

SHaRP Salon Report Back: Sharing Data with Community and Participants

Why Programs Collect Data

At the SHaRP Salon on March 14th, 2024 participants discussed why SSPs and harm reduction programs collect data. Below are 3 themes that came out and examples from each theme.

Required by funders or other reporting entities Unfortunately, the number one reason participants reported their program collected data was that it was required by funders and/or local and state health departments.

Track services provided Participants said that tracking participants served and supplies distributed was the second most common reason to collect data. This was used both internally (e.g. understanding inventory) and to use when engaging with funders and the local community.

Understanding participant needs to improve service quality Participants talked about collecting data in order to understand where participants are coming from, to adapt outreach locations, and to document current trends and improve health equity. This was mentioned by some as the most important reason they collected data.

Strategies and Tactics to Share Data and Findings

Salon participants discussed how they've shared data in the past and considerations when sharing data. Below are overall strategies that came up, and specific tactics people mentioned.

- **Establish guiding principles for data sharing.** (Write principles down; consider “what rooms will we share data in?”; establish the language you'll use to discuss your work; consider “how can we make sure participants have more dignity and autonomy?”; consider “how can we make sure our data isn't used to generate fear?;” point to system/structural barriers as context when necessary [e.g., “How can we fund SSPs for everything but syringes, everything but pipes- you want us to do it with everything but the tool!”]; share back data with staff and participants first.)
- **Protect participants and staff.** (Use stigma-free/non-stigmatizing language in your data sharing, regardless of the intended audience; only share deidentified data; protect participant confidentiality [e.g., when sharing stories, when sharing small numbers] within participant communities or the wider community [especially important in small and/or rural areas]); take care not to report out data or stories that could lead law enforcement to harass/investigate/arrest participants or staff; push back on requests from funders or others whose intent is to surveil participants; be careful when sharing participants' stories; ; Naloxone and narcan distribution data can be shared on a one on one basis to try and attend to traumatic experiences and ensure that folks are cared for; try to focus on overdose reversals rather than overdose deaths when reporting to participants; try to avoid sharing anything about participant substance use – feels invasive to ask, people tend to shut down, staff don't even want to ask those questions.)
- **Prioritize communicating with participants and staff.** (Voice appreciation to participants for sharing data with your program; run findings and/or external presentations by participants before sharing with wider audiences; contextualize changes in services/data collection for participants [e.g., SSP used to be able to provide xylazine test strips via state, not sure if/when can get them back, it's nice to tell participants why we don't have them- our funders can't get the funding for them]; outreach settings might be better-suited to tailoring your data sharing to participants in that area while brick-and-mortar settings might be fine for sharing data that applies to all participants; participant/community advisory/action boards could be a



good place to disseminate data; 1:1 conversations are good for sharing data with participants because staff are already trusted and not all participants have access to internet/cell use; you can put reminders on SSP forms for staff to share data back; discussing change achieved with participant data with participants is exciting and can help encourage folks to get more involved; share drug checking results on a whiteboard for participants to see as they come in; visuals on vending machines can report back to participants who access them; sharing with staff is an important step for getting data to participants/into community because staff are part of community and a direct line to participants; one program shares data monthly with staff in check-ins before sharing elsewhere; in one program the person who does most of the data stuff holds office hours where any staff can approach to ask questions, report issues, etc. and helps with tech issues or data interpretation; see if analysis team can develop brochures and cards to share with participants who want to know more; some programs host quarterly meetings with participants to provide data with other services like clothing; staff like 1:1 conversations too.)

- **Know your audience.** (Format matters; participants may not want to hold onto a flyer or leaflet; some participants might have varying literacy levels; research unfamiliar orgs or individuals asking for data, especially if you are in an area with political opposition to harm reduction, and consider why they might be asking for it; language and framing matters [e.g., is it most important to talk about *overdose reports* or *overdose fatalities* or *overdose reversals*?]; funders and officials like quantitative data; community partners like stories; feedback from participants can be super-impactful to share; formal and informal data have a place in different audiences; think about data to funders as feedback not sharing data reports—how can data be used to advocate for participants?; one program sent a survey to clients at different ssps, shared back findings by site for participants and staff to see findings for their sites; online dashboards can be good for getting info/data to community partners; states can share data back via spreadsheets to programs; know how highly stigmatized program data will land for county board of supervisors vs community partners; some programs hold once a month meetings with other audiences [e.g., naloxone trainings with law enforcement] and can share data then.)
 - **Law enforcement audiences require special consideration.** (Law enforcement relationships are complex – some have close ties with staff, others don't even listen to data; don't share data that could criminalize participants or staff with these audiences; when law enforcement reports out data that your program knows to be incorrect, think about the potential consequences of correcting them [e.g., maybe local police grossly under-report overdoses locally, and your program knows better- maybe this number is so low because participants aren't calling the police and are reversing overdoses themselves; is correcting law enforcement going to achieve your goals or potentially hinder them?]; distributing data on highly-stigmatized programs to law enforcement doesn't always go well.)
- **When asked to share data, consider the ways that data may be used.** (Ask for time to think about asks for sharing data [e.g., "Can we have 48 hours to think this over?"]; sometimes the data that external partners are asking for is answering the wrong question (e.g., program being asked to share 'trends in SUD' but the real trend is 'we don't have resources'- people have needs for SUD treatment, medical referrals, housing- help us with THAT!); add important context when necessary [e.g., very few referrals to MOUD providers because there are no quality MOUD providers locally]; some requests for data might come from anti-harm reduction entities, so balance when transparency is the best choice and when not providing data is the better outcome [e.g., sharing with wide community 'number of folks who use services' has been construed as 'you're enabling drug use']; pause and humanize quantitative data, acknowledge that these numbers (especially overdose deaths) are real people.)

- **Consider who may end up with data you've shared with others.** (Be careful what goes in writing; flyers might end up on the ground somewhere; consider reporting on “safer use kits” rather than detailing what’s in them; presentations on new services may be sent to oppositional audiences who will draw negative attention to those services [e.g., drug checking].)
- **Data-sharing wins** (Able to use data to advocate for Good Samaritan Law expansion; able to use data to advocate for fentanyl test strip access; able to advocate to funders for less data collection—survey of participants of wait time and length of data collection and were able to stop individual level data at outreach.)
- **Current challenges** (How to share data with geographically disparate communities?; when to provide data that could potentially fuel outrage/anti-harm reduction sentiment vs when to decline to provide it and potentially invoke “what are they hiding?” campaigns; sometimes data just doesn’t matter to an audience/some people just aren’t interested in evidence-based data; reporting to government partners can be difficult and not useful; funders are not in the headspace to realize how burdensome some data requirements are and that asking questions takes a lot of time; who wants to see our data?; who would are data be useful to?; some programs are trying to map ODs to help focus where services should be provided, especially in rural areas but it’s hard to keep anonymous in sparse areas.)