Findings from the SSP Indicators Stakeholder Convening

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All convening attendees were given the opportunity to review and comment on these findings. Convening attendees were also invited to be named as contributors. While being named does not mean they agree with every statement, we believe it is important to recognize the valuable contributions and provide visibility into the stakeholders who were present. Not all attendees opted to be named.

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Purpose

This statement summarizes the outcomes of the SSP Indicators Convening, the University of Washington Supporting Harm Reduction Programs (SHaRP) team hosted from June 6th to 7th, 2023 in the Chicago area. The original purpose of the convening was to identify indicators the workgroup felt would be ethical and potentially useful for harm reduction programs to collect and/or track. During the convening several themes emerged around data collection, relationships with funders, programmatic autonomy, and data ethics that the group felt were essential to accompany recommended indicators. The following is a list of concepts the workgroup developed that now serve as the findings from the convening. These findings are meant to be read and understood prior to reviewing the indicators that have been vetted and approved by workgroup members.

Overview

The SHaRP team received and reviewed over 200 applications for the convening from SSP staff, volunteers, board members, and participants; researchers; funders; and, state-and-local government employees. The SHaRP team selected thirty-eight convening participants, primarily SSP staff, based on their harm reduction direct service and data experience. Thirty-six were able to attend. Of these, two-thirds (n=24) had a current SSP affiliation, and most of the remainder had a past SSP affiliation.

Prior to the convening, the SHaRP team provided workgroup members with a literature review on good practices and ethical data collection at harm reduction programs, which included peer-reviewed articles, white papers, and grey literature from programs and drug user organizers.

Concepts from this literature review were also presented at the beginning of the convening. During the convening, the workgroup discussed challenges related to data collection and reporting at harm reduction programs. While most workgroup members saw benefit to data collection for the purposes of program improvement, there was not agreement about other important aspects of data collection. This included concern that the potential burden of collecting data with few resources outweighs its benefits, as well as potential harms to program participants caused by individual-level data collection (i.e. data collected directly from harm reduction program participants). An additional consideration was how over-burdened SSP staff are and that they are often members of marginalized groups themselves. Thus, when setting data collection parameters, it is essential to consider the vicarious trauma harm reduction staff face in addition to the lived/living experience they carry. As a result of this dialogue, workgroup members determined that identifying recommended indicators was not the priority of the in-person time, and instead the workgroup discussed what might be useful findings from the convening.

Findings

The workgroup identified core principles that should supplement recommended indicators. Some of these agreements were informed and supported by the literature review, as shown below.

The SHaRP team summarized the notes from the convening into the below agreements and reviewed the first draft of the below during a virtual meeting all convening attendees were invited to. Members of the original workgroup reviewed them for accuracy.

This section of convening findings is related to how funders and other stakeholders with power can support harm reduction programs to collect data ethically.

- Harm reduction's efficacy has been proven by decades of research. Programs should not be made to justify their existence to the public through accumulation of additional evidence by way of unnecessary data collection, such as extensive information about naloxone utilization or personal health information like HIV risk or status.
- Harm reduction programs should not be used to surveil their participants, which has been critiqued in the past, and instead data should be used to advance the goals of the program.[i]
- As stated previously by drug user organizers[ii], *mandatory* data collection is unethical and should not be required for either funding (on the program level) or services (on the participant level).
    - Funders who have reporting requirements should be explicit about which data points are required. Ambiguous language encourages over-collection due to fear of losing respect or funding if data is not collected.
    - Funders should publish data collection and reporting requirements with each request for application (RFA)/request for proposal (RFP). Funders should offer specific, targeted guidance to programs who are new to data collection.
        - Funders should consider tailoring data reporting to individual organizations' systems and preferences rather than requiring the same data from all recipients.
    - To assess utilization of grant funding, funders should focus on program-level instead of individual-level data.
- Funders, researchers, and public health officials should recognize that harm reduction programs own their own data and should not expect to be given access to individual-level harm reduction program data.
    - Any individual-level data that is provided to funders should be made clear to and approved by program participants. Collection of these data must have a clear public health benefit and an explicit purpose and analysis plan.
    - Even optional reporting can be coercive given the power dynamic.

- Funders should include a budget for participants to be compensated for providing any personal information that is not directly tied to a service, which has been advocated for previously.[2,6,7]

This section of convening findings is related to what harm reduction programs might consider and implement to collect data ethically.

- Any data that could be potentially incriminating must be completely anonymous.
- Although participant enrollments or unique identifiers are sometimes required by law and may thus protect participants from legal repercussions, they are generally coercive and unethical due to the increased barrier to receiving services, higher level of participant tracking, and frequent use of identifiers (whether in full or in part). Collecting these data can inhibit trust with program participants. The SHaRP team has described these challenges in greater detail here.
    - Lifesaving services should have the lowest possible barriers to access.
- As a standard good practice[2,6,7,10], any aggregated participant-level or program-level data that harm reduction programs collect should be shared back/made available to participants in multiple ways and in plain language an appropriate literacy level.
- Collecting less data increases the likelihood that programs can feasibly use or share findings. Harm reduction programs often have limited capacity to analyze their own data and funders should build in dollars for training and dedicated staff time – thus improving data stewardship.

This section of convening findings is related to considerations for harm reduction programs and funders when deciding which data to collect and how.

- As shown in previous research[iii], individual-level data collection may be damaging to rapport between harm reduction program staff/volunteers and program participants, even if the participant can decline to answer. Funders and harm reduction programs may enhance rapport by limiting intrusive questions and/or reducing data collection frequency, and focusing instead on program level and service level data collection.
    - Data collection that is intrusive or too frequent (e.g. encounter-level data) may result in poor-quality data (as shown in previous research[3,iv]) and should be minimized or ceased.
- When designing data systems, program participants should have input into which data are collected, as advocated by other drug user organizers and researchers[2,v,vi,vii,viii,ix,x,xi,xii]. Input from Black, Indigenous, and other participants of color, as well as gender and sexual minorities who have been historically and systematically harmed by legal and health care systems should be emphasized. Participants who have been directly harmed

by the War on Drugs (e.g. history of incarceration, child removal, being unhoused) and those who have been economically disenfranchised should also be included.
    - In every instance participant level data collection questions should be framed with neutral and non-triggering language.
- Limiting quantitative individual-level data collection may create space for storytelling and support a narrative for the program rooted in qualitative data and participants' voices.
    - Any qualitative data collection should be tested to ensure questions are not re-traumatizing.
    - As with quantitative data collection, qualitative data collection should be optional.

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[i] Brett Wolfson-Stofko et al., "The Portapotty Experiment: Neoliberal Approaches to the Intertwined Epidemics of Opioid-Related Overdose and HIV/HCV, and Why We Need Cultural Anthropologists in the South Bronx," *Dialectical Anthropology* 40, no. 4 (2016): 395–410, https://doi.org/10.1007/s10624-016-9443-4.

[ii] Louise Boilevin et al., *Research 101: A Manifesto for Ethical Research in the Downtown Eastside* (Vancouver: Research 101, 2019).

[iii] Peter Davidson, Priya Chakrabarti, and Michael Marquesen, "Impacts of Mandated Data Collection on Syringe Distribution Programs in the United States," *The International Journal on Drug Policy* 79 (2020): 102725, https://doi.org/10.1016/j.drugpo.2020.102725.

[iv] Jules Netherland et al., *Oregon's Measure 110 Principles and Metrics for Effective Evaluations* (M110 Evaluation Working Group, 2021).

[v] Ruchi M. Sanghani, Alexandra L. Carlin, and Alexander K. Moler, "Assessing Success—a Commentary on the Necessity of Outcomes Measures," *Substance Abuse Treatment, Prevention, and Policy* 10, no. 1 (2015): 20, https://doi.org/10.1186/s13011-015-0017-2.

[vi] Drug Policy Alliance, "Recommendations for Community Driven Drug Policy Research" (https://drive.google.com/file/d/10lBcJ-7JigbcHfaO_ur4zzxn86lNoED9/view, 2022).

[vii] Caty Simon et al., "We Are the Researched, the Researchers, and the Discounted: The Experiences of Drug User Activists as Researchers," *International Journal of Drug Policy* 98 (December 1, 2021): 103364, https://doi.org/10.1016/j.drugpo.2021.103364.

[viii] Carol Strike et al., *Ontario Needle Exchange Programs: Best Practice Recommendations* (Toronto: Ontario Needle Exchange Coordinating Committee, 2006).

[ix] Susan Boyd and NAOMI Patients Association, "Yet They Failed to Do so: Recommendations Based on the Experiences of NAOMI Research Survivors and a Call for Action," *Harm Reduction Journal* 10, no. 1 (April 18, 2013): 6, https://doi.org/10.1186/1477-7517-10-6.

[x] North Carolina Survivors' Union, "Ethical Research Manifesto," 2020, https://docs.google.com/document/d/1UFm5EYCCgr5Shv9TjOCobobF4JwI12i8uN98TV8Fr34/edit?usp=sharing.

[xi] *Nothing About Us Without Us: A Manifesto by People Who Use Drugs* (Toronto: Canadian HIV/AIDS Legal Network, International HIV/AIDS Alliance, Open Society Institute, and International Network of People Who Use Drugs, 2008).

[xii] Carol Strike et al., "Guidelines for Better Harm Reduction: Evaluating Implementation of Best Practice Recommendations for Needle and Syringe Programs (NSPs)," *International Journal of Drug Policy* 22, no. 1 (2011): 34–40, https://doi.org/10.1016/j.drugpo.2010.03.007.