SHaRP Salon Report Back: Asking Sensitive Questions

At the SHaRP Salon on March 28th, 2024, participants discussed the collection and use of sensitive data at harm reduction programs. We focused on overdose prevention indicators, participant interactions with law enforcement, and participant housing status. Other sensitive indicators that participants mentioned were sexual activity data and pregnancy or parental data.

Strategies and Tactics to Collect and Use Sensitive Data

Below are themes, along with specific examples, that emerged from participant discussions about how to best collect and use sensitive data at harm reduction programs. These are generalized themes not focused on a specific indicator.

Limit data collection. Asking questions quarterly or annually for point-in-time surveys often feels less intrusive to staff and participants than asking questions at every encounter or visit. Participants should never be forced to provide data to receive services. Participants should be able to decline to take part in a survey and all survey questions should have a decline or refuse to answer option. Funding and reporting agencies ask programs to collect intrusive data that could be used to criminalize people who use drugs, such as coordinates of a drug overdose, and many programs refuse to collect these data. Some indicators programs collect are only used for grants and not used internally, so as soon as a program no longer has that grant, they stop collecting the data.

Receiving data from participants instead of directly asking may let participants feel empowered to share without making folks feel forced into sharing. For example, one program has a hero board where people write their names on a heart when they reverse an overdose, but participants are not asked or obligated to share, which limits the burden of data collection on staff and participants. In another program, staff note stories participants share about police harassment, with participant consent, in staff notes instead of asking participants directly if they've had negative encounters.

Collecting data from staff instead of participants may lessen the burden of data collection. For example, instead of asking participants about negative experiences with law enforcement, programs document when police infringe on harm reduction program space or when staff encounter law enforcement during outreach. Other programs use informal qualitative data from staff to guide programming for people who are unhoused, instead of asking directly about housing status. Of note, a risk in using data only from staff and not from participants is that staff (even staff with lived/living experience) may not have a full understanding of participants' lives outside of participant interactions with the harm reduction program. Everyone has biases from their own individual experiences that may not apply to everyone's experiences.

Some programs feel like they're in a bind. Many programs do limit data collection and put services ahead of data, but that hurts programs when they're writing for grants. Because they don't have the data for grants, they continue to go underfunded and understaffed, and therefore don't have the time collect or analyze data. This is a hard loop for many programs who are pouring so much into their community.

Timing is based on local context and program resources. While limiting data collection helps reduce the burden of data on staff and participants, all the indicators addressed (i.e., overdose prevention indicators, participant interactions with law enforcement, housing status) change and accrue over time. Asking these questions at every visit or encounter feels like too much, but asking just once at enrollment is inadequate. The frequency of data collection may depend on changing local context (e.g., asking more if there's a new drug entering the supply or new police chief), staff resources (e.g., staff time, access to easy data collection tools), and participant buy-in.

Be open about data limitations. Much public health data is limited. For example, overdose data overall is inadequate, like when a county only recognizes overdose counts from emergency departments. Overdose data may also be secondhand, so programs are not capturing every reversal or counting some reversals multiple times. Just because data is limited doesn't mean it isn't worth collecting if it can still help a program, it's just important to be open about those limitations. For example, a lot of programs hear about participants' negative experiences with police, housing authorities, and medical providers, but don't feel like they can't collect these stories because they're not directly asking everyone about their experiences. But these stories can be collected, with participant consent, as informal qualitative data and can help programs tailor services and referrals.

Flexible data collection. Different types of data collection work better for certain indicators and in certain local contexts. For example, multiple choice survey questions about housing status can get information from a lot of people, which may be helpful, but they may not capture the nuances between the experiences of folks who live in different kinds of housing (e.g., sleeping in a car versus on the sidewalk). Open-ended survey questions and informal qualitative data can provide space for people to talk about the difference in their experiences.

Trust and rapport are key. Before asking sensitive questions, it is important for staff to have built rapport and trust with participants so that asking these questions feels comfortable, instead of staff reading down a long list of questions. Of note, even if staff and participants feel comfortable with each other, staff should always ask permission or consent to collect data and should not make assumptions about participants (e.g., guessing participant age, gender, race/ethnicity). Staff training around tone and approach is important. This training is for everyone in the organization, whether they are in direct service or not, because many staff also

have lived/living experience and deserve the same amount of respect. Specific tactics to show respect while listening to people's stories include:

- Show openness to listening with tone and gestures
- Be affirming
- Reflect what you are hearing without asking questions, which creates a space to share, but does not require it
- Never push people to share

Sensitive data may be beneficial for funding and programming. The primary ways programs used all indicators discussed was to fund needed supplies (e.g., naloxone) and programs (e.g., rental assistance) and to inform program services. While these data were useful for many programs, unintended consequences of collecting and using data should be examined before data collection begins.

Strategies and Tactics to Collect and Use Specific Indicators

Overdose reversal data are the most collected sensitive indicator. These data are often collected at each encounter, but programs should decide, with participants and staff, the best frequency to collect these data. Programs have used overdose reversals to inform the community about spikes in overdose.

Many programs don't formally collect data about participant interactions with law enforcement, but have still successfully used informal data. A few ask if naloxone was confiscated by police and if police arrived at an overdose, which are indicators that may be important in some local contexts, but not in others. More programs informally collect qualitative data about participants' interactions with law enforcement and have successfully used these data to advocate for participants. Several programs collected enough stories to show patterns of police abuse. One program had an okay relationship with police and took those stories to ask police to do better by their participants. Even if these stories cannot be used with police, other local leaders may act. One program took these stories to their DA, who pushed police to give the harm reduction program more space. Another program took these stories to their public health department, who pushed police to not harass participants with smoking supplies.

Making better referrals and participant education. Information about structural violence, such as housing status and interactions with police, helps programs build better referral networks so they know which housing programs to connect people to, and which programs to steer people away from. These data also help educate people about their housing and other legal rights.