
Pre-Packet for the SSP Indicators Workgroup Convening

June 6-7, 2023

Chicago



SHaRP: SUPPORTING HARM REDUCTION PROGRAMS

UNIVERSITY *of* WASHINGTON

School of Medicine

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What's happening?

We're meeting in Chicago, June 6-7, at the Hyatt Regency Schaumburg. We'll discuss ethical data collection at SSPs and which data we think SSPs and funders should collect. We'll hopefully leave this working group meeting with a proposal for recommended SSP indicators.

What's an indicator?

The way we talk about data at SSPs becomes full of jargon quickly. We'll try to cut the jargon and call each other in if it becomes too much. There are a few terms we'll use and will define from the start:

Monitoring and evaluation – Involves collecting program data on an ongoing basis to determine if programs are meeting their goals.

Domain – A category of indicators that are related to a similar question or purpose. Examples: service coverage, overdose prevention, demographics.

Indicator – A specific, observable measure of something we want to know about. Examples: # of syringes distributed, # of naloxone doses distributed, race and ethnicity of participants.

There are other terms we'll have to work on defining together along the way so we can build a shared vocabulary and understanding.

What work has the UW SHaRP team done so far, and what have we learned?

We've been working over the last several months to read all the articles, papers, and presentations we know of on program monitoring and evaluation at SSPs. We've also spoken to numerous SSPs, funders, and state health departments about data collection and reporting. We want to share some of what we've learned about SSP data collection so we come to the convening with a head start, since we have a lot of ground to cover.

Good practices for data collection at SSPs: Notes from the literature

Below is a summary of what we learned from the literature about data collection and data use at SSPs and other harm reduction services. We included citations and can share the full text of any article if you email us at sharpta@uw.edu.

Making programs better – Program monitoring and evaluation data should help programs understand their services and participant needs.¹ It's important for program staff and participants to work together to create program goals and ways to measure those goals.²⁻³ If programs agree on indicators and how to measure those indicators, this may help us better understand gaps that exist in harm reduction, like if certain programs are effective and if there is inequity between participant populations.⁴⁻⁵

Culturally and structurally appropriate practices – Indicators and data collection methods should be trauma-informed, use non-stigmatizing language, and use accessible language.^{2,6,7,8,9,10} A good way to make methods appropriate is to include people who use drugs in creating methods.¹¹

Data collection methods – There are all sorts of data collection methods that can be used (e.g. surveys, interviews, observations), but methods should be tailored to what works well for a program.¹²⁻¹³ Using point in time surveys (PiTS), which are surveys that are usually collected every one to two years, decreases the data collection burden on participants and staff.^{8,14}

How to pick an indicator – One of the purposes of this convening is to propose indicators that are helpful for a variety of contexts and SSPs. Here are some things to think about when we discuss what makes a good indicator, adapted from MacDonald¹⁵ (listed in alphabetical order, not according to importance):

Criteria	Description
Accepted History of Evidence-Based Use	Includes a discussion of advantages and limitations of using the indicator, evidence for use in published and unpublished literature, and peoples’ experiences using the indicator
Applicability in Different Settings	The ability to collect comparable and consistent data across diverse settings (e.g. mobile programs, underground programs, programs in different policy environments, etc.)
Burden of Data Collection	The ease or difficulty of collecting data in terms of the time, effort, and emotional labor on participants and staff
Burden of Data Analysis	The ease or difficulty of analyzing data in terms of the quality, timeliness, and resources required for data analysis
Cultural and Structural Relevancy	The degree to which an indicator is appropriate for the people, places, and systems where it’s collected
Data Quality	The degree to which the data collected can be complete, reliable, and accurate
Opportunity to Detect Unexpected Findings	Some indicators should be flexible enough to include unexpected or unintended findings
Pathway for Data Use	Includes a discussion of all ways that data may be actionable and by whom, as well as the consequences of that use. All data collected should have a clear use
Relevance to Evaluation Questions	The degree to which an indicator answers evaluation questions and represents what is being evaluated
Value within a Set of Indicators	Decide if there is enough diversity of indicators to answer evaluation questions and if a single indicator adds meaning to sets of indicators. This may help identify redundancies in data collection

Pilot testing – Programs should review data collection systems with staff, volunteers, and participants to make sure everyone understands the reasons for data collection, how data is collected, and the specific questions asked.⁶

Ethical data collection at SSPs: Notes from the literature

Problems with unethical data collection – Data collection may be intrusive, stigmatizing, exploit peoples’ pain, create fear, and exhaust valuable resources, especially in communities that are over-researched and underserved.² Harm reduction data collection often reflects trends of surveilling the individual, instead of measuring inequities and structural violence.¹⁶ Data collection in programs may decrease trust with participants and deter new participants.⁸ Data collection that is intrusive, outsider imposed, or otherwise flawed often results in poor-quality data.¹⁰ For instance, participants may give inaccurate data when questions feel rude and staff may guess at data when collection is too burdensome.⁸

Harmonized data collection with local control – Reporting requirements should be similar across partners, including community-based organizations and funders. This makes efficient use of limited resources and limits the burden of data collection.¹⁷ Funders should engage programs when creating data requirements.⁸ With standardized data collection systems, there should be flexibility in systems so local data collection efforts reflect local needs.⁷ Local sites should have access to their own data and data reports.^{2,7,17}

Consent – Both programs and participants should have the right to refuse to take part in data collection.²

“Nothing about us without us” – The tenet of “nothing about us without us” is key to harm reduction data collection. A diverse group of program participants should be highly engaged in every step, from phrasing questions, to collecting and analyzing data, to disseminating results.^{9,11,13,18,19,20,21}

With strong participant engagement, data may lead to positive program changes, challenge stigma, educate, empower, and organize the community, and create evidence to support programs and policies that benefit people who use drugs.^{1-2,7,9,22-23} Including participants improves the quality of data collected.²²

Before data is collected, it should be clear how data will be used.^{2,9,21} Staff and participants should work together to try to predict how data could be used against programs and people who use drugs.² There should be plans to present data back to participants and to use their feedback. This process is “member checking”.^{2,11} During member checking, needed resources should be provided, such as community friendly food and accessible spaces.^{2,9} Different methods of engagement should be used, like being able to read reports and to listen to presentations.⁹

After member checking and after data reports are final, data should be disseminated in many ways that are accessible and that can have the greatest positive impact for participants. Participants should be involved in deciding which methods are appropriate.^{9,11,19}

Minimalist approach – Data collection should never be a barrier to services and should not consume the resources of underfunded programs.^{1-2,7,21,24} If a program cannot show how and why data are used, they should not collect those data.^{1,7-8,11,21}

Compensation – Programs should work with participants to decide when compensation is necessary and feasible (e.g. according to how long it takes to complete a survey), how compensation compares to local living wage estimates, and the preferred method of compensation, which may be cash, but is unlikely gift cards.^{2,9,11} Whether compensation is provided or not, data collection should never be a barrier to services and all other ethical data collection guidelines should be considered.

Privacy and security – Programs should be clear with participants about how data collection may affect participant privacy and security.²⁵ Data that includes potentially identifying information should be stored in secure databases¹ and data about people who use drugs should never be shared with law enforcement.²⁶⁻²⁷

Questions to think about before the convening

- What isn't working about past and current data collection practices at SSPs?
- What makes for good data collection at SSPs?
- What else would we add to guidelines about ethical data collection?
- What are our goals for monitoring and evaluating SSPs?
- What are some indicators that can help us reach those goals?

The [Supporting Harm Reduction Programs \(SHaRP\)](#) team at the University of Washington offers expert technical assistance about harm reduction data monitoring and evaluation. To reach out to the SHaRP team, please e-mail sharpta@uw.edu. Follow SHaRP on Instagram at @UW_SHaRP.

To request technical assistance from the National Harm Reduction Technical Assistance Center, go to <https://harmreductionhelp.cdc.gov/>.

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