One important component is compensation. Payments should be proportional to the time, effort and expertise of PWLLE. Currently, many PWLLE who engage in research or serve on community advisory boards are compensated with gift cards. This is inequitable, especially when other experts who are not PWUD are paid with cash or have their time covered by their institutions.

> ***"When we were discussing the stipends for our lived experience partners, we offered this because of the valuable insight that they provide into substance use disorder and recovery. We appreciate our lived experience partners' time and effort. Our lived experience partners share knowledge and expertise on substance use disorder and how it intersects with numerous facets of injury and violence...such as suicide, domestic violence, child abuse, neglect and dating violence. We discuss the challenges of returning citizens as they manage substance use disorder and re-enter and navigate their communities."***
>
> *— Alicia Goodman, Public Health Coordinator, Michigan Department of Health and Human Services*

Community-based participatory research (CBPR) and drug user-led research

Community-based participatory research (CBPR) is a collaborative approach to engage PWLLE, community members, researchers and organizations alike as equal partners in the research process. Health departments can use CBPR to improve overdose prevention efforts by enhancing the understanding of substance use to create lasting change. This method of co-creation starts with collaborating with PWLLE to identify the research agenda and priorities, and then continues as an iterative process. CBPR allows health departments to integrate cultural and social dynamics and build relationships with diverse communities to promote mutual understanding and build and share knowledge (National Resource Center for Refugees, Immigrants and Migrants, 2024).

> ***"It's really gotta be all about co-creation. We're all about co-development, co-creation, co-design, all that type of stuff. And that really has to be an inner part of this process."***
>
> *— Brad Finegood, Strategic Advisor, Public Health – Seattle & King County*

Whether in CBPR or other research methodologies, health departments can employ PWLLE as peer researchers. In these roles, PWLLE can help health departments to partner more successfully and facilitate research projects with harm reduction organizations, such as drug user unions. PWLLE also can be involved on the other side of the research project, to provide context and real-world understanding, such as by assessing and reviewing how collected data and results are summarized and presented to the community (Bailey et al., 2023; Salazar et al., 2021; Simon et al., 2021; Simon et al., 2022).

PROUD cohort study: CBPR and CACs

The **Participatory Research in Ottawa: Understanding Drugs (PROUD) cohort study** relied on a CAC of PWLLE to oversee the project and serve as key contributors to the research design, collection, analysis and dissemination.

Another avenue to include PWLLE in research efforts is through the use of community advisory boards (CABs) or committees (CACs). Usually made up of community members based on shared identity, interest, experience, culture and other criteria, CAB/CACs are fundamentally designed to "reflect local priorities" and "bridge the gap between the community and researchers," which health departments can use to increase the relevance of their research (Kubicek & Robles, 2016; Bosak et al., 2024).

> ***"For the CAB, we prepare to recruit a new cohort every year. We have a large list of contracted agencies ... that have really great community ties but are also, in and of themselves, diverse in the way that they run their operations. ... We have an FAQ about what the community advisory board is. The requirement is that they have lived experience, whether that be active drug use or someone who's no longer using but used previously. And then other identities like their race, ethnicity, gender identity, sexual orientation. Also, experience and advocacy. We've had some folks that have specific experience with drug user advocacy, their experience in sex worker advocacy. So, different things like that. Things like housing status, things that we find are very much intersectional with the experiences that folks who use drugs tend to have. We're encouraging people to think that through."***
>
> *— Yarelix Estrada, Drug Checking Manager, BADUPCT, NYC DOHMH*

Health departments can leverage CBPR and CABs/CACs more intentionally to help researchers design methods for reporting and disseminating overdose data. For example, CABs that include harm reductionists and PWLLE can work together with epidemiologists and biostatisticians to co-create digital platforms for reporting overdoses, or to ensure that survey questions use language that reflects the way the community talks about drug use. Involving the community in overdose prevention and surveillance efforts is instrumental to addressing the inherent mistrust that PWUD often have toward health care, health departments and criminal justice organizations. Over time, this may increase the willingness of PWUD to report overdoses and, in turn, improve the accuracy of surveillance data (Claborn et al., 2022).

> ***"The first part of working with drug users is building trust. And everybody skips that step because that step is work intensive. They want to build trust, but there's no time for it. And so, the people that have already developed trust, you have to work with them. And that's people like me. We already have the trust of the community. ... If you want to really work on building trust and have us tell you how we can engage with your group so that we can get services, we want you to come out of your office and we want you to come here."***
>
> *— Louise Vincent, Founder and Executive Director, North Carolina Survivors Union*

Regardless of how PWLLE are engaged in research, health departments should ensure that their methods for engaging PWLLE are meaningful and powerful, not tokenizing. With advisory boards in particular, health departments should avoid creating further division between PWLLE and epidemiologists/researchers, instead giving PWLLE enough power to provide insight and create actual change through bidirectional leadership (Salazar et al., 2021).

Peer engagement and evaluation project (PEEP)

Lessons learned from applying the Peer Engagement Process Evaluation Framework, a unique approach of engaging PWLLE in research.

Research led by PWUD

Commentary from PWLLE on centering the lived expertise of PWUD in research, using the North Carolina Survivors Union as an example.

> ***"An excellent model ... is what's going on in North Carolina between the Greensboro Urban Survivors Union and UNC Chapel Hill. It is a super respectful, authentic power-sharing relationship between super smart academics, and super smart people who run programs and people who use drugs. And that is the model that I think we should be striving for. And that's how you keep drug checking services away from the slide into academia or elite over-professionalism."***
>
> *— Maya Doe-Simkins, Co-director, Remedy Alliance / For The People*

Finally, health departments should ensure that CABs/CACs and CBPR engage PWLLE in ongoing overdose research, evaluation and surveillance efforts and forge lasting relationships for continued engagement, rather than as part of discrete, one-off research projects (Greer et al., 2018).

"Rapid" data is not always best

When conducting surveillance, health departments must balance an important tension. Timely data is critical to rapidly informing communities of overdose clusters or changes in the drug supply. At the same time, collecting accurate, comprehensive data requires established relationships with communities, which take time to cultivate and maintain. Investing in these connections before a period of crisis will allow for faster data collection during crises. Additionally, many public health trends and patterns that are useful to inform response are not urgent or particularly time-sensitive; this data will be richer and more robust if time is taken to gather the proper nuance and context.

Data collected may be more complete when collected by a PWLLE. Hiring PWLLE to collect data may be less efficient if they have not received formal epidemiological training, but investing time and on-the-job training for PWLLE ultimately will benefit the validity of the data.

Regardless of who is administering surveys and conducting interviews, health departments should dedicate time to building trust with the people about whom they want to collect data. This may happen slowly but will result in greater community participation during data collection.

> ***"That word of mouth helps, because once you do that, then people say, hey, this agency actually reached out to me, asked me questions, gave me a stipend or an incentive or a gift card. They tell their friends, hey, you should talk to them. And it ends up being either an individual interview or, in some cases, those folks make up an actual advisory committee that will continue to guide the work for the life of the project. And [building trust is] really hard to do in some communities because, unfortunately, the local health departments don't always have a good reputation, and the state health department also doesn't have a good reputation in some communities. ... There's still a lot of work to be done, but I feel like we're much more trusted than we ever have been before, and a lot of that just is relying on those personal relationships, making sure that we are connecting with the right people."***
>
> *— Andrés Guerrero, Overdose Prevention Unit Manager, Colorado Department of Public Health and Environment*

When disseminating data

While most epidemiology and surveillance activities may be focused on data collection and analysis, dissemination must be more than just an afterthought as it is often the only piece that the public sees. When experts were asked about how overdose data related activities can better include and involve PWLLE, dissemination was an area that came up frequently.

Implement feedback loops to the communities that provided the data

PWUD often note that research and surveillance efforts by health departments and others are extractive and view PWUD solely as research subjects, not as key consumers of the data, champions of policy and advocacy and experts in the field (Salazar et al., 2021; Simon et al., 2021). As such, they are left out of the dissemination phase, may be unable to access the final research product due to paywalls or other restrictions and have no further interactions with the researchers after the initial data collection.

There is longstanding mistrust of government and medical professionals among communities of PWUD, due to a long history of mistreatment, neglect and stigma. In service of maintaining trusting relationships, health departments should be transparent with data collected from PWUD communities and prioritize sharing that data back to those communities rather than to academic and medical audiences. The PWUD community can transform findings swiftly into actionable, on-the-ground change.

> ***"I think that's our intent around a lot of the drug checking work, is to be able to share back surveillance on drug supply with community and community-based providers. It's actually their data and their information. So, they're the ones that's going to be sharing it with us to be able to collaboratively understand what's in the drug supply in the community."***
>
> *— Brad Finegood, Strategic Advisor, Public Health – Seattle & King County*

Two examples of how health departments can implement a feedback loop to PWUD communities are:

- Hosting listening sessions or other types of community activities with groups of PWUD once the data has been collected and analyzed, to confirm the key findings are accurate.
- Sharing any published products with the PWUD communities who contributed data, either electronically (full-text PDF to avoid paywalls) or on paper.

> ***"We did a series of design workshops where we went back to the people that we interviewed, people who use drugs, and first responders on that project, and presented the findings of our research and said, help us co-create recommendations. So, we invited everybody who had participated in an interview, plus we invited them to invite other people. And that was great. We did five of those workshops. They were fantastic."***
>
> *— Jenna van Draanen, Assistant Professor, University of Washington School of Public Health and School of Nursing*

Ensure data is applicable and actionable to people who need it

Departments should work with PWLLE to ensure data is presented in helpful and accessible ways, so that they can best make use of it. Part of good dissemination practice is not merely sharing a one-size-fits-all report with all audiences, but instead ensuring that data is presented in ways most useful to the intended audience. This goes beyond merely writing for an academic audience versus writing for a lay audience, as many PWUD have undergraduate and advanced degrees; it is about which pieces of information are important and actionable. Optimally, health departments should employ PWLLE, but at a minimum they should get feedback from PWLLE via advisory boards or other feedback loops on what information is most useful for the community to have. For example, one health department received community feedback that it should present the information that is most impactful and relevant to their community, so the department created a slide deck specifically for community members and partners. It also incorporated feedback to include language acknowledging that the data represents overdose, which might include or apply to audience members' loved ones, and to hold space for that acknowledgment.

"And so, I think that was important too – one of the things that we've done, at least for a standard lay audience slide deck. We incorporated more language about acknowledging that these are our family and friends and loved ones – it's about people and letting people know that they get to step away if anything is too much. And really starting off with that, I think is helpful."

— Ellenie Tuazon, Director of Surveillance, BADUPCT, NYC DOHMH

Present information in ways that are not stigmatizing and do not cause harm

When presenting information, it is critical to use non-stigmatizing language and present information in ways that do not unintentionally cause harm to PWUD no matter who is in the audience.

Stigmatizing language can perpetuate misunderstandings about the nature of addiction and can further isolate people with SUDs. Identifying stigmatizing language and highlighting it as an opportunity for improvement can help to prevent these misunderstandings, harm and isolation to PWUD and people with SUDs. Two types of stakeholders – health care and government - are crucial partners in reducing this type of stigma (Shatterproof, 2020).

Language do's and don'ts

Shatterproof's **addiction language guide** provides information on stigmatizing language, recommendations and rationale for language use, and implementation resources.

Because the use of drugs is criminalized and stigmatized, data must be presented thoughtfully, to avoid unintentionally causing harm. This is particularly relevant when it comes to policing drug use and aggregating drug trends by small geographic areas, such as neighborhoods.

"The [data analyst] really helped me understand the importance of the data but also the importance of being careful with data too, to protect people who use drugs. We have to be really careful in how we present certain things because we can sometimes cause unintentional harm. And for me, it's been a real hard juggling act of learning that authenticity that I have in my life and in my recovery program, but also being mindful of how we portray it. And I'm not saying that the numbers don't tell you the truth, but the context is super important. So, he really worked with me on proper presentation of the data, as well."

— Seth Dewey, Health Educator and Kansas Certified Peer Mentor, Reno County Health Department, Kansas

It's also important to have strict policies in place regarding when information is redacted prior to dissemination and how data is shared with outside agencies, particularly law enforcement. Cell suppression, a common method of privacy protection in tabular data, involves withholding or removing the true value in a cell if the cell size is below a determined quantitative threshold (National Birth Defects Prevention Network, 2004). Health departments should both have and consistently apply policies around suppressing data with small cell sizes to protect people's confidentiality and ensure data cannot be used to re-identify individuals. Intentionally choosing to use non-stigmatizing language and being mindful of how much data is shared across agencies helps to minimize harm to PWUD.

Regarding a partnership with the High Intensity Drug Trafficking Areas (HIDTA) program, one health department staff member said:

> ***"We're like, 'Look, we can't give you information so that you can use, like, ZIP code data,' because they're really big into OD mapping. So, it's being very, very mindful, very, very careful of how we have that relationship. We're not going to give you information so that you can now take that and use that to incarcerate people and arrest people. That's not what that is for."***
>
> *— Anonymous key informant*

Considerations when partnering with law enforcement

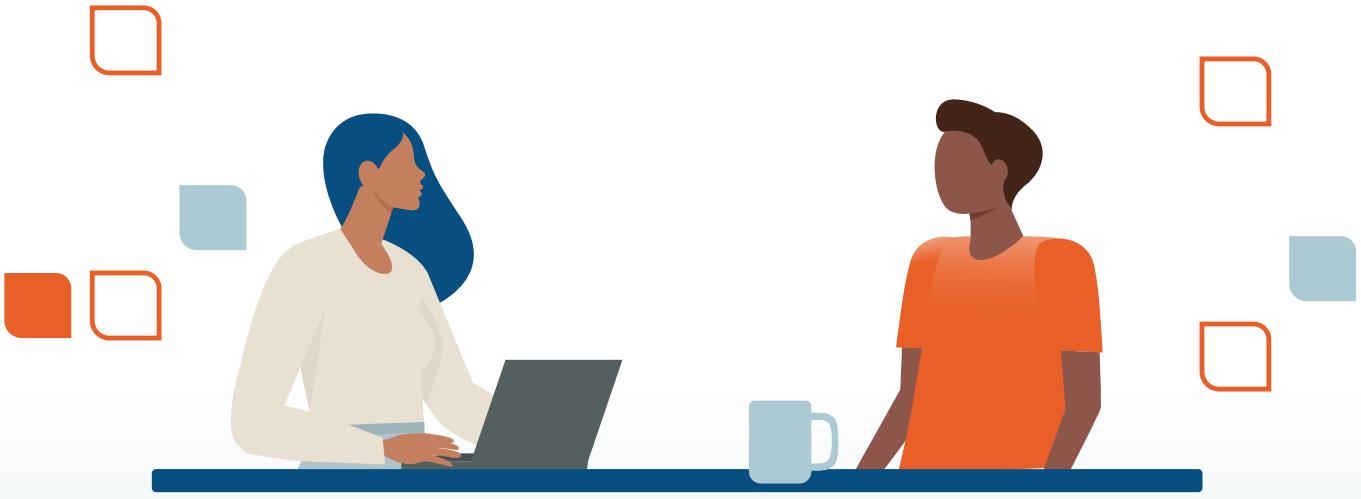
Health departments that employ PWLLE often are engaged in broader coalition work to coordinate services with various partners. In these scenarios, working groups that include PWLLE may also include representatives from law enforcement. This can present challenges to some members of the PWLLE workforce, so health departments workers may find it helpful to identify allies within law enforcement who recognize common goals. When this is successful, the culture of local law enforcement can change, improving the relationships between health departments, employees with lived or living experience, and people using drugs in the community.

> ***"We got some really good law enforcement agencies that really understand harm reduction. There are not very many, but there are a few. They were actually able to implement LEAD programs, Law Enforcement Assisted Diversion programs, and law enforcement — police on the street — were actually making referrals to the syringe service programs, which would have been unheard of 10 years ago. They would have just taken them to jail. [Now] they say, 'Hey, this is where you get safe supplies and here's naloxone.' We got a lot of law enforcement agencies now handing out naloxone to folks."***
>
> *— Andrés Guerrero, Overdose Prevention Unit Manager, Colorado Department of Public Health and Environment*

PWLLE partnering with law enforcement may find the experience re-traumatizing, especially in environments that already may be challenging, such as OFR committees. PWLLE also may interact with police during street outreach work. Health departments should have frank discussions with PWLLE during the interview process and pair them with other PWLLE staff for peer support, to discuss potential triggers and share strategies for engaging with law enforcement.

Health departments that partner with law enforcement may find this relationship strains their rapport with people currently using drugs. Departments should be transparent with all partners about information sharing, including the contexts in which information is shared, the precise data that is shared and the granularity of that data. Departments should be aware that information can be used in ways that are counterproductive to public health.

> ***"So, for me, because of my personal experience, I know the places, I know the things to look for. And I know too that some of the nuances that come along with it. Even in our trainings, for example, when we say check the individual's airway in an overdose response. And I often say, to check for a potential needle cap or something like that. And when I was saying that to our law enforcement partners, they said, 'I never thought of that.' But they taught me too, right? We teach each other. And so, it's just like with anybody who has experience in a field: The reason we work together is so we can make each other better."***
>
> *— Seth Dewey, Health Educator and Kansas Certified Peer Mentor, Reno County Health Department, Kansas*



Be transparent about limitations of the data

In communicating data findings, some health department staff have noted receiving feedback on key gaps in the data. It's important to clearly communicate limitations of data such as medical records extractions or EMS call data, and where such limitations come from. For example, people often will want to know about the housing status or criminal justice involvement of people who have overdosed, and usually this data is not systematically captured in or extracted from medical records or death certificates. Similarly, stakeholder groups may seek information specific to their community, which often is unavailable. For example, people very rarely are identified as LGBTQ+ in morbidity and mortality records, leaving gaps in our understanding of how this community is impacted by overdose.

Information on racial and ethnic groups often lacks critical detail. Hennepin County, Minnesota, described how their overdose data combines all people of African origin into one racial/ethnic group, though subgroups of recent East African immigrants have very different prevention and treatment needs than those of the more longstanding African American community. Michigan's Department of Health and Human Services similarly noted that, for their overdose data, all tribal communities are all combined into one ethnic category, and that Arab ethnicity is not tracked at all. To start to address these limitations, health departments can collaborate with racial and ethnic groups or communities on data projects to either validate, reclassify or inform future data collection.

> ***"For years I was working with the imams in the mosques, the elderly populations of the Somali, the moms, Somali stakeholders, youth, and creating groups of people to go out into their community and start spreading the word about how they changed their data practice. At that time, it was not super formal. Now, we have formalized the process and work with a Somali-specific community engagement professional who has created a coalition of stakeholders and is working on this in earnest."***
>
> *— Julie Bauch, Opioid Response Coordinator, Hennepin County Public Health*

> ***"Arab ethnicity is flat out not collected in most systems; I've been talking to some folks about what our options are. So, we have some ideas that we're exploring. There's an Arab surname list that we're thinking about doing a project with, sort of a validation and then recalculating rates. Similarly, with the tribal communities in Michigan, we are working on a project with GLITC, the Great Lakes Intertribal Council, to link the IHS Registry information with one of our data sources to look at race misclassification. So those are some things that we're excited about."***
>
> *— Rita Seith, Opioids and Emerging Drugs Unit Manager, Michigan Department of Health and Human Services*

Pairing data sources to tell a story

Subject matter experts identified the triangulation of qualitative data or patient stories with quantitative data as a best practice for communicating epidemiological messages to a wider audience. Triangulation is a well-known technique in public health and program evaluation, one that improves our understanding of a topic because each method accounts for some of the limitations of the other (BetterEvaluation, 2022). It may be particularly useful with regard to a criminalized and stigmatized health topic such as drug use, where some audiences may need more qualitative context to humanize the "research subjects."

For a great example of combining quantitative findings with qualitative stories, see "Example from the Field" on the following page, which discusses the Michigan Department of Health and Human Services' innovative use of patient mapping.

Different forms of purely quantitative data can be combined to tell a story more robustly, as well.

> ***"We started a public-facing dashboard here in Reno County that tracks our overdoses. Not just the fatalities but the non-fatal as well, because that's where I was like, dude, this is where we're missing. We're missing the stories. Because these people are still alive, man."***
>
> *— Seth Dewey, Health Educator and Kansas Certified Peer Mentor, Reno County Health Department, Kansas*

Example from the field

Patient journey maps, typically used in health care settings, are visual tools that can show the longitudinal "journey" a person may take through a health care system. Visually capturing interactions a person has over time can improve the delivery of health care. The Michigan Department of Health and Human Services is undertaking a journey mapping project to tell the stories of different PWUD — pregnant and parenting people, people who are involved in the justice system and people of faith. The journey maps will be generated based on the results of several listening sessions the department is hosting. They will pair these stories with data from SSPs and the treatment system.

"Reading about someone waiting a long time to get into treatment, that can incite empathy within the reader. But then pairing that with, well, here is the median time people are actually waiting to get into treatment is like, oh. No, that's a problem. Not only do I hear the story and I feel like it resonates with me, but then you're like, oh, the median is six days? That's huge. Let's put that into it. I think that just empowers that anecdotal information in the map," said Rita Seith, Opioids and Emerging Drugs Unit Manager, Michigan Department of Health and Human Services.

Summary

Ensuring the inclusion of PWLLE in overdose research, evaluation and surveillance efforts within health departments is paramount to sustaining effective overdose-related programs and initiatives. Including the voices and perspectives of individuals who are representative of their communities encourages the prioritization of community needs and enhances representation and diversity in decision-making procedures in health departments. PWLLE should be valued as subject matter experts with the knowledge and skills needed to research and contextualize drug trend data and inform health department surveillance program efforts. There are a multitude of methods health departments can use to successfully involve PWLLE in these efforts, including OFR committees, drug checking, patient surveys, overdose reversal reporting and CBPR methods like patient journey mapping, community advisory boards and research collectives with PWUD researchers. Through initiatives such as these, as well as by being intentional in their methods for data collection and dissemination, health departments can ensure the meaningful inclusion of PWLLE in overdose data use.

Appendix A. Resources

TITLE	SOURCE	DATE	DESCRIPTION
Overdose Fatality Review: Resource Library	The Comprehensive Opioid, Stimulant and Substance Abuse Program (COSSUP)	2024	This resource provides further technical assistance resources on starting OFR teams.
Strengthening Partnerships With State Public Health and Increasing Stakeholders' Knowledge by Identifying Underreporting of Somali Overdose Deaths Through Overdose Fatality Reviews	Minnesota Department of Health	2023	This resource contains a description of a culturally specific OFR for the Somali community in Minnesota, as well as background information on racial disparities, OFR-specific legislation, an overview of cases and recommendations.
Overdose Fatality Review Implementation Guide	Minnesota Department of Health	2020	This guide was based on the COSSUP resource and tailored to the needs of Minnesota. It includes an overview of OFRs and information on facilitating and managing OFR teams in Minnesota.
Drug Overdose Deaths in Dane County: Annual Report 2022	Public Health Madison & Dane County	2022	This report includes annual data on drug overdose deaths in Madison and Dane County, Wisconsin. Throughout the report are meaningful notes that center lived experience.
Enhancing Harm Reduction Services in Health Departments: Fentanyl Test Strips and Other Drug Checking Equipment	National Council for Mental Wellbeing	2023	This educational brief provides information on how health departments can implement or enhance harm reduction services to increase access to fentanyl test strips and drug checking services. It contains information on the role of health departments and considerations when partnering with harm reduction organizations to provide drug checking services, including the importance of centering the voices of PWLLE.
Creating Safer Spaces With Harm Reduction in Drug Checking Settings	The Drug Resource and Education Project	2021	This manual provides information, examples and practical guidance on how to create safer spaces for PWUD in drug checking settings.

TITLE	SOURCE	DATE	DESCRIPTION
Drug Checking Implementation Guide: Lessons Learned From a British Columbia Drug Checking Project	British Columbia Centre on Substance Use	2022	This guide provides an overview of and lessons learned from a British Columbia drug checking project, including detailed information on drug checking service models, service delivery, monitoring and reporting, evaluation, financial considerations and helpful resources.
Drug Checking for the People: Resources	Remedy Alliance / For The People	2024	This webpage contains resources, tools and templates for starting drug checking services. The tools include an example drug checking technician job description, a list of materials for drug checking, a pre-implementation tool for drug checking programs, a sample drug checking program budget and considerations for new drug checking technologies.
National HIV Behavioral Surveillance	CDC	2024	This webpage contains information on the NHBS and provides additional information and resources pertaining to populations and project areas, methods and questionnaires, a bibliography and lab collaborations.
Establishing a Community-based Participatory Research Partnership Among People Who Use Drugs in Ottawa: The PROUD Cohort Study	Harm Reduction Journal	2014	This article discusses the PROUD study, which meaningfully engaged PWLLE in a CAC and as peer researchers, using CBPR methods. The study shares important insights for including PWLLE in research efforts on PWUD.
Research Led by PWUD: Centering the Expertise of Lived Experience	Substance Abuse Treatment, Prevention and Policy	2021	A commentary from PWLLE on centering the lived expertise of PWUD in research, with key recommendations for how to meaningfully engage PWUD in research and support their career aspirations.
Participant, Peer and PEEP: Considerations and Strategies for Involving People Who Have Used Illicit Substances as Assistants and Advisors in Research	BMC Public Health	2018	This article includes lessons learned from PEEP and applying the Peer Engagement Process Evaluation Framework, offering key insights into and a unique approach for engaging PWLLE in CBPR.
Addiction Language Guide	Shatterproof	2021	This guide provides information on stigmatizing language, recommendations and rationale for language and implementation resources.

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